

# **The development of a primary level communication intervention protocol for children with severe disabilities**

---

**Juanita Bornman**

Submitted in partial fulfilment of the requirements for the degree

**Philosophiae Doctor in Augmentative and  
Alternative Communication**

In the Centre for Augmentative and Alternative Communication  
Faculty of Humanities

University of Pretoria

Pretoria  
June 2001

## Acknowledgements

---

### SOLI DEO GLORIA

Even though doing a PhD study is a solitary experience, I was never alone. My heartfelt gratitude to the following people and institutions who contributed to the study, particularly:

- Professor Erna Alant for her mentoring over the years and who was instrumental in getting and keeping me up to date with the latest trends in the AAC field. Her high level of skill, competency and professionalism inspired me.
- Professor Lyle Lloyd who acted as co-mentor and who read so many chapters of this research at airports and on aeroplanes... His input shaped my critical thinking in the AAC field.
- The two men in my life: My husband Werner, for his support, love and confidence in my ability to successfully complete this project and my son Heinrich who provided welcome diversion. It's great to have a family like you!
- My parents who provided unfailing support and most of all for encouraging me when I needed it the most.
- My friends and colleagues for their patience, selflessness and sufficient doses of humour.
- Mrs Maria Kabini for endless cups of coffee and who stood in for me regarding my domestic responsibilities.

## Acknowledgements

---

- Mrs Rina Owen, Department of Statistics : Research Support, University of Pretoria for her valuable input, advice and assistance with the statistical analysis.
- Professor Chris Smit, Department of Statistics, University of Pretoria, for sharing his knowledge on statistical procedures and their interpretation.
- Ms Ntbeng Mosupyoe who acted as research assistant and taught me so much about Moretele and its people.
- Mrs Enid Moolman who acted as independent rater for her insightful views and willingness to assist during difficult times.
- Mrs Ina Bruwer for the meticulous language editing.
- Mrs Cyrillene Henn and Mrs Corlien Venter for the careful technical editing and for not being too mad when changes kept happening.
- Ms Dot Pelser for her endless and creative efforts in producing and refining the communication boards used in the BCIP.
- Ms Ina van den Heever, Telematic Learning and Educational Innovation, University of Pretoria, for the graphics and CD-ROM.
- Photographs used in the BCIP were taken especially by Melita Moloney and Charmaine Vermeulen of Telematic Learning and Educational Innovation : Photography and the videos by Mr Andre du Plessis of Telematic Learning and Educational Innovation: Video Productions.

## Acknowledgements

---

- Mrs Pauline Mosupyoe, the Assistant Director of Health: Moretele and all the community health nurses who participated so enthusiastically and became true partners in our striving towards more effective service delivery to all children with severe disabilities.
- The financial assistance of the Mellon Foundation Mentoring Programme and the National Research Foundation (NRF) towards this research project is hereby acknowledged. Opinions expressed in this report and conclusions arrived at, are those of the author and not necessarily attributable to the Mellon Foundation or the NRF.
- Finally, to the memory of all those who started this project with me, but who did not see the end result: Mr Dietlof Maré, Mrs Emily van den Berg, and little Inge de Ruyter – you all helped to shape my life and reminded me that there is a reason for doing what I do every day.

## Table of Contents

---

<b>Acknowledgements</b>	<b>ii</b>
<b>Table of Contents</b>	<b>v</b>
<b>List of Figures</b>	<b>xviii</b>
<b>List of Appendices</b>	<b>xix</b>
<b>Miscellaneous</b>	<b>xx</b>
<b>Terminology</b>	<b>xxii</b>
<b>List of Acronyms</b>	<b>xxvii</b>
<b>List of South Africanisms</b>	<b>xxix</b>
<b>Opsomming</b>	<b>xxx</b>
<b>Abstract</b>	<b>xxxii</b>

### **1 ORIENTATION**

1.1 Introduction	1-1
1.2 Background	1-1
1.3 Chapter outlines	1-5
1.4 Summary	1-6

### **2 TRANSDISCIPLINARY TRAINING, PRIMARY HEALTH CARE AND COMMUNICATION INTERVENTION**

2.1 Introduction	2-1
2.2 Transdisciplinary training: relevance to CSD	2-2
2.3 Transdisciplinary service delivery within PHC	2-4
2.3.1 The three pillars on which effective PHC service delivery rests	2-7
2.3.1.1 Prevention	2-7
i. Primary prevention	2-8
ii. Secondary prevention	2-9
iii. Tertiary prevention	2-10
2.3.1.2 Participation	2-10

## Table of Contents

---

i. Protection	2-14
2.3.2 Comprehensive versus selective PHC approaches	2-16
2.4 Transdisciplinary training: communication orientation	2-18
2.4.1 Features of transdisciplinary training	2-18
2.4.2 Participants	2-21
2.4.2.1 Community Health Nurses	2-21
2.4.2.2 Primary Caregivers	2-26
2.4.2.3 Children with severe disabilities	2-31
2.4.2.4 Others	2-33
i. Community at large	2-34
ii. Professionals	2-34
2.4.3 Multiskilling as integrally related to transdisciplinary training	2-35
2.4.4 Collaboration is integrally related to transdisciplinary training	2-40
2.5 Summary	2-42

### **3 THE DEVELOPMENT AND EVALUATION OF THE BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP)**

3.1 Introduction	3-1
3.2 Discussion of Mithell's evaluation model	3-2
3.2.1 Programme input	3-2
3.2.1.1 Means analysis	3-3
3.2.1.2 Policy analysis	3-5
i. Legal requirements	3-6
ii. Consumer demands	3-6
iii. Research findings	3-6
iv. Team members philosophies	3-7
3.2.2 Programme goals	3-7
3.2.2.1 Outcome goals	3-8

## Table of Contents

---

3.2.2.2 Process goals	3-8
i. Defining the concept “efficacy”	3-9
ii. Intervention effectiveness	3-12
iii. Intervention efficiency	3-15
iv. Intervention effects	3-19
v. Problems with efficacy research	3-21
vi. Advantages of measuring outcomes	3-22
vii. Conclusions regarding efficacy	3-23
3.2.2.3 Programme design	3-24
3.2.3.1 Social policies	3-24
3.2.3.2 Administration and management	3-24
3.2.3.3 Physical environment	3-25
3.2.3.4 Curricula	3-25
i. Principle 1: Use of the ICIDH-2 to define the concept	3-25
ii. Principle 2: Uses Milieu teaching approaches	3-26
iii. Principle 3: Based on ADL, not play-based	3-27
iv. Principle 4: Communication is defined in terms of four domains: means, functions, partners and content	3-27
v. Principle 5: Provision of deliberate communication opportunities is essential	3-30
3.2.3.5 Teaching strategies and methods	3-31
3.2.4 Programme evaluation	3-31
3.3 Conclusion	3-32

# Table of Contents

---

## **4 RESEARCH METHODOLOGY**

4.1 Introduction	4-1
4.2 Methodology	4-1
4.2.1 Research question	4-1
4.2.2 Main research aim	4-1
4.2.3 Sub-aims	4-2
4.3 Research Design	4-2
4.3.1 Research design	4-2
4.3.2 Research phases	4-3
4.3.2.1 Section I: Pre-experimental phase	4-3
i.         Section I : Phase 1	4-4
ii.        Section I : Phase 2	4-15
4.3.2.2 Section II: Experimental phase	4-24
4.4 Pilot study	4-32
4.4.1 Objectives	4-32
4.4.2 Context and subjects	4-33
4.4.3 Procedures	4-33
4.4.4 Objective, results and recommendations	4-34
4.4.5 Summary	4-46
4.5 Main study	4-46
4.5.1 Participant selection and description	4-46
4.5.1.1 Selection of nurses to be trained	4-46
4.5.1.2 Descriptive information on the participants	4-47
4.5.2 Equipment and material	4-49
4.5.2.1 Equipment	4-49
4.5.2.2 Material	4-50
i.         Measuring instruments	4-50
ii.        Training programme	4-60

# Table of Contents

---

4.5.2.3 Data collection procedures	4-65
i.    Specific consideration	4-65
ii.    Procedures	4-66
4.5.3 Data analysis and statistical procedures	4-69
4.5.3.1 Descriptive statistics	4-69
4.5.3.2 Contingency tables	4-70
4.5.3.3 Inferential statistics : Parametric tests	4-70
4.5.3.4 Inferential statistics : Non-parametric tests	4-70
4.6 Summary	4-71
<b>5 RESULTS</b>	
5.1 Introduction	5-1
5.2 Reliability	5-2
5.2.1 Reliability of the scoring procedure	5-2
5.2.1.1 Inter-rater reliability	5-3
5.2.1.2 Intra-rater reliability	5-4
5.2.2 Reliability of participant scores	5-4
5.3 Outcomes	5-5
5.3.1 Primary outcomes	5-5
5.3.1.1 Knowledge	5-7
i.    Prior knowledge	5-7
ii.    Applied knowledge	5-16
5.3.1.2 Skills	5-32
5.3.2 Secondary outcomes	5-39
5.3.2.1 Attitudes	5-39
i.    Motivation	5-43
ii.    Job satisfaction	5-44
5.3.2.2 Exposure and service delivery	5-45

## Table of Contents

---

5.3.2.3 Self-evaluation	5-49
5.4 General training evaluation	5-54
5.4.1 Training methodology	5-56
5.4.2 Training content	5-59
5.5 Conclusions	5-63
5.5.1 Reliability	5-63
5.5.2 Outcomes	5-63
5.5.2.1 Primary outcomes	5-63
5.5.2.2 Secondary outcomes	5-64
5.5.3 General training evaluation	5-65
5.5.3.1 Training methodology	5-65
5.5.3.2 Training content	5-65
5.6 Summary	5-65

## Table of Contents

---

### 6 DISCUSSION OF RESULTS

6.1 Introduction	6-1
6.2 Multiskilling levels and accompanying outcomes	6-1
6.2.1 Level 1: Cross-training of basic client care skills	6-3
6.2.2 Level 2: Cross-training of professional non-clinical skills	6-3
6.2.2.1 Awareness and information	6-3
6.2.2.2 Referral	6-6
6.2.2.3 Feedback	6-7
6.2.2.4 Follow-up	6-7
6.2.3 Level 3: Cross-training of administrative skills	6-8
6.2.3.1 Prevention	6-9
6.2.4 Level 4: Cross-training of clinical disciplines	6-11
6.2.4.1 Identification and screening	6-11
6.2.4.2 Service delivery	6-13
6.3 Impact of the BCIP training on achieving these outcomes	6-15
6.3.1 Interactive nature of the BCIP training	6-15
6.3.2 Use of a problem-based approach	6-17
6.3.3 Repetition and revision	6-17
6.3.4 Transfer of learning	6-18
6.4 Summary	6-20

## Table of Contents

---

<b>7 SUMMARY, CONCLUSIONS AND RECOMMENDATIONS</b>	
7.1 Introduction	7-1
7.2 Summary of results and conclusions	7-2
7.3 Clinical implications	7-3
7.4 Evaluation of the studies	7-4
7.5 Recommendations for further research	7-5
7.6 Summary	7-7

## List of Tables

---

- Table 2.1 PHC aspects and their application to communication training of CSD
- Table 2.2 Indirect therapy: basic assumptions and realisation for communication training
- Table 2.3 Role transition process and realisation in communication training
- Table 2.4 Multiskilling levels as applied to various nursing tasks and disability
- Table 3.1 Application of Mitchell's process goals to the proposed communication Training
- Table 3.2 Measuring outcomes: implications for communication training Programmes
- Table 3.3 Application of the WHO model to proposed communication training Programme
- Table 3.4 A comparison of the most important intervention programmes / checklists / approaches for young children with severe disabilities
- Table 4.1 Research phases
- Table 4.2 Focus group with community nurses
- Table 4.3 Increasing trustworthiness of the pre-experimental phase of the research during focus groups with community health nurses
- Table 4.4 Descriptive information about nurses in the Moretele Health District
- Table 4.5 Significance of exposure to disability vs. comfortableness in handling disability

## List of Tables

---

- Table 4.6 Frequency of exposure to intellectual impairment vs. comfortableness in handling it
- Table 4.7 Frequency of exposure to children with LNFS vs. comfortableness in handling them
- Table 4.8 Service delivery and needs of CSDs as perceived by nurses
- Table 4.9 Focus group with caregivers of typically developing children
- Table 4.10 Background information on primary caregivers of typically developing children
- Table 4.11 Focus group with caregivers of children with disabilities
- Table 4.12 Background information on primary caregivers included in the focus group
- Table 4.13 Results and recommendations from piloting PCS communication boards
- Table 4.14 Objectives, results and recommendations following the pilot study
- Table 4.15 Descriptive information on the participants (n=20)
- Table 4.16 Development of Response Form I
- Table 4.17 Development of Response Form II
- Table 4.18 Development of Response Form III
- Table 4.19 Summary of the training procedure
- Table 5.1 Inter-rater reliability
- Table 5.2 Friedman test of prior knowledge
- Table 5.3 Number of nurses who answered the true-false questions correctly during the various research phases (n=20)
- Table 5.4 Number of nurses who answered the multiple choice questions correctly during pre- and post-training and post-withdrawal (n=20)

## List of Tables

---

- Table 5.5 Number of nurses who answered the ranking question correctly during pre- and post-training and post-withdrawal (n=20)
- Table 5.6 Results obtained from the Spearman rank order correlation coefficient for each individual participant during the three research phases
- Table 5.7 Friedman test of knowledge pertaining to representational levels
- Table 5.8 Friedman test of applied knowledge
- Table 5.9 Friedman test of current skills depicted in the case study
- Table 5.10 Friedman test of identified communication means
- Table 5.11 Frequency of communication means
- Table 5.12 Friedman test of identified communication functions
- Table 5.13 Communication functions identified by nurses
- Table 5.14 Friedman test of identified communication partners
- Table 5.15 Friedman test of combined recommendations
- Table 5.16 Communication means
- Table 5.17 Friedman test of recommended communication means
- Table 5.18 Communication functions
- Table 5.19 Friedman test of recommended communication functions
- Table 5.20 Communication partners
- Table 5.21 Friedman test of recommended communication partners
- Table 5.22 Increasing communication opportunities
- Table 5.23 Friedman test of recommended communication opportunities
- Table 5.24 Advice given following a particular case study

## List of Tables

---

- Table 5.25 Friedman test of advice given
- Table 5.26 Friedman test of combined skill areas
- Table 5.27 Friedman test of skill in representational level grading
- Table 5.28 Friedman test of skill in using objects for communication
- Table 5.29 Friedman test of skill in using photographs for communication
- Table 5.30 Friedman test of skill in using communication boards
- Table 5.31 Friedman test of skill in using gestures
- Table 5.32 Friedman test of skill in using the EasyTalk 4-option digital speaker
- Table 5.33 Friedman test of confidence in facilitating communication
- Table 5.34 Focus group with community nurses after training and follow-up
- Table 5.35 Attitude towards disability during different research phases (n=20)
- Table 5.36 Nurses' motivation as measured by using the reversal theory of motivation (n=20)
- Table 5.37 Job satisfaction during the various research phases (n=20)
- Table 5.38 Nurses' exposure to children with disabilities and amount of time spent with them (n=20)
- Table 5.39 Independent utilisation of the BCIP (n=20)
- Table 5.40 Nature of contact with colleagues regarding the BCIP
- Table 5.41 Nurses' self-evaluation of general nursing skills during the various research phases (n=3x20=60)
- Table 5.42 Nurses' self-evaluation of nursing skills specific to working with CSDs and their parents during the various research phases (n=3x20=60)

## List of Tables

---

- Table 5.43 Nurses' self-evaluation of skills specific to working with CSDs and their parents that they would like to improve/receive training during the various research phases (n=3x20=60)
- Table 5.44 Nurses' rating of the extent to which the training improved their knowledge regarding disability (n=20)
- Table 5.45 Nurses' overall rating of the quality of the training
- Table 5.46 Nurses' evaluation of the training methodology (n=20)
- Table 5.47 Training methodology aspects that were most enjoyed
- Table 5.48 Training methodology that could be improved
- Table 5.49 Nurses' evaluation of the training content (n=20)
- Table 5.50 Training content aspects that were most enjoyed
- Table 5.51 Training content that could be improved or enhanced

## List of Figures

---

- Figure 2.1 Transdisciplinary training, PHC and communication intervention
- Figure 2.2 Graphic presentation of the ICIDH-2
- Figure 2.3 Roles and tasks of community health nurses within multiskilling levels
- Figure 3.1 Mitchell's evaluation model (1991)
- Figure 3.2 Four main areas of communication
- Figure 3.3 Benefits for primary and secondary participants in the BCIP training
- Figure 4.1 Different phases of research conducted during the experimental research Phase
- Figure 5.1 Schematic presentation of the results of the study
- Figure 5.2 Global increase in knowledge and skills after the BCIP training
- Figure 5.3 Communication partners
- Figure 5.4 Change in skills, confidence and prompts
- Figure 5.5 Type of service delivery rendered during the various research phases
- Figure 6.1 Multiskilling levels nursing tasks and BCIP training outcomes

## List of Appendices

---

The appendices are on the CD ROM.

- APPENDIX A** Beginning communication intervention protocol (BCIP) for children with severe disabilities
- APPENDIX B** Demonstration of the BCIP
- APPENDIX C** Summary of themes delineated after two independent focus groups with nurses
- APPENDIX D** Nurses' information: Questionnaire used during needs analysis
- APPENDIX E** Differences in translations in focus group of caregivers of typically developing children
- APPENDIX F** Summary of themes delineated after focus groups with caregivers of typically developing children
- APPENDIX G** Differences in translation in focus group of caregivers of children with disabilities
- APPENDIX H** Summary of themes delineated after focus group with caregivers of children with disabilities
- APPENDIX I** Training of interviewers
- APPENDIX J** Comments on BCIP training in visitors book

## List of Appendices

---

<b>APPENDIX K</b>	Description of in situ follow-ups
<b>APPENDIX L</b>	Response Forms 1.1 to 1.4
<b>APPENDIX M</b>	Response Form II
<b>APPENDIX N</b>	Response Form III
<b>APPENDIX O1</b>	Beginning communication intervention protocol (BCIP) for children with severe disabilities : Handout - Day 1
<b>APPENDIX O2</b>	Beginning communication intervention protocol (BCIP) for children with severe disabilities : Handout - Day 2
<b>APPENDIX O3</b>	Beginning communication intervention protocol (BCIP) for children with severe disabilities : Handout - Day 3
<b>APPENDIX O4</b>	Beginning communication intervention protocol (BCIP) for children with severe disabilities : Handout - Day 4
<b>APPENDIX O5</b>	Beginning communication intervention protocol (BCIP) for children with severe disabilities : Handout - Day 5
<b>APPENDIX P</b>	<b>Summary of themes delineated after focus group with nurses post-training and follow-up</b>

## Miscellaneous

---

Photograph 1: The elements of the BCIP

Map 1: Area map of the Moretele Health District

## Terminology

---

### Adult learning

The literature lists four features that distinguish adults from children in their learning: self-directedness, a rich experience base, the need to address real-life problems and the need to apply learning immediately (Heimlich & Norland, 1994; Shine-Hoff, 1995). In order to facilitate learning in adults a climate of mutual respect (which includes trust, support and caring) must be created (Shine-Hoff, 1995). In the development of this training programme these premises and principles were kept in mind.

### Attitudes

Attitudes refer to the affective domain of learning (Bradshaw, 1989). It can be described as “*affect for or against, evaluation of, like or dislike of, or posstiveness or negativeness toward a psychological object*” (Heimlich & Norland, 1994, p.36). In the present study community health nurses’ attitudes towards disability and their perception of their role in providing services to this population are important. Attitude is a complex construct as it is based on a set of beliefs and guided by underlying principles (resulting from an individual’s own culture and unique context related to, and apart from the teaching-learning process)(Heimlich & Norland, 1994). Consequently attitudes do not form or change in a short time. Although attitudes form an important component of learning and strongly influence behaviour, it was not included as one of the focus areas of the study.

### Augmentative and Alternative Communication (AAC)

The field of clinical/educational practice to improve the communication skills of individuals with little or no functional speech (Lloyd, Fuller & Arvidson, 1997, p.524). This can be done by using aided symbols which requires a transmission device (e.g. real objects, photographs, graphic symbols, devices with speech output, etc.) or unaided symbols which requires only the body (e.g. gestures, manual signs, fingerspelling, etc.).

## Terminology

---

### **Beginning communicators**

This term refers to individuals across the age range who do not yet demonstrate communicative intentionality and/or who rely primarily on prelinguistic communication means and/or who are learning to use aided or unaided communication means to represent basic communication functions (e.g. rejecting, requesting, etc.) and/or who use low technology communication systems (e.g. communication boards) for participation (Beukelman & Mirenda, 1998).

### **Children with severe disabilities**

In this study severe disability does not rely on the particular systems that are affected, the medical diagnosis, or the intellectual status. Rather, it attempts to describe the functional limitations induced by the severity of the disability and/or the range of disability (i.e. the different areas of involvement that result in limited participation of the individual). This term therefore includes all individuals who have to rely on others in their environment to support them to some extent in order to ensure functional participation in their communities. Children with little or no functional speech (which is typical of beginning communicators) would thus be incorporated in the term “*severe disabilities*” as this is an aspect with causes and maintains limited social participation. All beginning communicators can thus be regarded as having a severe disability due to the severity of the communication deficit and its impact on general functioning. “Children” in this study refers to all children younger than 18 years of age.

### **Community health nurse**

Nurses with training in the field of community health nursing which can be described as a synthesis of nursing practice and public health practice, applied to promoting and preserving the health of communities. This practice is general and comprehensive and not

## Terminology

---

limited to a particular age group or diagnosis and is continuous, not episodic. The dominant responsibility is to the population as a whole; nursing directed to individuals, families or groups contributes to the health of the total population (Thomas, 1999a).

### **Knowledge**

This refers to the cognitive domain of learning, and is associated with an understanding and/or reproduction of facts (Bradshaw, 1989). However, Bloom's taxonomy broadened this definition, and also included the application of knowledge (the ability to apply knowledge to new situations) analysis of knowledge (ability to break information down into its component parts in order to clarify meaning), knowledge synthesis (being able to combine components to make a new whole) and evaluation (the ability to make judgements using relative criteria)(Wilson, Lanza & Barton, 1988). In the present study the knowledge domains that were tapped using Response Forms I & II included reproduction of knowledge, comprehension, application, analysis and evaluation.

### **Multiskilling**

Multiskilling is a form of role diversification which refers to the cross training of a service provider to perform procedures and functions in two or more disciplines (Salvatori, 1997). It does not necessitate the loss of a person's professional identity nor does it imply the demise of specialists, but rather offers opportunities for job expansion and job enrichment in the form of new or expanded roles, knowledge and skills. ASHA (1996) identified four dimensions of multiskilling, namely the cross-training of basic patient care skills, cross training of professional, nonclinical skills, cross-training of administrative skills and the cross-training of clinical disciplines. These four dimensions are discussed at length in Chapter 2. In the present study multiskilling was used as the strategy through which community health nurses were equipped with the knowledge and skills to provide services to children with severe disabilities and their primary caregivers.

## Terminology

---

### Primary caregivers

In the present study, “*primary caregiver*” refers to the individual who is responsible for the rearing of the CSD and who performs the majority of caregiving tasks (e.g. feeding, hygiene, ADL, discipline, etc.). The role of primary caregiver is predominantly a female one, and society may view this as a natural role for women (Hitchcock, 1999). In the specific context where the study was conducted this usually refers to the parents (in particular the mother) or a grandmother or older sister. The caregiver burden experienced by primary caregivers of CSDs that can lead to social isolation, exhaustion, financial hardship and despair, should not be overlooked.

### Prior knowledge

Prior knowledge refers to the whole of a person’s knowledge. As such prior knowledge is dynamic in nature, is available before a specific learning task, is explicit and contains conceptual and metacognitive knowledge components (Dochy, 1996). In the present study prior knowledge will thus refer to the specific knowledge of community health nurses before the BCIP training.

### Skills

This refers to the psycho-motor domain of learning, and encompasses the practical skills in performing a particular task. While skills require a knowledge base, they are easily learnt through the strategies of demonstration and practice under supervision (Bradshaw, 1989). A danger exists when teaching skills without knowledge (as the individual might not understand the rationale for doing something), consequently the present study focused on including both these domains of learning.

## List of Acronyms

---

AAC	Augmentative and Alternative Communication
ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
ALS	Aided Language Stimulation
ASHA	American Speech-language Hearing Association
ASL	American Sign Language
BCIP	Beginning Communication Intervention Protocol
CAAC	Centre for Augmentative and Alternative Communication
CBR	Community-based Rehabilitation
CP	Cerebral Palsy
CSD	Child with a severe disability
CSDs	Children with severe disabilities
DPO	Disabled People/Parent organisation
DPSA	Disabled People South Africa
DiCAG	Disabled Children's Action Group
FAS	Foetal Alcohol Syndrome
HIV	Human Immune Deficiency Virus
ICIDH	International Classification of Impairment, Disability and Handicap
ICIDH-2	International Classification of Functioning and Disability
II	Intellectual impairment
INDS	Integrated National Disability Strategy
LFNS	Little or No Functional Speech
NPA	National Programme of Action
OT	Occupational Therapist
PCS	Picture Communication Symbols

## List of Acronyms

---

PHC	Primary Health Care
PKU	Phenylketonuria
PT	Physiotherapist
2	Rank order
SASL	South African Sign Language
SLP	Speech-language pathologist
TB	Tuberculosis
VOCA	Voice Output Communication Aid
WHO	World Health Organisation

## List of South Africanisms

---

Braai	Barbecue : Outdoor social event at which meat cooked over a charcoal or wood fire is eaten.
Fridge	Refrigerator
Jam	A sweet substance made by boiling fruit with sugar to a thick consistency.
Jellytots	Soft, round jelly-based sweets covered in sugar
Maltabella	Sorghum grain porridge
Mealie porridge	Maize meal porridge
Paraffin	Oil obtained from petroleum or coal that is used as a fuel (in lamps, heating and cooking-stoves)
Simbas	Potato crisps
Smarties	Chocolate-coated sweets in assorted colours
Spaza shop	Small general dealer that usually operates from an individual's house
Takkies	Soft-soled canvas shoes
Zip	Zip fastener

## Opsomming

---

### **Die ontwikkeling van ‘n primêre vlak kommunikasie-intervensie protokol vir kinders met erge gestremdhede**

Dienslewering aan kinders met erge gestremdhede in ontwikkelende lande het sekere kenmerke in gemeen. Dit sluit ontoeganklike dienste as gevolg van die feit dat die meeste dienste in ‘n paar groot stede gelokaliseer is; die fokus van dienste is gewoonlik op skoolgaande kinders (met min vir voorskoolse kinders); baie dienste benodig gespesialiseerde personeel en gevorderde tegnologiese hulpmiddels wat nie altyd beskikbaar is nie, en professionele persone wat in isolasie werk met minimale integrasie tussen dienste. ’n Besonder weerlose groep in die sfeer van kinders met erge gestremdhede is beginnende kommunikeerders as gevolg van hul onvermoë om hul behoeftes, emosies en regte bekend te maak. Programme wat daarop gemik is om hierdie kommunikasiebehoeftes aan te vul deur sulke kinders van die nodige vaardighede te voorsien, ten einde in die samelewing te kan deelnem, is baie beperk.

Skakeling met die gemeenskapsverpleegkundige is dikwels die eerste kontak wat primêre versorgers van kinders met erge gestremdhede met professionele persone het. Voorts bly die verpleegkundige dikwels die enigste professionele persoon wat deurlopende ondersteuning en hulp aan hierdie versorgers bied. Dit is dus duidelik dat hierdie verpleegkundiges toegerus moet word met die nodige kennis en vaardighede ten einde versorgers in staat te stel om hul kinders met erge gestremdhede te kan hanteer. Dit kan gedoen word deur die opleiding van hierdie verpleegkundiges (deur middel van multi-vaardighedsopleiding) om as transdissiplinêre professionele persone te funksioneer. Verder bestaan daar ook ‘n behoefte aan toepaslike materiale vir dienslewering aan hierdie populasie. Gevolglik is die BKIP (Beginnende Kommunikasie Intervensie Protokol) ontwikkel. Die BKIP spreek vier belangrike kommunikasiedomeine aan, naamlik kommunikasie metodes (insluitend objekte, fotos, gebare, PCS simbole en ‘n vereenvoudigde 4-opsie digitale spreker), funksies (naamlik versoekfunksies, bv. vra vir nog, vra vir hulp, en sosiale funksies bv. groet, aandag op self vestig, ens.),

## Opsomming

---

gespreksgenote (beide volwassenes en portuurgroep) en die doelbewuste skep van kommunikasiegeleenthede (bv. slegs klein porsies gee, verlangde items buite bereik plaas, ens.). Sorg is gedra om kulturele sensitiwiteit en geldigheid van die BKIP te verseker.

Twintig gemeenskapsverpleegkundiges is opgelei in die toepassing van die BKIP. Opleiding het gebruik gemaak van die beginsels van volwasse leer en het ‘n week geduur, met drie in-situ opvolgbesoek (onderskeidelik twee weke, ses weke en vyf maande na opleiding). Veelvuldige metings is gemaak om die verworwe kennis en vaardighede na opleiding te evalueer, naamlik gestructureerde onderhoude, vaardigheidsdemonstrasies (wat deur middel van ‘n video opgeneem is en deur die navorser en ‘n onafhanklike evaluerder geëvalueer is) en ‘n fokusgroep.

Resultate het aangetoon dat die BKIP opleiding relevant is om ‘n betekenisvolle verandering in die teikenareas, naamlik kennis en vaardighede, te weeg te bring. Perifere gedrag (naamlik houdings, werkstevredenheid en tipe dienslewering) het aan die begin van die projek reeds ‘n hoë telling getoon, dus het kwalitatiewe data nie ‘n verbetering weerspieël nie. Kwalitatiewe data vanuit die fokusgroep het egter wel op ‘n verbetering gedui.

**Sleutel terme:** Aanvullende en Alternatiewe Kommunikasie (AAK); Beginnende kommunikeerders; Gemeenskapsverpleegkundige; Houdings; Kennis; Kinders met erge gestremdhede; Multi-vaardigheidontwikkeling; Primère gesondheidssorg; Primère versorgers; Trans-dissiplinäre dienslewering; Vaardighede; Volwasseleer.

## Abstract

---

### **The development of a primary level communication intervention protocol for children with severe disabilities**

Service delivery to children with severe disabilities (CSDs) in developing countries share some common characteristics. These include inaccessible services due to the fact that the majority of services are located in a few large cities, the focus of services are usually on school-age children (with few for pre-schoolers), many services require specialised staff and high technology equipment that is not always available and professionals who tend to work in isolation with minimal integration between services. A particularly vulnerable group within the sphere of CSDs are beginning communicators because of their inability to articulate their needs, feelings and rights. Programmes to specifically address these communication needs by equipping them with the necessary skills to interact and participate in society, are very limited.

Often the first contact that primary caregivers of a CSD have with professionals, is with the community health nurse. Furthermore, they often remain the only professionals who provide continuous support and assistance to these caregivers. It is therefore clear that these nurses need to be equipped with the necessary knowledge and skills in order to assist caregivers in dealing with their children with severe disabilities. This can be done by training these nurses (through multiskilling) to function as transdisciplinary professionals. Furthermore, a need for appropriate materials for service delivery to this population also exists. Consequently the BCIP (Beginning Communication Intervention Protocol) was developed. The BCIP addresses four important communication domains, namely communication means (including objects, photographs, manual signs, PCS symbols and a simplified 4-option digital speaker), functions (namely informational functions e.g. requesting more, requesting help, etc. and social functions, e.g. greeting, drawing attention to self, etc.), partners (both adults and peers) and the deliberate creation

## Abstract

---

of communication opportunities (e.g. by providing small portions, placing desired items out of reach) etc. Care was taken to ensure cultural sensitivity and the authenticity of the BCIP.

Twenty community health nurses were trained in the application of the BCIP. Training employed adult learning principles and was one week long, followed by three follow-ups that were conducted in situ (at two weeks, six weeks and five months post-training). Multiple measurements were used to evaluate the knowledge and skills acquired after training, namely questionnaires, structured interviews, skill demonstrations (which were video recorded and rated by the researcher and an independent rater) and a focus group.

Results indicated that the BCIP training is relevant in bringing about a significant change in the targeted domains, namely knowledge and skills. Peripheral behaviours (namely attitudes, job satisfaction and type of service delivery provided) were all rated high at the onset of the research and thus quantitative data failed to show improvement. On the other hand, qualitative data from the focus group suggested improvement.

**Key terms:** Adult learning; Attitudes; Augmentative and Alternative Communication (AAC); Beginning communicators; Children with severe disabilities; Community health nurses; Knowledge; Multiskilling; Primary caregivers; Primary health care; Skills; Transdisciplinary service delivery.

# CHAPTER 1

## ORIENTATION

### 1.1 INTRODUCTION

This chapter provides an orientation to the research and includes background information, the purpose of the research as well as a graphic representation of the chapter outlines.

### 1.2 BACKGROUND

When looking at the focus of developing countries regarding service delivery to children with severe disabilities (CSDs), it is clear that the services that had been established in developing countries in the past share some common characteristics.

Since the birth of South Africa's new democracy in 1994, different attempts had been made to create opportunities for everyone - not only in the educational and vocational sectors, but also in health. Although some progress has been made, particularly regarding policy development and legislation, some pertinent challenges still need to be addressed, one of which is disability. It is evident that there is a high incidence of disability in South Africa. It is estimated that 5 - 12% of South Africans are moderately to severely disabled (NPA, 1999). Of South Africa's total population of 40 million, 73% are women and children (Government Gazette no 17910, 1997) placing them at a higher risk for disability. More than 80% of black children with a disability live in extreme poverty and have poor access to appropriate health facilities or early childhood

developmental opportunities (NPA, 1999). In the sphere of individuals with severe disabilities, a particularly vulnerable and neglected group is that with communication and intellectual impairments due to their inability to articulate their needs, feelings and rights (Thorburn & Marfo, 1990). A study conducted in schools for children with cognitive impairment in and around Pretoria (South Africa) indicated that 39% of these children were using less than 15 intelligible words (Bornman & Alant, 1997). This percentage is significantly higher than that of comparable international studies such as the 2,4% reported in North Dakota (Burd, Hammes, Bornhoeft & Fisher, 1988) and 6% in rural areas in Washington state (Matas, Matthy-Laikko, Beukelman & Legresley, 1985). There are different reasons for this, including the fact that persons with severe disabilities in South Africa are not exposed to Augmentative and Alternative Communication (AAC) strategies as it is still a relatively new field of expertise in our country. Internationally it is also reported that programmes to specifically address these communication needs by equipping these children with the necessary skills to interact, are limited (Werner, 1987, WHO, 1995).

Apart from the high incidence of disability in developing countries, these individuals also share commonalties in terms of services the offered. It is well-documented in the literature that people with severe disabilities receive less education and vocational training, and are often unemployed, resulting in poverty (Lundgren-Lindquist & Nordholm, 1993). The aura of charity still pervades many of the services offered to help and rarely are the persons with disabilities given the chance to help themselves (McConkey, 1996). Due to long held low expectations of people with severe disabilities, they are often excluded from any leadership position or from any planning and decision-making in their

communities, resulting in a lack of representation of their needs.

In addition, very few professionals in South Africa are trained in AAC implementation, and thus able to provide AAC intervention to people in need. This is due to the fact that communication intervention for CSDs has not been a priority, and that international sanctions limited South Africa's participation in the international AAC field until the early nineties. In addition, the majority of services provided by professionals are located in a few large cities making it inaccessible to the rural population, leading to services being provided to less than three percent of disabled people in need (Thorburn & Marfo, 1990). Professionals also tend to work in isolation, with minimal integration between services, which led many people to believe that service provision to disabled people was too complicated to be administered by persons other than professionals. It was thought that any other form of rehabilitation would be ineffective (Thorburn & Marfo, 1990).

At present, much of the discourse in the health and rehabilitation fields revolve around the way to address issues related to disability and the lack of manpower within the resources of the developing world. One of the possible solutions might be the fact that professionals began to realise the importance of teamwork (O'Toole, 1988). This not only reduces the duplication of services, it also addresses the fragmentation that currently exists amongst different service providers. The sharing of information and the planning of intervention will enable parents, professionals and all persons involved with the disabled child to work towards a common goal (McConachie & Pennington, 1997). Consequently, when accepting the primary health care philosophy, one has to acknowledge the fact that

rehabilitation is too important to be left only to the professionals. Communities have to be made aware of persons with disabilities in their midst and of what can be done to assist them in becoming more active participating members of society (McConkey, 1996). Training therefore needs to be conducted at all levels and should include community leaders, professionals, primary level workers, family members of persons with disabilities, and the persons with disabilities themselves. Primary caregivers should therefore receive support from professionals so that they can make knowledgeable and informed choices regarding their child's rehabilitation.

Added to this, it should be realised that the available Western materials are not applicable to the African context. Thus, when attempting to train individuals regarding disability and communication issues, appropriate materials and methods for assessment and intervention that are ecologically valid, need to be developed. In an UNESCO declaration (in Thorburn & Marfo, 1990) the importance of culturally sensitive materials that are suitable to a specific context are highlighted.

In summary it can thus be said that CSDs and their primary caregivers are a neglected group with few resources.

On the positive side, CSDs and their primary caregivers often have contact with community health nurses as primary health care clinics are relatively easily accessible to all South Africans, even those living in rural and remote areas. Furthermore, they often remain the only professionals who provide support and assistance to caregivers of pre-school children. It is therefore clear that these health care workers need to be equipped with the necessary skills and

expertise to assist caregivers in dealing with their children with severe disabilities.

This led to the development of the Beginning Communication Intervention Protocol (BCIP). This is a training programme that is aimed at equipping community health nurses with the knowledge and skills (through multiskilling) to function as true transdisciplinary professionals. It aims at defining beginning communication skills in terms of various communication means (both aided and unaided), communication functions (e.g. requesting help, requesting assistance, protesting, etc.), increasing communication partners as well as the creation of deliberate communication opportunities. The BCIP thus equips the community health nurse to provide training and support to the primary caregivers of CSDs, so that the rehabilitation process can begin. This is in strong contrast to the way in which services are currently being delivered, namely referral to large centres, with little or no compliance (for a number of reasons, e.g. lack of transport, financial difficulties, insensitivity to culture and beliefs, etc.) and little or no follow-up of these individuals.

The aim of this study is therefore to develop and apply a communication intervention protocol aimed at facilitating beginning communication skills (e.g. choice-making, turn-taking, labelling, initiating, drawing attention to self, requesting help, requesting more, rejecting, commenting and indicating humour and surprise) between primary caregivers and CSDs. This protocol is intended for use by community health nurses who work in primary health care clinics in the training of caregivers (parents) to interact with their children.

### 1.3 CHAPTER OUTLINES

The research will be presented in seven chapters. Chapter 1 provides a basic orientation and motivation for the study as well as an outline of the chapters.

In Chapter 2 the concept "transdisciplinary training" is discussed by focusing on its relevance to children with severe disabilities (CSDs). This discussion continues by placing transdisciplinary services within the primary health care (PHC) domain, highlighting three important aspects namely prevention, participation and protection. This chapter concludes by providing a communication orientation to transdisciplinary training in which two approaches, namely multiskilling and collaboration are highlighted. The roles of the main participants in this process, namely community health nurses, primary caregivers of CSDs, and CSDs themselves, are highlighted.

The concept "*communication*" is the focus of Chapter 3. It describes the main elements of a beginning communication protocol (the BCIP) by highlighting the importance of including communication means, functions, partners and the deliberate creation of communication opportunities. It also includes an outline of the training programmes / packages that currently exist, and describes the components that should be included in a programme to ensure efficacy. This chapter is concluded a brief discussion of important elements of adult training.

The methodology is set out in Chapter 4. This includes a description of the aims and objectives, the research design, pilot study and the main study, highlighting the participant selection procedure and a description of the community health nurses who were included, the equipment and materials

used, as well as the data collection and analysis procedures.

Chapter 5 presents an overview of the results obtained. Emphasis is placed on results that yielded the primary outcomes of the study (namely knowledge and skills). This is followed by a description of secondary outcomes (attitudes, job satisfaction, and motivation to work with CSDs and their primary caregivers as well as type of services provided to this population). Finally, a general evaluation of the training (in terms of methodology and content) is provided.

This is followed by a discussion of the results, which is the focus of Chapter 6. Outcomes of the BCIP training were integrated with the various nursing tasks required from community health nurses working with CSDs and their primary caregivers. The change noted in knowledge and skills is highlighted and the role of the BCIP in facilitating this process is explored.

In Chapter 7 the conclusions and implications of the study are presented, together with a critical evaluation of the study and recommendations for future research.

#### **1.4 SUMMARY**

This chapter provided the motivation for the study by describing the background information that led to its development as well as a description of the research purpose. It concludes by providing an outline for the different chapters by which the aims of the study will be realised.

## CHAPTER 2

# TRANSDISCIPLINARY TRAINING, PRIMARY HEALTH CARE AND COMMUNICATION INTERVENTION

### 2.1 INTRODUCTION

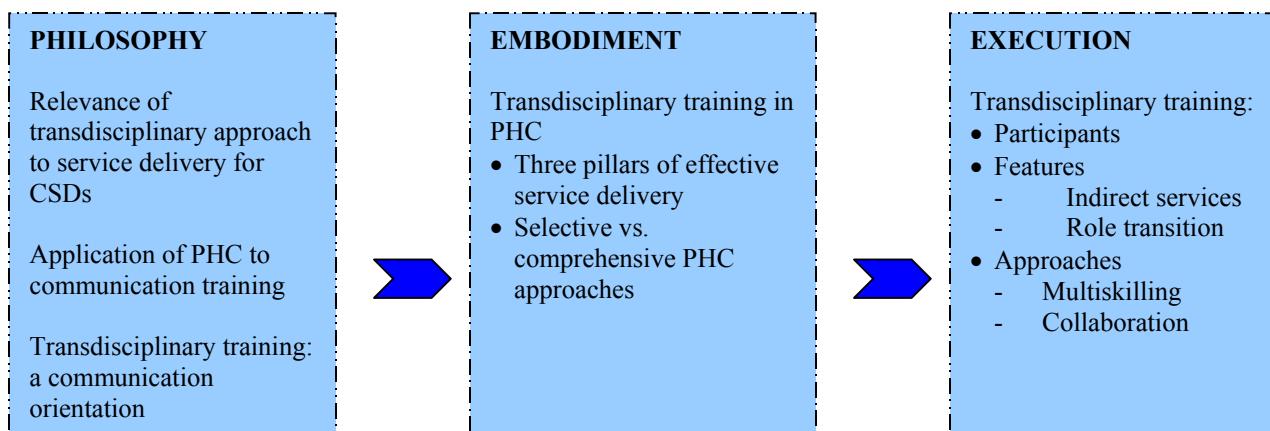
Meeting the diverse needs of children with severe disabilities within the primary health care (PHC) sphere is a complex task that cannot be effectively addressed by one profession (Bailey, Simeonsson, Yoder & Huntington, 1990). However, by training existing personnel at this level (e.g. community health care nurses) to function as transdisciplinary professionals, service delivery to this traditionally neglected group of individuals becomes viable. This chapter discusses a transdisciplinary approach to service delivery and its relevance for CSDs and then links transdisciplinary training within a PHC context and communication training to this population. The chapter continues by describing how the principles of PHC can be applied to a transdisciplinary communication-focused training programme. The features of transdisciplinary training (i.e. role transition as a process relating to role release where professionals cross traditional professional boundaries and continuous development of personnel) as well as the specific approaches that were used to obtain this (i.e. multiskilling and collaboration) are highlighted.

Traditionally a medical approach to service delivery was followed, which defined health as absence of disease (Slajmer-Japeli, 1995). This made way for the community development or social approach that is currently used and which defines health as a human condition which is the result of social, economic and political development (Thomas, 1999a). This implies that one professional is not equipped to address all the health needs of an individual effectively. In addition, a lack of trained professionals who are equipped to provide services to all in need, particularly those in rural and remote areas, exists (Bortz, Jardine &

Tshule, 1996; Moodley, Louw & Hugo, 2001). These factors highlight the importance of transdisciplinary functioning of professionals, which emphasizes collaboration and the transfer of information, knowledge and skills across discipline boundaries (Zangari & Wasson, 1997). Professionals are required to share knowledge so that they become proficient in areas other than their primary specialities – a concept known as role transition which includes role extension, role enrichment, role expansion, role exchange and finally role release (Orellove & Sobsey, 1996; Parker, 1994).

A summary of the contents of Chapter 2 is presented graphically in Figure 2.1

**Figure 2.1 Transdisciplinary training, PHC and communication intervention**



## 2.2 TRANSDISCIPLINARY APPROACH TO SERVICE DELIVERY: RELEVANCE TO CSD

Defining “*children with severe disabilities*” poses serious problems as it brings to mind a vast number of images, ranging from a Down’s Syndrome to a spastic quadriplegic person. Often these individuals cannot easily make themselves understood. They may be passive – either partially or completely, which may be the result of their level of cognitive functioning or due to the fact that all their needs are anticipated and met, leading to learned helplessness (Reichle, 1991). They may exhibit challenging behaviour (Durand, 1990). They may seem to understand more than they are able to communicate.

They may not be motivated to communicate, as they may not have anything to communicate about or anybody to communicate with. These images are all relevant, as are many others. Apart from the different aetiologies leading to disability, it comes from all age, socio-economic and ethnic groups.

One approach in defining this population is by defining their characteristics and examining the different areas of involvement, e.g. "*A severely disabled child is one who, because of the intensity of physical, mental or emotional problems, or a combination of such problems, needs educational, social, psychological and medical services beyond those which have been offered by traditional regular and special education programs, in order to maximise his full potential for useful and meaningful participation in society and for self-fulfilment. Such children include those classified as seriously emotionally disturbed (schizophrenic and autistic), profoundly and severely mentally retarded, and those with two or more serious handicapping conditions such as the mentally retarded deaf, and the mentally retarded blind*" (US Department of Education in Sailor & Guess, 1983, p.5). From this definition it is thus clear that the combination of physical, cognitive, communicative, sensory and/or socio-emotional dependence on support, result in far-reaching and diverse rehabilitative, educational and medical needs of this population. Therefore, CSDs present an immense challenge to all professionals working with them (Orelove & Sobsey, 1996).

It is thus evident from the above that one single profession is not equipped to provide services to CSDs and their families. Expertise from a number of different professions are required, e.g. OT, SLP, PT, nursing, teachers, psychologists etc. Professionals consequently began to recognise the need for sharing expertise across traditional disciplinary borders, for assimilating knowledge from other disciplines and for collaboration, resulting in a transdisciplinary approach to service delivery (Atkins-Burnett & Allen-Meares, 2000; Orelove and Sobsey, 1996; Zangari & Wasson, 1997).

The ability of professionals to function in a transdisciplinary manner is thus not only beneficial to meeting the diverse needs of CSDs, but supports one of the principles

underlying South Africa's National Health System, namely primary health care. The Alma Ata declaration identified PHC as “... *essential health care made universally accessible to individuals and families in the community by means acceptable to them, through their full participation and at a cost that the community and country can afford*” (WHO/UNICEF in Rifkin 1986:240). Therefore, in order to meet the needs of as large a number of people as possible in a culturally appropriate, cost effective way, all possible resources must be utilised (House, McAlister & Naidoo, 1990; Stanhope, 1995). Consequently, professionals began to realise that primary caregiver involvement is central to service delivery, that a high degree of collaboration and joint decision making between primary caregivers and professionals should be established, and that the cross training of professionals and para-professionals in providing services to CSDs should be highlighted (Chapman & ware, 1999; O'Toole, 1988). These three aspects form the basis of a transdisciplinary approach to service delivery— an approach that not only reduces the duplication of services but one that also addresses the fragmentation and duplication that currently exists amongst different service providers. The transdisciplinary approach is therefore closely linked with PHC as it becomes meaningful within a more comprehensive model of service delivery.

### **2.3 TRANSDICIPLINARY SERVICE DELIVERY WITHIN PHC**

PHC can be viewed as an approach to health care – it is not only seen as the first level of care but rather as a reorientation of the health care system from its present concentration on late stage, high technology hospital services to community and preventive services (Willis, Biggins & Donovan., 1999). The WHO states that PHC should incorporate the following principles (Thomas, 1999b; McGivern, 1995; Willis *et al.*, 1999):

- Build self-reliance at a personal and community level
- Support community participation in the development of health care programmes
- Collaborate at an intersectoral level to establish environments that are supportive to health

- Integrate health services to facilitate continuity of care and efficiency in resource use
- Provide special attention to high risk and vulnerable groups (e.g. CSDs), as a precondition for equity in health outcomes and health care processes
- Use appropriate technology (McLaren, Philpott & Hlophe, 1997)

PHC is thus seen as the vehicle by which the WHO is attempting to reach the principles of the *Health for All by the Year 2000* document which includes each individual's right to health, equity in health, community participation, intersectoral collaboration and health promotion (Lockhart, 1999; Willis, *et al.*, 1999). PHC is also the underlying philosophy for the restructuring of the South African health system (Department of Health, 1999). When looking at both the principles outlined in PHC and the *Health for All by the Year 2000* document a few interesting trends are seen. Firstly, it highlights community participation, accessibility of services, and the importance of the environment in relation to the health of individuals and communities (Thomas, 1999a). Secondly, it embodies the spirit of partnerships, requiring collaboration and consensus building not only amongst professionals, but also between professionals and communities (Bjäräs, Haglund & Rifkin, 1991; Werner, 1987). Thirdly, it specifically mentions the poor and disenfranchised members of communities, emphasising equity of service delivery (Thomas, 1999a). The emphasis is on self-care, implying that individuals have to be educated to make knowledgeable decisions about their own health and care (Thomas, 1999b). Finally, the preventive rather than the curative end of the health care continuum is advocated (Sameroff & Fiese, 2000).

When viewing PHC within a rural health care system additional factors come to the forefront (Thobaben & Biteman, 1999). Five important aspects related to the training of CSDs and their primary caregivers in PHC were identified. These aspects and their application to communication training are discussed in Table 2.1.

**Table 2.1 PHC aspects as applied to communication training of CSD**

PHC aspect	Application to communication training
<b>Community-based Rehabilitation (CBR)</b> Focus of rehabilitation shifts from segregation to community integration (Bradley & Knoll, 1995; Murray, 1980). Should include: <ul style="list-style-type: none"> <li>• Community participation</li> <li>• Appropriate technology</li> <li>• Specific type of service delivery</li> </ul>	<ul style="list-style-type: none"> <li>• Strong focus on collaboration, where CSDs and their primary caregivers are seen as partners (Griffel, 1991; Kisanji, 1995).</li> <li>• Equip community health nurses to conduct health talks to increase the community's knowledge about disability. They will also train primary caregivers of CSDs to enable them to take greater responsibility for their own child's development (Reynolds, Mavrogenes, Bezruczko &amp; Hagemann, 1996).</li> <li>• Use of everyday objects (spoon, cup, plate, etc.) as well as photographs that can be obtained from magazines, PCS symbols that can be drawn and gestures of these objects and pictures. Familiar objects enhance learning of CSDs (Beukelman &amp; Mirenda, 1998; Piché &amp; Reichle, 1991).</li> <li>• Inclusion of appropriate technology, namely a relatively inexpensive digital speaker with four options, which is appropriate to the multilingual South African context as any language can be recorded (Bornman, Alant &amp; Meiring, 2001). In addition, digital speakers are also gender appropriate (as a boy or a girl's voice can be recorded) and age appropriate (younger versus older voice).</li> <li>• Skill orientated training so that community health nurses and primary caregivers know where to start the service delivery process and what to do. It is also locally relevant using ADL as opposed to the more frequently used play-based programmes.</li> </ul>
<b>Equity</b> Address needs of previously disadvantaged groups, e.g. CSDs and their primary caregivers, particularly those in rural areas.	<ul style="list-style-type: none"> <li>• Access to services during the critical 0 – 5 years of development (Dworkin, 2000) is limited for CSDs living in rural areas. Due to misconceptions and negative attitudes of the community at large, they are frequently hidden from society. Service delivery to CSDs should start as early as possible to enhance growth and development (Meisels, 1992).</li> </ul>
<b>Accessibility</b> The RSA government is attempting to provide a clinic within a five km. radius of every South African (Department of Health, 1999).	<ul style="list-style-type: none"> <li>• Community health clinics are often the only centres in rural areas where professional services are available to CSDs, and therefore community health nurses should be the target professionals for providing communication training to CSD and their primary caregivers at this level.</li> </ul>
<b>Environment and availability</b> Existence of essential services and the necessary personnel to provide these essential services to all South Africans, particularly those in rural / remote areas.	<ul style="list-style-type: none"> <li>• High incidence of disability in rural areas, as 53% of the South African population live in rural areas (Government Gazette, 17910, 1997) and 80% of black CSDs live in extreme poverty and have poor access to appropriate health facilities (NPA, 1999). A communication training programme should therefore keep this population in mind.</li> </ul>
<b>Acceptability / Social utility</b> Services should be congruent with values, beliefs and customs of the target population (Schubert, Hitchcock & Thomas, 1999).	<ul style="list-style-type: none"> <li>• Ensure cultural sensitivity and relevance. Community health nurses are often from the same community as the ones they serve, heightening their awareness and understanding of cultural factors in health and disability issues (Clark, 1996).</li> </ul>

From the above discussion it is clear that the provision of services (particularly communication training) to CSDs and their primary caregivers within a PHC context is a

challenging task. Professionals require knowledge and skills that move beyond the boundaries of their traditional roles and they need to collaborate more effectively with professionals, family members (e.g. primary caregivers) and the community at large.

### **2.3.1. The three pillars on which effective PHC service delivery rests**

In viewing sustainable service delivery to rural CSDs and their primary caregivers within the PHC sphere, three concepts form the pillars on which sustainable service delivery rests, namely prevention, participation and protection. Each of these aspects will now be described in more detail.

#### **2.3.1.1 Prevention**

According to the Integrated National Disability Strategy (INDS) (1997) prevention is one of the cornerstones of any disability policy as the majority of disabilities are preventable. Orem (1995) noted that prevention requires knowledge of specific interferences with normal health structure and functioning at various stages in an individual's life in particular environments.

The South African Department of Health (1998) has developed a set of objectives to ensure disability prevention. These objectives are generic and pertain to prevention at all three levels. This includes stronger collaboration and co-operation amongst various government departments and communities, the encouragement of greater involvement by DPOs and more community interest in disability prevention, stronger teamwork amongst members of the rehabilitation team, as well as the development of legislation to protect and promote the rights of all citizens (Department of Health, 1998). All of this will be done in accordance with a PHC approach.

**i.) Primary prevention**

Primary prevention encompasses health promotion and disease prevention (Hitchcock, 1999; Stokes, 1997). It identifies action taken to prevent the occurrence of health problems in families, by taking measures to alter risk factors before the disease begins (Orem, 1995). It also refers to the prevention of accidents which may cause impairments and disabilities (INDS, 1997). When looking at disability, primary prevention refers to activities to intervene in the course of a disease so that a disability does not occur (Gilion, 1999). According to the INDS (1997) the major policy objectives to reach this goal are the promotion of a healthy lifestyle in the home, school, and vocational arenas as well as protective measures (e.g. immunisations, protection against accidents, etc). One of the major nursing activities in prevention is “*anticipatory guidance*”(Hitchcock, 1999). This includes obtaining a health history, a physical examination, measurements, sensory screening, developmental and behavioural monitoring, immunisation and age specific counselling (Dworkin, 2000; Solomon, Clougherty, Shaffer, Hofkosh & Edwards, 1994). In primary health care settings, this is often done by offering primary caregivers guidance and support in promoting their child’s development (Dworkin, 2000).

A communication training programme should therefore explain the concepts “*disability*” and “*communication*” to community health nurses, who, in turn can explain it to primary caregivers. This anticipatory guidance will enable primary caregivers to better monitor their child’s progress. In addition, primary prevention can be enhanced by making community health nurses aware of peri-natal and environmental factors that can cause disability.

**ii.) Secondary prevention**

Secondary prevention is appropriate after the onset of the impairment or disability (Orem, 1995) and is directed at the early recognition of impairments and disability followed by treatment (Gilion, 1999; Stokes, 1992). This would also include screening tests (Hitchcock, 1999). Secondary prevention may result in a cure, a slower rate of

progression of the impairment or the prevention of complications (INDS, 1997). The INDS (1997) hopes to achieve this by decreasing poverty, avoiding violence, improving health services (e.g. immunisations, mother-and-child care, family planning, genetic counselling, etc.) reducing environmental accidents and monitoring disease.

A communication training programme that is focused at this level of prevention is required. This programme should adhere to the following principles:

- Equipment of community health nurses with the knowledge and skills to provide services to CSDs and their primary caregivers at a PHC level which can be achieved through multiskilling (Section 2.4.3).
- Comprehensiveness to facilitate close collaboration between primary caregivers and community health nurses and address issues related to disability and communication (Kaplan-Sanoff, Parker & Zuckerman, 1991).
- Continuity of services to ensure that CSDs can be kept at home and be stimulated by their primary caregivers after having been trained by community health nurses.
- Training of community health nurses to refer primary caregivers to other possible resources when necessary, e.g. social services (information on disability grants), genetic counselling (family planning), occupational therapy (seating and mobility), etc. (Eggbeer, 1995).
- Provision of information and modelling of appropriate behaviour to provide primary caregivers with relevant information enabling them to make appropriate and knowledgeable decision about their child's rehabilitation (Freeman & Heinrich, 1981; Roberts, Rule & Innocenti, 1998).

### **iii.) Tertiary prevention**

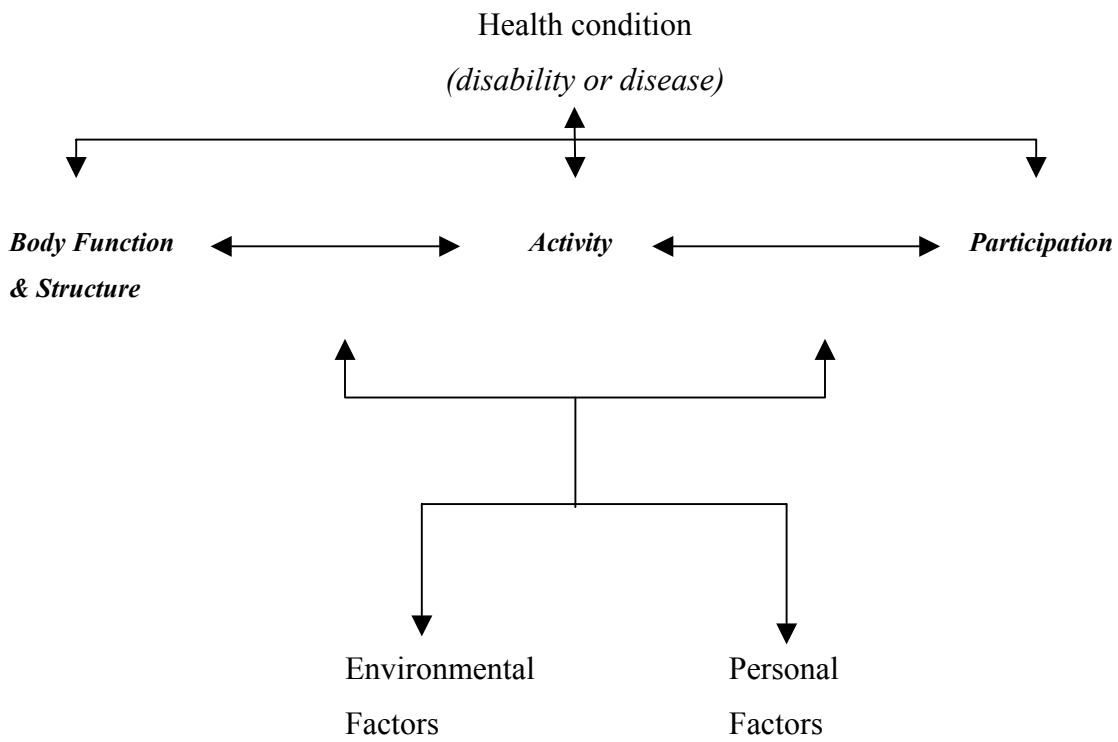
In the past, resources were channelled to tertiary prevention despite indications that a focus on the other two levels of prevention is required (Stokes, 1997). Tertiary prevention has to do with the rehabilitative level of health care (treatment) (Hitchcock, 1999; Orem,

1995). For disability it would refer to activities aimed at limiting the disability or associated problems (Gilién, 1999) and preventing complications (Orem, 1995). As the focus of this study is not on this level, it will not be discussed further.

### **2.3.1.2 Participation**

In 1980 the WHO published the International Classification of Impairment, Disability and Handicap (ICIDH) which provided a scientific model of disability as well as clarification of the earlier terminology (i.e. impairment, disability and handicap) for clinical use, data collection and research (WHO, 1998). However, in using the ICIDH it became evident that diagnosis alone failed to predict service needs, the level of care provided and required, the outcomes of intervention and/or the receipt of services such as disability benefits, scholastic or vocational performance and social inclusion. These factors together with international focus on the participation and functioning of individuals within a particular community and a sharper look at the barriers that restrict or facilitate participation, necessitated the redefinition of the ICIHD. This process started in 1995 and it is estimated that the complete ICIDH-2 will be available towards the end of 2001 (WHO, 1998).

A major advantage of the ICIDH-2 is that it is a tool which codes information about an individual's health status while at the same time bridging the medical and social approaches to health. It is based on human functioning, and disability is viewed from the perspective of an individual's life circumstances without attempting to "*label people*". The ICIDH-2 is also etiologically neutral, emphasises parity, is culturally appropriate and covers the whole lifespan. It can thus be used by any individual, not only the disabled, making it a universal (and not a minority) model (WHO, 1999). The ICIDH-2 is graphically presented in Figure 2.2.



**Figure 2.2      Graphic presentation of the ICIDH-2 (WHO, 1999).**

From Figure 2.2. it is seen that the ICIDH-2 looks at functioning and disability at three levels:

- **Body level/ Body functions and structure.** This refers to the physiological and psychological functioning of body systems and the body structure, i.e. the anatomic parts such as organs, limbs and their components. This is similar to the impairment level used in the ICIDH (WHO, 1980).
- **Individual level/ Activities.** This refers to the range of activities or tasks performed by an individual and is similar to the disability level used in the ICIDH (WHO, 1980).
- **Society level/Participation.** This refers to opportunities and/or barriers that impact on the areas of life in which the individual is involved, or has access to and is similar to the handicap level used in the ICIDH (WHO, 1980).

In addition, the ICIDH-2 highlights the complex relationship and dynamic interaction between different environmental and personal factors that impact on activity and participation that is associated with health conditions, namely

- **Environmental factors.** This refers to the physical, social and attitudinal environments in which people live and conduct their lives (WHO, 1998). These factors have an external influence on functioning and can impact on all three levels. They are extrinsic (outside of the individual) e.g., the attitudes of society, architectural characteristics or the legal system. Environmental factors are organised from the immediate environment to the general environment. This is similar to the Lloyd, Quist and Windsor (1990) model for AAC, which highlights the importance of different communication environments and partners in service delivery to CSD.
- **Personal factors.** This refers to the features of the individual that are not part of health conditions or functional state. These factors have an internal influence on functioning and may include gender, age, fitness, lifestyle, habits, coping styles, social background, education, past and current experience, overall behaviour pattern, individual psychological assets and other characteristics. These factors impact on resilience and protective factors as discussed in section 2.3.1.3.

Functioning and disability have a complex relationship between the health condition and the contextual factors (e.g. environmental or personal factors). The WHO (1999) uses **functioning** as the umbrella term to indicate positive aspects at all three levels of the ICIDH-2 whilst **disability** is the umbrella term for the negative aspects (problems) at all three levels. Disability is thus seen as a multidimensional phenomenon resulting from the impaired interaction between people and the environment. The focus should not be on the **disability** but on the **ability** and how that can be used optimally to ensure full participation in everyday activities. Brandt and Magyary (1989) refer to this process as one of avoiding difficulties and maximising strengths.

The implications of using the ICIDH-2 for communication training are:

- Greater emphasis on the strengths of CSDs by focusing on their participation in their respective communities with some facing more barriers that restrict participation than others.
- Communication training in its broadest sense, and in particular communication training to CSDs by means of AAC, aims at assisting individuals to become communicatively competent in order to heighten their participation in society (Beukelman & Mirenda, 1998). The ICIDH-2 thus brings disability classifications more in line with the expected outcomes of communication training.
- The stronger focus on social inclusion (participation) highlights the importance of training various communication partners, which might impact on changing of attitudes towards disability (Johnson, Baumgart, Helmstetter & Curry, 1996).
- Provides an indication of the environmental (e.g. lack of communication partners) and personal factors (e.g. limited communication means) that might hamper participation. This information can be used to assist with the planning of communication training.

### **2.3.1.3 Protection**

Protection of children in South Africa takes on many forms. It includes housing (recently the number of homeless children had risen dramatically), the provision of an infrastructure viz. sanitation, water and electricity (25% of schools do not have water within walking distance and 57% of schools do not have electricity) and protection from child labour (hundreds of thousands of South African children between 10 and 14 years of age are engaged in some kind of labour) (NPA, 1999). In addition, children need protection against communicable diseases e.g. TB, cholera and other diseases that threaten their general health e.g. HIV/AIDS. South Africa is facing one of the worst TB epidemics in the world, with over 90 000 new reported TB cases and an estimated 3 000

deaths in 1995 (Government Gazette 17910, 1997). Consequently the Department of Health has declared TB a top national health priority (Government Gazette 17910, 1997). Foetal Alcohol Syndrome is the most common preventable cause of intellectual impairment worldwide, and one which all unborn children should be protected against (Viljoen, 1999). In a study conducted in the Western Cape, 55% of the women in the sample admitted to varying degrees of alcohol ingestion during their current pregnancy, of which the drinking patterns and intake of 23,7% was sufficient to place their unborn children at high risk for Foetal Alcohol Syndrome (FAS)(Croxford & Viljoen, 1999). Children also need protection from abuse and neglect. Children need good nutrition as the nutritional status of children is a sound indicator of overall development and well-being (Government Gazette 17910, 1997). All of these factors affect CSDs to an even greater extent due to their vulnerability and low immunity.

Despite this bleak picture, children have an inherent resiliency. “*Resilience*” and protective factors refer to good developmental outcomes of children from high risk backgrounds who overcome great odds e.g. economic hardships, parental mental illness, child abuse and neglect, teenage motherhood, and peri-natal complications (Werner, 2000). These protective factors exist in multiple domains and can be found within the child, within the family and/or within the community (Beckwith & Sigman, 1995). The factors within the child will be mentioned but not described in detail, as it is not the emphasis of a communication training programme which is focused at a secondary prevention level. These factors include aspects such as low distress, active, alert children with high vigour and drive, sociable children with easy engaging temperaments, children with advanced self-help skills, those who have average to above-average intelligence, an internal locus of control, a positive self-concept and strong achievement motivation (Werner, 2000). Within families some of the protecting factors are small family size (< four children), mother’s level of education, maternal competence, close bond with the primary caregiver and supportive grandparents and siblings (Kaplan-Sanoff *et al.*, 1991; Werner, 2000). Finally, the protective factors in the community need to be addressed. This includes aspects such as having friends, access to schools and having teachers who can become mentors (Werner, 2000).

Although these protective factors are not the main focus of communication training, they should be mentioned within a comprehensive PHC programme, aimed at addressing the communication needs of CSDs. It is expected that an awareness of broader issues will impact on the quality of services provided and therefore the following 2 generic principles and their application to a communication training programme for CSD and their primary caregivers, should be kept in mind:

- A comprehensive PHC approach should address broader issues, such as protective factors. An awareness of protective factors by community health nurses (together with training in collaboration and multiskilling) should enable them to address these issues with the primary caregivers of CSDs. This might in turn impact positively on the grandparents, siblings etc. (Eggbeer, 1995).
- A comprehensive PHC approach should aim at maximising protective factors that have been known to impact positively on development and growth (Meisels, 1992). The maximising of protective factors by community health nurses should impact on the social inclusion of CSDs and impact positively on the number and variety of communication partners that CSDs are exposed to (Johnson *et al.*, 1996).

### 2.3.2 Comprehensive versus selective PHC approaches

Following the debate related to measuring the effectiveness of PHC programmes, two schools of thought emerged. “**Selective PHC**” focused on the transferring of existing technology and skills in as short a time as possible. This refers mainly to medical interventions aimed at improving the health of most individuals at the lowest possible cost. On the other hand, “**comprehensive PHC**” focuses on the developmental process through which people could improve both their life and their life style, stressing the importance of good health (Rifkin & Walt, 1986).

Selective PHC raises a number of concerns. One of the major concerns being the fact that it negates community participation, reinforcing authoritarian attitudes as professionals decide which aspects should be addressed in the programmes (Brown, Baine & Neufeldt, 1996). This is inconsistent with one of the main focuses of PHC, namely the inclusion of the community in all aspects of service delivery, including a needs assessment. In the past, the exclusion of community members resulted in a lack of representation in community affairs with a consequent neglect of their needs and a skewed view of the realities and needs of the particular community (Brown *et al.*, 1996; Lundgren-Lindquist & Nordholm, 1993). Selective PHC also focuses on individual with so-called “priority diseases”, leaving the rest of the community to suffer. Despite these concerns, this type of model is often selected, due to the fact that funders tend to allocate money for selective PHC projects, as results are recordable (as opposed to measuring abstract variables such as community participation) and the fact that selective PHC service delivery can be provided to a large population (e.g. vaccinations) with relative ease, leading to arguments that it is cost effective (Rifkin & Walt, 1986).

In addition, by identifying and promoting specific programmes, attention is diverted from the process of development (which is the focus of comprehensive PHC). This can lead to selective PHC programmes being seen as “magic bullets” that are fired into countries to solve specific problems, raising false hopes in the communities regarding improved health. Health is thus seen as a static, measurable unit which can be described in terms of health status as a result of the medical intervention (Rifkin & Walt, 1986). The philosophy of the medical model of intervention, namely active service provision by professionals who each focussed on their own discipline, acting as experts who assessed, developed and prescribed services to passive recipients in the communities, thus prevails to a large extent in selective PHC (Atkins-Burnett, 2000).

On the other hand, comprehensive PHC views health as a dynamic changing condition, which is the result of motivation, action and/or attitudes. In an attempt to improve health as such, programmes therefore have to be aimed at improving a wide range of lifestyle issues (Lequerica, 1997). Health is also seen as a condition which improves gradually and instead

of expecting major changes in the shortest time possible, programmes should move one step at a time (Brown *et al.*, 1996). With comprehensive PHC the improvement of health can only come over time as change has to not only be on the health level, but also on the social, economic and political levels (Rifkin & Walt, 1986). The control of the outcome therefore lies in the hands of those who use, or should use the intervention programmes, but due to the different levels of expected outcomes (e.g. social, economic and political), the programme planners have no control.

In the present study, a comprehensive PHC approach is advocated as community health nurses will be trained to provide communication training to CSDs and their primary caregivers. The scope of the training programme should not only focus on one specific skill, but should aim to address prevention, participation and protection of CSDs within a PHC context. In addition, the process of developing such a training programme should be highlighted, as community health nurses should be included in all the phases of development, including the needs assessment. This is an essential element in the empowerment of community health nurses to provide services to CSDs and their primary caregivers which will impact on the sustainability of service delivery. It has been recorded that a personal interest and/or investment in a project, the opportunity to take action and make meaningful contributions and the development and recognition of individual resources, all impact positively on empowerment (Homan, 1999). A training programme should therefore be aimed at adherence to these principles.

## **2.4 TRANSDISCIPLINARY TRAINING : A COMMUNICATION ORIENTATION**

In this section the features of transdisciplinary training and how it relates to communication training, will be described, followed by an outline of the participants involved in the proposed training. This section will be concluded with a description of two approaches to transdisciplinary training in communication training, namely multiskilling and collaboration.

### 2.4.1 Features of indirect services

The provision of beginning communication skills to CSD by means of community health nurses training primary caregivers of CSD, is characterised by an indirect service approach implying that professionals involve themselves as collaborators to a greater extent (Buysse, Schulte, Pierce & Terry, 1994). This should, however, not imply that professionals provide less direct, hands-on services. In fact, professionals who cease to do this, become less effective professionals, both to clients and colleagues. According to Orelove and Sobsey (1996) indirect service delivery to CSDs incorporates four basic assumptions, which are described in Table 2.2. The realisation of these assumptions for communication training is also included.

**Table 2.2 Indirect service delivery: basic assumptions and realisation for communication training**

<b>Indirect therapy assumptions</b>	<b>Realisation of assumptions for communication training</b>
Milieu teaching yields best results with CSDs	Communication training should be conducted in the natural environment by the primary caregiver (Leahy, 1989). All communication means and functions are thus embedded naturally during the CSDs routine and are not seen as separate aspects that require training (Bricker, 1992). Therefore additional “ <i>communication time</i> ” or “ <i>therapy time</i> ” is not set aside (McGregor, Young, Gerak, Thomas & Vogelsberg, 1992).
Activities should be functional	ADL (e.g. mealtime, washing and dressing) can provide the content for interaction training (Coupe, Barton & Walker, 1992). These activities should be conducted in a functional manner, i.e. at appropriate times during the day with natural consequences, e.g. if CSDs request “ <i>more porridge</i> ” during mealtime, more porridge is given (McGregor <i>et al.</i> , 1992).
Rehabilitation should be provided throughout the day and in all the settings in which CSDs function	Research has shown that “ <i>salt and pepper contacts</i> ” spread throughout the day yield favourable results with CSDs (McCormick & Schiefelbusch, 1984). Therefore activities that occur relatively frequently should be selected. The nature of many of the communication functions that are taught should be generic, e.g. requesting “ <i>more</i> ” which can be used irrespective of the activity. Likewise, the deliberate creation of communication opportunities should not be restricted to specific activities, e.g. putting a desirable object out of reach.
Skills must be taught and verified in settings in which they occur naturally.	Primary caregivers should be taught how to provide communication opportunities within naturally occurring settings throughout the day in order to enhance and extend communication functions and means, and how to be sensitive towards existing communication attempts (Reichle, Mirenda, Locke, Piché & Johnson, 1992).

The second major feature of transdisciplinary training is that it is characterised by role transition. This implies the crossing of traditional disciplinary boundaries where professionals work together and share their expertise and exchange certain roles and responsibilities to develop new ideas and strategies for service provision (Chapman & Ware, 1999; Lloyd, Fuller & Arvidson, 1997; Orelove and Sobsey, 1996). This would specifically mean that the skills associated with one profession could be taught to others who work with the specific client, e.g. the SLP can train community health nurses to train primary caregivers how to deliberately provide communication opportunities to CSDs when teaching the concept of “*requesting help*”. This will lead to less fragmented services and will provide CSDs with more opportunities to practise this communication function. Role transition is a process and consists of six separate but related processes, (Orelove & Sobsey, 1996; Parker, 1994) which are described in Table 2.3. The realisation of these assumptions in communication training is also included.

**Table 2.3 Role transition process and realisation in communication training**

<b>Role transition process</b>	<b>Realisation in communication training</b>
<b>Role extension</b> Increasing theoretical knowledge and clinical skill in own discipline.	Emphasise the nursing task (e.g. prevention). This is similar to multiskilling Level 1.
<b>Role enrichment</b> Development of a general awareness and understanding of the terminology and basic practices of other disciplines.	Programme should explain concepts such as “communication” and “severe disability” which are novel to community health nurses. Service delivery to CSDs traditionally takes on the form of direct referral. Training aimed at increasing the knowledge in the communication and disability fields by explaining some of the basic concepts. This is similar to multiskilling Level 2.
<b>Role expansion</b> Acquiring sufficient information to make knowledgeable observations and recommendations outside own discipline.	Sensitising of community health nurses to the issues pertaining to CSDs and their primary caregivers and enabling them to make informed recommendations while also providing support. This is similar to multiskilling Level 3.
<b>Role exchange</b> Learning the theory, methods and procedures of other disciplines and beginning to implement the techniques.	Equipping community health nurses with the necessary knowledge and skills to provide basic services to CSD and their primary caregivers. Four important communication elements, namely communication functions, means, partners and how to create deliberate communication opportunities should be addressed (Reichle, <i>et al.</i> , 1992). This is similar to multiskilling Level 4.
<b>Role release</b> Putting newly acquired techniques into practice with consultation from the team member from the discipline is accountable for those practices.	After initial training, all community health nurses should be visited in situ to assist them with the implementation of the communication training programme and to help with problem-solving of difficult cases. The effective functioning of a professional at this level is often dependent on whether this type of support is given. In training efficient transdisciplinary professionals caution should be taken not to terminate training without this process.
<b>Role support</b> Informal encouragement from other team members and back-up support by the team member for the appropriate discipline.	A cadre of community health nurses from the same health district (Moretele) should be trained to provide an infrastructure for service delivery to CSDs in this area. In addition, the trainer should be available to the community health nurses for an extended time.

From this discussion it is clear that in order to function effectively as a transdisciplinary professional, knowledge and skills are crucial features. One way of equipping professionals with the necessary knowledge and skills is through the use of multiskilling. This will be described in detail in Section 2.4.3. This leads to the question of who the participants in the proposed transdisciplinary training are.

## 2.4.2 Participants

As discussed in the previous section, transdisciplinary training has two major features, namely indirect service delivery and collaboration, raising the question as to who should participate in this process. In a communication training programme aimed at a PHC

level,, three major participants are involved, namely the community health nurses, the primary caregivers of CSDs and the CSDs themselves. Brief mention will also be made of “other” participants, who are involved to a lesser extent namely the community at large and other professionals. However, it should be noted that although the roles of all these participants are mentioned, the focus of this research is on the community health nurse.

#### **2.4.2.1 Community health nurses**

Community health nursing is not merely the performance of nursing activities in the community setting. It should rather be seen as ongoing, comprehensive and general practice that is not limited to a specific age or diagnostic group aimed at the promotion of health and the prevention of illness (Clark, 1996; Lerner & Ross, 1991). It is also differentiated from other nursing fields by the fact that it includes nursing directed at individuals, families and the community at large, placing community health nurses in a prime position to assist with the paradigm shift away from the medical model to the social model of service delivery (Thomas, 1999a).

Defining the roles of community health nurses is difficult due to the fact that it remains in transition due to the changing needs of the communities they serve (Clark, 1996). However, regardless of the setting in which community health nurses work, they must be capable of performing certain generic roles. These roles within the four multiskilling levels (as discussed in Section 2.4.3) are depicted in Figure 2.3.

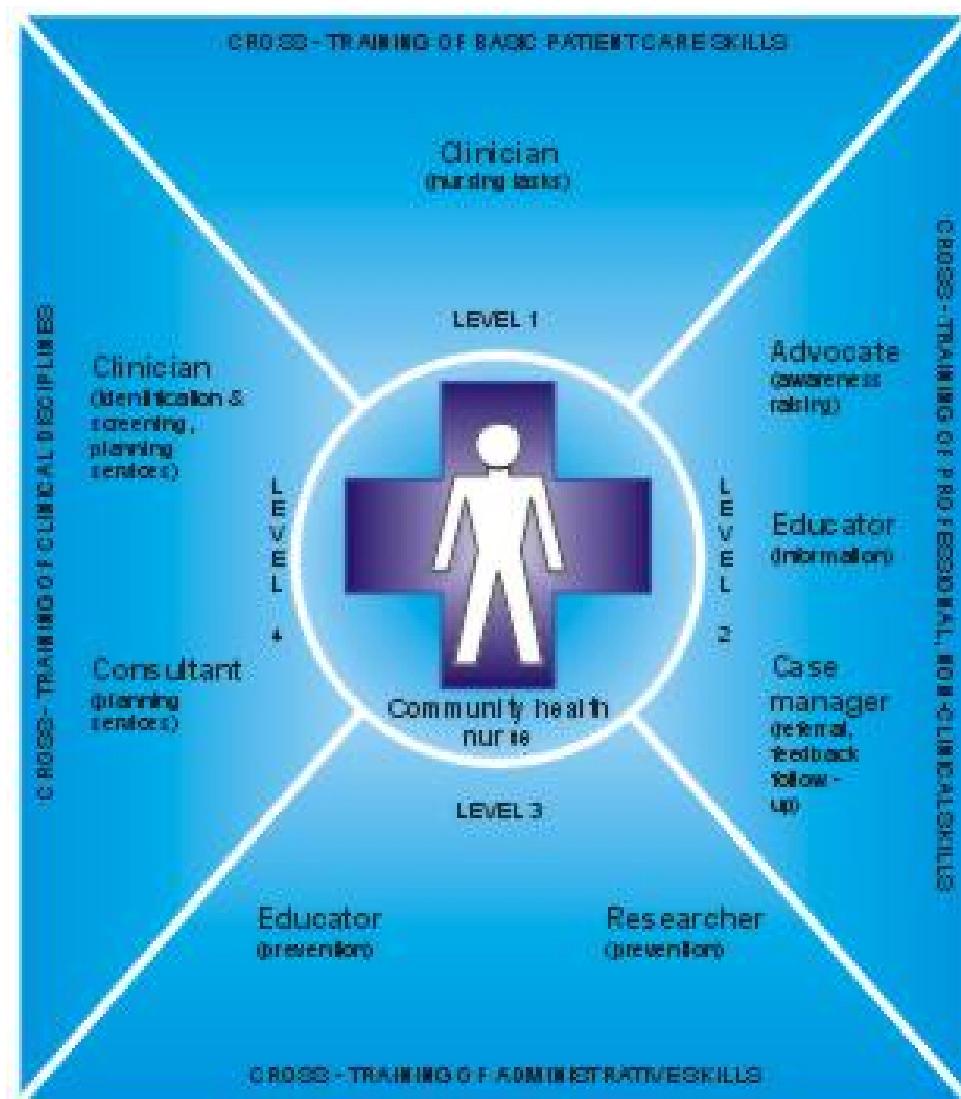


Figure 2:3: Roles and tasks of community health nurses within multi-skilling levels

Regarding the first multiskilling level, the community health nurse has the role of **clinician**. Community health nursing includes both personal health (that focuses on the individual and mostly includes the maintenance of health and recovering from illness) and public health (that promotes and protects health of the community) (Wilkey & Gardner, 1999; Thomas, 1999a). At this level the activities mostly refer to traditional nursing tasks based on the basic nursing curriculum. Therefore it will not be discussed any further.

At the second multiskilling level the community health nurse has three major nursing roles, that of advocate, educator and case manager. The ***advocate*** role requires of the community health nurse to speak or act for individuals who may be unable to speak for themselves (e.g. CSDs and their primary caregivers) (Clark, 1996; Glassman-Feibusch, 1984). The reasons for this may include a lack of knowledge, difficulty or inability to articulate needs or ideas, fear, perceived lack of power and/or intellectual/physical disability (Wilkey & Gardner, 1999). However, advocacy does not only mean taking the part of others, it also entails the preparation of individuals to stand alone and speak for themselves rather than remaining dependent of the nurse (e.g. by introducing them to DPOs) (Clark, 1996). Because of the close contact with CSDs and their primary caregivers nurses are often the best health professional to promote their needs and desires. One of the major nursing tasks would be awareness raising in the community about disability issues, e.g. by having health talks. Linked closely to the advocacy role is that of ***educator***. Health teaching and the provision of information are viewed as essential nursing responsibilities. This can be conducted at the individual level (assisting CSDs and primary caregivers to make informed decisions about rehabilitation) or at a community level (e.g. health talks about disability) (Wilkey & Gardner, 1999). Thirdly, the nurses act as ***case managers*** at this level, implying the application of strategies for co-ordinating and allocating services for individuals who cannot manage their own care (e.g. CSDs and their disempowered primary caregivers) (Lerner & Ross, 1991; Wilkey & Gardner, 1999). The primary nursing tasks as applied to CSD and their caregivers would entail identification of CSDs, referral when needed, highlighting the importance of feedback and follow-up in an attempt to monitor progress. Community health nurses should be sensitive to the needs and circumstances of the primary caregivers as they may appear to be non-compliant (e.g. may not attend referral and/or not return for feedback and follow-up) if they do not share the professional's values and priorities which in turn leads the nurse to experience frustration and hostility (Humphry, 1995).

At the third multiskilling level community health nurses act primarily as ***educators*** and researchers. The importance of education has already been highlighted. At this level

education is specifically related to the prevention of disability (at primary, secondary and tertiary levels). In order to enhance this prevention function, the community health nurse also has to act as **researcher** (Wilkey & Gardner, 1999). This may include tasks such as identifying problem areas, collecting, analysing and interpreting data, applying findings, and evaluating, designing and conducting research (Griffith, 1994; Wilkey & Gardner, 1999). Research is an excellent tool in addressing the complex issues pertaining to prevention.

Finally, at the fourth multiskilling level, the nurse also has two main functions – that of clinician and that of collaborator. The role of **clinician** at this level is broader than on the first level as it also entails a rehabilitation function. At this level it is expected that nurses act as transdisciplinary professionals, moving beyond the traditional boundaries of their discipline. It requires that community health nurses identify, screen and plan services for CSDs. Grebin (1981) spelt out what the exact nursing tasks with specific populations, e.g. a child with Down Syndrome, would be. This included determining aetiology (to provide genetic counselling), assessment and the management which entails counselling / prevention, follow-up, providing medication, collaboration and referral. The **collaborator role** is closely linked to providing services. This is also closely linked to other roles (e.g. advocate and educator) as consultancy requires of community health nurses to help individuals to understand their disability and to make knowledgeable decisions about their own rehabilitation.

One of the specific settings in which community health nurses are required to function, are rural PHC clinics. These clinics are usually single settings which are visited by individual clients with a wide range of health problems (Lequerica, 1997). According to the Department of Health (1999) these clinics should render comprehensive integrated PHC services using a one-stop approach (also termed “supermarket approach”) for at least 8 hours a day, 5 days a week. In addition, a seamless system of care is also promulgated. A seamless system of care is one which provides primary, secondary and tertiary services to ensure continuity. Although care at all three these levels is not offered at rural PHC clinics, community health nurses working at this level must be able to

arrange for services at the other levels (Roberts, Rule & Innocenti, 1998). In addition, a seamless system of care provides the full array of services through collaboration with various partners (e.g. in the public or private sectors) that allow access to all families needing a service, regardless of their ability to pay (Roberts *et al.*, 1998). In South Africa access to health services is ensured for all children under six years of age, but this is restricted as it refers only to public services. Collaboration with the private sector is seldom seen and then usually only if payment for the services can be guaranteed. Finally a seamless system of care helps families through the transition from one clinic to another (e.g. should they move) so that there is not a breakdown in services (Roberts *et al.*, 1998). In conclusion, it can thus be said that a seamless system of care is ideal, as it would create a safety net for all individuals within a particular community. In reality, however, this has not as yet been implemented effectively in the South African context.

The specific requirements of rural PHC clinics necessitate community health nurses to function in a slightly different manner. Community health nurses at these clinics:

- must be expert generalists because of the diverse skills they need when working with individuals across the lifespan with diverse health conditions (Clark, 1996; Hamell-Bissell, 1992; Tiffany & Hourigan, 1992).
- need to be independent and self-reliant since they make on-site decisions at clinics that can be some distance from support (Thobaben & Biteman, 1999).
- should have community ties and relationships, which provide close family contact and potential for continuity of care. Must be able to tap local resources (Eayrs & Jones, 1992; Hamel-Bissell, 1992; Thobaben & Biteman, 1999).
- have a high social visibility (leading to relatively little privacy) and their social and professional roles intertwine to such an extent that inadvertent breaches of confidentiality are a concern (Hamell-Bissell, 1992).
- have a positive community visibility that has been linked to professional pride, self-esteem, and potential role in shaping health policy at the community level (Tiffany & Hourigan, 1992).

- require a broader blend of knowledge and skills because fewer service options are available (Hamel-Bissell, 1992; Thobaben & Biteman, 1999).
- display certain personal attributes including a higher level of emotional maturity and a greater desire for autonomy (Hamell-Bissell, 1992).

The major problems experienced at these rural PHC clinics relate to professional isolation, limited support services, insufficient continuing education opportunities, limited peer contact, excessive workloads and time demands (Gordon, 1994; Tiffany & Hourigan, 1992). In order to address these problems, to meet the diverse demands placed on community health nurses, and to be compatible with the new health care environment which requires more flexibility in the deployment and management of health resources, interesting trends in service delivery are seen (Salvatori, 1997). Two suggested approaches in a communication training programme to address these issues are multiskilling and collaborative practice which are described in detail in Sections 2.4.3 and 2.4.4 respectively.

#### **2.4.2.2 Primary caregivers**

Primary caregivers are defined as those individuals who assume the majority of caregiving responsibilities (Shippee-Rice & Mahoney, 1992). In southern Africa these are primarily mothers, as many women are abandoned by their husbands as a result of the birth of their disabled child (Miles, 1996).

The belief that service delivery to CSDs is a complex and specialised task that should be left to professionals, is visible in the fact that primary caregivers are not getting enough help with the care, education and training of their CSDs (O'Toole, 1988). This was highlighted in a study by Dunbar & Reed (1999) where professionals who work at PHC clinics reported a lack of awareness of primary caregivers regarding developmental milestones and how to foster developmental skills, as well as a need for support in child

rearing. It was also noted that limited opportunities for typical play experiences exist and that primary caregivers are unaware of disciplinary alternatives (e.g. available services).

The lack of support to, and training of primary caregivers happens despite the fact that the importance of training is highlighted time and again in the literature (Coats & Lewis, 1984; House *et al.*, 1990; Kalmanson & Seligman, 1992; Kelly & Barnard, 2000; Ramey & Ramey, 1992). Early, intensive family support has the potential to improve long-term functioning in families, stressing the fact that social support to the primary caregiver as a protective factor, should not be overlooked (Beckwith & Sigman, 1995). If training is therefore focused on achieving long-term effects it should focus on increasing the primary caregiver's knowledge, attitudes and practices regarding the child's development (Downs & Walker, 1996; Parush & Hahn-Markowitz, 1997). Primary caregivers should share the responsibility of rehabilitation and care with professionals to ultimately lead to joint decision-making (Chapman & Ware, 1999; McDaniel, Campbell & Seaburn, 1990). Primary caregivers should also act as a support network for each other and opportunities for them to meet and share ideas and experiences and to help solve each other's problems should be a high priority of any programme (Atkins-Burnett & Allen-Meares, 2000; House *et al.*, 1990). The fact that they often share beliefs, behaviours and values with other parents in a similar position, makes them ideally suited to take on this role (McDaniel *et al.*, 1990). PHC settings are the most logical and likely place to start when capturing interest and involvement of parents who feel motivated and willing to help (Downs & Walker, 1996; Dunbar & Reed, 1999). Case-Smith (1997) also reported that sustainability is increased if the proposed service could be latched onto an existing service (e.g. latching communication training to clinic visits).

It has been reported that primary caregivers have a positive effect on their children's development and that guidance enhances their ability to function comfortably and completely in their parental role (Case-Smith, 1997). Links have been found between parent-child interaction and the child's later cognitive and social development (Mavrogenes, Bezruczko & Hagemann, 1996; Ramey, Farran & Campbell, 1978; Sameroff, Seifer, Barocas, Zax & Greenspan, 1987). It has also been reported that if

primary caregivers participate in training programmes which emphasise empowerment and nurturance, a number of positive outcomes that will impact favourably on the growth and development of their CSDs are seen (Case-Smith, 1997; Downs & Walker, 1996; Blumberg, 1987), including:

- Increased sensitivity and responsiveness towards their children, resulting in more positive parent-child interaction.
- Heightened involvement with their children, resulting in improved physical care.
- Increased enjoyment of the child resulting in increased stimulation and interaction.

These training programmes also tend to increase parental nurturance and mothering (Provence, 1985). Mothering can be described as intrinsically (actions and responses that are naturally mediated) and learned (where knowledge is gained about child development). This knowledge is gained in a variety of ways, including the modelling of one's own mother's behaviour, through the dynamic involvement with the child, through reading literature on child development and also through attending mothers' groups (Provence, 1985). In a study conducted by Parush & Hahn-Markowitz (1997) it was found that prevention programmes contributed to the mother's knowledge about child development, regardless of the number of years of formal education, thus minimising the effect of formal education. This aspect is particularly relevant in the South African context where a large proportion of mothers do not have more than 13 years of formal schooling and research has shown that with higher education comes a greater awareness and knowledge of child development. However, it was reported that the determining fact in increasing knowledge and skills in the specific study was the mother's drive to learn new skills and the awareness that she needs new skills (Parush & Hahn-Markowitz, 1997). In cases where a mother is unaware or unmotivated that she needs mothering skills, motivation and encouragement from an outside source is needed. From the above it is clear that the involvement of primary caregivers is essential for young children, as they provide the guided stimulation and take on the roles of observer, describer, interpreter,

evaluator and validator of behaviour inside and outside service delivery (Blacklin & Crais, 1997).

In conclusion it can be said that long-term benefits of early intervention programmes appear to be closely linked to the inclusion of primary caregivers as active participants in efforts to bring about change and facilitate development (Chapman & Ware, 1999; Kelly & Barnard, 2000; Provence, 1985). It should also be stressed that parent-professional collaboration is a continuous process (Brandt & Magary, 1989). Furthermore, research showed that the nature of interaction is more important than teaching the child specific skills or directing his activities (Case-Smith, 1997). The reason is that the primary caregiver's interactional style highly influences the child's development. Two important aspects of the primary caregiver's interactional style have been singled out as important predictors for outcomes: their control (directiveness) and their responsiveness (based on sensitivity). Regarding children's behaviour, three important aspects have been singled out: attention, readiness and responsiveness (Kelly & Barnard, 2000). It should, however, be noted that if a child has a disability, not only the quantity but also the quality of interaction is changed.

Several factors contribute to feelings of satisfaction in caring for CSDs or mediating the level of burden and stress, e.g. the empowerment of knowing what to do (Shippee-Rice & Mahoney, 1992). Higher levels of satisfaction reduce the chances of abandonment and institutionalisation. Consequently programmes must be sensitive in promoting and reinforcing factors that enhance the caregiver's experiences but should also look at caregiver's stress and burden (Dunst, Trivette & Deal, 1994; Shippee-Rice & Mahoney, 1992). This includes the extent of disruptions or changes in the caregiver's life and household as well as the stress and nervousness related to the situation and the extent to which the caregiver feels manipulated by the CSD. Caregiver stress leads to "burn out", the development of health problems and the provision of poor care and possibly mistreatment the CSD (Shippee-Rice & Mahoney, 1992).

One way of counteracting caregiver stress is by joining a support group and being involved in disability and advocacy groups (e.g. DiCAG). In South Africa primary caregivers have argued that they are disabled by virtue of being full-time carers of their CSDs and that together with their children they are affected by the stigma of disability (Miles, 1996). Consequently they joined DPOs which enabled them to pursue their own specific agendas while at the same time maximising the opportunity of being part of the disability organisation (Miles, 1996). These primary caregivers no longer feel isolated and “left out”. The key to sustainable service provision is empowerment of primary caregivers as they are learning new skills, acquiring a raised self-esteem and confidence and are committed (Dunst *et al.*, 1994; Miles, 1996). Trained caregivers experience changes in attitude and have a greater appreciation for disability issues. They often feel committed towards rehabilitation, the changing of negative community attitudes, the counselling of other CSDs and their caregivers about education, employment and rehabilitation. They consider themselves as a responsible resource in their communities which has given them the confidence to provide advice and information to families, support groups and self-help groups (Miles, 1996). The community health nurse can play a definite role in assisting primary caregivers to join support groups and DPOs.

This discussion has argued that involvement of the primary caregivers is non-negotiable when attempting to ensure sustainable service delivery. The importance of involvement, empowerment (to facilitate joint decision-making) and the joining of DPOs as a method of decreasing caregiving stress and increasing competency, were emphasised. A communication programme should thus aim at the training of the primary caregiver (as well as any other interested person, (e.g. older sister), by a trusted person from the community, to facilitate basic communication principles in the particular child. In order to ensure sustainability of services the training programme should have a transdisciplinary PHC focus, while being accessible, available, acceptable, equitable and be conducted in a spirit of collaboration in order to ensure prevention, protection and participation for the CSD. The community health nurse is in an excellent position to conduct this type of service given the fact that she receives knowledge and skills training.

### 2.4.2.3 Children with severe disabilities

Research has indicated that the majority of children with mild to moderate intellectual impairment come from families with extremely low resources and with parents who have limited intellectual resources themselves, but these families are the ones most in need of early intervention and who benefit the most (Ramey & Ramey, 1992). Young children of low IQ mothers (mothers with an IQ<70) are particularly vulnerable if they are not exposed to early, intensive intervention. Fortunately research indicated that these children respond positively to intensive, high quality intervention, leading to a dramatical decrease in the rates of intellectual impairment (Ramey & Ramey, 1992.) Young children thrive in a supportive environment that offers basic opportunities and interaction with those who are responsible for their everyday well-being (Ramey & Ramey, 1992).

Within the sphere of CSD one particularly vulnerable group are the beginning communicators. According to Beukelman & Mirenda (1998) beginning communicators refers to individuals across the age range who have one or more of the following characteristics:

- They do not demonstrate communicative intentionality
- They rely primarily on pre-linguistic communication means such as gestures, vocalisations, eye-gaze and body language
- They are learning to use aided or unaided symbols to represent basic messages for communicative functions such as requesting, rejecting, sharing information and engaging into conversations
- They use low technology communication means (e.g. communication boards, switches or electronic devices with limited message abilities) for communication and participation.

Beginning communicators should be the target population for intervention for a number of reasons. Firstly, due to the fact that CSDs who do not receive services from a relatively

early age (as typically seen in rural areas in South Africa) often remain at this level of interaction. Secondly, the term “*beginning communicators*” includes individuals from across the age range which typically covers the different age groups that community health nurses would be confronted with in PHC clinics. Although it could thus theoretically include adults, the focus of this research is on children. Thirdly, it encompasses individuals with a wide variety of disability types, and is not specific to only one aetiology – as such a specific programme runs the risk of being so “elitist” that it is never used. There is evidence that individuals who experience similar communication difficulties (e.g. beginning communicators) have much in common regardless of the specific disability involved (Granlund & Sundin, cited in Granlund & Olsson, 1999). Finally this may also include individuals who have a mild or moderate disability and who are in the early stages of rehabilitation. All beginning communicators require support to learn that through communication they can have a positive impact on their environment and the people around them – the beginning of participation.

It is also important to note that if beginning communicators is the target population, early intervention would be ensured. Early intervention in this sense is a broad term which refers to a timely intervention, and as often stated in the literature the earlier intervention starts, the better (Meisels, 1992). Due to the fact that beginning communicators are not necessarily ascribed to a specific age group, early intervention in this sense should not be confused with early childhood intervention that typically refers to children aged 0 – 3 years (Louw & Weber, 1997) or the expanded version of this definition used by the Department of Health which includes all pre-schoolers (typically 0 – 6 years)(Government Gazette, 17910, 1997).

Bronfenbrenner (1994) identified three important types of characteristics of this population which are likely to impact on the outcome of the service delivery, viz.

- **Personal attributes.** This includes the type of disability, age and gender. These aspects have a weak to moderate influence on the effects of communication intervention in everyday interaction.

- **Personal qualities.** This relates to all the factors that invite or discourage reactions from the environment and includes the bio-behavioural state (alertness level), the individuals affective expressions and the temperament/behaviour style (fussiness, frustration and goal-directedness). These three aspects have an impact on the frequency and type of communication interactions.
- **Developmentally structuring attributes.** These attributes include aspects such as intellectual curiosity and exploration of the environment and involves the active orientation towards the environment.

It can be seen that these characteristics are closely related to the protective factors mentioned in section 2.3.1.3.

#### 2.4.2.4 Others

“*Others*” refer to participants who are not necessarily directly involved in communication training, but who should be considered throughout the training process to ensure the sustainability of the services. It includes the community at large and other professionals.

##### i.) Community at large

In placing service delivery within a PHC approach, it must be acknowledged that rehabilitation is too important to be left only to the professionals (Thorburn & Marfo, 1990). Communities have to be made aware of the persons with disabilities in their midst and of what can be done to assist them in becoming more active participating members of society (McConkey, 1996). The “*person-within-community*” principle, should be adhered to at all times as all individuals are part of a larger community (Kelly & Barnard, 2000; Murray, 1980). Community participation is the heart of PHC and should capitalise on the community members’ experiences, wisdom and cultural sensitivity (Rifkin, 1986). Furthermore, service providers and communities often do not discuss their expectations of PHC, leading to expectations not being met, resulting in decreased motivation and

participation. It is important to realise that community participation is a dynamic process that constantly changes and it should remain flexible as people and objectives change. For communication training to thus be effective, community health nurses should be encouraged to have frequent health talks on disability and related issues in order to raise awareness of these issues. They should also be encouraged to assist DPOs in their specific communities by raising awareness of the existence and operation of these DPOs.

## ii.) Professionals

Transdisciplinary training does not attempt to negate the importance of specific disciplines. Rather it attempts to create a greater understanding and appreciation of the specific roles of each of the disciplines involved. It also emphasises the role of closer collaboration between team members (Blackstone, 1995). The traditional roles of therapists are changing despite the initial inertia. In order to increase time management and to provide services to all in need, they need to refocus their attention on consultation and collaboration as opposed to providing direct therapy (Hesketh and Hopcut, 1997). In future professionals (and in particular therapists) will become increasingly important as trainers and they will have to adapt their professional skills and share their knowledge (House *et al.*, 1990).

An effective communication training programme should address the issue of a shortage of trained professionals who could provide rehabilitation services to CSDs (Bortz *et al.*, 1996; Moodley *et al.*, 2000). It should also regard service delivery to this population as too important to be left until such a time as professional involvement seems feasible (Jephson, 1992). Thus the focus should be on training community health nurses to provide a basic level of communication training to CSDs and their primary caregivers in an attempt to initialise the rehabilitation process.

### 2.4.3 Multiskilling as integrally related to transdisciplinary training

Multiskilling is a form of role diversification and refers to the cross-training of professionals to perform procedures and functions in two or more disciplines (Allerton, 1997; Salvatori, 1999). It is thus a redesign strategy aimed at enhancing cost-effectiveness, efficiency, quality and co-ordination of services (ASHA, 1996). Multiskilled health professionals can be defined as “*Persons cross-trained to provide more than one function, often in more than one discipline. These combined functions can be found in a broad spectrum of health related jobs, ranging in complexity from the non-professional to the professional level, including both clinical and management functions. Traditional functions (skills) added to the original health care worker’s job may be of a higher, lower or parallel level*” (Bamberg in ASHA, 1996:54).

Multiskilling is much more than simply transforming staff into “*jacks of all trades*” (Salvatori, 1997). It offers opportunities for job expansion and job enrichment in the shape of new or expanded roles and responsibilities, skill sets and job titles, and it usually implies in-service training rather than formal education (as is done in the BCIP training). It does not mean the loss of one’s professional identity nor does it imply the demise of specialists. Opportunities exist for all service providers to maintain their speciality skills and at the same time develop or expand roles, skills sets without giving up their professional identity (Salvatori, 1997). Service providers with skills and competencies in more than one area are likely to be regarded as more cost-effective and more employable than their traditional single skilled counterparts (ASHA, 1996). Multiskilling was selected as the initiative by which community health nurses are equipped with transdisciplinary skills to deal with the problems that confront them in rural PHC clinics when having to deliver high quality sustainable services to CSDs and their primary caregivers.

As discussed in this chapter an increasing emphasis on community health versus individual health, community-based care versus hospital-based care and health promotion and illness prevention versus curative approaches are currently seen (Salvatori, 1997). The role of community health nurses was elaborated as they are often the first and only professionals in rural areas where no other services are available and therefore they

should take leadership roles in emphasising the need for human care, as the right to health is one of the principles of *Health for All by the Year 2000* (Graham, 1981). This is further enhanced by the fact that they understand the concerns of the people they serve – they see where people work, play, live, study, worship and die (Humphry, 1995). In addition a shortage of manpower to provide services to CSD is experienced. Although community health nurses are thus in an excellent position to provide services to CSDs and their primary caregivers, traditional nursing curriculums do not include specific service delivery strategies for this population. One way in which this can be addressed is through the multiskilling of community health nurses to equip them with the knowledge and skills to function as transdisciplinary professionals. Therefore the focus of a communication training programme should be on training community health nurses to provide a basic level of services to CSDs and their primary caregivers in an attempt to initialise the rehabilitation process.

A communication training programme that focuses on CSDs and their primary caregivers, raises the question as to why community health nurses should know about disability. They include:

- Community nurses are often the first professionals who come into contact with CSDs who are able to participate on different levels, depending on the degree and type of disability (Clark, 1996). In about 90% of cases intellectual impairment is moderate (IQ of 50 – 70) and with proper support and nurturing these children can live and learn in the community. It is known that most of these children live at home with their parents (or extended families) and thus need to adapt to community living, making it mandatory that their needs be viewed within the context of the family and the community (Freeman & Heinrich, 1981).
- The impact of disability is profound. It is permanent, placing high financial and care demands on the family and on the community (Beukelman & Mirenda, 1998). Timely services to this population will impact positively on the financial and care demands. There has also been evidence that if mothers of CSDs receive

training, they are more likely to be employed (Case-Smith, 1997; Downs & Walker, 1996).

- A strong move away from institutionalisation to “*inclusion*” of CSDs in all aspects of community living and learning (with increased participation of CSDs) is noticeable. This implies that CSDs are not sent to boarding facilities at an early age and that they remain in their communities for longer periods (Orellove & Sobsey, 1996). Consequently community health nurses come into contact with CSDs and their primary caregivers over longer periods of time.
- Community health nurses are part of the PHC team and often act as the bridge between caregivers and professionals. Caregivers usually perceive the nurse as an approachable and concerned advisor who can identify with the problems that concern the family. They will therefore discuss problems with her that they feel are too trivial to discuss with the doctor (Shanks, 1983). In addition the nurse also contributes valuable knowledge to the rest of the team due to her particular training, expertise and function (Bailey *et al.*, 1990). As previously mentioned, the importance of transdisciplinary functioning in a team is necessary when implementing community-based, family-centred, comprehensive and co-ordinated health care to disabled children and their families (ASHA, 1989).
- In view of the shortage of qualified health care professionals in South Africa (Bortz *et al.*, 1996), the community health nurse is ideally positioned to provide services to primary caregivers of CSDs (Moodley *et al.*, 2000). She is equipped to perform this task as she is viewed as a sensitised professional who has the skills to observe behavioural patterns and environmental concerns and thus able to make recommendations where necessary.

Consequently the pivotal role of the community health nurse within PHC rural clinics, together with the changing of services towards more client-centred, holistic, wellness-focused and community-based care, necessitates multiskilling. This is further compounded by factors such as changing demographics (with the majority of people in rural areas being very young or very old), technological advances and consumer

expectations which have contributed to the demand for more equitable distribution of resources, improved efficiency, public accountability and more consumer participation in decision-making (ASHA, 1996). Individuals are taking more interest in their own health, and want to choose their own service providers. Quality management demands more client-focused care and more emphasis on effectiveness and efficiency, including improved health outcomes.

In the proposed training programme, multiskilling was addressed by looking at the specific nursing tasks and its application to disability. This is also related to the different roles of the community health nurses as depicted in Figure 2.3. The four-multiskilling levels and how they apply to disability are provided in Table 2.4.

**Table 2.4 : Multiskilling levels as applied to various nursing tasks and disability**

Multiskill level	Nursing task	Application to disability
<b>Level 1</b> Cross-training of basic patient care skills		Not addressed in a communication training programme, as this is part of the regular nursing curriculum.
<b>Level 2</b> Cross-training of professional, non-clinical skills	Awareness	<ul style="list-style-type: none"> <li>▪ Create community awareness regarding the needs of CSDs.</li> <li>▪ Discuss community awareness with other professionals (e.g. school nurses and teachers).</li> <li>▪ Make parents and teachers aware of the importance of adequate, effective and appropriate communication skills.</li> </ul>
	Information	<ul style="list-style-type: none"> <li>▪ Provide information regarding CSD.</li> <li>▪ Provide information regarding expectations.</li> <li>▪ Provide information regarding further communication needs (long-term plan).</li> </ul>
	Referral	<ul style="list-style-type: none"> <li>▪ Initiate referrals to therapists.</li> <li>▪ Initiate referral for further medical management.</li> <li>▪ Assist therapists and teachers in determining whether a medical referral is necessary.</li> </ul>
	Feedback	<ul style="list-style-type: none"> <li>▪ Make primary caregivers aware of the importance of providing feedback to referring nurse.</li> <li>▪ Encourage other professionals to provide feedback to referring nurse.</li> <li>▪ Provide feedback to caregiver regarding the changing communication skills after implementation of the protocol.</li> </ul>
	Follow-up	<ul style="list-style-type: none"> <li>▪ Encourage caregivers to bring their children for regular follow-ups to monitor progress.</li> <li>▪ Assist caregivers to monitor the quality and quantity of communication (use the progress chart).</li> </ul>

Multiskill level	Nursing task	Application to disability
<b>Level 3</b> Cross-training of administrative skills	Prevention	<ul style="list-style-type: none"> <li>▪ Educate the community on causes of disability and how some conditions can be averted and prevented, e.g. pre-natal care, good nutrition (To some extent already being done).</li> <li>▪ Refer high-risk mothers.</li> <li>▪ Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-up.</li> </ul>
<b>Level 4</b> Cross- training of clinical disciplines	Identification and screening	<ul style="list-style-type: none"> <li>▪ Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history.</li> <li>▪ Conduct health assessment on identified children (at-risk and established risk).</li> <li>▪ Obtain baseline data on current functioning</li> <li>▪ Assist in obtaining the necessary medical evaluations.</li> </ul>
	Planning services	<ul style="list-style-type: none"> <li>▪ Initiate and implement the proposed beginning communication intervention protocol.</li> <li>▪ Suggest modifications to present communication means, functions opportunities and partners.</li> <li>▪ Reassuring caregivers of humanity and likeability of CSDs.</li> <li>▪ Encouraging caregivers of CSDs to start a support-group while waiting at the clinics.</li> <li>▪ Sustaining families through support and being an anchor (willing to listen and help).</li> </ul>

Modified and based on ASHA 1996, Dublinske, 1983, Mast 1983, Freeman & Heinrich, 1981 and job descriptions for community health nurses provided by the Assistant Director of Health in the Moretele Health District).

When looking at these multiskilling levels, it is important to note that these skills cannot be viewed as distinct categories and that extensive overlapping occurs. These skills are also dynamic in nature and may therefore change over time. However, in an attempt to clarify specific nursing tasks as it pertains to disability, this distinction was made.

#### 2.4.4 Collaboration as integrally related to transdisciplinary training

The second feature that is central to training transdisciplinary service delivery is collaboration. Collaboration is a process of joint decision-making in an atmosphere of mutual respect and co-operation (Buysse *et al.*, 1994; Wilkey & Gardner, 1999). Collaboration is required at many different levels. Firstly, the concept of holism in service delivery is emphasised as the CSD is viewed in interaction with the primary caregiver (usually the parent), but also as part of the community at large. This makes it

necessary for the community health nurses to collaborate closely with primary caregivers, and also with community members. Secondly, collaboration with other professionals are also required – ranging from other health care professionals (fellow nurses, doctors and therapists) to educational professionals (e.g. teachers) and professionals in the human and social fields (e.g. the church, social workers, psychologists, etc). It is important to note that this perspective should be kept at all times as one type of collaboration cannot be seen without being aware of the others.

Collaboration emanates from an understanding and appreciation of the roles and contributions that each discipline brings to the service delivery experience (American Association of Colleges of Nursing, 1996). While each discipline has its own focus, all participants are equal partners with mutual understanding and respect for the actual and potential contributions of the other disciplines as basis. Professionals, should therefore be seen “*as part of*” the service delivery plan and not as “*apart from*” this plan (McDaniel, *et al.*, 1990).

As mentioned earlier, the ability to collaborate is clearly vital when the plethora of health professionals and their increasing specialisation and role differentiation combine with the complexity of demands made by CSDs. Sharing information and the planning of services enables primary caregivers, professionals and all persons involved with the disabled child to work towards a common goal (McConachie & Pennington, 1997). Shared decision-making and joint responsibility should not only be viewed as impacting favourably on the CSD and the family. It also has positive outcomes for professionals, as energy is preserved, preventing “*burn-out*” (McDaniel *et al.*, 1990).

The specific skills needed for collaboration are negotiation, team-building, joint decision-making, and problem-solving, but despite the fact that they are all learnable skills, they are not often addressed in teaching curricula (American Association of Colleges of Nursing, 1996). Although the BCIP does not focus on these skills, it sensitises community health nurses to the importance of collaboration and the fact that within a transdisciplinary approach one professional has to take primary responsibility for

service delivery. Collaboration is seen as one of the primary tasks of a community health nurses as described in the “*Standards for Community Health Nursing*” (cited in Wilkey & Gardner, 1999:307). It notes that “*community health nursing requires planning and sharing with others in the community to promote health for the community, family and individual. Through the collaborative process, the special abilities of others are used to communicate, plan, solve problems and evaluate services.*” The role of the nurse has thus shifted away from the role of servant to the medical profession towards the role of helper and partner of people and communities (Salvage, 1995).

Collaborative practice is not new but will continue to be promoted because it scrutinises costs and maximises efficiency of care.

## 2.5 SUMMARY

The purpose of this chapter was to describe a transdisciplinary approach and its relation to CSDs. Transdisciplinary training was then linked to PHC with a communication orientation, highlighting the pillars of effective PHC service delivery (prevention, participation and protection) and a discussion of comprehensive and selective PHC approaches. Finally, transdisciplinary training was discussed in terms of the participants, the features and finally the approaches. Two specific approaches, namely multiskilling and collaboration that are used in the BCIP training, were highlighted.

## **CHAPTER 3**

# **THE DEVELOPMENT AND EVALUATION OF THE BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP)**

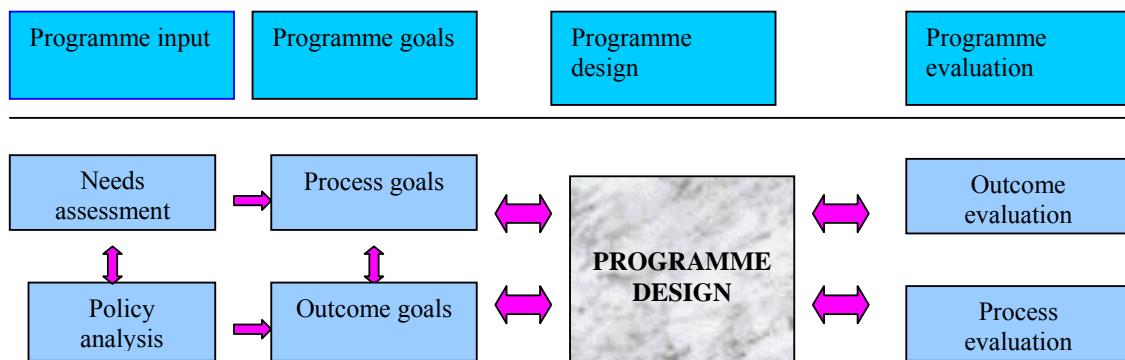
### **3.1 INTRODUCTION**

In Chapter 2 transdisciplinary training was described as an approach essential to providing communication training to CSDs and their primary caregivers at a PHC level. In this chapter the emphasis will fall on the principles that are required to develop an effective programme that can be used by community health nurses to meet the needs of CSD and their primary caregivers at a PHC level.

In order to ensure that the training of primary caregivers of CSD's by community health nurses is accountable and sustainable, a baseline measurement of what works, how well it works for whom it works and at which level of economic efficiency it works, is necessary (Granlund & Blackstone, 1999). Bricker (1997) argues that in order to achieve this, outcome measurements should be linked to the continuous evaluation of the programme that is used. In order to effectively evaluate a programme, Mitchell (1991) states that outcome evaluation and process evaluation as well as the relationships between the programme inputs, goals, design and evaluation, should be included. The advantages of using this Mitchell's Evaluation Model (Mitchell, 1991) to evaluate the proposed training programme are twofold. Firstly, it gives trainers the impetus to think clearly about the aims of the training programme facilitating an understanding of the assumptions and principles upon which it is based. Secondly, the programme evaluation becomes a process, which provides regular feedback, enabling an improvement of the programme for the target population.

### 3.2 DISCUSSION OF MITCHELL'S EVALUATION MODEL

As mentioned in the introduction, Mitchell's Evaluation Model is used for the purpose of this study due to its specific advantages and the value it will add when verifying the proposed training programme. The elements of this model are presented in Figure 3.1.



**Figure 3.1** Mitchell's Evaluation Model (1991)

#### 3.2.1 Programme input

The programme input consists of two elements, namely the needs assessment and the policy analysis.

One component of PHC (as discussed in Chapter 2) is the development of human resources, as equipping individuals with the necessary knowledge to care for themselves is seen as a major step towards improved health (Government Gazette 17910, 1997). This led to the development of the proposed training programme aimed at equipping community health nurses who work in rural PHC clinics with the knowledge and skills to guide primary caregivers of CSDs in the communication training of their children in an attempt to increase participation and independence. Although the primary focus (with subsequent outcomes) of the training programme is on the knowledge and skills of community health nurses, a number of secondary outcomes are also expected. This relates to factors that are not directly trained and include an increased understanding of

## **University of Pretoria, etd - Bornman, J**

their role in training primary caregivers and their CSD's (training the trainer), greater autonomy in assisting this population, more knowledgeable referrals to other professionals, e.g. speech therapy, social services, etc., increased motivation to work with CSDs and more attempts to raise community awareness in terms of disability issues. Although not the scope of this study, it is expected that it will lead to an increase in the child's health and well-being (as the importance of regular intervention and compliance with medical appointments are highlighted) as well as better emotional adjustments of the primary caregivers and other family members (Eayrs & Jones, 1992).

The above discussion highlights two important principles, the first being comprehensiveness, which was discussed in detail in Chapter 2. Due to the diverse needs of CSDs and their primary caregivers, the importance of role transition, training the trainer and collaboration of community health nurses, which is achieved through multiskilling, is advocated in this research. The second important principle is that the training programme should be criterion-referenced, rather than norm-referenced, as it will allow the measurement of community nurses' knowledge and skills against their own baseline (Bricker, 1997; Eayrs & Jones, 1992).

Apart from the input derived from the needs assessment, all programmes are subjected to other influences – some explicit, some more subtle, some originating in the broader community in which the programme operates, others in the theories and values of the professionals involved, making a policy analysis necessary (Mitchell, 1991). Three main sources that will impact on the present study have been identified.

Firstly, legal requirements should be considered and then that the proposed training programme is in line with the South African Qualification Authorities (SAQA) Act (South Africa, 1995) as it is based on essential outcomes and competencies (skills). Essential outcomes, such as those required by community health nurses when training primary caregivers and their CSDs, should be cross-curricular (as described in multiskilling), and broad (e.g. problem-solving as achieved by using a problem-based format) (Geyer, 1997). The focus of the training programme should thus be on skills and

how knowledge can be used and applied in their own work context. Although not the focus of this research, this training programme will also facilitate the realisation of a number of acts in the South African Constitution (South Africa, 1996a) and the South African Bill of Rights (South Africa, 1996b) which state that all children should have access to intervention and medical care, granting them the opportunity to achieve their full potential. In the longer term the timely provision of communication training could also make inclusive education which is the aim of the South African School's Act (South Africa, 1996c) a reality for many children.

Secondly, consumer demands should be considered. Focus group discussions and questionnaire responses indicated that community health nurses request training regarding CSDs and their primary caregivers (discussed in Chapter 4). However, in the development of the proposed training programme the end consumers (namely the primary caregivers of CSDs) were also consulted, which is in line with the motto of the Disabled Children's Action Group (DICAG): "*Nothing about us, without us.*"

Thirdly, different philosophies regarding intervention to CSDs and their primary caregivers prevail, due to the fact that participants trained at different colleges and/or universities. Some have not had an orientation towards parent-focussed intervention and/or viewing CSDs as part of the larger community. In addition, all the nurses involved have their own attitudes towards disability based on personal beliefs and guided by underlying values (Heimlich & Norland, 1994). This is a particularly important aspect in the multi-cultural, multi-lingual South Africa. Differences are therefore expected in how community nurses view intervention with this population (e.g. the belief that CSDs should be loved and cared for without any formal instruction, is still prevalent). These factors are considered in the design of the proposed training programme. Focus groups were held with community health nurses to determine what their experiences in working with CSDs are and their attitudes regarding disability. In order to address this, the training programme also commences with a short introduction regarding the way to define CSDs and what the role of community health nurses are in providing training to this population.

### **3.2.2 Programme goals**

The second section of Mitchell's Evaluation Model (Mitchell, 1991) provides a description of the programme goals, comprising two elements, namely process and outcome goals which interact with each other and exist in close synergy.

Process goals relate to the process to be followed in order to achieve the outcome goals and reflects the values, beliefs and theories that characterise a programme (Mitchell, 1991). The six main process goals defined by Mitchell (1991), and applied to the proposed training programme, are displayed in Table 3.1

**Table 3.1: Application of process goals to the proposed communication training programme**

<b>Process goals</b>	<b>Application to communication training</b>
Enhanced community coherence	Primary caregivers, CSDs and the community at large are viewed as the community health nurse's " <i>partners</i> ", which is in line with the PHC approach advocated by the proposed training programme. Community health nurses also receive information about " <i>social inclusion</i> " and are asked to discuss it during health talks focussed on disability issues.
Cultural sensitivity	The proposed training programme was developed locally; it is not a translation of a Western test. Focus groups and discussions with experts in the field and from the community ensured this.
Right to services	Community health nurses are the frontline workers in ensuring that all South Africans, in particular CSDs and their primary caregivers receive training so that they can reach their full developmental potential. As PHC clinics are relatively easy accessible to individuals who live in rural areas, this might also lead to earlier provision of training to this population.
Family integrity	The training programme is based on the assumption that the training of CSDs could be provided by their primary caregivers, provided they receive instruction and training. The training programme will aim at equipping community health nurses with the knowledge and skills to train primary caregivers in the provision of communication training to their CSDs in order to increase participation and independence. Primary caregivers will thus be strengthened and empowered by respecting their integrity, by enhancing their competence (through the provision of knowledge and skills in dealing with CSDs) by assisting them to access appropriate resources and by recognising their uniqueness.
Professional standards	The training programme focuses on the multiskilling of community health nurses in order to equip them with the necessary skills to function as true transdisciplinary professionals. By doing so they will be able to comply with all the roles and tasks set for them as described in Figure 2.3.
Accountability	Efficacy can be viewed as the measurement required in order to provide accountable services.

In designing outcome goals, short- and long-term goals should be considered, criteria for evaluating success, as well as timelines that can be used to determine the progress towards achieving the outcome goals (Mitchell, 1991). For the purpose of this study the short-term goals were to determine what knowledge and skills community health nurses could acquire with the specific training programme (the BCIP) within a period of one week with three in situ follow-up visits. The long-term goal was to see which knowledge and skills could be retained over a 5-month period. A positive long-term result would be a favourable indication that this type of training should be provided to all community health nurses as a part of their basic training curriculum.

Sevcik, Romski & Adamson (1999) raised the question of how to measure the specific changes following communication (AAC) training, given the fact that change is multi-dimensional. Should measures be general, e.g. increasing quality of life, or should they be specific, e.g. increased use of manual signs to request “*help*”? In addition, the expected change should be based on the criteria specified for the individual. It will not be possible to measure unanticipated effects in a pre-planned manner, therefore a clearly defined conceptual basis in relation to what would be considered as a “*positive outcome in intervention*” is needed (Granlund & Olsson, 1999). Functionality of the desired change, the interrelationships between the change observed and the goal of the intervention provided, as well as the development and stability of more mature interaction patterns can be used as guidelines. However, it will also be important to document and discuss the unanticipated effects of intervention at all levels (Granlund & Olsson, 1999).

In order to clear up some of the confusion in this regard, five domains of AAC outcome measurement have been proposed (Blackstone, 1995b; Granlund & Blackstone 1999). These domains and their implications for the proposed study are presented in Table 3.2.

**Table 3.2 Application of outcome goals to the proposed communication training programme**

<b>Outcome goals</b>	<b>Description</b>	<b>Implications for proposed communication training programme</b>
1. Clinical status	Teaching strategies and approaches	See section 3.2.3 where the principles on which a communication training programme should be based (e.g. the importance of milieu teaching) are described.
2. Functional status	Increasing functional communication skills and user satisfaction	Should aim at increasing participation and independence and should address the issue of expanding the range of communication partners.
3. Quality of life	<ul style="list-style-type: none"> <li>• Social impact</li> <li>• Educational / vocational impact</li> <li>• Increased communication opportunities</li> </ul>	Increased opportunities for communication (e.g. through increased partners and the deliberate creation of communication opportunities). Earlier detection and identification of CSDs might enhance school referral. Nurses should be trained to value the opinions of the primary caregivers.
4. Consumer satisfaction	Meeting of needs	The satisfaction of the community health nurses, the primary caregivers and CSDs and the community at large will impact on the level of participation. The CSDs and their primary caregivers should be more involved in rating output, as this will help with the planning of training, placing emphasis on functionality and not on test scores (Hesketh & Hopcutt, 1997). In addition, nurses should be asked to evaluate themselves regarding their knowledge, skills and attitudes towards CSDs, pre- and post-withdrawal to determine if significant changes occurred over time.
5. Cost implications	Appropriate technology	The programme should include both aided and unaided communication means. The means selected should be easily obtainable (e.g. real objects and photographs) and should be easy to reproduce (e.g. PCS). A low cost digital speaker could also be included.

In conclusion, it is crucial to note that interrelationships among these domains exist, and when outcomes are measured, attempts should be made to include measurements across all five the different domains. The perspective of the person determining the outcome (e.g. whether they are a user, therapist, or primary caregiver) should be clarified as the outcomes of a programme is largely determined by the factors considered, which depends on the perspective of the person determining the outcome (Provence, 1985).

## University of Pretoria, etd - Bornman, J

One way of evaluating the effectiveness of a programme is by determining its impact on the three levels of the ICIDH-2 (WHO, 1999). Firstly, the impact on the body function and structure (indicating a focus on the traditional rehabilitation) could be determined. This is similar to tertiary prevention, which is not the focus of the research, and which will therefore not be discussed any further. Secondly, the impact on the activity level could be determined, indicating a focus on the use of functional communication skills. Thirdly, the impact on the participation level where the focus is on expanding communication opportunities, could be determined. The latter two levels refer to training at the secondary level of prevention, which is the focus of this research. Blackstone (1995b) applied the ICIDH model (WHO, 1980) to AAC in order to measure individual outcomes. This was adapted to provide information regarding the impact of the proposed communication training programme on the ICIDH-2 (WHO, 1999). The focus of the training, the skills addressed in the communication training programme and desired outcomes are displayed in Table 3.3.

**Table 3.3: Application of the ICIDH-2 to the proposed communication training programme**

<b>Level</b>	<b>Training focus</b>	<b>Skills addressed</b>	<b>Desired outcomes</b>
Body function and structure	Reduce deficits through traditional speech therapy, e.g. articulation drills, language training, oral, motor exercises	Not included in the proposed communication training programme	Not included in the proposed communication training programme.
Activity	Increase functional communication skills through the use of AAC strategies, devices and techniques in everyday contexts	Communication means (aided and unaided) Communication functions (informative and social) Communication partners (adults and peers)	Increased knowledge regarding these aspects as well as skills to demonstrate these skills to primary caregivers of CSDs by which training is facilitated.
Participation	Increase access, expand communication opportunities, educate significant others, change attitudes and expectations. Reduce access and/or opportunity barriers that restrict participation.	Using skills addressed at the activity level to facilitate interaction with others to increase participation and independence. Creation of deliberate creation of communication opportunities to increase interaction and participation.	Increased skills to demonstrate participation potential to primary caregivers of CSDs. In the longer term participation and independence of CSDs should be increased.

## **University of Pretoria, etd - Bornman, J**

From the above table it can be seen that the desired outcomes and the types of measurements differ across the ICIDH-2 levels. The aim of the proposed training programme is to increase CSDs' participation and independence by the provision of communication means, functions, partners and opportunities. This will be done by training community health nurses to provide training to CSDs and their primary caregivers. In other words if the CSD's circle of friends increased due to more effective communication skills, a positive outcome is noted despite the fact that speech intelligibility might not have improved. If a desired outcome is therefore only focussed on the body function and structure level, it will be of limited use as the outcome will prove to be negative, despite the fact that the provision of AAC might make a significant impact on the CSD's quality of life (i.e. on the participation level).

Schlosser and Braun (1994) expanded on the issue of effectiveness by suggesting that the generalisation of behaviour change should also be included. Stimulus generalisation refers to the transfer of learned behaviours to stimulus conditions that differ from those in which instruction took place, implying that the focus should not only be on the aspects in which training took place (context), but should also investigate the untrained dimensions. In the present research this refers to the way nurses can apply their knowledge and skills to the new cases they meet in their workplace.

Another important factor to consider in determining outcome goals relates to the comparative effectiveness of at least two interventions on specific criteria. In order to determine this, different training programmes and approaches were studied. It should, however, be noted that irrespective of the programme selected, some children will benefit more than others (Ramey & Ramey, 1992) and that each child develops at his/her own pace (Blacklin & Crais, 1997). The most prominent intervention programmes and approaches (as well as one unpublished checklist) aimed at providing communication training for young CSDs will now be compared in Table 3.4.

**Table 3.4 A comparison of the most important intervention programmes / checklists / approaches for CSDs**

CRITERIA	<i>PACT: Partners in Augmentative Communication Training</i>	<i>START Integrated Program: Striving Towards Achieving Results Together</i>	<i>Small Steps / Macquarie Program</i>	<i>Portage Guide to Early Education</i>	<i>Hanen Program</i>	<i>AEPS Measurement for Birth to Three Years: Assessment, Evaluation and Programming System</i>	<i>ACSD Checklist: Augmentative Communication Skill Development Checklist</i>
<b>Name</b>							
<b>Author(s) &amp; date published</b>	Culp & Carlisle, 1988	Goodman, Katz & Greene, 19XX	Pieterse & Treloar, 1989	Bluma, Shearer, Frohman & Hilliard, 1976	Manolson, 1985	Bricker, 1997	Cress, Havelka, Dietrich & Linke, 1998
<b>Country</b>	USA	South Africa	Australia	USA	USA	USA	USA
<b>Format</b>	Book	Manual / kit	Manual/Kit	Kit	Book / Manual	Manual	Unpublished checklist
<b>Population intended for</b>	<ul style="list-style-type: none"> <li>• Severe expressive disorder</li> <li>• Receptive language <math>\geq</math> 2 year level</li> <li>• Basic representational skills</li> <li>• Uses AAC system / device</li> <li>• Reliable means to indicate / transmit messages</li> </ul>	Young CSD's (range of disabilities included)	<p>For primary caregivers of young developmentally delayed (intellectually disabled) children to teach in the home environment.</p> <p>Initially programme was focussed at children with Down Syndrome, but now is broader.</p>	Pre-school children	Language delayed and/or impaired children	Young CSDs and those who are at risk	Young children who rely on AAC
<b>For use by</b>	Professionals	Non-professionals	Non-professionals	Professionals	Non-professionals	Professionals	Professionals
<b>Age intended for</b>	Not age specific	1 – 3 years	0 – 5 years developmentally	0-1yrs ; 2-3yrs 3-4yrs ; 4-5yrs 5-6yrs	Pre-schoolers	1 month – 3 years ( <i>developmentally</i> ) 1 month – 6 years ( <i>chronologically</i> )	1 – 3 years
<b>AAC specific?</b>	Yes	No	No	No	No	No	Yes
<b>Areas covered</b>	<ul style="list-style-type: none"> <li>• Priority communication (partner &amp; user, communication means and functions,</li> </ul>	<ul style="list-style-type: none"> <li>• Gross motor skills</li> <li>• Fine motor skills</li> <li>• Communication skills</li> <li>• Cognitive skills</li> <li>• ADL</li> </ul>	<ul style="list-style-type: none"> <li>• Communication skills (including pre-verbal and verbal children)</li> <li>• Gross motor skills</li> <li>• Fine motor skills</li> </ul>	<ul style="list-style-type: none"> <li>Infant stimulation</li> <li>1) Socialisation</li> <li>2) Language</li> <li>3) Self-help</li> <li>4) Cognitive</li> <li>5) Motor</li> </ul>	<ul style="list-style-type: none"> <li>• Initiating interaction: child</li> <li>• Initiating interaction: adult by</li> </ul>	<ul style="list-style-type: none"> <li>• Fine motor skills</li> <li>• Gross motor skills</li> <li>• Adaptive ADL skills</li> <li>• Cognitive skills</li> <li>• Social / communication</li> <li>• Cueing hierarchy</li> </ul>	Eleven groups of behaviours that tend to occur together in development (non-hierarchical). Includes

	<ul style="list-style-type: none"> <li>discourse behaviour)</li> <li>• Communication assessment guidelines</li> <li>• Communication intervention guidelines</li> <li>• Psychological considerations</li> </ul>		<ul style="list-style-type: none"> <li>• Receptive language skills</li> <li>• Personal and social skills</li> <li>• Developmental Skills inventory (assessment checklists)</li> </ul> <p><i>Also includes generic intervention principles</i></p>		creating communication opportunities	<ul style="list-style-type: none"> <li>skills (including pre-linguistic skills)</li> <li>• Social skills</li> </ul>	<ul style="list-style-type: none"> <li>• Modality e.g. behaviour/natural gesture; symbol/picture; speech and/or device</li> </ul>
<b>Advantage(s)</b>	Includes very important aspects of training partners and is AAC specific.	Culturally appropriate for the South African context, e.g. songs provided in major languages. Logically structured and well organised with colour coding.	Good resource guide for primary caregivers. Provides suggested activities. Checklists can be used to monitor progress.	Used extensively in developed and developing countries for a number of years. Outcomes data available. Provides activity sheets that correlate with the checklist. Different activities are colour coded.	Guides primary caregivers to observe children by looking at what the child does, what the child says and what the child understands. Suggest some play activities and how they can be used interactively.	Measures functional skills. Can be used by CSDs. Comprehensive as it covers important skill areas, assessment, intervention and a progress evaluation.	Short checklist with 25 items. Includes cueing hierarchy and different communication means. Applicable to young AAC users. Works with assumption that no prerequisites for communication are needed.
<b>Disadvantage(s)</b>	Child needs AAC system before PACT can be implemented. Not applicable to young CSDs.	Not applicable to all pre-schoolers and does not include AAC principles (e.g. multi-modality). Training is recommended before using the START for non-professionals. Affordability is problematic.	No specific reference to AAC. Includes aspects like learning to attend & respond, play, turn-taking, and imitation for pre-verbal children, without addressing multi-modality or more communicative functions.	No specific reference is made to AAC and therefore it does not include multi-modal communication issues.	Although it guides primary caregivers to look for the use of natural gestures, it does not teach manual signs or graphic symbols. No proposed adaptations for CSDs.	Need skilled person to utilise AEPS with understanding of general developmental patterns. Assessment takes at least one to two hours per individual. Complex, multi-level, multi-faceted program requiring extensive training.	Does not provide suggested intervention activities. Does not work in a hierarchical manner. Not applicable – need knowledge on AAC terminology to complete it.

## **University of Pretoria, etd - Bornman, J**

From Table 3.3 it is clear that only the PACT and the Augmentative Communication Skills Development Checklist (ACSD Checklist) focused on AAC. The PACT, however, focuses on the training of communication partners and is only intended for use once the child already has an AAC system. On the other hand, the ACSD Checklist, which is still under further development, (personal communication XXXXXXXXXXXX) does not provide intervention guidelines and can only be used by professionals who are familiar with AAC terminology. Three of the programmes mentioned can be utilised by non-professionals, namely the START, Hanen and Small Steps programs. It is unfortunate that they do not provide guidelines for the use of AAC strategies, in spite of the fact that they were developed for CSDs. It should, however be noted that the Hanen program includes sensitising the communication partner to the interpretation of unaided communication strategies (mostly natural and/or idiosyncratic gestures). The partner then attempts to model the desired behaviour (speech) while initially acknowledging any communication attempts (verbal and non-verbal) in order to increase the communication. However, it does not provide guidelines for the expansion of manual signs or for the use of graphic symbols (e.g. PCS), as speech is the preferred communication means. The Portage Guide to Early Education is also a useful tool as it addresses areas of pertinence for CSDs. Furthermore it has been used extensively for the past 25 years in both developed and developing countries, and a number of publications pointing to the effectiveness of the Portage have seen the light (Ferguson, 1996; Hardy & Sturmey, 1994; O'Grady, 1996; Shearer & Shearer, 1972; Wolfendale, 1998). However, Hardy and Sturmey's (1994) study indicated that despite the effectiveness of the Portage, more research was needed in the area of parent training. Additionally, for the purposes of this research, it falls short in the area of training CSDs to use AAC systems and/or strategies. Likewise, the EAPS Measurements is a powerful intervention tool for use in the clinical setting as it is a comprehensive programme for young CSDs, that provides information pertaining to the assessment, intervention and evaluation phases. As with the PACT and ACSD Checklist though, it can only be used by professionals and similar to the Portage, START and Early Steps, it provides no specific guidelines in terms of AAC stimulation. This is despite the fact that all these programmes / approaches have a "*communication area*" with a section that highlights the pre-verbal or pre-linguistic child.

Although a number of programmes / approaches thus exist that can be utilised by professionals and non-professionals alike when stimulating young CSDs, a need exists for a programme that includes AAC intervention. A programme of this kind should focus on the different communication functions (both informational and social), and also include the teaching of multi-modal communication (including aided and unaided AAC strategies). Furthermore attention should be given to the structuring of the environment to provide deliberate opportunities for communication (the creation of so-called “*communication temptations*” or sabotage) as well as opportunities for increasing the number of communication partners (adults and peers alike) (Butterfield, 1995; Calculator, 1997).

### **3.2.3      Programme design**

This aspect deals with the specific procedures and structures that must be established in order to achieve the output and programme goals. According to Mitchell (1991) five broad areas (namely social policies, administration and management, physical environment, curricula, teaching strategies and methods) should be included. Each of these aspects, and their relevance to the proposed training programme, will now be described.

Social policies are closely related to the aspects that were discussed under the process goals, e.g. cultural sensitivity, right to services, etc. The social policies are also embedded within the PHC approach that is the philosophy of the proposed training programme. The administration and management of the training programme is controlled by the researcher as it is part of a formal study. Once the effectiveness of the programme has been proven in equipping community health nurses with the knowledge and skills to provide training to this population, consideration must be given to the implementation of the programme within the context of national service delivery, e.g. Department of Health, the Department of Maternal and Child Studies, the Department of Welfare and Child studies, etc. The content of the proposed training programme is portable, and does not require special

physical environments and/or facilities. It is intended for use in rural and remote PHC clinics, irrespective of the size of the clinic or the facilities available (e.g. electricity).

When looking at the **curricula** of the proposed training programme, it is once again important to look at existing programmes as discussed in Table 3.3. The aim of the proposed training programme is to equip community health nurses with knowledge and skills about beginning communication skills enabling them to train primary caregivers of CSDs to train their children (training the trainer). In order to achieve this a specific training programme, namely the Beginning Communication Intervention Protocol (BCIP) was developed. The complete BCIP is provided in Appendix A and it is demonstrated in Appendix B. The five principles on which it is based, will now be discussed in more detail.

### **3.2.3.1 Principle 1 Use of the ICIDH-2 to define an individual's functioning**

The relevance of using the ICIDH-2 to determine the individual's functioning and disability from the perspective of his/her life circumstances was discussed in Chapter 2. By using this definition, there is a move away from the "labelling" of individuals (closely related to the medical model) to rather look at the environmental and/or personal factors that may limit or facilitate the individual's participation and independence in society (social model). This model also highlights the underlying concept of social inclusion, as it alludes to factors that may impact at an activity level (e.g. the CSD cannot attend the local Sunday school due to attitudes that prevail) and/or at a participation level (due to LNFS the individual cannot make himself understood and therefore he has no friends). Disability is thus seen as a multi-dimensional phenomenon resulting from the impaired interaction between people and the environment. The training programme should also highlight the fact that the focus should not be on the **disability**, but rather on the **ability** and how that can be used optimally to ensure full and active participation in everyday activities.

### **3.2.3.2 Principle 2 Use of milieu teaching approaches**

Milieu teaching is a naturalistic strategy for teaching functional communication skills within everyday occurring routines (Hart & Risley, 1975; Kaiser, Yoder & Keetz, 1992). It includes specific teaching techniques, e.g. time delay, incidental teaching and the mand model. All these techniques share common characteristics and have been used singly or in combination. This includes that the child's lead or interest is followed and expanded, that multiple, naturally occurring examples are used to teach simple communication skills (e.g. deliberately providing opportunities for interaction during ADL), and that the child's response is prompted (e.g. provide the child with the aided or unaided communication means to meet his needs (Kaiser *et al.*, 1992). Milieu teaching approaches also provide logical stimuli (e.g. when requesting milk he/she receives milk) and naturally occurring, real consequences, meaning that the communication act affects the environment which, in turn responds in accordance with the intent of the communication (Rowland & Schweigert, 1993). Research has indicated that milieu teaching is appropriate when teaching CSDs to use aided and unaided communication strategies (Blischak, Loncke & Waller, 1997). Teaching in the natural context thus allows the primary caregiver to take advantage of cues and consequences that are natural parts of the setting (Light, 1997). All milieu teaching approaches requires that the facilitator (in this case the primary caregiver) is trained to identify potential communication contexts (in this case ADL) and that they use a number of specific techniques to deliberately create communication opportunities (Beukelman & Mirenda, 1998; Blischak *et al.*, 1997; Glennen, 1998a; Rowland & Schweigert, 1992).

### **3.2.3.3 Principle 3 Based on activities of daily living**

The environment in which a CSD learns, lives and functions must provide opportunities for interaction. Typical routines and activities (such as ADL) within the environment offer repeated opportunities for a person to learn to anticipate events and to respond to needs or changes within these events (Johnson *et al.*, 1996). Light and Kelford-Smith (1993) found that CSDs spend significantly more time in daily care routines (such as

## **University of Pretoria, etd - Bornman, J**

eating, dressing and bathing) than their typically developing peers. In addition, these activities can take a long time to complete and often the day consists of little other than these fixed routines (von Tetzchner & Martinsen, 1992). Routines conducted within natural environments offer reasons for communication that cannot be recreated in simulated places. CSDs in rural areas (such as the Moretele Health District) often do not engage in typical play activities with adults. Adults are viewed as caregivers who should keep themselves busy with domestic duties and childrearing. Therefore, in order to maximise the opportunities for interaction within this context, ADL were selected to provide the context and content for instruction. In addition, primary caregivers were familiar with these tasks, and did not see them as treats or “*extra work*”. Community health nurses assisted primary caregivers in the use of an existing routine (e.g. feeding) and the way to adapt it slightly in order to provide more opportunities for interaction.

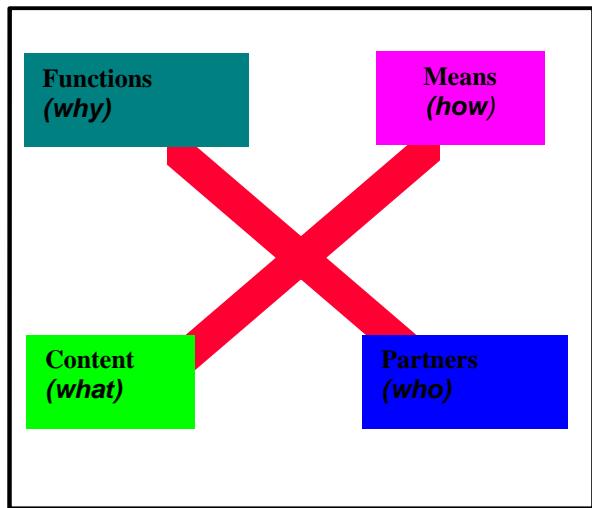
### **3.2.3.4 Principle 4 Communication is defined in terms of four domains: functions, means content and partners**

Communication is defined as any act by which one person gives information to, or receives it from another person about that person’s needs, desires, perceptions, knowledge or emotions. This can be done via gestural, signed, spoken, and/or written means. Communication is generally considered to be intentional and involves social interaction. The whole process is embedded in a specific context and environment (Beukelman & Mirenda, 1998; Fuller & Lloyd, 1997; Glennen, 1998b; Johnson *et al.*, 1996).

From this definition four main areas arise, namely:

- i. Communication functions (*why* the child communicates)
- ii. Communication means (*how* the child and others communicate)
- iii. Communication content (*what* the child and others communicate about – role of the environment)
- iv. Communication partners (who the child communicates with)

**Figure 3.2 Four main areas of communication**



A number of beginning communication functions (including both informational and social functions) are included in the BCIP. It has been reported that it is important to teach a broad repertoire of communication functions, otherwise only the request function is used (Romski & Sevcik, 1988). Specific strategies (communication temptations) are then taught to facilitate each of these functions, e.g. in order to teach “*requesting help*” a desired item is placed out of reach. These activities are based on the Analysing the Communication Environment (ACE) checklist (Rowland & Schweigert, 1992).

In order to provide the child with a means way of communicating, the BCIP addresses a number of aided communication means (namely real objects, photographs and line-drawings that are displayed either on a communication board or the EasyTalk 4 Option digital speaker) as well as unaided communication means (manual signs from South African Sign Language {SASL}). The sequence of the aided communication means are based on the practice of some AAC clinicians that follows the approach that three-dimensional symbols are easier to identify than two-dimensional symbols (Kitty, 1993; Kitty, 1993). Although this sequence does seem to be the way in which some typically developing children acquire these skills, it is not true in all cases (Dixon, 1981). In Hochberg’s (1962) study it was demonstrated that the ability to recognise line-drawings is not dependent on training, as individuals without any formal training of paired-

associates could recognise line-drawings. Gibson (1969) reported studies where typically developing children could identify cartoons at an earlier age than some line-drawings, with photographs and shaded drawings about equal to each other, somewhere between line-drawing and cartoons). It should, however be mentioned that in one of the studies that reported this finding (Ryan & Schwartz, 1956), the participants were adults who already knew the object's identity (in other words it would not refer to a person seeing the PCS for “*more*” for the first time), and the critical characteristics of the objects were three-dimensional (unlike the elements in the proposed training programme, e.g. sock, spoon, etc.). Dixon (1981) also alluded to the fact that CSDs do not only develop at a slower pace than typically developing children, but that differences also occur and therefore the assumptions in terms of the developmental levels of perceptual grading should be treated with caution. Apart from only looking at the representation of concepts (e.g. on object, graphic symbol level etc.) the complexity of the initial symbol acquisition process for CSD should also be considered as the meanings of some symbols appear to be broader (e.g. the symbol for MUG might be interpreted as “*drink*”, “*thirsty*”, “*milk*”, etc.) or more loosely integrated (Romski & Sevcik, 1989). In a study by Gerber and Kraat (1992) they also alluded to the difficulties of using a developmental model when planning communication training for CSDs. However, there seems to be a general agreement in the literature that CSDs may no longer be denied communication intervention simply because they are unable to demonstrate certain pre-requisites (e.g. object permanence) (Beukelman & Mirenda, 1998; Kangas & Lloyd, 1988; Romski & Sevcik, 1988). The BCIP therefore starts at an object level for CSDs who may still be functioning at this level, but also provides opportunities for expansion and more abstract messages (e.g. “*full*”) by means of PCS. Regardless of the type of symbol used (e.g. object or graphic symbol), it has the advantage of being permanent, implying that it can be touched or manipulated, requiring only recognition out of an array of symbols, rather than recall from memory (Rowland & Schweigert, 2000). Additionally, it requires only simple motor movements (e.g. pointing or picking up of the symbol or even eye-gaze). This study also clearly indicated that the introduction of aided low technology means did not cause CSDs to abandon the speech that they were using nor did it prevent the acquisition of new spoken vocabulary, but rather assisted the CSDs in developing additional spoken

vocabulary and an overall increase in the level of communication (Rowland & Schweigert, 2000).

**Photograph 1      The elements of the BCIP**



The BCIP also includes some principles for facilitating interaction with both peers and adults (e.g. by having a party and inviting neighbourhood children) in order to facilitate social inclusion. One of the key characteristics of increasing participation and interaction is that people have close proximity and frequent opportunities to interact with each other (Falvey, Forest, Pearpoint & Rosenberg, 1994). In order to facilitate close proximity with potential communication partners CSDs should be included in their communities (e.g. attend local schools, church, etc.) as this will heighten the possibility of forming bonds that will result in friendships. Therefore a communication training programme should highlight the importance of social inclusion to increase the number of potential communication partners. Communication partners should be taught to recognise the CSDs' communication means (which are often subtle and ambiguous), how to

acknowledge these means and attach possible meaning to it (i.e. determining the communication function) and how to respond contingently (Zangari & Kangas, 1997). Rowland and Schweigert (2000) have demonstrated that CSDs who understand how to use pre-symbolic behaviour for intentional communication, will more readily learn how to use a symbolic system to communicate expressively.

### **3.2.3.5 Principle 5 Provision of deliberate communication opportunities is essential**

It has been recorded that CSDs communicate at a low rate (Gerber & Kraat, 1992). This could be for a number of reasons, including few reasons to communicate and few opportunities for meaningful interaction as adults typically provide CSDs with fewer opportunities to communicate than is the case with their speaking peers (Zangari & Kangas, 1997). Some partners also have little or no expectations that CSDs can or will participate in interaction, with the main focus of interaction often being exclusively on caring and nurturing. Few demands are thus placed on them, leading to reduced communication opportunities and little motivation to develop more effective communication skills (Van Tatenhove, 1987).

The provision of deliberate communication opportunities is complex, as a delicate balance must be achieved between the elicitation and pre-emption of communication behaviour (Calculator, 1997; Rowland & Schweigert, 1993). Often, when a child is learning how to communicate by using a specific communication means (e.g. manual signs), it is appropriate for the adult (primary caregiver) to offer deliberate cues as this provides many opportunities to practise emerging communication skills (as discussed in the milieu teaching section). As the child's abilities improve, the deliberate overt cues should be reduced to allow the interaction to become child-controlled instead of remaining adult-controlled. As CSDs are often passive in communication and rarely initiate interaction, this aspect should be addressed (Calculator, 1997; Van Tatenhove, 1987).

## **University of Pretoria, etd - Bornman, J**

As stated earlier, the strategies for providing deliberate communication opportunities was based on guidelines from the ACE checklist (Rowland & Schweigert, 1993b).

The final aspect of the programme design that should be included relates to the teaching strategies and methods that were used. Adult learners have a number of characteristics in common. They have a rich background of knowledge and experience and learn best when this experience is acknowledged, and when new information builds on their past knowledge and experience (Caffarella, 1994). As they are able to learn through the greater part of their lifespan, attention has to be paid to the method of learning, as well as to the content of what is learned (Jarvis & Gibson, 1997). Consequently a problem-based learning approach that includes the use of case studies and video presentations should be included (Savin-Baden, 1997). In addition, adult learners are more willing to engage in learning if the content is meaningful to them. They are also pragmatic in the learning which means that they want to apply their learning to present situations (Caffarella, 1994), which necessitated the inclusion of role-play activities. Adults also prefer to be actively involved in the learning process rather than being the passive recipients of knowledge, implying that the training should focus on interactive training that involves workshops where community nurses will have ample opportunities to practise skills hands-on, also video discussions and role play. Finally, adults are more receptive to learning in situations that are physically and psychologically comforting (Caffarella, 1994). Regarding the teaching of skills, a reflective approach is followed which implies that the participants are not merely expected to copy a demonstration (Jarvis & Gibson, 1997), but rather to consider the strategy most acceptable to themselves and to the case study, provided that the desired outcome is achieved (e.g. when teaching the function "*requesting more*", the trainer demonstrated bouncing a child on her lap and stopping. This was adapted by the participants to include pushing a child on a swing and stopping, tickling and stopping, swinging a child and stopping, etc.). When teaching skills to adults it has been suggested that a problem-based learning approach whereby participants actually discover the relevant principles for themselves is effective. Trainers should also focus on creating a supportive environment in which participants are given the

confidence to practise. This had an impact on the teaching style of the trainer as well as on the venue that was selected (as discussed in Chapter 4).

### **3.2.4      Programme evaluation**

This is the process by which a systematic evaluation is made to ascertain whether the programme has reached its goals and objectives. The discussion pertains to both the evaluation of the outcome and the process. For the purpose of this study, both qualitative and quantitative measures are used in the evaluation. The qualitative data provides information on the training process, as focus groups were held to determine what nurse's exposure to CSDs was and at the end of the five month training period, focus groups were again held to evaluate the training process. The quantitative data provides data on the outcomes (for primary and secondary outcomes). However, it should be noted that the training outcomes and the process are related and impact on each other, and thus a clear separation of these components is not possible.

## **3.3      CONCLUSION**

Involvement in the BCIP will have benefits on many different levels, e.g. for the community health nurses, for the primary caregiver, the CSD and the community at large. In the present study, however, the focus is on community health nurses, as they are the primary beneficiaries of the training. It is expected, however, that the BCIP training will also have an impact on the secondary beneficiaries (who were not directly trained during training, but who receive training from the community health nurses).

Chapter 3 described the factors and principles that have to be considered when developing a communication training programmes for CSDs and their primary caregivers that can be provided at a PHC level by community health nurses. Mitchell's Evaluation Model (1991) was used as a basis for the discussion. Specific emphasis was placed on the measurement of outcomes in order to evaluate the proposed training programme (BCIP).

## CHAPTER 4

# RESEARCH METHODOLOGY

### 4.1 INTRODUCTION

In this chapter the research methodology used in the research is discussed. Firstly, the aims and objectives of the research are identified, followed by a discussion of the research design. The pilot study is then presented in terms of results and recommendations. Finally, a description of the subjects, data collection procedures and data analysis used in the main study follows.

### 4.2 METHODOLOGY

#### 4.2.1 Research question

Which knowledge and skills were acquired by community health nurses post-training in the use of a beginning communication intervention protocol (BCIP)?

#### 4.2.2 Main Research Aim

To develop, apply and evaluate a protocol for training community health nurses who work in PHC settings to increase their knowledge and skills about beginning communication skills (i.e. informational and social communication functions using aided and unaided communication means, creating content for interaction by using ADL and fostering adult and peer communication partners). This protocol is intended to assist community health nurses when training primary caregivers of CSDs to facilitate interaction with their children. The focus of the protocol is not on children of a particular age, but rather on beginning communicators as defined in the previous chapter.

### 4.2.3 Sub-aims

Four objectives delineate the means by which the aim of the research was realised, namely:

- i) To identify the perceptions and the exposure of community health nurses regarding services to CSDs.
- ii) To describe the multiskilling dimensions relevant to community nursing when working with CSDs.
- iii) To develop a beginning communication intervention protocol (BCIP) aimed at training the identified multiskilling dimensions, namely Level 2 (cross-training of professional non-clinical skills), Level 3 (cross-training of administrative skills) and Level 4 (cross-training of clinical disciplines), for use by community health nurses.
- iv) To apply the BCIP to a group of twenty community health nurses and to determine the outcomes.

## 4.3 RESEARCH DESIGN

### 4.3.1 Research design

The research is a descriptive survey followed by a quasi-experimental time series group design O<sub>1</sub>-X-O<sub>2</sub>-O<sub>3</sub>- O<sub>4</sub> -O<sub>5</sub> with withdrawal (Leedy, 1993). This design was selected as it would be appropriate to determine the specific skill dimensions acquired by nurses following the implementation of the BCIP. The strength of this type of design lies in the repeated data collection over time, after introducing the independent variable (the BCIP) (Brink, 1999). All subjects act as their own control, providing a strong indication that the independent variable could be responsible for the observed change in the dependent variables (e.g. knowledge, skills and attitudes). In addition, Eayrs and Jones (1992) noted that there is often a lack of control groups due to ethical concerns related to “*no treatment*”. Information can also easily be contaminated as nurses tend to talk to each other and to “*try out*” advice given to each other.

The O<sub>1</sub> represents the skills of the community health nurses before training, X represents the training of the community nurses and O<sub>2</sub> represents the skills of the community nurses post-training. The O<sub>3</sub> phase is the first follow-up consultation conducted two weeks after the training and aimed at identifying problem areas in the BCIP and the problem-solving thereof. The O<sub>4</sub> phase again evaluates the skills of the community nurses after a withdrawal period of six weeks. Finally, a withdrawal period of five months (O<sub>5</sub>) follows when skills and knowledge are evaluated after a follow-up consultation, as well as their evaluation of training over the 5-month period.

#### **4.3.2 Research phases**

This research consists of two major sections. Section I is the pre-experimental phase and is divided into two phases and Section II, the experimental phase, is divided into six major phases, namely O<sub>1</sub>, X, O<sub>2</sub>, O<sub>3</sub>, O<sub>4</sub> and O<sub>5</sub>. The research phases are outlined in Table 4.1.

**Table 4.1      Research phases**

RESEARCH PHASES					
Section I : Pre-experimental phase					
Phase 1 <i>Needs analysis: Nurses</i>		Phase 2 <i>Needs analysis: Primary caregivers</i>			
Perceptions of, and exposure to severe disability were evaluated by means of focus groups and questionnaires		To ensure cultural relevance and sensitivity of the BCIP, focus groups were conducted with primary caregivers of typically developing children & primary caregivers of CSDs in the specific area			
Section II: Experimental phase					
Phase O <sub>1</sub>	Phase X	Phase O <sub>2</sub>	Phase O <sub>3</sub>	Phase O <sub>4</sub>	Phase O <sub>5</sub>
Identifying skill dimensions: Skills, knowledge and attitudes of community nurses before training.	Training community nurses in the application of the BCIP.	Skills, attitudes and knowledge of community nurses directly post-training.	Follow-up 2 weeks post-training: Assessing skills of community nurses and identification of problem areas and problem-solving.	Follow-up 6 weeks post-training: Assessing skills of community nurses and identification of problem areas and problem-solving.	Follow-up consultation 5 months post-training: Assessing skills, attitudes and knowledge as well as an evaluation of the training.

The phases will be described in detail in Sections 4.3.2.1 and 4.3.2.2.

##### **4.3.2.1      Section I: Pre-experimental phase**

Section I consists of two phases and deals with the needs analysis of the community health nurses and primary caregivers of CSDs in the Moretele Health District. This information stands central in the development of the BCIP.

### i) Section I: Phase 1

Phase 1 aimed at determining community health nurses' perceptions of and exposure to childhood disability. In order to obtain this data, qualitative as well as quantitative measures were employed.

#### **Qualitative description of community health nurses' perceptions and exposure**

In order to determine community health nurses' perceptions of and exposure towards CSDs two focus groups with community nurses were held. Focus groups were selected as the method of data collection as they yield information from multiple sources and contain rich contextual data, and are also excellent tools for capturing the nature of experiences, individual perspectives and opinions (Brotherson & Goldstein, 1992; Krogh & Lindsay, 1999; Krueger, 1988; Morse, 1996). A summary of these focus groups is presented in Table 4.2.

**Table 4.2 Focus group with community health nurses**

Category	Description
<b>Participants</b>	A number of community nurses from the Moretele Health District are involved in an in-service training programme, called " <i>Nurses-in-Training</i> " that meet monthly and receive talks on various nursing-related topics. Due to the vast spread out nature of the different clinics and the impracticality of closing a clinic so that nurses can partake in the research, it was decided to include all nurses who attended the first " <i>Nurses-in-Training</i> " programme for 2000 in the focus group. These nurses all met the selection criteria that were set, namely that they should be employed by the Moretele Health District and that they should currently be working as a nurse. The qualifications of the nurses were not included as a selection criterion, so that it covered a whole range, from nursing assistants to professional nurses. This resulted in two large focus groups: one focus group with 10, and the other with 11 participants. Literature suggests groups of 6 – 15 participants (Frey & Fontana, 1993). As a result of the commonalities they share and the fact that they mostly knew each other, rapport was quickly established, therefore the focus group was experienced as non-threatening. <u>Each focus group was facilitated by a SLP with a primary interest in AAC and CSDs.</u>
<b>Aims</b>	To determine nurses' perceptions and exposure to CSDs and to encourage them to respond from their own experience, three open-ended interview questions were used (Krueger, 1988), namely: <ol style="list-style-type: none"> <li>How often do you see the primary caregivers of CSDs? Tell us about your experience.</li> <li>What do you think are the biggest problems these primary caregivers have?</li> <li>What can we do to help you to help the primary caregivers of CSDs better?</li> </ol>

Category	Description
<b>Method</b>	<p>Both facilitators led the respective focus groups in a semi-structured discussion of the open-ended questions (Frey &amp; Fontana, 1993). During the discussion the facilitators asked for clarification when some concepts were unclear or in cases where the data were open to misinterpretation (Bryman, 1994; Krefting, 1991). They also encouraged the nurses to take part actively, to share their wealth of experiences, to understand that no comments would be regarded as “<i>stupid</i>” or “<i>silly</i>” and reassured them that they would remain anonymous. Flexibility was allowed in terms of the sequence of questions so that facilitators were able to listen to the discussion, observe and respond to what they saw and heard. Structural coherence of the topic was thus maintained, increasing credibility (Krefting, 1991). In an attempt to enhance trustworthiness, member checks were included, which entailed that the facilitators gave a short summary at the end of the discussion of each of the three questions. Participants were then asked whether they agreed, disagreed, or if any important issues raised were overlooked (Hoffart, 1991).</p> <p>The two facilitators spent some time debriefing directly after the focus groups to discuss their interpretations in order to enhance trustworthiness (Peshkin, 1993). No areas that needed additional probing or clarification were noted. Debriefing is an important part of investigator triangulation and was included to heighten the credibility of the data obtained (Brotherson &amp; Goldstein, 1992; Kimchi, Polivka &amp; Stevenson, 1991)</p> <p>Verbatim transcriptions of these two focus groups were made: Focus group 1 lasted 58 minutes and Focus group 2 lasted 67 minutes.</p>
<b>Analysis</b>	<p>The researcher delineated themes from each of the two focus groups and came to tentative conclusions. Transcriptions were then handed to the other facilitator and she was also asked to delineate themes (peer debriefing). Care was taken to avoid “<i>coding fetishism</i>” where coding becomes a mechanical process of labelling involving obsessive and unnecessary details (Webb, 1999). Rather, coding was seen as part of the whole analytic process that also involves theoretical perspectives and interpretations. When two researchers separately code and then cross-check data, the issue of analytic stability comes to the foreground (Brotherson &amp; Goldstein, 1992). In order to address this, both researchers received a set of coding guidelines pertaining to the content and the analytic procedure, e.g. the initial questions that were appropriate as well as the decision rules for determining the categories.</p> <p>Following the development of the themes the two facilitators met to review the theme analysis with a request for verification, correction, clarification and/or elaboration of tentative conclusions drawn from the data analysis. This process is essential in order to ensure the credibility of the data (Krueger, 1988). Apart from only obtaining significant and consistent themes in the data it is also rich in providing illustrative examples. In order to not fragment, decontextualize and/or misinterpret data, it was crucial to go back to the complete text frequently (Webb, 1999).</p>
<b>Results</b>	<p>A summary of the themes delineated from these two independent focus groups is provided in <b>Appendix C</b>. Five major themes crystallised, namely the nurses’ perception of problems experienced by primary caregivers of CSDs, how nurses perceive their role regarding disability and the type of services they currently provide, problems they experience, their own experiences regarding CSDs and, finally, what they need in order to enhance their service delivery. Regarding problems experienced by primary caregivers aspects such as disempowerment (including a lack of knowledge, poor parenting skills, poverty, limited resources, unemployment and illiteracy), external influences (religion, culture and tradition, family and community), emotional problems (ranging from denial to anger) and the impact (e.g. a loss of status in the community) were mentioned. Nurses perceived their current role mostly as obtaining a case-history, conducting a physical examination, detecting the problem, conducting health promotion and co-ordinating CBR activities, treatment of minor medical ailments, referral and follow-up. However, nurses acknowledged that follow-ups are not done in practice and that most of the service delivery is based on referral. Nurses spontaneously spoke about the problems they encountered in the workplace, despite the fact that this information was not probed. This included aspects such as feelings of inadequacy due to the fact that they do not know how to handle primary caregivers of CSDs, depression, attitudinal barriers due to limited staff and time constraints and the fact that no follow-ups are done.</p>

Category	Description
<b>Results (continued)</b>	Regarding their experiences it was noted that their exposure varied. However, despite the fact that in some instances exposure was limited, the impact was high as most nurses could recall details about the CSDs, even if they had seen them more than a year ago. In addition it was interesting to note how many CSDs are identified informally (e.g. neighbours inform nurses). When asking nurses what they required to enhance their service delivery it became clear that knowledge (education), skills, a positive attitude and raising community awareness were high priorities.
<b>Implications</b>	The focus groups clearly identified that nurses felt inadequate about the way they handled CSDs and their primary caregivers and that they required more knowledge and skills that would in turn have a positive impact on their attitudes. It was also evident that nurses are well aware of primary caregivers' problems and that primary caregivers trust them regarding discussions of their personal problems. This would make the nurses ideally suited to provide training of this nature. It was also clear that many primary caregivers in the Moretele Health District have poor parenting skills and that nurses would like to educate these primary caregivers. Furthermore, there are limited resources in the area, making appropriate referrals difficult. This might impact on the poor feedback that nurses receive (primary caregivers probably do not take their children to the referred places due to poverty, transport issues, etc.). This makes it clear that training should focus on equipping nurses to train these primary caregivers so that their CSDs can remain in the community and that they do not have to move away. The focus group also sensitised the researcher to the terminology that nurses use (e.g. " <i>Mental retardation</i> " as opposed to " <i>developmental delay</i> " or " <i>intellectual impairment</i> ", etc.)

From the above table it is thus clear that the focus group was able to provide a thick, rich description of the context, rather than to quantify, operationalise or test hypotheses (Krogh & Lindsay, 1999). It made the researcher aware of important information about nurses' expectations and exposure towards CSDs and how they perceived their roles within the community regarding service provision to this population. Due to the fact that the data are descriptive in nature, the same terminology and criteria used in quantitative research (e.g. reliability and validity) cannot be used, but that a new set of criteria, developed for and fit for qualitative research should be used (Cutcliffe & McKenna, 1999; Kirk & Miller, 1986). One such a concept is "*trustworthiness*". Attempts made to increase the trustworthiness of this research through the use of specific techniques as well as the relationship between the qualitative terms and better known quantitative terms are discussed in Table 4.3.

**Table 4.3      Increasing trustworthiness of the pre-experimental phase of the research during focus groups with community health nurses**

Strategy	Technique	How technique was addressed in present research
<b>Credibility</b> <i>What is the truth-value of the research?</i>	Prolonged, sustained engagement (Spencer, 1993)	The researcher has been involved in the Moretele Health District for approximately eight years. Before conducting Phase 1 of the research, one month was spent observing the clinics in an informal way. This prolonged engagement ensured trust between the researcher and the participants, providing her with the opportunity to become entrenched in the culture and work ethics of the nurses and aided in the removal of certain misconceptions (e.g. the number of CSDs seen by nurses).

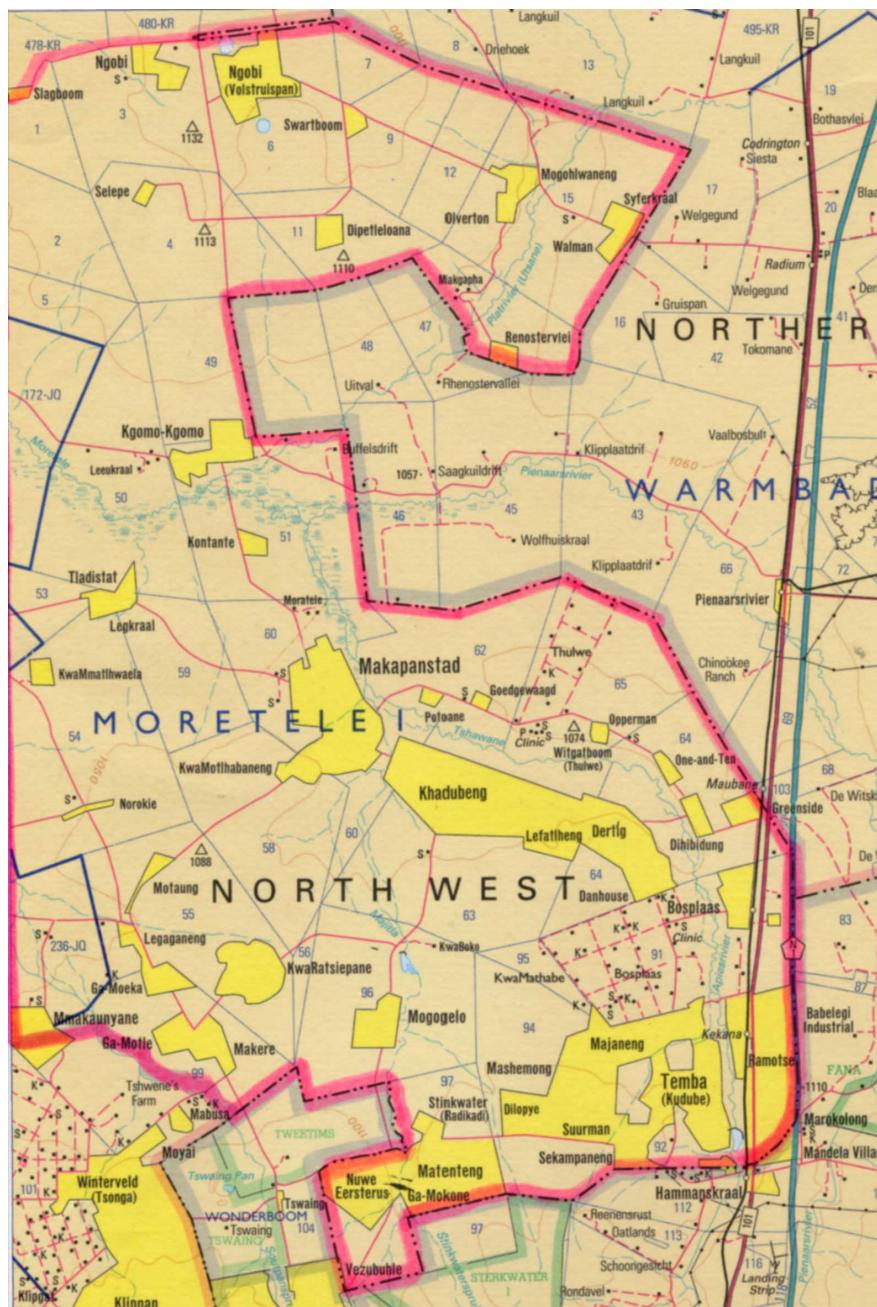
Strategy	Technique	How technique was addressed in present research
Known as <b>internal validity</b> in quantitative research.	Persistent observation of phenomena in various contexts and situations.	All clinics in the given health care district were visited, not only a select few. Furthermore, the pilot study was conducted in a different geographical area (ODI Health District). Disability, and the provision of services at PHC level was not only viewed from the nurses' perspective, but information was also obtained from the health care district managers and primary caregivers.
	Triangulation	A number of different triangulation types were used for the purpose of the research. They are as follows:
	Data triangulation at person level	<b>Person triangulation</b> involved the collection of data on individual levels (questionnaires) and on group level (focus groups). Data collected from one source was used to validate data from the other source.
	Method triangulation	A <b>between-methods triangulation</b> was used as the research employed qualitative data (obtained from the focus groups) as well as quantitative data (obtained from questionnaires).
	Investigator triangulation	Researchers from <b>diverse backgrounds</b> (Nurse, SLP, AAC specialist) with experience in qualitative research were included in the research. This enhanced the quality of data as each researcher brought her own expertise to the research.
	Analysis triangulation	Both <b>qualitative and quantitative approaches</b> were applied in analysing the data. By comparing the results from these two techniques the researcher was able to note similar patterns and thus verify findings.
	Multiple triangulation	Multiple triangulation occurs when <b>more than one type of triangulation</b> is used, intensifying the advantages of the different types of triangulation, further validating the findings and obtaining a more comprehensive and satisfactory sense of the phenomenon. The present research achieved this.
	Peer group examinations and discussions	Two independent researchers involved in PhD studies with experience in qualitative research but diverse backgrounds (nursing and speech-language pathology) were involved in order to assist with the exploration of concepts and the analysis of data. This provided the researcher with the means to discuss insights and problems, to "test" ideas regarding certain aspects and also to prevent personal bias. This bias can be attributed not only to the researcher's own culture, background, interest, etc. but could also arise from the prolonged engagement in the particular community. These peer discussions also led to deeper reflexive analysis of the data.
	Member checking	This is one of the most important aspects of ensuring credibility. After themes were developed and the data analysed, results were presented to the participants to ensure the correctness of conclusions. It provided nurses with the opportunity to correct factual mistakes and to volunteer new information, and also provided the researcher with the opportunity to record the nurse's reactions after seeing the data in the new format. The importance of using the actual words of the participants is also highlighted by Cutcliffe and McKenna (1999) as participants recognise their own words and respond better, as it has specific meaning for them.
	Stakeholder review	Stakeholders were involved throughout the process to assist with reviewing the findings, clarifying points of interpretative or descriptive disagreement, prioritising unresolved issues and collecting information on those issues. One such issue was the time nurses would spend in training. After collecting the data to demonstrate the effect that nurses with specialised training in disability would have, it was decided that the weeklong training would not be problematic.

<b>Strategy</b>	<b>Technique</b>	<b>How technique was addressed in present research</b>
<b>Transferability</b>  <i>How applicable will the data be in other contexts or with other respondents?</i>  Known as <b>external validity</b> in quantitative research	Selection of information about the phenomena by a panel of experts	The researcher attempted not to work in isolation, and frequently had meetings with stakeholders, experts in the nursing, disability and AAC fields, government representatives as well as primary caregivers of CSDs throughout the whole research project. Examples include the assistance of nursing experts when the information questionnaire was drawn up, discussions with AAC and nursing experts in determining applicable questions for the nursing focus groups and discussions with primary caregivers and AAC experts regarding questions applicable to the primary caregiver focus groups. AAC experts assisted in reviewing the videos selected for training. All the above-mentioned parties provided input regarding the development of the protocol.
	Use of multiple cases or groups	Two focus groups were used to ensure rich descriptive data and to enhance the transferability of the data. Results from the two groups were compared and this was also compared with data obtained from the questionnaire. Data obtained in the two primary caregiver focus groups were also compared with each other as well as with information from the nurses' focus groups and the questionnaire.
	Ensure representativeness of participants (Spencer, 1993)	The background information of the participants for the focus groups with primary caregivers and nurses was obtained from a short questionnaire. This was then compared with the available demographic information for the whole group in order to ensure representativeness.
	Look at the data rather than the topic of investigation	It is important to determine whether the data obtained can be seen as typical or atypical of the phenomenon under investigation. This is briefly described in Chapters 5 and 6.
<b>Dependability</b>  <i>How consistent are the results? Can the research be repeated?</i>  Known as <b>reliability</b> in quantitative research	<b>Indirect method</b> Look at internal and external validity measurements	The above-mentioned discussion on credibility and transferability is important for this section, as Lincoln and Guba (1985) state that no validity is possible without reliability (and thus no credibility without dependability). A demonstration of the former is sufficient to establish the latter.
	<b>Direct method</b> Triangulation	This method, and how it pertains to the current research, has already been discussed in detail.
	<b>Direct method</b> Stepwise replication	In qualitative research the researcher always aims to provide a "thick" or "rich" description of the context. Rigour was applied in describing the context, how data was obtained, analysed (i.e. the development of themes) and interpreted. The methodology should be explicit enough for an independent researcher to repeat.
	<b>Direct method</b> Dependability audit	A researcher independent from the present research was asked to establish how dependable data is presented, and to determine the accuracy of the data (including analysis and recommendations).
<b>Confirmability</b>  <i>How neutral is the research?</i>  Known as <b>objectivity</b> in qualitative research.	Confirmability audit / Process audit trial on described chain of events.	An independent knowledgeable researcher with experience in the field of qualitative research was asked to evaluate the degree to which the research process, including the raw data, data reduction and analysis products (condensed notes and qualitative summaries), data reconstruction (thematic categories), findings, interpretations and recommendations follow acceptable research practice. This researcher (the "auditor") stood completely neutral to the research. It should be emphasised that neutrality is not seen as a way to avoid "contamination". Rather the researcher's characteristics, attitudes and feelings are recognised as influencing the research and hence made explicit.

Conceptualised from Brotherson and Goldstein, 1992; Cutcliffe and McKenna, 1999; Kimchi, Polivka and Stevenson, 1991; Klopper, 1995; Krefting, 1991; Krogh and Lindsay, 1999 and Krueger, 1993.

## Quantitative description of community nurses' perceptions and exposure

Apart from the above-mentioned qualitative data, quantitative data in the form of a questionnaire was also obtained. This questionnaire is included in **Appendix D**. All nurses working in clinics (stationary clinics and mobile points) in the Moretele Health District were asked to complete questionnaires.



**Map 1      Area map of the Moretele Health District (Government Printers, 1998)**

Only nurses who were present on the day of data collection were included; those who were on

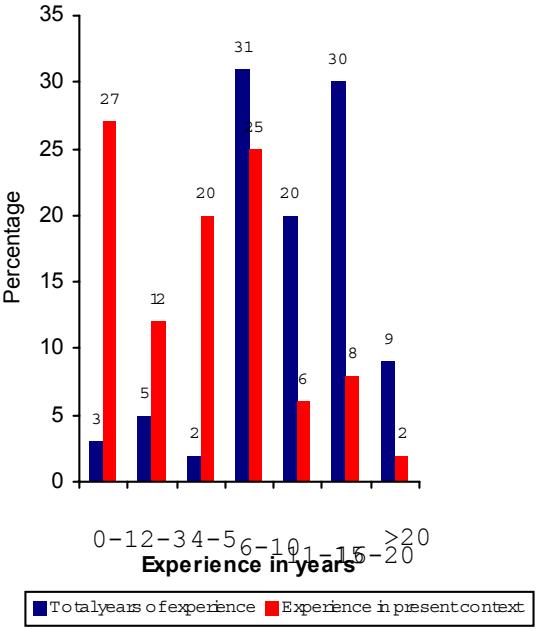
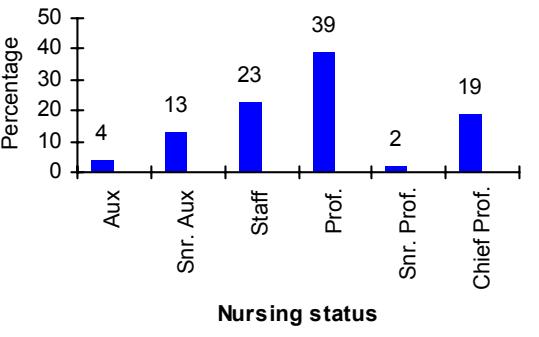
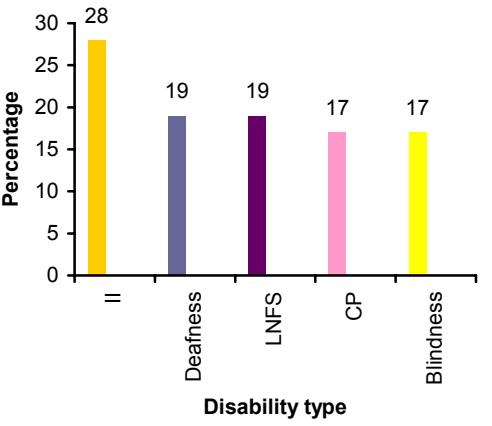
leave or who were sick on that particular day were excluded. All nurses (ranging from nursing assistants to professional nurses) who performed nursing tasks were included. Nurses who had attended the focus groups were also asked to complete the questionnaires. Although this could have impacted on the quality of the answers, it was felt that the questions asked during the focus groups varied substantially from the questions asked in the questionnaire and consequently the impact is regarded as minimal.

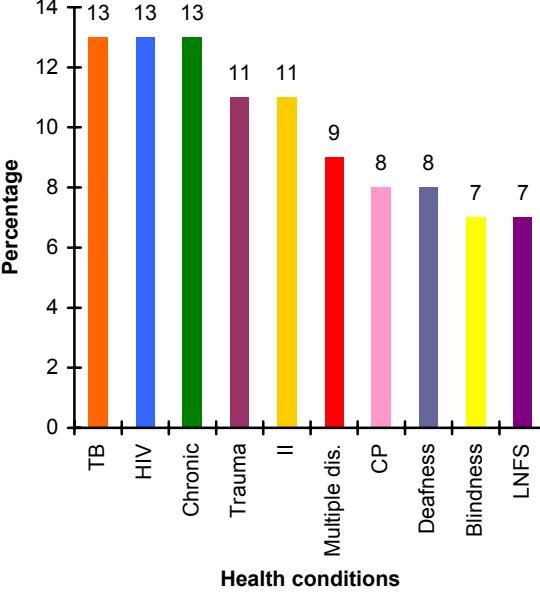
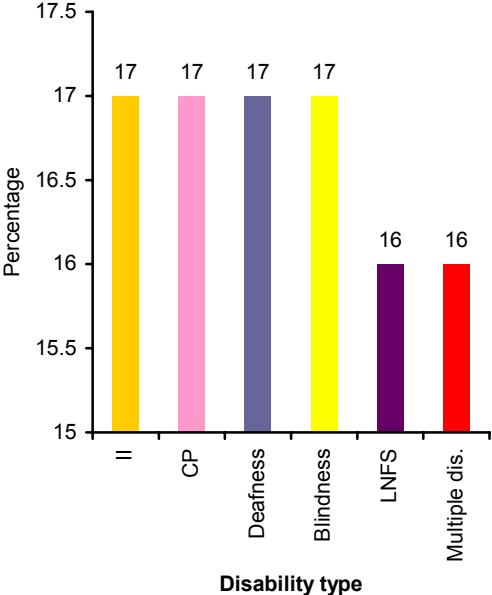
A total of 25 clinics and 14 mobile points, which serve an estimated average of 4365 persons per day, was included. The clinics differ in size, ranging from some with only two nurses serving approximately 30 people daily to some clinics with eight nurses serving 300 people daily. A research assistant was appointed to assist with the completion of the questionnaires. All questionnaires were completed between 14 February and 21 February 2000. A total of 111 questionnaires was completed. This implies that 92% of the total population was surveyed (111 of 121 nurses employed in the Moretele Health District).

More detailed information on the nurses' biographic background, educational levels, current exposure and service delivery to CSDs as well as the needs of these children as perceived by the nurses, are described in Table 4.4.

**Table 4.4 Descriptive information about nurses in the Moretele Health District (n=111)**

Description	Results												
Nurses generally tended to be older (85% in their thirties and forties), impacting on the teaching principles used when training these nurses in the proposed protocol, as issues related to adult learning styles will have to be adhered to.	<table border="1"> <thead> <tr> <th>Age in years</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>20-29</td> <td>4</td> </tr> <tr> <td>30-39</td> <td>42</td> </tr> <tr> <td>40-49</td> <td>43</td> </tr> <tr> <td>50-59</td> <td>10</td> </tr> <tr> <td>60+</td> <td>1</td> </tr> </tbody> </table>	Age in years	Percentage	20-29	4	30-39	42	40-49	43	50-59	10	60+	1
Age in years	Percentage												
20-29	4												
30-39	42												
40-49	43												
50-59	10												
60+	1												

Description	Results																								
<p>More than half the total number of nurses (59%) had more than ten years experience, highlighting the fact that they tended to be a stable workforce who stayed employed for a long time and because of this, had a vast amount of experience. This makes them excellent candidates for additional in-service training, as they will be able to utilise the new knowledge and skills for a long time. The movement between clinics is varied as 27% had spent less than one year in the present clinic but 25% had spent 6 to 10 years and 20% had spent 4 to 5 years in the present clinic. Given the high rates of staff turnover during the past decade, the stability of the nursing workforce in the Moretele Health District is important.</p>	 <table border="1"> <caption>Data for Experience in Years</caption> <thead> <tr> <th>Experience in years</th> <th>Total years of experience (%)</th> <th>Experience in present context (%)</th> </tr> </thead> <tbody> <tr> <td>0-12</td> <td>3</td> <td>27</td> </tr> <tr> <td>12-34</td> <td>5</td> <td>12</td> </tr> <tr> <td>34-56</td> <td>2</td> <td>20</td> </tr> <tr> <td>56-101</td> <td>31</td> <td>25</td> </tr> <tr> <td>101-152</td> <td>20</td> <td>6</td> </tr> <tr> <td>152-200</td> <td>30</td> <td>8</td> </tr> <tr> <td>&gt;200</td> <td>9</td> <td>2</td> </tr> </tbody> </table>	Experience in years	Total years of experience (%)	Experience in present context (%)	0-12	3	27	12-34	5	12	34-56	2	20	56-101	31	25	101-152	20	6	152-200	30	8	>200	9	2
Experience in years	Total years of experience (%)	Experience in present context (%)																							
0-12	3	27																							
12-34	5	12																							
34-56	2	20																							
56-101	31	25																							
101-152	20	6																							
152-200	30	8																							
>200	9	2																							
<p>Almost half the respondents were professional nurses (45%). Staff/enrolled nurses refer to nurses who are currently undergoing training in order to become professional nurses (23%). Chief professional nurses refers to those in charge of specific clinics. Auxiliary nurses refer to nursing assistants.</p>	 <table border="1"> <caption>Data for Nursing Status</caption> <thead> <tr> <th>Nursing status</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>Aux</td> <td>4</td> </tr> <tr> <td>Snr. Aux</td> <td>13</td> </tr> <tr> <td>Staff</td> <td>23</td> </tr> <tr> <td>Prof.</td> <td>39</td> </tr> <tr> <td>Snr. Prof.</td> <td>2</td> </tr> <tr> <td>Chief Prof</td> <td>19</td> </tr> </tbody> </table>	Nursing status	Percentage	Aux	4	Snr. Aux	13	Staff	23	Prof.	39	Snr. Prof.	2	Chief Prof	19										
Nursing status	Percentage																								
Aux	4																								
Snr. Aux	13																								
Staff	23																								
Prof.	39																								
Snr. Prof.	2																								
Chief Prof	19																								
<p>Weighted frequency scores were obtained, and children with intellectual impairment (II) were seen most frequently (28%). This was expected as the reported prevalence rate for intellectual impairment in South Africa is 3% comprising 2,5% mild, 0,4% severe and 0,1% profound (Year of the Disabled Persons Report, 1987). The high incidence of epilepsy and the nurses' awareness of it indicates that this is an issue that needs to be addressed in the protocol. Furthermore, multiply handicapped children and children with intellectual impairment frequently have epileptic seizures, including petit mal and grand mal. Literature suggests that as many as 31% of people with severe disabilities have been reported to have seizures and that about 35% of children with cerebral palsy will develop seizures (Sobsey &amp; Thuppel, 1996).</p>	 <table border="1"> <caption>Data for Disability Type</caption> <thead> <tr> <th>Disability type</th> <th>Percentage</th> </tr> </thead> <tbody> <tr> <td>II</td> <td>28</td> </tr> <tr> <td>Deafness</td> <td>19</td> </tr> <tr> <td>LNFS</td> <td>19</td> </tr> <tr> <td>CP</td> <td>17</td> </tr> <tr> <td>Blindness</td> <td>17</td> </tr> </tbody> </table>	Disability type	Percentage	II	28	Deafness	19	LNFS	19	CP	17	Blindness	17												
Disability type	Percentage																								
II	28																								
Deafness	19																								
LNFS	19																								
CP	17																								
Blindness	17																								

Description	Results																						
<p>According to the Department of Health (Government Gazette 17910, 1997) the following health issues should receive the highest priority: namely tuberculosis (TB), HIV/AIDS, chronic diseases (e.g. asthma) and violence and trauma. These health issues together with intellectual impairment (II) were reported as being the most serious problems with which nurses are confronted in the respective clinics.</p>	 <table border="1"> <thead> <tr> <th>Health condition</th> <th>Percentage</th> </tr> </thead> <tbody> <tr><td>TB</td><td>13</td></tr> <tr><td>HIV</td><td>13</td></tr> <tr><td>Chronic</td><td>13</td></tr> <tr><td>Trauma</td><td>11</td></tr> <tr><td>II</td><td>11</td></tr> <tr><td>Multiple dis.</td><td>9</td></tr> <tr><td>CP</td><td>8</td></tr> <tr><td>Deafness</td><td>8</td></tr> <tr><td>Blindness</td><td>7</td></tr> <tr><td>LNFS</td><td>7</td></tr> </tbody> </table>	Health condition	Percentage	TB	13	HIV	13	Chronic	13	Trauma	11	II	11	Multiple dis.	9	CP	8	Deafness	8	Blindness	7	LNFS	7
Health condition	Percentage																						
TB	13																						
HIV	13																						
Chronic	13																						
Trauma	11																						
II	11																						
Multiple dis.	9																						
CP	8																						
Deafness	8																						
Blindness	7																						
LNFS	7																						
<p>Weighted frequencies indicated that there were no significant differences in their level of comfort in dealing with children with different types of disabilities, i.e. they did not feel more uncomfortable with a child with intellectual impairment 1(II) than with a child with CP.</p>	 <table border="1"> <thead> <tr> <th>Disability type</th> <th>Percentage</th> </tr> </thead> <tbody> <tr><td>II</td><td>17</td></tr> <tr><td>CP</td><td>17</td></tr> <tr><td>Deafness</td><td>17</td></tr> <tr><td>Blindness</td><td>17</td></tr> <tr><td>LNFS</td><td>16</td></tr> <tr><td>Multiple dis.</td><td>16</td></tr> </tbody> </table>	Disability type	Percentage	II	17	CP	17	Deafness	17	Blindness	17	LNFS	16	Multiple dis.	16								
Disability type	Percentage																						
II	17																						
CP	17																						
Deafness	17																						
Blindness	17																						
LNFS	16																						
Multiple dis.	16																						

In order to explore nurses' comfortableness in dealing with CSDs further, contingency tables were created as they indicate the relationship between sets of nominal data. They were therefore used to correlate the relationship between exposure to the different disability types, and how comfortable nurses felt in dealing with these children. The Pearson Chi-square test was administered to all the categories. Results are as follows:

**Table 4.5 Significance of exposure to disability vs. comfortableness in handling disability**

Disability type	Chi-square value	Significance : p< 0.05
Intellectual impairment	0,024	Yes
Cerebral palsy	0,159	No
Deafness	0,252	No
Blindness	0,352	No
LNFS	0,004	Yes

As intellectual impairment and LNFS proved to be statistically significant, further testing was done. These results are as follows:

**Table 4.6 Frequency of exposure to intellectual impairment vs. comfortableness in handling it**

Exposure:	Description	Uncomfortable	Comfortable	Total
<i>Never</i>	Frequency	<b>1</b>	<b>15</b>	<b>16</b>
	Percentage	1.0	13.5	14.5
	Row %	6.3	93.7	
	Column %	2.8	20.0	
<i>Once a week to once a month</i>	Frequency	<b>17</b>	<b>37</b>	<b>54</b>
	Percentage	15.3	33.3	48.6
	Row %	31	68.5	
	Column %	47.2	49.3	
<i>Less than once a month</i>	Frequency	<b>18</b>	<b>23</b>	<b>41</b>
	Percentage	16.2	20.7	36.9
	Row %	43.9	56.1	
	Column %	50.0	30.7	
<b>Total</b>	Frequency	<b>36</b>	<b>75</b>	<b>111</b>
	Percentage	32.5	67.5	100%

This 2x3 contingency table (Table 4.6) clearly shows that the majority of nurses (67.5%) felt comfortable in handling children with intellectual impairment. Only a small number of nurses had indicated that they never see children with intellectual impairment (16 nurses). This table also indicates that despite their exposure to children with intellectual impairment all of them felt more comfortable than uncomfortable in handling these children. However, the nurses who had never seen children with intellectual impairment were notably the group who felt the most comfortable in handling them (93.7%). This might be due to the fact that they were unaware of the potential problems and issues of dealing with these children.

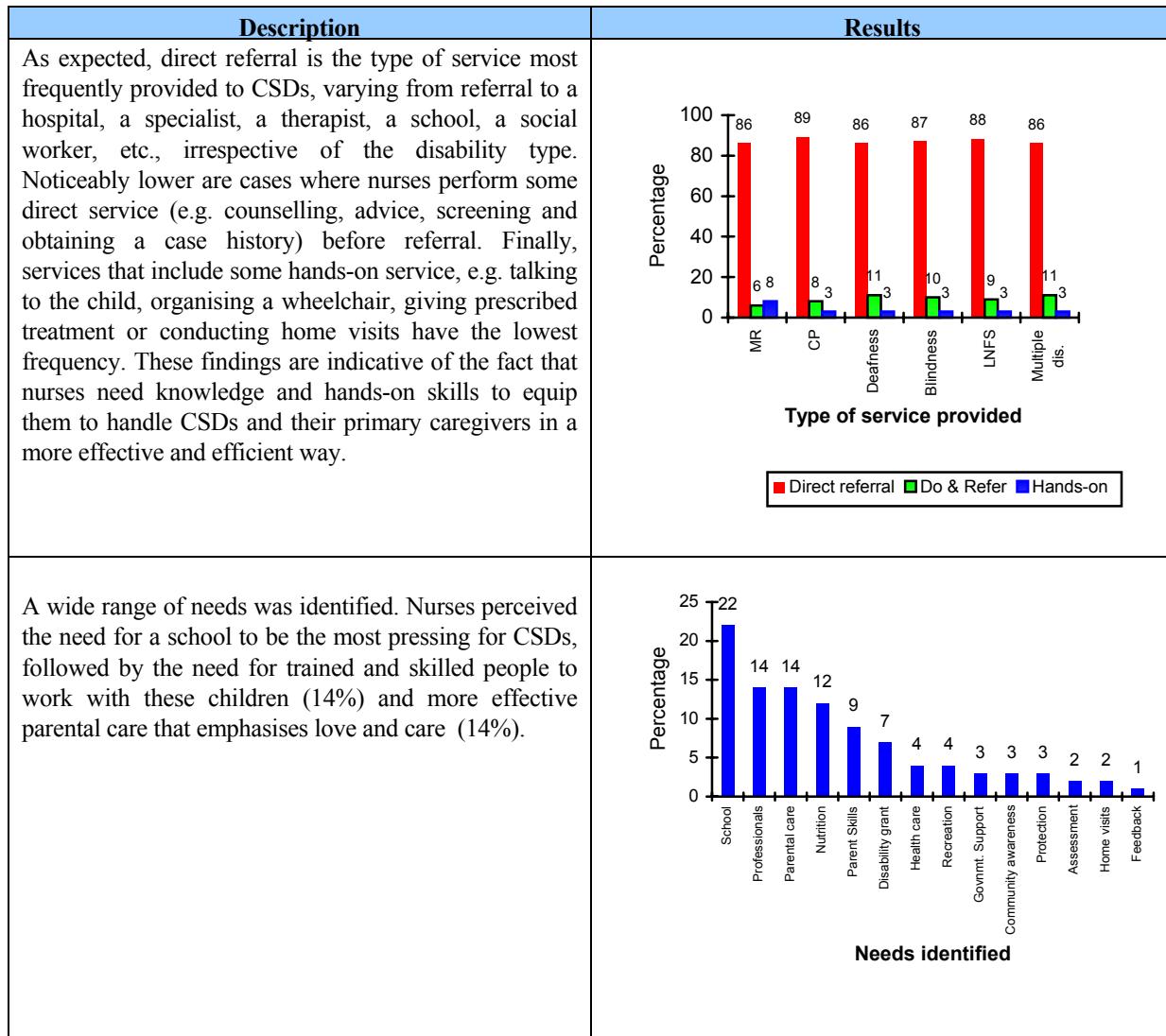
The second disability category that indicated significance on the Pearson Chi-square test, namely children with LNFS. Data for this group is shown in Table 4.7.

**Table 4.7 Frequency of exposure to children with LNFS vs. comfortableness in handling them**

Exposure:	Description	Uncomfortable	Comfortable	Total
<i>Never</i>	Frequency Percentage Row % Column %	16 14.4 27.6 34.0	42 37.8 72.4 65.6	<b>58</b> 52.2
<i>Once a week to once a month</i>	Frequency Percentage Row % Column %	11 9.9 57.9 23.4	8 7.2 42.1 12.5	<b>19</b> 17.1
<i>Less than once a month</i>	Frequency Percentage Row % Column %	20 18.0 58.8 42.6	14 12.6 41.2 21.9	<b>34</b> 30.6
<b>Total</b>	Frequency Percentage	<b>47</b> 42.3	<b>64</b> 57.6	<b>111</b> 100%

This 2x3 contingency table indicates that the majority of nurses (57.6%) felt comfortable in handling children with LNFS. The difference between the two groups (42.3% vs. 57.6%) is smaller than the similar difference when viewing intellectual impairment in Table 4.6 (32.5% vs. 67.5%). Children with LNFS are also a phenomenon that nurses do not see as frequently, as 52.2% noted that they had never seen a child with LNFS. Of this 52.2% substantially more nurses felt comfortable (72.4%) rather than uncomfortable (27.6%) in handling these children. However, once they were exposed to these children they became more uncomfortable in handling them, implying that even very infrequent exposure to a child with LNFS is sufficient to sensitise a nurse to the problems associated with dealing with this population. This also provides a strong impetus for training nurses in the handling of CSDs.

The last section that covers the descriptive information regarding the community health nurses of the Moretele Health District is presented in Table 4.8. This relates to the type of service delivery and the needs of the CSDs as perceived by the nurses.

**Table 4.8 Service delivery and needs of CSDs as perceived by nurses**

## ii) Section I: Phase 2

This section deals with the needs analysis of primary caregivers. In order to ensure the applicability and cultural relevance of the activities selected for the BCIP, two different focus groups were held in the Moretele Health District where the research was conducted. One focus group was held with caregivers of typically developing children with an understanding of the cultural context, and one with caregivers of CSDs. Both of these focus groups will now be discussed in more detail.

**a) Focus group 1      Caregivers of typically developing children**

This focus group was conducted as an initial stage in determining which activities children in the Moretele area are engaged in, and also to determine how children are perceived and what is expected of them. A summary of this focus group is presented in Table 4.9.

**Table 4.9      Focus group with caregivers of typically developing children**

Category	Description
<b>Participants</b>	The Gateway clinic was targeted as it has a high number of patients and was easily accessible to the researcher. Although it is now expected of clinics to have a “supermarket approach” implying that all services should be available at any given time (Government Gazette 17910, 1997), Tuesdays were traditionally set aside for the “ <i>Under 5 Clinic</i> ”. As the majority of mothers with pre-schoolers still tend to attend the Tuesday clinics, it was decided to conduct the focus group on a Tuesday. Six caregivers of typically developing pre-schoolers were asked whether they would be willing to participate. All of them met the selection criteria that were set, namely that they resided in the Moretele Health District, that they had pre-school children and that they were willing to discuss their interaction and the stimulation of their children. <u>Background information on these six caregivers is included in Table 4.10.</u>
<b>Aims</b>	To determine in which activities children in the Moretele area are engaged, how children are perceived and what is expected of them, two open-ended interview questions were used, namely: i)     What do children in your village enjoy doing? ( <i>Activities</i> ) ii)     What is your idea of a very good child? What must this child do and not do? ( <i>Communication opportunities</i> )
<b>Method</b>	As this focus group was a one-off event, it was important to establish rapport quickly and to set the participants at ease so that they would talk freely about their experiences. In order to establish a relaxed, non-threatening environment, all participants enjoyed tea and cake before commencing (Fuller, Edwards, Vorakitphokatorn & Sermsri, 1993). This focus group was conducted in the mother tongue of the group, namely Setswana. The research assistant who assisted with the questionnaires facilitated this focus group, as she is a Setswana mother-tongue speaker and has had exposure to some of the most important issues pertaining to disability in the Moretele Health District. She had received training prior to the start of the focus group regarding the facilitation of interaction, how to ask for clarification, how to summarise key issues and how to ask for confirmation of the factual correctness. In order to increase trustworthiness, member checks were done directly after the discussion of each of the questions. This was necessitated by the fact that this focus group was a one-off event. As this was the research assistant’s first attempt at facilitating a focus group, optimal facilitation techniques were absent, despite earlier training. She did not always follow-up on some of the ideas presented, and did not steer the participants to obtain more comprehensive data, e.g. when discussing feeding, <i>what</i> children were fed was discussed continuously, and the facilitator could have probed to also obtain information on <i>how</i> children are fed. Towards the end of the group facilitating improved, e.g. “ <i>What else can they chose from?</i> ” The focus was relatively short (43 minutes). This can be ascribed to the fact that all the caregivers had their young children with them, some of whom were ill, and the children became bored and started crying, fidgeting and moping, leading to the caregivers becoming irritable and impatient. In
<b>Method (continued)</b>	addition none of the participants brought any toys or snacks to help their children occupy the time. A similar tendency was seen in a health clinic of low-income urban parents in Detroit, USA (Downs & Walker, 1996). In future a childminder and/or toys will be highly recommended. <u>Apart from the interview questions, a short questionnaire to gain biographic background information of</u>

Category	Description
	<p>the participants was completed by the facilitator. This information was essential for increasing the trustworthiness of the research as it heightens the transferability (Krefting, 1991). The characteristics of the caregivers were compared with the demographic information of the whole group (primary caregivers from the Moretele Health District) to ensure representativeness.</p> <p>The focus group interaction was audio recorded, and verbatim transcriptions were made.</p>
<b>Analysis</b>	<p>The research assistant made a verbatim transcription of the Setswana interaction and then translated it into English. She was asked to do the first translation, as she is from the Moretele area, and thus familiar with the specific colloquial. In order to heighten the reliability, a mother-tongue Setswana speaker from the Moretele district who lectures at the Department of African Languages at the University of Pretoria was asked to also translate the verbatim Setswana transcription. Minor differences between the two translations were found. These differences are included in <b>Appendix E</b>. On the whole, the second translation tended to be richer in description and provided more examples, e.g. translation one read “<i>helps me clean the house...</i>” whilst translation two read “<i>when I clean the house and I hold my broom like this, she hold hers the same...</i>” In addition, translation one omitted three facts. This could possibly be due to either negligence or the fact that it may have been a difficult concept to translate. In addition, it must be kept in mind that translator two is a professional with more background in language and translations. Because translation two tended to be more complete and correct, this was used for data analysis. This entailed that the main researcher and an independent researcher with experience in qualitative research (who assisted with the community nurses’ focus group) analysed the data and delineated themes, following the same procedure as outlined in the previous focus group discussion. This specific method was used as it could enhance the trustworthiness of the results.</p>
<b>Results</b>	<p>Background information of the participants is presented in Table 4.10, indicating that all were mothers and housewives spending the majority of their time at home with the children. All had at least two or more children, making them information rich participants regarding the specific topic. Ages ranged between 21 and 36 years with the majority being in their thirties. When comparing the ages of the mothers and their children, it can be seen that Mother 5 was a pre-adolescent mother whilst the others all seemed to have had their first child in their early twenties. They covered the four ethnic groups frequently found in this area, namely Setswana, Xitsonga, Sepedi and isiZulu. Four of the six mothers lived in informal settlements, while two had formal housing. Only two mothers reported that they had support from grandmothers, and both of these mothers were from the informal settlements, which might be due to the fact that the extended families are more active in these situations. The mothers’ highest qualifications varied as one had never attended school, another had Grade 5 and two had Grade 11. Background data also revealed that these six mothers were representative of the larger Moretele area.</p> <p>A summary of the themes delineated from this focus group is presented in <b>Appendix F</b>. Two major themes developed, namely the activities children were involved in and the specific communication functions they used. A few general comments were also made, which indicated the mothers’ perspectives on children and child-rearing, e.g. that mothers usually have all the responsibility for their children, they generally tend to enjoy “<i>teaching</i>” them and place a high value on good manners. It was noted that the activities children engage in are mostly of a domestic nature and involve ADL, e.g. mealtimes, bathtime, sweeping the floor, etc. Play was not frequently mentioned and usually involved interactive games rather than playing with toys. Participants from the formal housing areas indicated that their children had literacy exposure while the children from the informal settlements had none. Regarding communication functions, a whole range was mentioned, including greeting, requesting, providing information, choice-making, signalling presence, etc.</p>
<b>Implications</b>	<p>Results provided invaluable information for the development of the BCIP as the researcher obtained in-depth knowledge and insight into the activities that children in this particular area participate in, as well as the specific communication functions displayed by them. Both of these aspects are corner elements of the BCIP. It became clear that the BCIP would have to focus on ADL rather than on play, as children were usually not engaged in play activities with their primary caregivers. Play was mostly amongst peers and interactive in nature. The activities that had the highest frequency throughout the day, and that involved both the caregiver and child, was mealtime and washing time. Various authors have mentioned that activities spread throughout the day and which frequently occur provide ideal intervention opportunities (Goossens’, Sapp-Crain &amp; Elder, 1994; Westling &amp; Fox, 2000). Due to the high incidence of poverty in the area, toys and literacy material is not freely available. Regarding the communication functions it was noted that a strong culture of choice-making prevails regarding dressing and eating.</p>

Category	Description
	Caregivers also placed a high value on greeting, as this is a sign of respect.

The biographic background of the caregivers of typically developing children who participated in this focus group is presented in Table 4.10.

**Table 4 .10 Background information on primary caregivers of typically developing children**

Category	Mother 1	Mother 2	Mother 3	Mother 4	Mother 5	Mother 6
<b>Age</b>	21 yrs. 4 months	31 yrs. 7 months	33 yrs. 8 months	33 yrs. 0 months	26 yrs. 4 months	24 yrs. 9 months
<b>Ethnic background</b>	Sepedi	Setswana	Xitsonga	Sepedi	Setswana	IsiZulu
<b>Housing</b>	Informal settlement	Formal housing	Informal settlement	Informal settlement	Formal housing	Informal settlement
<b>Highest qualification</b>	Grade 9	Grade 11	Never attended school	Grade 5	Grade 8	Grade 11
<b>Occupation</b>	Housewife	Housewife	Housewife	Housewife	Housewife	Housewife
<b>Support?</b>	Yes: Grandmother	No	No	No	No	Yes: Grandmother
<b>Children</b>	<b>Daughter</b> 15 days <b>Son</b> 2 yrs. 7 mths	<b>Son</b> 12 yrs. 8 mths <b>Son</b> 7 yrs. 0 mths <b>Daughter</b> 3 yrs. 1 mth	<b>Son</b> 13 yrs. 7 mths <b>Daughter</b> 8 yrs. 8 mths <b>Son</b> 2 yrs. 0 mths	<b>Daughter</b> 13 yrs. 0 mths <b>Daughter</b> 10 yrs. 3 mths <b>Son</b> 1 yrs. 10 mths	<b>Son</b> 15 yrs. 5 mths <b>Son</b> 13 yrs. 7 mths <b>Son</b> 8 yrs. 3mths <b>Daughter</b> 2 yrs. 4 mths	<b>Son</b> 13 yrs. 3 mths <b>Son</b> 2 yrs. 5 mths <b>Son</b> 13 days

**b) Focus group Primary caregivers of CSDs**

Following the focus group with primary caregivers of typically developing pre-schoolers, a focus group with primary caregivers of CSDs was held as it was expected that differences might exist, e.g. caregivers of typically developing pre-schoolers and caregivers of CSDs might not conduct ADL in the same way. In addition, CSDs and typically developing children might not have the same opportunities for interaction with peers and social inclusion (e.g. attending Sunday school), they might not engage in the same activities, caregivers might have lower expectations from CSDs, etc. The main purpose of this focus group was to determine the similarities and differences between these two groups. In addition, information obtained from this focus group would provide guidance in the development of the BCIP.

**Table 4.11 Focus group with primary caregivers of CSDs**

Category	Description
<b>Participants</b>	<p>All caregivers of the 14 children in the junior phase of a special school in the Moretele Heath District were invited to attend the focus group. It was scheduled on a Wednesday at 12h00, a time that primary caregivers and teachers considered convenient. Invitations were sent by means of a formal letter from the school principal that the children took home a week before the scheduled date. Teachers checked the children's bags to ensure that the letters had been distributed. In cases where the children could understand, they were asked if they had given the letters. A follow-up letter was sent the day before the focus group. Primary caregivers were also assured that their travelling expenses would be covered. This school caters for all disability types, except Deaf children, as there is a separate school for them in the area. A total of four mothers and one father turned up. Five participants is the smallest useable sample (Brink, 1999). Background information on these five caregivers is included in Table 4.12.</p>
<b>Aims</b>	<p>As for the focus group with caregivers of typically developing children, the aims were to determine which activities the children engaged in, how they are perceived and what is expected of them. The two open-ended interview questions that were answered were:</p> <ul style="list-style-type: none"> <li>i) What do children in your village enjoy doing? (<i>Activities</i>)</li> <li>ii) What is your idea of a very good child? What must this child do and not do? (<i>Communication opportunities</i>)</li> </ul>
<b>Method</b>	<p>Despite the fact that the CSDs attended the same school, caregivers had not previously met except for Mothers 1 and 4, therefore it was necessary to create a non-threatening environment from the onset. Initially teachers had coffee and cake with the caregivers and researchers in an attempt to break the ice. Teachers knew the primary caregivers, and were able to introduce them to each other and also to introduce the researcher and the research assistant. When the focus group discussions started, the teachers left. This was previously arranged, as it was feared that primary caregivers might not feel free to express themselves if the teachers were present. They might have wanted to impress the teachers, so that the teachers would form a positive impression of them, and consequently of their children, leading to the so called <i>halo effect</i> (Guy, Edgley, Arafat &amp; Allen, 1987). The same research assistant who had conducted the previous focus group also facilitated this group, again in Setswana. It was evident that she had become more confident and skilled, and that she was able to reflect and summarise better than the previous time. The whole 54 minutes of interaction was audio recorded and verbatim transcriptions were made.</p>
<b>Analysis</b>	<p>As in the case of previous focus group, the research assistant did the first translation and the professional translator (lecturer at the Department of African Languages at the University of Pretoria) the second. Only three differences were noted. This might also be because the research assistant became more skilled and confident. Again the second translator provided more contextual data e.g. "<i>I don't enjoy it when he plays inside the house with others</i>" whilst the first translation only read "<i>I don't like it when he plays with others</i>". Two facts were also omitted in the first translation An exposition of the two translations is included in <b>Appendix G</b>. Consequently, translation two was used to delineate themes from following exactly the same procedure described in the previous focus group (Table 4.9).</p>

Category	Description
<b>Results</b>	<p>Background information on the participants is presented in Table 4 .12. Results indicate an age range of between 27 and 56, with the father being the eldest. The CSDs were relatively young, ranging from 5 to 8 years, covering a range of disabilities, i.e. intellectual impairment, multiple handicaps (intellectual impairment and CP) and no speech (caregivers were unsure about the aetiologies). All the caregivers had at least two children and the CSDs included eldest, middle and youngest children. Two ethnic groups were covered, namely Sepedi and Setswana, and housing included formal housing, informal settlements and a farm. All the mothers were housewives, while the father saw himself as unemployed. Three of the caregivers reported that they had some form of support (mostly from the spouse or grandmother) while two had no support. As in the previous focus group, one mother had never attended school, while the rest had had poor schooling (ranging from Grade 5 to Grade 9).</p> <p>A summary of the themes defined from this focus group is presented in <b>Appendix H</b>. Five major themes emerged. Factors pertinent to disability, such as communication means (usually speech is the most obvious means used by typically developing children) and receptive language skills were added. Regarding the activities the children engage in, three participants stated that their children did not really enjoy anything. The activities most frequently seen, as with typically developing children, is mealtimes, bathtime and domestic tasks. Games included interactive games rather than toy-based games. Despite the fact that all these children were exposed to books, three showed no interest. The need for frequent reinforcement was also raised. Communication functions mentioned were almost identical to those of the typically developing children, except for inappropriate interaction (causing shame for the family) that was present in some of the CSDs. A range of communication means were described, namely speech, crying and the use of objects. No mention was made of more formal AAC methods (e.g. line-drawings or manual signs) despite the fact that these children attended a special school. Primary caregivers also noted that their children's receptive language skills were limited, causing frustration and struggle (on the caregiver's side). Challenging behaviour was also noted in cases where the CSDs could not cope with some of the demands placed on them (avoidance). Caregivers generally perceived their children's behaviour to be inappropriate. Some of the children were integrated into their community, while one participant stated that she did not encourage her child to play with typically developing peers as they tease her child and she wants to protect her. Another participant also reported that the typically developing peers tend to take (steal) her child's toys as the child has no form of self-defence.</p>
<b>Implications</b>	<p>Results indicate a great need for the BCIP as young CSDs in the particular area are not receiving effective rehabilitation services. Despite the fact that all five the children under discussion were obvious AAC candidates, none of them received any kind of intervention. As in the previous focus group, it appears that ADL (e.g. mealtimes and bathtime) are done jointly by the primary caregiver and child on a frequent basis throughout the day, providing ample opportunities for communication, e.g. choice-making was frequently mentioned during mealtimes. All caregivers highlighted the importance of greeting. Primary caregivers again stressed the point that they did not play with their children as this was perceived by the community as a sign of being a "<i>lazy adult with no better work to do.</i>" Both primary caregiver focus groups provided information about the best activities to use, how the activities were conducted, and what the specific concepts in the particular environment would be, e.g. "<i>Simbas</i>" instead of "<i>chips</i>", etc. Consequently the examples provided in the BCIP could be more culturally sensitive. Information from this focus group was also used to compile the case studies (Response Form I).</p>

The biographic background of the primary caregivers of CSDs who participated in this focus group is shown in Table 4.12.

**Table 4.12 Background information on primary caregivers of CSDs**

Category	Mother 1	Father 1	Mother 2	Mother 3	Mother 4
----------	----------	----------	----------	----------	----------

Category	Mother 1	Father 1	Mother 2	Mother 3	Mother 4
<b>Age</b>	36 yrs. 9 months	56 yrs. 5 months	27 yrs. 1 month	44 yrs. 7 months	34 yrs. 4 months
<b>Ethnic background</b>	Setswana	Sepedi	Sepedi	Setswana	Setswana
<b>Housing</b>	Formal housing	Farm	Informal settlement	Formal housing	Informal settlement
<b>Highest qualification</b>	Grade 9	Grade 6	Never attended school	Grade 9	Grade 5
<b>Occupation</b>	Housewife	Unemployed	Housewife	Housewife	Housewife
<b>Support?</b>	No	Yes: Wife	Yes: Husband	Yes: Grandmother	No
<b>Children</b>	<b>Son</b> 19 yrs. 7 months <b>Son</b> 14 yrs. 9 months <b>*Daughter</b> 7 yrs. 11 months <b>Daughter</b> 4 yrs. 11 months	<b>Daughter</b> 28 yrs. <b>Son</b> 26 yrs. <b>Daughter</b> 23 yrs. <b>Daughter</b> 21 yrs. <b>Son</b> 15 yrs. <b>*Daughter</b> 5 yrs.	<b>Son</b> 9 yrs. 6 months <b>*Daughter</b> 7 yrs. 5 months <b>Son</b> 3 yrs. 1 month	<b>Daughter</b> 13 yrs. 5 months <b>*Daughter</b> 8 yrs. 2 months <b>Son</b> 6 yrs. 3 months <b>Daughter</b> 3 yrs. 7 months	<b>*Daughter</b> 7 yrs. 4 months <b>Son</b> 3 yrs. 3 months
<b>Type of disability</b>	No speech	No speech	Intellectual impairment and cerebral palsy	Intellectual impairment and no speech	Intellectual impairment

*The CSD is indicated with an asterisk (\*)*

### c) BCIP development

Following the two focus groups a literature review was conducted. This led to the development of the BCIP which was described in the previous chapter (**Appendix A** and **Appendix B**). It is, however, important to again highlight some of the most important aspects. It should be noticed that the BCIP is based on three activities of daily living, namely mealtimes, washing and dressing, as these were seen as the most pertinent activities. In addition, it covers a range of beginning communication functions, namely choice-making, turn-taking, labelling, initiating, requesting, rejecting, commenting and greeting. These activities are taught through the use of deliberate communication temptations, based on the ACE (Bornman, 1998; Rowland & Schweigert, 1993). Five different communication means, namely real objects, photographs, PCS communication boards, manual signs and a digital voice output device (EasyTalk 4-Option) are included.

In an attempt to ensure cultural sensitivity, the three activity-based boards PCS communication boards (adapted from Goossens', Sapp-Crain & Elder, 1994) were translated into all 11 official South African languages. Some of the symbols were also adapted to ensure that it fell into the experiences of the participants (e.g. “*washing*”) and that it was appropriate to the cultural/ethnic groups in the Moretele Health District (e.g. “*open*”, “*dry*”, “*mine*”, etc.) (Huer, 2000). In order to test the correctness of the translations and to establish whether children were familiar with the concepts depicted on these communication boards, a pilot study was conducted. The research assistant who is a mother tongue Setswana-speaker residing in the Moretele Health District visited two day care centres and two primary schools in the area. She explained the purpose of the research, and requested permission to interview all the five to seven year old children as well as their class teachers. She showed the children a choice of 4 PCS symbols, and asked them to identify a specific symbol, e.g. “*Show me which one you would use for pour*”. All instructions were presented in the child’s mother tongue. After this children were also asked if the word used by the research assistant, was the word that they would use. Exactly the same procedure was used with the teachers. In cases where children were unable to identify the correct picture, e.g. “*help*” teachers were asked whether this was a familiar concept, and which word the children mostly used.

A total number of 100 children with ages ranging between five and seven were interviewed. The ages were distributed as follows: 29% were 5 years old, 70% were 6 years old, and 1% was 7 years old. The children’s mother tongues also reflected the distribution of languages in the specific area: 83% were Setswana-speaking, followed by 9% Sesotho-speakers, 6% isiZulu-speakers and 2% Sepedi-speakers. A total of 18 teachers taught these children and their ages ranged from 30 – 54 years with 50% in their thirties, 38% in their forties and 12% in their fifties. Their mother tongues also correlated with those of the children with 77% being Setswana and one teacher each being Sesotho, isiZulu, and Sepedi. Results and recommendations are shown in Table 4.13.

**Table 4.13 Results and recommendations from pilot study on PCS communication board translations**

Category	Children	Adults	Recommendations
<b>NOUNS</b>			
Mug	100% correct of which 56% used synonym “komiki”	100% correct of which 50% used synonym “komiki”	Include both words on final communication board
Spoon	98% correct of which 35% used synonym “lelepolo”	78% correct of which 11% used synonym “lelepolo”	Include both words on final communication board
Water	100% correct	100% correct	No changes
Soap	100% correct	100% correct	Name of well-known brand was added before the pilot.
Pants	100% correct	100% correct	No changes
Shirt	100% correct	100% correct	No changes
Underwear	100% correct	100% correct	No changes
Socks	100% correct	100% correct	No changes
Shoes	100% correct	100% correct	No changes
Pyjamas	78% correct of which 54% used synonym “dibijame”	95% correct of which 72% used synonym “dibijame”	Replace with “cap”, as it is more familiar. Children in rural areas often do not sleep in pyjamas.
<b>VERBS</b>			
Want	91% correct of which 54% used synonym “nyaka”	100% correct of which 47% used synonym “nyaka”	Include both words on final communication board
Pour	100% correct	100% correct	No changes.
Open (mouth)	100% correct	100% correct	Changes were made prior to pilot study to enhance iconicity.
Eat	91% correct, whilst 9% described it as “brushing teeth”	100% correct	Change spoon to fork and draw picture from front angle, not sideways
Drink	100% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
Wash	97% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
Dry	94% correct, whilst 6% described it as “crying”	100% correct	No changes.
Open (tap)	99% correct	100% correct	Changes were made prior to pilot study to enhance iconicity.
Close (tap)	94% correct	100% correct but 5% used synonym “tima”	Changes were made prior to pilot study to enhance iconicity.
Put on	100% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
Take off	87% correct, 13% unsure	100% correct	Change picture to be clearer.
Help	41% correct	100% correct. (Reported that children know the concept, but couldn't identify picture)	Not picture producer, but was adapted prior to the pilot study to ensure cultural sensitivity.
<b>PREPOSITIONS</b>			
Beside	44% correct	100% correct	Not picture producer.
In	100% correct	100% correct	No changes.

Category	Children	Adults	Recommendations
<b>DESCRIPTIVES</b>			
More	57% correct	100% correct (Reported that children know the concept, but could not identify picture)	Not picture producer.
Finished	40% correct	100% correct. (Reported that children know the concept, but could not identify picture)	Not picture producer.
Dirty (face)	97% correct, of which 87% used synonym “ <i>ditšila</i> ”	94% correct of which 44% used synonym “ <i>ditšila</i> ”	Changes were made prior to pilot study to enhance iconicity. Include both words on final communication board.
Clean (face)	100% correct, of which 82% used synonym “ <i>skono</i> ”	100% correct of which 56% used synonym “ <i>skono</i> ”	Changes were made prior to pilot study to enhance iconicity. Include both words on final communication board.
Good	100% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
Yuckie	100% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
Wet	100% correct, of which 57% used synonym “ <i>thapile</i> ”	100% correct, of which 44% used synonym “ <i>thapile</i> ”	Include both words on final communication board.
Dirty (pants)	19% correct, of which 81% used synonym “ <i>ditšila</i> ”. 81% described it as “ <i>pants</i> ”	100% correct, of which 44% used synonym “ <i>ditšila</i> ”	Changes were made prior to pilot study to enhance iconicity. Include both words on final communication board.
Clean (pants)	16% correct, of which 84% used synonym “ <i>skono</i> ” 84% described it as pants	100% correct, of which 67% used synonym “ <i>skono</i> ”	Changes were made prior to pilot study to enhance iconicity. Include both words on final communication board.
<b>COMMUNICATIVE WORDS</b>			
I	100% correct	100% correct	Changes were made prior to pilot study to ensure cultural sensitivity.
No	85% correct of which 72% used synonym “ <i>aowa</i> ”	100% correct, of which 61% used synonym “ <i>aowa</i> ”	Include both words on final communication board.
Uh Uh	18% explained it as “ <i>shock</i> ” or “ <i>surprise</i> ”	50% explained it as “ <i>shock</i> ” or “ <i>surprise</i> ”	Not picture producer.

In summary, it can be stated that all the concepts displayed on these three communication boards (mealtime, dressing and washing) were familiar to typically developing children in the specific area. In addition they were able to correctly identify the majority of symbols, indicating that the researcher had succeeded in ensuring cultural sensitivity. The correctness of the translations also proved to be high, although in some cases it was recommended that a synonym be included. Although the synonym was not always linguistically correct, it was the word used by the majority of the participants.

### 4.3.2.2      Section II: Experimental phase

The second main phase of the research, namely the experimental phase, consists of six different phases, all of which followed a linear course. Figure 4.1 illustrates these different phases and is an extension of Table 4.1.

<b><u>PHASE</u></b>	<b><u>DESCRIPTION</u></b>
Phase <b>O<sub>1</sub></b>	Identifying skill dimensions: Skills, knowledge and attitudes of community nurses before training
Phase <b>X</b>	Training community nurses in the application of the BCIP
Phase <b>O<sub>2</sub></b>	Skills, attitudes and knowledge of community nurses directly post-training
Phase <b>O<sub>3</sub></b>	Follow-up consultation 2 weeks post-training: Assessing skills of community nurses. Identification of problem areas and problem-solving
Phase <b>O<sub>4</sub></b>	Follow-up consultation 6 weeks post-training: Assessing skills of community nurses.
Phase <b>O<sub>5</sub></b>	Follow-up consultation 5 months post-training: Assessing skills, attitudes and knowledge of community nurses.

**Figure 4.1    Six experimental research phases**

A detailed discussion of the research procedures implemented at each of the six phases of the experimental research phase follows.

## **Phase Q<sub>1</sub>**

Purposeful sampling was used to select the 20 community nurses who would attend the training. Of the 111 nurses who completed the questionnaires, a total of 74 (67%) indicated that they were keen to receive training in this field and therefore put their names on the training list. The nurses who were not interested stated that they had already enrolled for other courses while some indicated that they would be on leave during the proposed time of training, and two nurses indicated that they were to go on pension within the next year. As people's attitudes have a direct impact on the training outcomes, it was decided to use only nurses who showed an interest in the field of disability. The Assistant Director of Health selected the 20 nurses from the training list, as she had to ensure an even distribution across the different clinics, so that service delivery at the clinics could continue as usual and not be hampered by the absence of nurses.

During this first phase the skill dimensions that impact on the type and quality of service delivery before training was established through the use of an interview and questionnaire.

Firstly, skills were assessed by means of a structured interview that included an opportunity for demonstration. On the first day of training, after they had been welcomed, nurses were called individually for the structured interviews, while the rest of the group gathered informally around a cup of tea. Nurses who had completed the interviews joined the main group, and were asked not to discuss the interviews.

Results were coded on the interview schedule, namely Response Form I. This interview schedule is discussed in more detail in the material/measuring instrument section. Nurses were provided with a specific case (Case 1), and asked a number of knowledge-based questions about the case, followed by questions on possible recommendations (a skill dimension related to service delivery). Then they were presented with the BCIP and asked to demonstrate how they would use each of the communication means (real objects, photographs, PCS communication board, manual signs and a digital speaker) to teach the case one communication function (choice-making) during a specific ADL (mealtime). This demonstration was based on the specific case study. Each structured interview lasted approximately 30 minutes. Due to logistic considerations four interviewers assisted the researcher in completing these interviews.

Practical considerations, however, resulted in the four interviewers not remaining consistent during the O<sub>1</sub> and O<sub>2</sub> phase and a total of seven different fieldworkers were used, who all received the same training.

Despite various professional backgrounds (six SLP's and one occupational therapist (OT) all interviewers were personnel from the Centre for Augmentative and Alternative Communication (CAAC). They were selected because they all have knowledge and experience in the field of AAC as well as basic interviewing skills due to the nature of their training (Gouws, 1993) which was required to complete Response Form I effectively. They were all female.

All interviewers were trained in a group to ensure that they received the same instructions, thus increasing the reliability of the responses obtained (Punch, 1986). Training commenced with a discussion on the aims and objectives of the research followed by a discussion on the purpose of the structured interview, practical considerations and the method that would be used. Practical considerations included the dress code, e.g. in an attempt to dress like the nurses who wore uniform, interviewers were requested to wear navy blue (Babbie & Mouton, 2001). After this, general and specific information pertaining to the recording of responses was provided. Interviewers were restricted to the questions, their wording and the order in which they appeared, but were allowed to provide neutral feedback, e.g. “mmm”, “anything else?” and “okay” (Fowler & Mangione, 1990). Examples that could be provided were also listed on Response Form I, minimising the role and influence of the interviewer and enabling a more objective comparison of results (Brink, 1999). The main researcher and interviewers then went through the questionnaire together, question by question until all uncertainties were cleared. The handout given to interviewers for the training session is provided in **Appendix I**. After the training, all interviewers completed Response Form I while watching a video example. Uncertainties were discussed and all interviewers reported that they felt comfortable in interviewing and recording the data on the form.

The structured interview and the demonstration were video recorded and coded directly onto Response Form I by each interviewer. The main researcher watched every interview on video and also completed a form, in an attempt to check inter-rater reliability and to verify that interviewers had followed the correct procedure. In addition, an independent rater was trained

to cross-check all the interviews conducted by the main researcher and the interviewers. This independent rater did not receive the same training as the interviewers as she only needed training on the recording of responses. This independent rater was a qualified SLP with a master's degree in AAC, providing her with the theoretical background to score the interviews as all the concepts discussed were familiar to her.

After all the nurses had been interviewed individually they gathered as a group at the training venue. They were all handed Response Form II and asked to complete it without talking to their colleagues. The researcher was available throughout to provide assistance with the completion. Question 9, where various elements had to be graded according to representational levels, proved to be problematic. After this questionnaire had been completed, a tea break was given, after which training commenced. The focus of Response Form II is on the primary outcomes of the research (i.e. knowledge and skills) but also includes secondary outcomes (i.e. attitudes, type of service delivery provided and finally, a reflexive self-evaluation section). All aspects included in the BCIP training were covered in Response Form II. The format was mostly close-ended questions but three open-ended questions (for the reflexive self-evaluation section) were included. Details follow in the material/measuring instrument section.

## **Phase X**

This phase comprised the training of the community nurses in the application of the BCIP. Training was conducted over five consecutive days, namely Monday to Friday. As nurses had no other work-related responsibilities for this period they could give their undivided attention to the training (Grissom, 1992). Training was conducted at the University of Pretoria's Hammanskraal campus in the Moretele district, as it restricted travelling time and costs for the nurses. This venue is part of a former monastery and is set in park-like surroundings, setting the mood for a non-threatening learning environment with minimum distraction (Jarvis & Gibson, 1997). The venue is also well-equipped (e.g. video facilities and overhead projectors) contributing to the professional nature of the training.

As the questionnaires from the pre-experimental phase indicated that these nurses were generally older with vast experience (Table 4.4) it was crucial to incorporate the principles of adult learning into the training, as discussed in Chapter 3. Each day of the training started with

a brief revision of the previous day's work. The nature of the training was problem-based as it has repeatedly been shown that adult learners are more satisfied with learning if it applies to their everyday life and if it is practical and current (Barrows, 1985). In addition, working in a problem-based manner with various case studies also enabled the nurses to extend and improve their knowledge base (in particular regarding disability and beginning communication skills), to remain contemporary in their field and to provide appropriate care for the unique problems they might face in their work (Jacobs, 1997; Savin-Baden, 1997). As it was expected of nurses to work independently after the training and to apply the principles to the various CSDs and their caregivers in their caseloads, the value of this approach is evident.

Apart from working in a problem-based format, it was crucial to use educational methods such as interactive workshops with activities that encourage a variety of forms of expression. Activities such as role-play and observation elicited rich personal stories and concerns that, through facilitation, lead to the development of a clear set of principles in completing case studies (Krogh & Lindsay, 1999). This technique was also helpful in developing problem-solving skills required to address anticipated or unexpected dilemmas. Although workshops, in order to reduce fatigue, never exceeded 60 minutes they were long enough to ensure that the nurses could master and practise the skills taught during the particular session.

After the training had been completed all the nurses received a certificate of attendance from the University of Pretoria, leading to a feeling of achievement and general pride. See **Appendix J** for comments on the BCIP training that were made in the *Visitors Book* at the training venue.

### **Phase O<sub>2</sub>**

The skills gained by the community nurses directly post-training was established through the use of the same procedure as outlined in Phase O<sub>1</sub>. Case study 2 was used. The content of the different case studies remained fairly consistent, with minor variations, namely the names of the children and their gender differed, the objects they used for communication purposes differed (e.g. mug, spoon, plate) as well as the mothers' occupation (hairdresser from home, clothing alterations from home, spaza shop at home and selling food from home). These modifications were necessary in order to combat over-familiarity that could result in boredom, influencing reliability of results as these case studies were repeated at five different intervals. In addition,

the post-training forms were all pink as opposed to the blue of the before training questionnaires used in phase O<sub>1</sub>. In order to ensure that the case studies remained consistent and comparable, the independent rater and interviewers evaluated all four. The use of a panel of experts to ensure the same level of difficulty (namely the same level of functioning of the various case studies) is crucial to maintaining external validity, as it is critical that the pre-test and post-test material are exactly the same (Leedy, 1993).

After the structured interviews (Response Form I) Response Form II was completed by all the participants. In addition, a short two-page questionnaire, Response Form III, with closed-ended and open-ended questions was used to evaluate the training. This questionnaire is discussed in more detail in the material / measuring instrument section. All three measuring instruments provide pre- and post-training information, enabling the researcher to identify areas in which the most progress was seen, but also the areas in which more training and support are needed. The skills of each nurse post-training will be compared with her skills before training. As each participant is thus compared with herself the use of a control group is unnecessary.

### **Phase O<sub>3</sub>**

This phase was the first follow-up after withdrawal and was conducted two weeks post-training. It was decided to have the first follow-up shortly after the training, so that the researcher could assist with any problems the nurses had when they started implementing the BCIP. For the purpose of the follow-ups it was decided to only measure the nurses' skills (Response Form I). Case study 3 was used for the first follow-up, following the same principles as outlined in phase O<sub>2</sub>.

Due to the vastness of the Moretele Health District and the almost impassability of some of the roads, travelling time is long and fatiguing so that this phase was spread over a period of three consecutive days, from Monday to Wednesday. There is no telephonic contact between the different clinics, and thus it was felt the reliability of the results was not influenced. It should also be documented that 4 of the 20 nurses were on leave, but that they specifically went to the respective clinics to see the researcher. See **Appendix K** for a description of the in situ follow-up visits.

The three follow-up phases (O<sub>3</sub>, O<sub>4</sub> and O<sub>5</sub>) pose definite ethical problems. The researcher had to consider the implications of her actions (being physically in the particular clinic) and had to

make arrangements to address this without contaminating the results. As this area is severely under-served by therapists, and to ensure accountability, the researcher assisted with the problem-solving of issues after having completed Response Form I. At one clinic a nurse had arranged on her own initiative that four CSDs and their primary caregivers attended on the day that the researcher came. Although she had started implementation of the BCIP (children were already making choices and she had taught them between three and five manual signs each), she needed confirmation from the researcher that she was on the right track. She also wanted to increase her credibility with the caregivers by having a lecturer from the University of Pretoria (the researcher) approve the strategies that she was implementing. All issues discussed during this phase were documented.

#### **Phase O<sub>4</sub>**

This measurement was conducted six weeks after the training, and followed the same procedure as outlined in phase O<sub>3</sub>, using Case study 4. As three nurses were on leave this follow-up was conducted over a period of four days. During this phase it became clear that the nurses who had started using the BCIP with specific clients were noticeably more skilled than the rest of the group. The nurse who had arranged the group in phase O<sub>3</sub> expanded the group (including one more CSD as well as the “*teachers*” at the local care group attended by these children). Three more nurses also arranged for CSDs and their caregivers to meet the researcher. A number of nurses who had not seen any CSDs with whom they could implement the BCIP stated that they would make a serious attempt to find suitable clients.

## **Phase Q5**

A withdrawal of five months post-training was done following the procedure described in phase O<sub>4</sub>, using the pre-training case, Case study 1. The follow-up was conducted over a period of three days, and on the fourth day nurses met at the original training venue. During this time nurses completed Response Form II (the knowledge-based questionnaire) as well as Response Form III (the training evaluation questionnaire). They were asked to consider the follow-ups as part of the training. After completing the questionnaire a tea break was given. A focus group was then held during which the nurses' experiences and perceptions of the training were discussed. This qualitative data could then be interpreted together with the quantitative data in order to form a more holistic picture of the training.

## **4.4 PILOT STUDY**

### **4.4.1 Objectives**

The objectives of the pilot study were to evaluate and test the applicability of the BCIP, the training procedures and the measuring instruments. They are discussed in detail in Table 4.14.

### **4.4.2 Context and subjects**

The pilot study was conducted in Ga-Rankuwa, one of the residential areas in the ODI Health District. This health district adjoins the Moretele Health District and was selected due to the many similarities, e.g. geographical area, functioning of the clinics and service delivery as well as the nurses' profile. Despite these factors a number of differences also exist. Although these two health districts appear to be comparable in physical size (square kilometres) it appears that the ODI Health District is more densely populated and more peri-urban whereas the Moretele Health District includes a number of truly rural villages. In order to realise the objectives of the pilot study it was essential that the pilot study was highly comparable with the main study.

The profile of nurses also had to be comparable to the profile of the nurses expected for the main study. All the nurses were female, with the majority having between six and ten years

experience, although one nurse had less than one year experience and one more than 20 years. Regarding training in the disability field, one nurse reported that she had an hour's in-service training regarding disability. However, a difference between the profile of the nurses' highest qualifications and nursing categories between the pilot study and main study was found. It was not planned in this way, but it later appeared that the ODI Health District mostly selected the poorer qualified and more junior nurses. Only 7% had a nursing degree, 33% had a nursing diploma and 60% had only school qualifications, including 7% with Grade 8, 47% with Grade 10 and 6% with Grade 12. It was therefore not surprising to note that 60% were working as nursing assistants and staff nurses. One of the nurses commented on Response Form III (training evaluation) that "*more professional nurses should attend, not only juniors*". However, for pilot purposes this was sufficient as it can be assumed that if the poorer qualified junior nurses found the BCIP training useful and applicable, the better qualified, professional nurses would also do so.

#### **4.4.3 Procedures**

The Director of Health: ODI Health District was requested to select 10 nurses who would be interested in the disability field and be able to attend the training. The first training date was cancelled due to a compulsory immunisation campaign of the national Department of Health. A second date, two weeks before the start of the main study, was set. Due to logistic problems the pilot study could only be conducted over a four day period instead of the required five days. Nurses were keen to receive this training and eventually 15 nurses were included. The same steps as outlined for the main study were followed and all three measuring instruments were completed and coded.

#### **4.4.4 Objectives, results and recommendations**

The objectives, results and recommendations made after completion of the pilot study are given in Table 4.14.

**Table 4.14 Objectives, results and recommendations following the pilot study**

Objectives	Materials & Equipment	Procedures	Results	Recommendations
<i>With respect to the BCIP to the following objectives were set:</i>				
1. To evaluate the general usefulness of the BCIP	Response Form III Informal discussions	Response Form III asked nurses if they found the BCIP helpful. The usefulness of the BCIP was also discussed informally during lunchtime and tea breaks.	100% of the nurses stated that they found the BCIP useful, with 93% indicating that it should be included in the regular nursing curriculum. Informal discussions revealed their enthusiasm and eagerness to implement the BCIP as they said that they had needed something of this nature for a long time.	No changes to the BCIP recommended. Minor modifications will be described individually under the relevant headings.
2. To determine the relevance of the communication functions included in the BCIP	Handout Training material	Before providing nurses with the communication functions included in the BCIP they were asked what they regarded as the most important messages that children had to communicate.	High correlation between list of communication functions nurses generated and those included in the BCIP was noted. The only function that nurses did not include was requesting interaction (e.g. seeking a partner to play with) but after explaining this function general agreement on its importance was reached. This high correlation is possibly due to the fact that the list of functions were based on information from the focus groups with primary caregivers of typically developing children and CSDs respectively.	These communication functions should be revisited every morning during the main study, as nurses became confused when the terminology increased, e.g. means, functions and temptations. Use the same method of asking nurses to generate a list of what they regard as the most important functions, before providing them.
3. To evaluate the appropriacy of the communication means included in the BCIP	Handout Training material Role-play	Before discussing the different aided and unaided communication means nurses were asked to brainstorm on all the possible ways in which a message could be conveyed. All the different means were then demonstrated (e.g. explained concept of elephant through mime) and nurses were asked if they had ever observed this.	Nurses were aware of unaided communication means, which might be attributable to the strong oral tradition in their culture. Initially they were unaware of the difference between natural gestures and sign language, but they grasped these concepts once they were explained. With prompting, nurses were able to identify the greatest disadvantages of the different means (e.g. inability to convey abstract concepts with facial expressions). Frequent use of manual signs during tea times! Traditional orthography and pictures were the only aided means they could identify with the use of objects, symbol systems and digital voice output devices being novel. After discussion and demonstration their function was clear.	The same teaching methodology for teaching communication means should be followed in the main study. Nurses did not find it threatening and consequently actively participated, e.g. when asked to demonstrate all the natural gestures they knew. The length of time provided for role-play can be extended in the main study as one complete day will be dedicated to communication means.
4. To test the ease of use of the BCIP	BCIP Training material Response Form III	Nurses were observed during role-play activities when they were actively using the BCIP and were also asked to rate the ease of using it.	13 of the 15 nurses found the BCIP easy to use and two found it difficult. However, all stated that they would be able to use the BCIP independently. During the training it also became clear that skills and the ease with which they handled the different BCIP elements increased over time as their confidence grew.	No adaptations to the BCIP. In order to increase the ease of implementation of the BCIP, the importance of using it should be emphasised in training.
5. To assess the ease of using	Handout Training material	The ease and naturalness of including different	The idea of deliberately creating communication opportunities (i.e. choice-making, naming, making desired items	Provide more opportunity to practise this during the main study. Additionally include a more

**University of Pretoria – etd – Bornman, J**

communication temptations to facilitate the acquisition and expansion of communication functions	Role-play	communication temptations in interaction was observed during the role play activities.	inaccessible, selecting materials that require assistance, providing small or brief turns, offering non-preferred items, asking yes/no questions and violating expectations) was novel. These strategies were demonstrated and practised in small-group sessions with role-play. As this concept was new, little creativity was seen with nurses copying the exact example that was demonstrated, resulting in few original examples.	complete differentiation between the communication functions and temptations should as nurses tended to become confused between these two concepts, e.g. when teaching the concept “more” (communication function) the communication temptations that can be used are providing small portions or brief turns.
6.To test the applicability of the BCIP in planning services for a specific CSD and his/her caregiver.	Case studies Response Form III	The training was conducted in problem-based format with ample opportunities for planning services for a particular individual which was observed during the feedback sessions. In addition, nurses were asked to rate the applicability of the BCIP.	All the nurses reported that the BCIP enabled them to plan intervention independently. This was also evident from the feedback sessions when each group had to plan an intervention programme for a particular case. Recommendations included the involvement of more communication partners, observing all the different communication attempts, to expect not only speech as communication and how to deliberately create communication opportunities. Facilitating the development of specific communication functions was still difficult.	As stated in recommendation four of this section the relationship between the communication functions and temptations should be made clearer, e.g. that a particular temptation is used to elicit a particular function. More time should be spent on this aspect. This will be possible in the main study due to the fact that the training is one day longer.
7. Suitability of physical presentation of BCIP (black bag)	Observation Informal discussion	The physical appearance of the BCIP content at the end of the four day training period was observed as well as the nurses' reaction when the BCIP was first handed out.	All the nurses felt that the BCIP looked smart and that they were keen to carry it. They also said that their colleagues and friends were inquisitive about the contents, providing them with the opportunity to discuss it. It was also noted that the bag provided protection for the BCIP elements and that nothing was damaged.	The BCIP should be presented in the same physical format as for the main study.

***With respect to the training procedure the following objectives were set:***

1.To determine nurses' understanding of, and familiarity with the terminology used	Transparencies Handout Training manual	Nurses received training in the BCIP in exactly the same way as was planned for the main study. Questions were asked throughout to determine if terminology was clear.	As terminology had been adapted after the focus groups to suit the terms most frequently used by nurses, they indicated that they found the content and terminology easy to understand. However, some concepts were difficult and caused confusion. It was anticipated that some concepts were new, and after they were explained, they proved not to be problematic. Nurses understood these concepts and used them correctly.	Difficult terminology was changed, e.g. “traditional orthography” was replaced by “normal writing”, “tangible objects” by “real objects” and “nurturance” by “care”. Novel concepts were explained, e.g. AAC, severe disability, multi-skilling, communication means, functions, communication temptations and ADL.
2.To test the clarity of instructions given during the training	Training manual Handout	All instructions pertaining to workshops and opportunities for hands-on practise was given in exactly the same format as was planned for the main study.	Although nurses understood the instructions and were independent in answering questions posed during the workshops, they needed reminding that they had to apply the workshop to the specific case study. Furthermore, nurses reported that the instructions provided with the “Progress Checklist” were clear and logical.	State the importance of referring to the case study more explicitly in the main study, e.g. “Think of Busi when you answer the following questions”. No changes to the Progress Checklist were recommended.
3.To evaluate the appropriacy of the specific case studies	Case studies Handout	Case studies were based on facts obtained after the focus groups with primary caregivers of both	Nurses reported that they could relate to and identify with the specific cases, and frequently remarks such as “There's one at our clinic just like this one” (referring to the case study) were	Some information on the way to answer case studies should be included in the main study (e.g. a 5-point plan to answering case studies).

**University of Pretoria – etd – Bornman, J**

and the use of a problem-based format	Training manual Response Form III	typically developing children and CSDs, and from the researcher's clinical experience. Cases were varied to include the whole spectrum of severe disability. In Response Form III (evaluation of the training), nurses were asked whether they could identify with the case studies.	heard. Nurses also reported that they found the problem-based format useful, as they felt that it equipped them with the necessary skills to apply their knowledge to their caseloads. However, it was seen that nurses had not previously received any training in the use of a problem-based methodology, therefore they found it difficult initially to apply their knowledge to the specific case. Response Form III indicated that 100% of the nurses felt that they could identify with the case studies, and 93% of the nurses enjoyed working in a problem-based format.	a 5-point plan to answering case studies). No changes to the use of a problem-based format or to the specific case studies.
4.To test the relevance of the video cases (i.e. were the nurses able to relate to the cases presented?)	Video cases Training manual	A number of different case studies were shown on video. Video cases were also used to demonstrate the concept of " <b>severe disability</b> " and covered the following aetiologies: spastic quadriplegia, severe intellectual impairment, challenging behaviour, CP and intellectual impairment, autism, intellectual impairment and visual problems, and acquired disabilities (burn wounds).	As with the written case studies it was clear that nurses could identify with the video cases. The video depicting all the different aetiologies was shown during the first hour of training, and resulted in everybody having the same understanding of the concept of " <i>severe disability</i> ". Especially the child with challenging behaviour caused a lengthy discussion. Three of these cases were also used on the last day of training to complete the "Progress Checklist". One nurse commented on the last day that she was looking at the child with new eyes and that she now saw that he could do many more things than she had initially observed on the first day. During workshops, nurses also referred back to these video cases, e.g. " <i>Remember that other one who could not sit...</i> "	The same videos should be used in the main study. The video depicting the child with burn wounds should be shown last as this was the most emotionally upsetting. Also recommended that a short discussion time should be given after each video so that nurses could share experiences and debrief as some of the video cases raised concerns and questions e.g. watching a child with challenging behaviour if one has not had prior exposure.
5.To test the use of teaching aids (overhead projector and video)	Overhead projector and transparencies Video	The same teaching aids that were to be used in the main study were used in order to determine the impact on training and well as its effectiveness.	As a result of power failures the video and overhead projector could frequently not be used, forcing the researcher to rely on the handouts. During times when the overhead projector and video were used, a noticeable improvement in the quality of participation was noticed. This might be because it was easier to follow the discussion and also that nurses did not feel insecure when they could not find the section that was discussed. This also led to increased concentration.	The use of these teaching aids is essential in the main study. Electricity problems are not anticipated. The size of the training venue for the main study necessitates the use of a large font type for transparencies to facilitate easy reading.
6.To evaluate the adequacy and usefulness of the handouts	Handouts Training manual Response Form III	Response Form III asked if the information provided in the handout was useful. Opinions about the handouts were also obtained during informal talks.	It was noted that nurses were proud of their handouts, and wrote their names on it, as well as additional notes and comments. They kept all their notes tidy and brought them with to the training every day. Results indicated that 93% felt that the handout was useful.	No changes to the content of the handouts, although changes in the layout are necessary. Include more space that nurses have more space for own comments. In addition, handouts should not be photocopied back-to-back.
7.To obtain feedback regarding the scope of the content covered	Training manual Handout Response Form III	This sub-aim relates closely to the previous sub-aim. Response Form III asked if nurses thought that important information missing was missing from the	Results from Response Form III indicated that 93% felt that there was no important information missing which closely relates to the 93% who indicated that they found the handouts useful. The questions asked during training did not pertain to content that was not covered in the handout, but were rather	No additional information will be included. The trainer should continue to encourage nurses to ask for clarification and explanation if they feel that any information is lacking or not well understood.

**University of Pretoria – etd – Bornman, J**

		BCIP training.	questions to clarify aspects in the handout.	
8.To test the usefulness of the method of presentation in adopting a non-threatening learning environment	Response Form III Discussions	A number of close-ended questions pertaining to this aspect of the training were included in Response Form III. Nurses had to reply with a "Yes", "No" or "Uncertain". Regarding the overall rating of the training, a 5-point Likert scale was used.	All the nurses (100%) indicated that they enjoyed the training, with 33% rating it as "very good", and 67% as "excellent". Their positive attitude towards the training and their enjoyment thereof is also reflected in the fact that 93% felt that the training should be compulsory and included in the general training curriculum for community health nurses. Shortly after the training a nurse who had been unable to attend phoned the researcher to enquire when a second training would be conducted as she felt that her junior now had more skills than herself in dealing with CSDs. One of the nurses also phoned to request further training for a group of 10 volunteers that she had assembled. One nurse commented " <i>The training was very much interesting and I think it is going to be of more use to me as a nurse, because usually when you come across a CSD you don't know what to do, to say "shame" to the mother or what, but now I know.</i> "	No changes recommended. The trainer should continue to be enthusiastic toward training and reflect her own positive attitude towards CSDs and their caregivers. The emphasis on <b>ability</b> as opposed to <b>disability</b> should also be maintained.
9.To test the effectiveness of small group workshop sessions with opportunities for hands-on experience	Response Form III Feedback from workshops	For the workshops nurses were grouped in small groups of three with one acting as a CSD, one as a primary caregiver and one as nurse. Response Form III included an open question " <i>Which 3 aspects of the training did you enjoy most?</i> "	40% of the nurses rated the use of small groups and role-playing as one of the three training aspects that they enjoyed most. Comments included "... <i>the role-playing and practise helped me to adopt a positive attitude towards rendering of service delivery at my clinic</i> "; " <i>I gained a lot from it, being a child with disability</i> " and " <i>I enjoyed the grouping and sharing of ideas</i> ".	Recommended that small groups of three participants be used throughout the main study as this provides all nurses with the most opportunity to experience all three possible roles.
10.To test the applicability and usefulness of the "Progress Checklist"	Progress Checklist	Training concluded by discussing the importance of monitoring progress and completing a Progress Checklist.	Nurses commended that the Progress Checklist is an applicable and useful tool that will enable them to plan better services for CSDs and also to assist them to be more accountable as they would be able to show the changes taking place. However they felt that three cases were not sufficient to make them proficient in completing it.	More time should be allocated for completing Progress Checklists in the main study, and five cases (instead of three) should be used. Provide each nurse with at least six Progress Checklists so that five can be used in training and one kept as a resource.
11. To assess the pacing and the sequence of the training programme	Programme Handout Training manual	Each day commenced with revisiting the important aspects, followed by an explanation of the aims for the current day.	The sequence of the training was effective, and there was a logical flow of information. When all four of the major dimensions of communication were explained, some confusion arose.	
12.To determine if the length of time required for the training is sufficient	Response Form III Discussions	Training was conducted over a four day period, starting at 08h30 and ending at 15h30 daily. Three close-ended questions regarding the time-related issues were included in	Results indicated that 53% felt that the length of training was insufficient despite the fact that 87% felt that the time for questions and answers were adequate, and 93% felt that the time to practise using the BCIP was adequate. It is therefore unclear why more time was recommended. However, it might reflect a general feeling of too much new information being	The large proportion of nurses who felt that training was too short might be attributed to the fact that the majority of nurses were nursing assistants who require a longer time to learn new information due to a limited training background. Time is not expected to be a major factor during

**University of Pretoria – etd – Bornman, J**

		Response Form III. Nurses had to reply with a “Yes”, “No” or “Uncertain”.	presented in too compact a form. It is also interesting to note that 53% of the nurses responded to the open-ended question “ <i>Suggestions on how to improve training</i> ” by referring to time issues. Comments ranged from extending training by at least eight hours or more to at least two weeks. One participant requested yearly follow-ups.	the main study as training will be conducted over a five day period and the majority of the nurses will be professional nurses.
<b><i>With respect to the measuring instruments the following objectives were set:</i></b>				
1.To evaluate familiarity with and understanding of the terminology used in the measuring instruments	Response Form I Response Form II Response Form III	Interviewers completed Response Form I after structured interviews with the nurses.  Nurses completed Response Forms II and III in a group, without discussing questions with each other. The researcher was available throughout.	<b>Response Form I</b> Some terminology and coding format was difficult to use. Some data were lost, as it could not be coded. Some questions were repetitive. Interviewers used their own examples and despite attempts not to, this did lead the nurses and biased the results.  <b>Response Form II</b> One nurse is the mother of three CSDs, consequently she had much more knowledge and skills than her colleagues which impacted on the quality of her answers. A question indicating this is important for descriptive purposes but was not included in Response Form II. This fact was only discovered during informal discussions. Some terminology concepts proved to be difficult.  <b>Response Form III</b> Only one question was raised when a nurse asked what the training manual was.	<b>Response Form I</b> Change “acquire” to “still learn”. Change matrix format to table format where questions are asked separately. Include more coding categories, e.g. “crying” or “clapping hands” to include all the possible answers that were provided during the pilot study. Provide more examples, e.g. “speech” is described as “words like Mama”. Include “providing opportunities” under the recommendation section.  <b>Response Form II</b> Include the question “Do you have a close friend or a relative with a disability?” Replace “traditional orthography” with “normal writing”. Add example, “line drawings, e.g. PCS”.  <b>Response Form III</b> Replace “training manual” with “handout”.
2.To test the clarity and preciseness of instructions	Response Form I Response Form II Response Form III	Interviewers completed Response Form I after structured interviews with the nurses.  Nurses completed Response Forms II and III in a group, without discussing questions with each other. The researcher was available throughout.	<b>Response Form I</b> Nurses frequently asked if their answers had to be related to the specific case study that was provided. <b>Response Form II</b> All the nurses found it difficult to rank the different items in levels of representation. Nurses tended to not apply their answers to the matrix question (Question 8) to the case study.  <b>Response Form III</b> No problems were found with marking more than one option if only one option was requested. No questions were left unanswered due to unclear instructions.	<b>Response Form I</b> Remind nurses to relate their answers to the specific case study. <b>Response Form II</b> Add a sentence to Question 8 “Answer the following questions pertaining to Emily...” Complete Question 9 as a group. Researcher will ask all nurses to stop before answering it, and explain the question to the whole class.  <b>Response Form III</b> Instructions are clear. No recommendations are made.
3.To test for ambiguous or misleading questions	Response Form I Response Form II Response Form III	Interviewers completed Response Form I after structured interviews with the nurses.  Nurses completed Response Forms II and III in a group, without discussing questions with each other. The researcher was available throughout	<b>Response Form I</b> Problematic questions were identified, e.g. it was difficult to explain the concept of communication functions before training.  <b>Response Form II</b> Only Question 7 seemed to be problematic, as many nurses guessed the correct option before training. This was problematic, as results from post-training would not indicate a gain in knowledge.  <b>Response Form III</b> No ambiguous or misleading questions were reported.	<b>Response Form I</b> Clearer description of questions should be given in order not to be misleading. Change Question 2.3 “What different things would you encourage Maria to communicate?” to “Which reasons for communication will you encourage Maria to learn? (e.g. what does she want to say with what she does?)

[University of Pretoria – etd – Bornman, J](#)

		was available throughout.		<b>Response Form II</b> Alter questions so that they are slightly more difficult and less easy to guess, e.g. “Communication functions refer to the way in which the environment is structured to provide opportunities for interaction” was changed to “Speech is an example of a communication function.” <b>Response Form III</b> No changes are needed.
4.To test the length of time required to complete Response Forms I – III	Response Form I Response Form II Response Form III	Interviewers completed Response Form I after structured interviews with the nurses.  Nurses completed Response Forms II and III in a group, without discussing questions with each other. The researcher was available throughout.	<b>Response Form I</b> Pre-training it took 25 minutes on average to complete and after training 30 min. This might be due to the fact that nurses had more information that they wanted to provide. However, the time provided for the practical demonstration remained consistent at 7 min. The length of time is crucial for this response form as it was video recorded, and arrangements pertaining to the number of videotapes required are important. <b>Response Form II</b> Before and after training the group of nurses all required 30 minutes to complete. <b>Response Form III</b> Although it is only two pages long, it contains four open questions, e.g. “Which three aspects of the training did you enjoy most?” This resulted in nurses needing 22 minutes on average to complete.	With clearer definitions of some of the terminology, the length of time needed to complete Response Forms I – III might be reduced.  Use allocated times as the minimum time required and allocate sufficient time during the main study.
5.To test the availability of all the information required by Response Forms I - III	Response Form I Response Form II Response Form III	Interviewers completed Response Form I after structured interviews. Nurses completed Response Forms II and III in a group, without discussing questions with each other. The researcher was available throughout.	<b>Response Forms I, II and III</b> All questions included provided valuable information and nurses were able to complete all the questions. Problematic questions were not due to the fact that they did not have the correct information, but because of a lack of knowledge regarding disability and communication.	Include all the questions in the main study.
6.To test the suitability of using date of birth as an identifying factor	Response Form I Response Form II Response Form III	As each participant will be compared with him/herself, it is essential that an identifying question should be included on all three measuring instruments before and after training.	In order to ensure anonymity, birth date was asked as identifying factor. Day, month and year were included and it appeared that all three these variables were needed as three nurses were born in the same year, and two had their birthdays on the same date. However, when all three the variables were included, no duplications were found.	Use three digit birth date as identifying factor (Day-Month-Year).
7.Suitability of the video recordings to evaluate skills demonstration	Response Form I Video recordings	Each interviewer rated Response Form I whilst conducting the interview. Afterwards the researcher and at least one other interviewer also rated the video.	Results indicated that a high inter-rater reliability was found on the structured interview section but a low inter-rater reliability for the practical demonstration section. On the whole it was noted that video recordings are suitable in providing the necessary information. However, in some instances the video had run out of tape without the interviewer noticing.	Specific guidelines are needed for the scoring of the practical demonstration in order to facilitate a higher inter-rater agreement. It is recommended that only one interview per videotape should be recorded, as V-8 videotapes have a maximum length of 45 minutes.

**University of Pretoria – etd – Bornman, J**

8. To evaluate the ease of coding Response Forms I – III	Response Form I Response Form II Response Form III	The researcher coded all three the measuring instruments before and after training to ensure the ease of encoding.	<p><b>Response Form I</b> Problems were encountered with coding in cases where provision had not been made for an open “other” category, e.g. communication means and functions. Inter-rater reliability was low as no specific descriptions for each category was available for the demonstration of skills section. <b>Response Form II</b> The matrix question (Question 8) proved difficult as the different sets of data were mixed-up. <b>Response Form III</b> No coding difficulties were experienced.</p>	<p><b>Response Form I</b> The encoding form needed revision in order to be applicable for double-digit scores in appropriate cases. In the demonstration section, a specific description for each category had to be added to heighten the inter-rater reliability.  <b>Response Form II</b> To keep the different categories apart, a letter was added before the numeral, e. “communication partners” was scored as a “P1”  <b>Response Form III</b> No adaptations required.</p>
9. To test the intended analysis of the data	Response Form I Response Form II Response Form III	Basic descriptive statistical procedures were performed, e.g. frequency counts, distributions and standard deviations	It was found that some variables had to be grouped together in order to reduce the number of “missing variables”.	The data definitions had to be clear for the grouping of variables.

#### 4.4.5 Summary

After completion of the pilot study, minor modifications to the BCIP, the training procedure and the measuring instruments (Response Forms I, II and III) were needed. Results indicated that the BCIP contained the most important beginning communication elements and that nurses could use it with relative ease. Results regarding the training procedures indicated that nurses identified with the use of a problem-based format and the various case studies. They reported that the method of presentation, the materials used and the clarity of terminology and instructions were adequate. The need for a longer training period was, however noted. When evaluating the results from the measuring instruments it can be seen that the use of Response Form I and the video provides a clear understanding of the nurses' skill in applying the BCIP, while Response Form II provides an adequate description of their knowledge, perceptions and attitudes.

### 4.5 MAIN STUDY

#### 4.5.1 Participant selection and description

The selection criteria for participants as well as their description are provided in this section.

##### 4.5.1.1 Selection of nurses to be trained

Two selection criteria were used for the purpose of this research, namely:

- **Employed by the Moretele Health District** This ensured that nurses from all the different nursing categories were included, and not only professional nurses. It was felt that this is an important consideration for the present research as the training focused on nurses at all the different categories, including auxiliary and staff nurses. It also meant that they were currently working as a nurse and not in a different profession, in-between jobs or retired.
- **Working context** The focus of the training was on PHC and therefore nurses had to be employed at community health clinics or mobile clinics. Nurses who were stationed at the Jubilee Hospital (and providing secondary health care) were excluded. This selection

Two non-probability sampling techniques were used to select the nurses who would receive training. This included purposeful sampling as the Assistant Director of Health in the particular health district (Moretele) selected nurses who were eager to receive further training and who had a positive attitude towards disability (Brink, 1999). As this was the first BCIP training programme it was felt that nurses who were keen to receive training in disability would be useful in refining the programme. As mentioned in the pre-experimental phase, nurses were asked to put their names on a list if they were interested in receiving training. A convenience sample was then taken from this list to ensure that two nurses from the same clinic were not selected (as this could hamper service delivery) and not selecting nurses who were due for leave, time off or night duty. Although these sampling techniques had many advantages for the present research, the sampling bias that limits the generalisability of the results should not be overlooked (Brink, 1999; Leedy, 1993).

This process resulted in the inclusion of twenty community health nurses from the Moretele Health District. These nurses are representative of the four health clusters (sub-districts) in this area, namely Makapanstad, Syferskuil/Moretele, Temba and Refentse (Map 1). This area was targeted as it is a large, spread out area comprising 25 clinics and 14 mobile points. It is situated in the North West Province (former Bophuthatswana), implying that in the past it was viewed as a deprived area. Despite numerous attempts to uplift this area much more Government support is still needed to ensure equality. The Moretele Health District is also a good example of close collaboration between the Health District which provides PHC and the Jubilee Hospital which provides secondary health care and is relatively close to Pretoria (where tertiary care, i.e. traditional rehabilitation by therapists, is provided). All these factors made this an ideal area in which to conduct the present research.

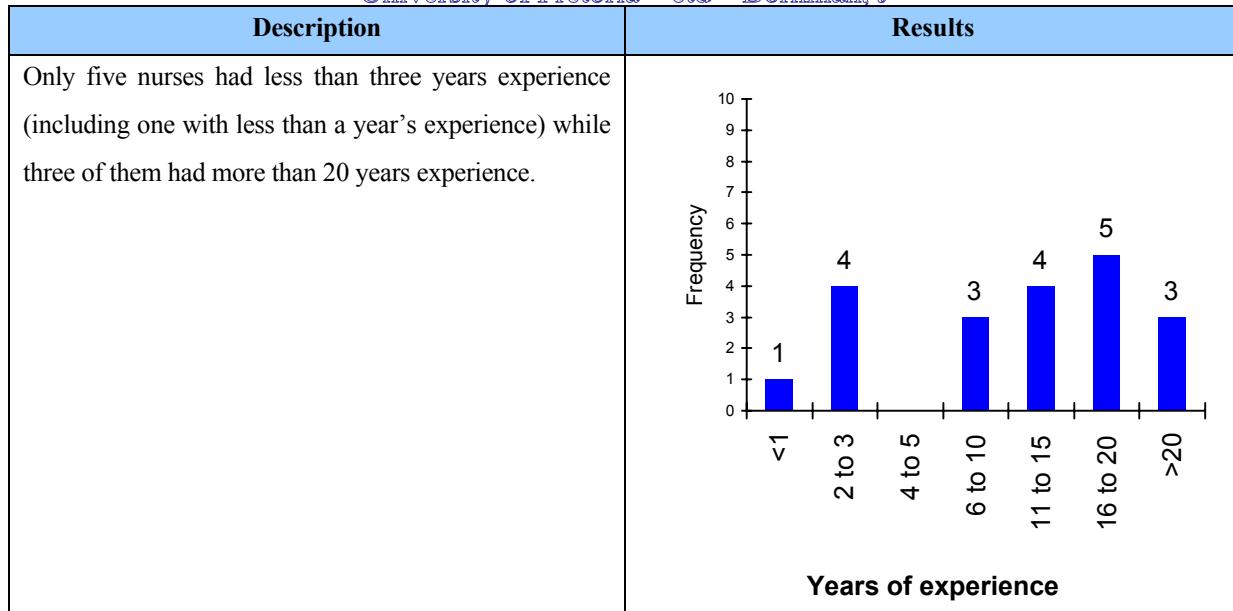
#### **4.5.1.2 Descriptive information on the participants**

Except for one nurse all were female and none of them had received any prior training in disability. Two of the participants had a relative with a disability, namely a sister with polio (that had resulted in a deformed left leg) and a sister whose daughter had hydrocephaly. More

detailed information on the participants is presented in Table 4. 15.

**Table 4.15 Descriptive information on the participants (n=20)**

Description	Results												
The nurses' ages ranged from 28 to 54 years and they tended to be older, with the majority being between 41 and 45 years of age. This highlights the fact that this is a group of adult learners and that adult teaching and learning styles had to be taken into consideration with the BCIP training.	<table border="1"> <thead> <tr> <th>Age Group</th> <th>Frequency</th> </tr> </thead> <tbody> <tr> <td>28-35</td> <td>4</td> </tr> <tr> <td>36-40</td> <td>3</td> </tr> <tr> <td>41-45</td> <td>8</td> </tr> <tr> <td>46-50</td> <td>2</td> </tr> <tr> <td>51-54</td> <td>3</td> </tr> </tbody> </table>	Age Group	Frequency	28-35	4	36-40	3	41-45	8	46-50	2	51-54	3
Age Group	Frequency												
28-35	4												
36-40	3												
41-45	8												
46-50	2												
51-54	3												
Qualifications covered a broad spectrum, ranging from no formal training after school (Grade 8) to being highly qualified (a nursing degree). Eight of the nurses had no formal training after leaving school and the majority had nursing diplomas (9).	<table border="1"> <thead> <tr> <th>Qualification</th> <th>Frequency</th> </tr> </thead> <tbody> <tr> <td>Gr 10</td> <td>5</td> </tr> <tr> <td>Gr 12</td> <td>3</td> </tr> <tr> <td>Diploma</td> <td>9</td> </tr> <tr> <td>Degree</td> <td>3</td> </tr> </tbody> </table>	Qualification	Frequency	Gr 10	5	Gr 12	3	Diploma	9	Degree	3		
Qualification	Frequency												
Gr 10	5												
Gr 12	3												
Diploma	9												
Degree	3												
The majority were professional nurses (including senior professional and chief professional nurses). No auxiliary nurses (nursing assistants) were trained but three senior auxiliary nurses were included. The four staff nurses are receiving in-service training to equip them with the skills to become professional nurses.	<table border="1"> <thead> <tr> <th>Nursing Status</th> <th>Frequency</th> </tr> </thead> <tbody> <tr> <td>Snr Aux</td> <td>3</td> </tr> <tr> <td>Staff</td> <td>4</td> </tr> <tr> <td>Prof</td> <td>4</td> </tr> <tr> <td>Snr Prof</td> <td>2</td> </tr> <tr> <td>Chief Prof</td> <td>7</td> </tr> </tbody> </table>	Nursing Status	Frequency	Snr Aux	3	Staff	4	Prof	4	Snr Prof	2	Chief Prof	7
Nursing Status	Frequency												
Snr Aux	3												
Staff	4												
Prof	4												
Snr Prof	2												
Chief Prof	7												



When comparing these results with the results obtained after completing the questionnaire in the pre-experimental phase (Table 4.4) similar tendencies prevailed. It can therefore be said that this sample of nurses who were trained is representative of the total nursing corps in the area.

#### 4.5.2 Equipment and Material

The equipment and material used in the research are discussed separately in this section.

##### 4.5.2.1 Equipment

The equipment used for the training of interviewers, data collection and analysis were as follows:

- Sony Combi Video Player
- BASF video cassettes
- Panasonic Video camera
- V-8 video cassettes
- Portable overhead projector
- Transparencies and transparency pens
- Pencils

#### 4.5.2.2 Material

The main material used in the research included the measuring instruments and training programme (the BCIP and handouts). Both of these will be described in more detail.

##### i.) Measuring instruments

The main aim of the measuring instruments is to answer the research question : “*Which knowledge and skills were acquired by community health nurses post-training in the use of a beginning communication intervention protocol (BCIP)?*” In order to meet the requirements posed by the research question and design, three measuring instruments were developed. They can briefly be described as follows:

###### a) Response Form I

This structured interview deals primarily with the skills and applied knowledge of the nurses. It was compared during various research phases, namely O<sub>1</sub> (before training), O<sub>2</sub> (directly post-training), O<sub>3</sub> (two weeks post-training), O<sub>4</sub> (six weeks post-training) and finally O<sub>5</sub> (five months post-training). Birth date was asked as the identifying factor which was used to code “*respondent number*” enabling the comparison of each participant with him/herself during the various research phases. Response Form I is based on a specific case study and four similar case studies were used (discussed in Phase O<sub>2</sub>). The same case study was used for phases O<sub>1</sub> and O<sub>5</sub> as it was assumed that nurses would not remember the exact details of the particular case study after the long time lapse during which time they were exposed to three other cases. Response Forms 1.1 – 1.4 are provided in **Appendix L**. Response Form I consists of five sections namely the biographic data, the applied knowledge about the current abilities of the particular case study, applied knowledge about recommendations, a practical skill demonstration in using the BCIP with the particular case and finally their exposure to the BCIP.

Basic considerations had to be taken into account when conducting these structured interviews and completing Response Form I as they impact on the reliability and validity of the data. This included the following:

- All interviewers received the same training before the commencement of the structured interviews and the completion of Response Form I. In addition, an external rater, (who also received training) viewed all the structured interviews independently and coded responses on Response Form I. Inter-rater reliability checks were done.
- These structured interviews were conducted in English. Although this was not the nurses' mother tongue, it was seen during the focus groups (pre-experimental phase) that their spoken English was good. It was assumed that this would not impact on the quality of the answers.
- All interviewers had access to Response Form I (containing explicit guidelines) as well as their interviewer notes to ensure that the procedure remained consistent. Eight open-ended questions were used for this purpose, e.g. "*If you were the nurse working with Sibusiso and Mrs Serudu, what advice would you give her?*"
- Due to the specific research design (involving a pre-experimental phase) rapport had already been established, and participants were aware of the aim of the research and were familiar with the researcher. The time series nature of the experimental phase of the research ensured that this rapport was maintained.
- An independent rater was used to code Response Form I in order to check the reliability of data.
- The researcher re-administered response Form I five months later to test the stability of judgements made, checking intra-rater reliability.

Table 4.16 provides a summary of the most important areas covered in Response Form I, with specific reference to the motivation for inclusion. The category, type and number of each question in each category are also discussed.

**Table 4.16 Development of Response Form I**

Section	Category	Question #	Total # of questions	Question area	Type of question	Motivation
A	Biographic data	1	1	1. Birth date	1 Open-ended question	Used for coding respondent number (thus to act as identifier) enabling comparison for a specific nurse between different research phases.

**University of Pretoria – etd – Bornman, J**

<b>Section</b>	<b>Category</b>	<b>Question #</b>	<b>Total # of questions</b>	<b>Question area</b>	<b>Type of question</b>	<b>Motivation</b>
B	Applied knowledge about current abilities of case study	1.1 1.2 1.3	3	1. Communication means 2. Communication functions 3. Communication partners	3 Open-ended questions coded in matrix format allowing for a “other” category	Application of knowledge that relates directly to the three most important aspects highlighted during training. This knowledge is on a higher level of cognitive reasoning, namely Level 3 (application) of Bloom’s taxonomy (Wilson, Lanza, Barton, 1988) than results from Response Form II that are on Level 1 (knowledge) of the taxonomy.
C	Applied knowledge about recommendations (advice)	2.1 2.2 2.3 2.4 2.5	5	1.General advice 2. Communication means 3. Communication functions 4.Communication opportunities 5.Communication partners	5 Open-ended questions recorded verbatim on this form	Used open-ended questions were to ensure that relevant information would not be neglected or overlooked. Care was taken to ensure that the most important training principles were evaluated by means of Response Form I. A general question on recommendations was included to pinpoint additional knowledge that nurses might have gained and which was not covered in any other sections.
D	Skill demonstration	3.1 3.2 3.2	3	1. Practical skills demonstration 2. Amount of prompting required 3. Confidence in using the BCIP	Question 3.1 was scored on a 4-point Likert scale while 3.2 and 3.3 were scored on a 3-point Likert scale	Nurses were asked to use the BCIP to teach the particular case to make choices during mealtimes. Performance was scored on a 4-point Likert scale. This question is linked to multiskilling Level 4 (cross-training of clinical disciplines) while Sections B and C deal with Level 2 (cross-training of non-professional, non-clinical skills). Amount of prompting was included to determine if the number of prompts decreased over time indicating that nurses functioned more independently. Likewise confidence was included as an increased in confidence may point to independent use of the BCIP.
E	Exposure	4.1 4.2	2	1. Utilising the BCIP with patients 2. Contact with colleagues about the BCIP	Two Yes/No questions followed by an open-ended question	These aspects directly impact on nurses’ skills and knowledge, as it is expected that the more often they use the BCIP, discuss it or demonstrate it the more skilled and knowledgeable they will become.

**b) Response Form II**

This questionnaire has a total of 17 questions and five categories (biographic information, prior knowledge about disability and communication, attitudes and values, other positive outcomes and self-evaluation). This questionnaire was administered on three different occasions, namely Phase O<sub>1</sub> (directly before training), O<sub>2</sub> (directly post-training) and O<sub>5</sub> (5 months post-training). The complete questionnaire is included in **Appendix M**.

The term “*questionnaire*” was not used on the questionnaires, as it could be threatening seeing that it implies that there are correct and incorrect answers. Nurses might have felt that their knowledge was tested, thus inhibiting them. As a section of the questionnaire involved questions pertaining to attitudes and values, this aspect was of crucial importance. It was decided to rather use the word “*response form*” as this suggested what the participants should do (Mertens, 1998).

Where possible, structured, close-ended questions were used. This format was selected to accommodate time constraints and to assist the auxiliary and staff nurses whose literacy skills were not as well developed as that of the professional nurses. Providing them with a choice of possibilities from which they had to select one acted as a prompt. This enabled the researcher to obtain an idea of what they knew, not merely of what they were able to write and spell as it was noted during the pre-experimental phase (**Appendix D**) that nurses feared to make spelling and grammatical errors. This type of format is also more motivational as it is easier and quicker to complete (Leedy, 1993). In addition, answers were easily scored and analysed due to pre-assigned codes.

The disadvantages of close-ended questions are that they are more difficult to construct and the fact that relevant answers can easily be overlooked (Leedy, 1993). In this research care was taken when reviewing the literature to determine possible answers, a pre-experimental phase was conducted (involving focus groups with open-ended questions to highlight aspects that might not be described in the literature) and finally the questions were tested by means of a pilot study.

Some questions, e.g. Question 15 “*When you think of your skills as a nurse, which three things do you do best?*” was asked in open-ended format, so that the participants were not guided in a direction, and also to allow them to answer in their own words. To a small extent, these questions were also used in an attempt to countercheck some of the other questions and to control bias in the development of the questionnaire (Leedy, 1993). This format was, however, not frequently used throughout the questionnaire.

Section C in the questionnaire, pertaining to the attitudes and values were coded using

structured, close-ended questions due to the fact that some participants might find this type of questioning threatening. Care was taken with the wording and construction of the questions to suggest to participants that it is acceptable to reveal some aspects that might not be socially desirable and to combat the effect of answering in a socially desirable manner (Bless & Higson-Smith, 1995; Mertens, 1998), e.g. Question 10 “*Many people who work in over-populated clinics feel that they become impatient when people give long case-histories.*” Research has also indicated that if the participant and researcher build rapport over a longer period (as in the case with this type of research design) the participants are more honest when providing information (Mertens, 1998).

Furthermore, care was taken in Section C to include questions about all three components of attitude namely the affective dimension (how nurses feel about disability), cognitive dimension (what they know about disability) and the action dimension (what they are willing to do) (Mertens, 1998).

A few general guidelines were taken into consideration with the development of the questionnaire:

- Likert scales did not include more than five options (so that the options did not become visually overwhelming and so that participants could remember the options (Brink, 1999)).
- Negative wording was avoided e.g. Question 7 “*Speech is an example of a communication function*” (Bynner & Stribley, 1979).
- Items were mostly short e.g. Question 10 “*I feel satisfied with my job*” and care was taken to ensure that each question dealt with only one concept (Brink, 1999).
- Care was taken to avoid any biased or leading questions, jargon and other difficult terminology, and to ensure the clarity of the questions, so that all participants understood the same concepts with the vocabulary used (Bynner & Stribley, 1979; Mertens, 1998).
- An attempt was made to keep the questionnaires as short as possible to ensure that participants did not lose interest and/or become fatigued resulting in the omission of any important information (Leedy, 1993).

- Meticulous care was taken with the visual appearance of the questionnaires. Questions used during the different phases were printed on differently coloured paper to make it visually more appealing and to accentuate the fact that different cases were used, so combating feelings of familiarity. Questions were all numbered, organised in logical sequence and did not have too many items per page. Care was taken to ensure correct spelling and grammar throughout (Mertens, 1998).
- Clear, brief instructions were included at the top of the questionnaires to guide the participants. They were encouraged to complete all questions as incomplete responses would impact on the reliability of the data (Leedy, 1993).

Table 4.17 provides a summary of the most important areas covered in Response Form II, with specific reference to the motivation for inclusion. The category, type and number of each question in each category are also discussed.

**Table 4.17 Development of Response Form II**

Section	Category	Question #	Total # of questions	Question area	Type of question	Motivation
A	Biographical data	1 2 3 4	4	1. Birth date 2. Close relative with a disability 3. Qualification 4. Nursing category 5. Experience at health clinic(s) 6. Training in disability	One Open-ended question, Two Yes/No questions (specify if “yes”) Three close-ended questions with “other” category.	Birth date was used to determine the age of respondents as it has a direct influence on training methodology and also to code the respondent number. Having a relative with a disability influences knowledge, skills and attitudes and thus this variable had to be controlled. Variation of qualification, nursing categories and experience is possible. This data is important for compiling a profile of the nurses as these aspects impact on knowledge and skills as well as on the type of services they provide. Prior training in disability will also impact on these aspects. Nurses with prior experience would, however, not be ruled out as each nurse was compared with herself.

**University of Pretoria – etd – Bornman, J**

<b>Sec-tion</b>	<b>Category</b>	<b>Ques-tion #</b>	<b>Total # of questions</b>	<b>Question area</b>	<b>Type of question</b>	<b>Motivation</b>
B	Prior knowledge about disability and communication	7 8 9	Three questions that include 23 items	1. Knowledge about AAC 2. Knowledge about severe disability 3. Multiskilling of nurses 4. Communication modes, functions, partners and temptations	One structured close-ended question using true-false-uncertain format. Two close-ended questions where answers are plotted on a matrix for one and graded in terms of difficulty for the other.	Directly relates to the different aspects highlighted during training. Includes a definition of disability as well as the importance of different communication means, functions, partners and temptations. Training aimed at adhering to multiskilling issues and to provide nurses with training on ASHA's Level 2 (cross-training of professional, non-clinical skills) and Level 4 (cross-training of clinical disciplines). This questionnaire focuses on Level 2. During training a problem-based approach was followed as it is the training approach currently used with training health workers in the RSA. This implies that nurses will be required to apply knowledge different case studies. This section starts with true-false questions (as it is less threatening than open-ended questions), followed by four knowledge questions (in a matrix format) and finally a grading question where items are placed according to their difficulty level. This is a crucial element of the training as it provides guidelines of where implementation should start.
C	Attitudes and values	10	One question that includes 20 items	1. Motivation 2. Stress and job satisfaction 3. Attitude towards disability	5-point rating scale for all ranging from strongly agree to strongly disagree a method frequently used in assessing attitudes (Brink, 1999). Question construction was done with caution to avoid socially desirable responses or the so-called " <i>halo effect</i> " (Bless & Higson-smith, 1995 and Guy <i>et al.</i> , 1987)	The reversal theory of motivation was used to determine the nurses' motivation to work with CSDs. This holds that people are predominantly telic (goal directed) or paratelic (more " <i>easy going</i> " and " <i>go with the flow</i> "). Determining a person's telic-paratelic focus provides important guidelines in terms of how the person experiences the work environment as it provides an indication of seriousness, planning orientation and arousal avoidance(if certain activities increase or decrease stress (Murgatroyd, Rustiton, Apter & Ray, 1978). It is assumed that nurses in community health clinics who are predominantly paratelic would find BCIP implementation with CSDs who do not make appointments and merely turn up, easier. This is also comparable to Bradshaw's definition of a Type B nurse who is flexible, thinking, problem-solving, autonomous, accountable and self-directing – the qualities of the nurse of the 21 <sup>st</sup> century (Bradshaw, 1989). This is, however, not a psychometric test and these six items were merely included for descriptive purposes and to provide insight to the researcher. The next six items were adapted from the Index of Job Satisfaction (Brayfield and Rothe, 1951). It is related to the amount of stress people experience in their jobs. If stress levels are very high their ability to perform additional creative service

**University of Pretoria – etd – Bornman, J**

<b>Sec-tion</b>	<b>Category</b>	<b>Ques-tion #</b>	<b>Total # of questions</b>	<b>Question area</b>	<b>Type of question</b>	<b>Motivation</b>
C <i>Con-tinued</i>						delivery (BCIP implementation) may be hampered. Finally, this section deals with attitudes towards service delivery as it directly impacts on knowledge and skills. Negative persons might not want to work with CSDs while very positive persons might overemphasise the care aspect and overlook the training dimension.
D	Other positive outcomes	11 12 13	3	1. Number of CSDs seen 2. Amount of time spent with CSD and caregiver 3. Type of service delivery provided	Three Close-ended questions	As nurses become better acquainted with the training programme, it is estimated that they will start using it with more patients and that the number of CSDs seen, will increase. It is also expected that initially they might spend more time with CSDs as they become more aware of this population and offer direct service to them. As familiarity with the BCIP increases, it is expected that the amount of time spent with CSDs will decrease as knowledge and skills increase. Finally, a change in the type of service delivery is expected away from direct referral as this is problematic (due to limited referral options, poverty and transport problems, little or no feedback to the referring nurse, etc.) using the BCIP nurses can provide a more accountable, affordable and effective service to CSDs and their caregivers.
E	Reflexive self-evaluation	14 15 16 17	Four questions and question 14 has six items	1. Comfortableness in handling disability 2. Effectiveness 3. Enjoyment 4. Opportunity for service delivery to CSDs 5. Case management (rapport and empathy) 6. Self-evaluation of skills	Six structured close-ended items using a 4-point Likert scale and three open-ended questions.	Participants should have the opportunity to reflect on their own knowledge, skills and attitudes. Specific questions were formulated for this purpose, combining close-ended and open-ended questions as both of these could assist with the effective training process. Areas covered relate to the effectiveness of a nurse during service delivery and enjoyment (if she does not enjoy working with CSDs it is assumed that she will not implement the BCIP independently. One disadvantage of self-evaluation is that it is difficult to be objective and to accept one's own strengths and weaknesses (Bradshaw, 1989). It is felt that after the weeklong training nurses would have a clear idea of what was expected of them in so far as service delivery to CSDs is concerned, providing them with the criteria against which they can judge their own performance. It is expected that this section might be difficult prior to training as nurses might not know of any other types of service delivery part from referral, leading them to think that their current knowledge and skills would suffice.

**c) Response Form III**

This is a short two page questionnaire that deals with the evaluation of training and was completed during the O<sub>2</sub> phase (directly post-training) and during the O<sub>5</sub> phase (at the five month withdrawal period). The complete questionnaire is attached as **Appendix N**. It aimed at obtaining the necessary data in as short a time as possible, as questionnaire length is an important variable that needs consideration. It must also be noted that this questionnaire was completed at the end of the training and consequently fatigue had to be considered. Response Form III consists of eight questions aimed at obtaining information about the training methodology and content.

Table 4.18 provides a summary of the most important areas covered in Response Form III, with specific reference to the motivation for inclusion. The category, type and number of each question in each category are also discussed.

**Table 4.18 Development of Response Form III**

Sec- tion	Category	Question #	Total # of questions	Question area	Type of question	Motivation
A	Biographic data	1	1	1. Birth date	One open-ended question	Used for coding respondent number enabling comparison between different research phases and measuring instruments.
B	Knowledge gained	2 3 4 5	3	1. Knowledge gained 2. Evaluation of training method and content 3. Enjoyment of training 4. Knowledge still lacking	One 4-point Likert scale rating, Two open-ended questions. One close-ended question (Yes / No / Uncertain)	Question 2 required of nurses to indicate on the 4-point Likert scale to which extent they had gained knowledge. Question 3 attempted to qualify the knowledge by probing specific aspects of the training content and methodology. Enjoyment of training impacts on the acquisition and retention of knowledge and a question on the three most enjoyable aspects of training was included. Nurses were also asked which knowledge aspects they felt lacking (implying a meta-cognitive reflection on the training). This information will be utilised to evaluate the BCIP training in terms of effectiveness and appropriateness.

**University of Pretoria – etd – Bornman, J**

<b>Section</b>	<b>Category</b>	<b>Question #</b>	<b>Total # of questions</b>	<b>Question area</b>	<b>Type of question</b>	<b>Motivation</b>
C	Recommendations	6 7	3	1. Suggestions to improve training 2. Additional comments	Two open-ended questions	The first question allowed nurses to note their suggestions that would improve training while the second was used for additional comments. As the research focused on the development of the BCIP training programme, feedback is essential for further improvement.
<b>Section</b>	<b>Category</b>	<b>Question #</b>	<b>Total # of questions</b>	<b>Question area</b>	<b>Type of question</b>	<b>Motivation</b>
D	Overall rating	8	1	1. Overall rating	One 5-point Likert scale rating, ranging from “ <i>very poor</i> ” to “ <i>excellent</i> ”	Necessary to obtain the nurses’ overall impressions of the BCIP training without isolating certain factors, for future improvement. In the literature it is well-documented that the adult learner’s impression of a training programme directly influences the gains (i.e. knowledge, skills and attitudinal) achieved.

## ii.) Training programme

Equipping nurses with the skills to provide services to beginning communicators constitutes the primary aim of this research. The proposed use of the BCIP with its accompanying handouts and training represents a method through which this can be achieved. During the development of this training programme the concept of multiskilling was addressed as it facilitates change on the knowledge and skill levels. The design and development of the training programme is central to this research and an extensive motivation for the use of this specific training programme is presented in Chapters 2 and 3. This includes the training philosophy, structure and process, consequently these aspects will not be discussed in this section.

As already mentioned the training was conducted over five consecutive days (6 – 10 July 2000) from 08h30 to 16h00 daily. The reasons for the weeklong training were logistical (it was convenient for the nurses to rather be away from their respective clinics for a week than being away at various intervals) and also because the trainer/researcher wanted to follow the principle of total immersion to introduce nurses to these new and unfamiliar concepts. The consecutive training also limited the possibility of forgetting new information as adults forget 50% of what they learn after two hours and an additional 20% after two days (Rosenthal, 1991). July was selected as no other in-service training programmes were presented at that time, nurses did not have to study for any exams and not many were scheduled to take leave.

Training could not be conducted in situ, as none of the clinics had training facilities. However, a venue in the Moretele Health District was selected as its central location provided easy access and reduced travelling time and costs for participants. The training context is

important as a friendly, non-threatening atmosphere is one of the principles of adult learning (Jarvis, 1995). The amount of work with a majority of new concepts, the hands-on teaching method requiring active involvement and the fact that they all wanted to perform well, led to fatigue. It was also anticipated that some nurses could experience stress due to their age or their lack of qualifications (especially the auxiliary nurses)(Merriam & Caffarella, 1991). In order to counteract this, sessions between tea or lunch breaks were never longer than 1½ hours. These

sessions were usually made up of theoretical discussions (lasting approximately 20 – 30 minutes) followed by short video clips, interactive workshops and role play sessions of 60 minutes in line with adult training principles (Jarvis & Gibson, 1997). The effective presentation of theoretical concepts were ensured by the use of various teaching aids, e.g. the overhead projector with transparencies and videos (discussed in detail in Section 4.5.2.1). Case studies shown on video ensured that all participants understood concepts in exactly the same way (e.g. the various manifestations of the concept “*severe disability*”), forming common ground and facilitating insightful understanding of the particular concept. The use of case studies and problem-based learning assist participants in applying new knowledge and skills to real life situations (Blackman, 1995). The trainer’s presentation style was informal, incorporating many examples and demonstrations, and encouraging questions and comments. In addition, the training venue was spacious with comfortable seating and few distractions (Jarvis, 1995). It was further enriched by the use of posters depicting various symbol systems, voice-output devices and AAC users in action, book displays, communication boards and voice output devices, flowers, peppermints and water carafes.

At the beginning of each day participants received the complete handout for that particular day. All five handouts are attached as **Appendices O1 – O5**. This enabled them to focus and concentrate on the information that was presented without anxiously trying to write down new information. These handouts also acted as a resource once the BCIP training had been completed. In compiling the handouts meticulous care was taken with the preparation and they were visually pleasing. This entailed that a 12-point font was selected to facilitate easy reading, headings were in bold type so that they stood out, enough space was left for own comments and important concepts were enhanced with pictures and graphics (Caffarella, 1994).

In conclusion a summary of the training procedure including the aim, competencies, equipment and instructional method, theoretical discussion and practical discussion is provided in Table 4.19.

**Table 4.19 Summary of the training procedure**

#	Aims	Competencies Learning outcomes)	Equipment & instructional method	Theoretical discussion	Practical session
1	<ol style="list-style-type: none"> <li>1. To contextualise the training within Primary Health Care (PHC) and the human rights of CSDs</li> <li>2. To highlight the importance of communication</li> <li>3. To explain the concept “severe disability”</li> <li>4. To discuss “multiskilling” and highlight the nurse’s role in training beginning communication skills</li> </ol>	Nurses will demonstrate their <b>knowledge</b> about the human rights of CSDs, the importance of communication for CSDs, the concepts “severe disability” and “multiskilling” and nurse’s role in training beginning communication skills	<ul style="list-style-type: none"> <li>• Overhead projector</li> <li>• Transparencies</li> <li>• Video recorder</li> <li>• Videos</li> <li>• Handouts for Day 1</li> <li>• Lecture</li> <li>• Case study</li> <li>• Small group discussion</li> <li>• Feedback</li> </ul>	The importance of the BCIP training in terms of PHC, the human rights of CSDs and the importance of communication were discussed. The devastating effect of LNFS was demonstrated by means of video clips. Next the concept “severe disability” and the difficulties of working with CSDs as well as the ICIDH-2 that focuses on participation were discussed. Finally disability was integrated into nursing practice by highlighting “multiskilling”.	<p>Nurses divided into small groups of three and discussed how they would plan a disability campaign to lessen the impact of disability in their health district. Each group addressed one of the following elements:</p> <ul style="list-style-type: none"> <li>• Awareness</li> <li>• Information</li> <li>• Referral</li> <li>• Feedback &amp; follow-up</li> <li>• Prevention</li> <li>• Identification &amp; screening</li> <li>• Planning services</li> </ul>
2	<ol style="list-style-type: none"> <li>1. To describe the four major areas that impact on communication</li> <li>2. To discuss the development of communication functions through the provision of deliberate communication opportunities</li> <li>3. To facilitate the development of skills related to beginning communication functions and the creation of communication opportunities during ADL</li> </ol>	<p>Nurses will demonstrate their <b>knowledge</b> about different beginning communication functions and deliberate communication opportunities.</p> <p>Nurses will demonstrate the <b>skill</b> to deliberately create communication opportunities through the use of communication temptations</p>	<ul style="list-style-type: none"> <li>• Overhead projector</li> <li>• Transparencies</li> <li>• Video recorder</li> <li>• Videos</li> <li>• Handouts for Day 2</li> <li>• BCIP</li> <li>• Lecture</li> <li>• Case study</li> <li>• Small group discussion</li> <li>• Feedback</li> </ul>	<p>Four main communication domains namely functions, means, content and partners were discussed. The focus was then placed on beginning communication functions (choice-making, labelling, requesting help, requesting more, drawing attention, protesting, “yes” concept and showing humour &amp; surprise). Specific strategies to elicit these functions (“communication temptations”) were then demonstrated. This included providing choices, making desired items inaccessible, selecting materials that require assistance, providing small portions or brief turns, deliberately withholding attention, offering non-preferred items and violating expectations. Finally a 5-point plan for answering case studies was given and discussed.</p>	<p>After the discussion and demonstration of a particular communication function and temptation, participants were asked to practise the skill using the BCIP. Finally nurses were divided into small groups and each group had to explain how they would conduct service delivery and then demonstrate their newly acquired skill. All case studies differed to ensure that there was no duplication of facts and that all the different functions that were taught could be demonstrated. An example of a case study is: “Simon is a four year old spastic boy. He cannot sit unsupported and although he can use his arms he cannot point effectively with an isolated finger. How will you teach him to point?”</p>

**University of Pretoria – etd – Bornman, J**

#	<b>Aims</b>	<b>Competencies Learning outcomes)</b>	<b>Equipment &amp; instructional method</b>	<b>Theoretical discussion</b>	<b>Practical session</b>
3	1. To revisit the four major areas that impact on communication 2. To discuss different communication means (aided and unaided) 3. To facilitate the development of skills related to the implementation of aided and unaided communication strategies	Nurses will demonstrate <b>knowledge</b> of the various aided and unaided communication means included in the BCIP  Nurses will demonstrate <b>skill</b> in implementing the various aided and unaided strategies in the BCIP	<ul style="list-style-type: none"> <li>• Overhead projector</li> <li>• Transparencies</li> <li>• Video recorder</li> <li>• Videos</li> <li>• Handouts for Day 3</li> <li>• BCIP</li> <li>• Lecture</li> <li>• Object &amp; PCS communication boards</li> <li>• SASL dictionary</li> <li>• Case study</li> <li>• Small group discussion</li> <li>• Feedback</li> </ul>	The four main communication domains were discussed, highlighting means. This was followed by a discussion of the concept “AAC” after which the aided and unaided strategies included in the BCIP were discussed and demonstrated. The unaided strategies included gestures (e.g. pointing, yes/no headshake, facial expressions, miming and gestures) sign language (SASL) and natural gestures. The aided strategies include real objects, colour photographs, PCS and a 4-option digital speaker. Received PCS communication boards in all 11 official languages ( <b>Appendix Q</b> ). Advantages and disadvantages aided and unaided strategies were highlighted.	After a discussion and demonstration of the various aided and unaided communication strategies included in the BCIP, nurses had the opportunity to practise these skills. All means were first practised in isolation (e.g. “ <i>Make the gesture for “open”</i> ”) after which they had to incorporate it with their skills of the previous day (e.g. use a gesture to provide a choice). This was done in small groups where the roles constantly changed between a nurse acting as the CSD, a caregiver and a nurse. Skills were then applied to a specific case.
4	1. To revisit the four major areas that impact on communication 2. To discuss different communication contexts / environments 3. To discuss the inclusion of different partners 4. To highlight general intervention principles	Nurses will demonstrate <b>knowledge</b> of the importance of including different communication partners and environments in the intervention process as well as the general intervention principles  Nurses will demonstrate <b>skill</b> in implementing the BCIP by including intervention principles, contexts and partners	<ul style="list-style-type: none"> <li>• Overhead projector</li> <li>• Transparencies</li> <li>• Video recorder</li> <li>• Video</li> <li>• Handouts for Day 4</li> <li>• BCIP</li> <li>• Lecture</li> <li>• Case study</li> <li>• Small group discussion</li> <li>• Feedback</li> </ul>	The four major communication domains covered by the BCIP were revisited, highlighting the importance of the communication context (environment) and partners. The importance of these two aspects were highlighted by discussions, demonstrations and video examples. All information was related back to the BCIP by focussing on the three contexts covered, namely bathtime, mealtime and dressing/undressing. To conclude a few general intervention principles that should be adhered to at all times, e.g. the importance of maintaining a “give-and-take balance” were addressed.	Small groups were formed where everyone had an opportunity to take on different roles while practising the implementation of the different contexts provided by the BCIP. Participants were asked to specifically address the issues of involving different communication partners. General intervention principles were integrated into these role play sessions. Finally nurses role-played their recommendations with a specific case, e.g. “ <i>Nomsa is 7-years old and spends her days with her 90-year old grandmother who doesn’t want her to attend school. Her only toy is a broom that she pushes around aimlessly</i> ”

#	Aims	Competencies Learning outcomes)	Equipment & instructional method	Theoretical discussion	Practical session
5	<ol style="list-style-type: none"> <li>1. To describe the importance of monitoring progress</li> <li>2. To complete a checklist designed for monitoring progress</li> <li>3. To apply the checklist to a case study.</li> </ol>	<p>Nurses will demonstrate <b>knowledge</b> regarding the importance of monitoring progress</p> <p>Nurses will demonstrate <b>skills</b> in applying the Progress Checklist to a particular case study.</p>	<ul style="list-style-type: none"> <li>• Overhead projector</li> <li>• Transparencies</li> <li>• Video recorder</li> <li>• Videos</li> <li>• Handouts for Day 5</li> <li>• Progress checklist</li> <li>• Lecture</li> <li>• Case study</li> <li>• Small group discussion</li> <li>• Feedback</li> </ul>	<p>The theoretical rationale for monitoring progress was discussed. Following this each item in the Progress Checklist that consists of three sections, namely the child (comprising communication means and functions), the partners and environment (comprising information about the partners and daily living information about the child within the environment) and the nurse's observation (in terms of communication temptations) were discussed.</p>	<p>Three Video cases were shown and a Progress Checklist was completed for each case. This was done in the group as a whole. Each score was then discussed in order to gain consensus and to act as in-service training. This was followed by two more video cases, which nurses completed a checklist in the small groups. Scores were again discussed and nurses were able to objectify their given scores. High correlation was found after the 5<sup>th</sup> video case. This was followed by a case study discussion similar to the one discussed in Response Form I.</p>

#### 4.5.2.3 Data collection procedures

Specific considerations that had to be taken into consideration with the collection of data to ensure reliability as well as the procedure for data collection follows.

##### i.) Specific considerations

In order to assure reliability specific considerations had to be taken into account during the collection of data, including the following:

- a) All interviewers received the same training and therefore had exactly the same knowledge and skills in conducting the structured interview and completing Response Form I. This was done in an attempt to minimise the personal interpretation of questions, to reduce bias and to clarify any possible problems resulting from terminology (Babbie & Mouton, 2001).
- b) All interviews were video recorded and rated by an external rater to check the reliability of the data.
- c) In an attempt to minimise the Hawthorne effect, interviewers explained to nurses that there were no correct or incorrect answers before conducting the structured interviews (Babbie & Mouton, 2001; Brink, 1999).
- d) In order to enhance co-operation all the nurses were informed that results from the three measuring instruments would be used to adapt the BCIP training and that they were specifically selected as participants. In addition, they received certificates of attendance from the University of Pretoria.
- e) As the amount of information and the degree of difficulty demanded close concentration from the nurses, attempts were made to keep the questionnaires as short and as user friendly as possible without sacrificing the quality of the information needed, and to have a break at the end of each questionnaire.

##### ii) Procedure

The procedure will be described as it pertains to the different experimental phases of the research.

- a) Permission to perform the research was obtained from the Assistant Director of Health in the Moretele District. First of all telephonic contact was made and a formal meeting arranged, during which the aim and procedures of the research was discussed. The Assistant Director then held formal discussions with all the matrons and the nurse in charge of continuous education programmes. Written permission to conduct the research was obtained.
- b) A pre-experimental phase followed that comprised a needs analysis, determining community nurse's perceptions and exposure to disability utilising focus groups and questionnaires and finally the development of the BCIP (based on literature reviews and focus groups with caregivers of typically developing children and caregivers of CSDs).
- c) The experimental phase commenced with the identification of community nurses' knowledge, skills and attitudes (Phase O<sub>1</sub>). This was done by means of completing Response Form I and II on the first day of the weeklong training before the formal training commenced. As previously discussed, six interviewers and one external rater who assisted in conducting the structured interviews and completing Response Form I, were trained. In order to heighten the reliability of the data, the structured interviews were video recorded and were viewed by an external rater. For this phase of the research the researcher acted as the second rater while the external rater rated all the structured interviews conducted by the researcher. After all the structured interviews were completed, nurses assembled in the training venue and completed Response Form II. This was followed by a tea break after which the BCIP training commenced.

- d) The training (Phase X) in the application of the BCIP was conducted over five consecutive days (Monday to Friday). The training context, procedures and content are summarised in Table 4.19.
- e) The same procedures as described for Phase O<sub>1</sub> were repeated for Phase O<sub>2</sub>, with the addition of Response Form III. After the training was concluded all the nurses were asked to complete Response Form III (training evaluation). Afterwards the different interviewers conducted the structured interviews and completed Response Form I. Random selections were made, implying that nurses were not necessarily interviewed by the same interviewer pre- and post-training. Finally nurses gathered in the training venue and completed Response Form II. This was followed by the presentation of certificates of attendance. It was felt that these certificates could be seen as a reward that made the nurses feel positive about their newly acquired skills and eager to learn in future (Jarvis, 1995). Training was concluded by 13h00 with an informal braai before participants left for home. All of them stated that an esprit de corps had formed during the week and that they felt a special friendship and bond with fellow nurses who also underwent the training.
- f) Training was followed by an in situ follow-up after the initial training (Phase O<sub>3</sub>) that lasted three days. This was necessitated by the fact that vast distances between the various clinics had to be covered, making it impossible to conduct this over a shorter time. Blackman (1995) reported that the quality of training is enhanced if it is followed by a training session during which the participants have the opportunity to interact individually with the trainer. These follow-ups were conducted in situ for logistical reasons (nurses did not have to take time off from work and consequently service delivery was only slightly disrupted) as well as the fact that the advantages of in situ training are documented (Bornman & Alant, 1999). Prior to conducting the structured interview nurses were shown photographs that were taken during training and they were handed an EasyTalk 4 Option digital speaker. Due to technical difficulties each nurse could not be equipped with her own device during training. Although this was not ideal, it appeared that the nurses were confident in handling the devices as they had had ample practise with similar devices two weeks earlier. The researcher then conducted the structured interviews and completed Response Form I. All interviews were video recorded by the fieldworker. The external rater then viewed the recordings and completed Response Form I independently. These sessions concluded with

the researcher addressing issues with which the particular nurses still had difficulty (e.g. the implementation of the communication board) and by answering all possible questions. The date for the next follow-up was confirmed. Each session lasted approximately 50 minutes.

- g) Phase O<sub>4</sub> was also done in situ and was conducted over four days. It entailed the completion of Response Form I, which was also video recorded. After the data collection procedure, individual questions were again answered. Some of the nurses had arranged for CSDs to be present and the researcher demonstrated some of the principles of the BCIP on these children. In addition, each nurse received five PCS symbols that could be placed on the digital speaker. In order to allow for some flexibility they received five symbols despite the fact that they only needed a maximum of four at a time. The date for the next follow-up was confirmed.
- h) The data collection procedure for Phase O<sub>5</sub> was exactly the same as O<sub>4</sub>. After all the follow-ups had been conducted, nurses gathered in the initial training venue on the fourth day. The purpose of this meeting was to determine what each nurse felt that she had gained from the training (and if not – why not) and to hear her recommendations regarding the training. This day commenced with nurses completing Response Form II in order to determine their knowledge and attitudes after having been involved in the training programme for five months. A focus group was then conducted to obtain qualitative information on benefits and recommendations. Finally, nurses were asked to complete Response Form III (training evaluation) taking the whole five months into consideration (implying the initial weeklong training and three follow-ups). The day was concluded by lunch, a short message by the Assistant Director of Health and the presentation of small Christmas gifts to each participant for their co-operation during the research.
- i) At the end of each phase the main researcher encoded all the measuring instruments.
- j) The encoded data was then captured, checked by the researcher for any capturing errors and the statistical analysis started. Finally the interpretation of results followed.

#### **4.5.3 Data analysis and statistical procedures**

All the data were documented on the three measuring instruments. A pre-designed column marked “*For official use*” was placed on the right-hand side of all the measuring instruments for encoding the raw data. This was encoded by the researcher according to the data definitions. Subsequently data were computerised for statistical analysis with the SAS and BMDP programs. The data were then analysed using a variety of statistical procedures. This included:

#### **4.5.3.1 Descriptive statistics**

- Discrete frequency distribution counts were calculated for all the variables on all three measuring instruments which implied that all variable values were listed and counted each time they occurred (Guy *et al.*, 1987).
- In some cases combined frequency scores were calculated for specific variables, e.g. “*List your three best skills as a nurse*”. This enabled the researcher to gain a holistic picture of all the possible answers to a specific question.
- Percentages of different variables were determined and compared.
- Mean scores and standard deviations (STD) were calculated in the applicable cases to provide information on the spread of distribution.

#### **4.5.3.2 Contingency tables**

A number of contingency tables (mostly 2x2 and 2x3) were included to determine the dependence of specific variables with the chi-square test. In cases where these tables indicated

significant dependency further statistical analysis was done.

#### 4.5.3.3 Inferential statistics : Parametric tests

- The t-test was used to compare the means pre-training and post-training in order to determine whether the differences between the means is significant due to change (Steyn, Smit, du Toit & Strasheim, 1998).

#### 4.5.3.4 Inferential statistics : Non-parametric tests

- Chi-square test was utilised to compare data sets in the form of frequencies (Steyn *et al.*, 1998)
- Wilcoxon test for correlated samples (Steyn *et al.*, 1998)
- Fisher's exact test to determine whether two aspects have a positive or negative affect on each other (Steyn *et al.*, 1998)
- The Friedman Test is an extension of the Sign Test and was used for determining whether the difference between the various research phases (e.g. the five data sets of Response Form I) deviate from one another significantly or merely by chance (Brink, 1999).

The results are displayed with bar graphs (especially when indicating change over time when comparing groups of data), histograms, frequency polygons and cumulative frequency graphs (Fink, 1995). Tables are used in cases where a summary of data is required (Fink, 1995).

### 4.6 SUMMARY

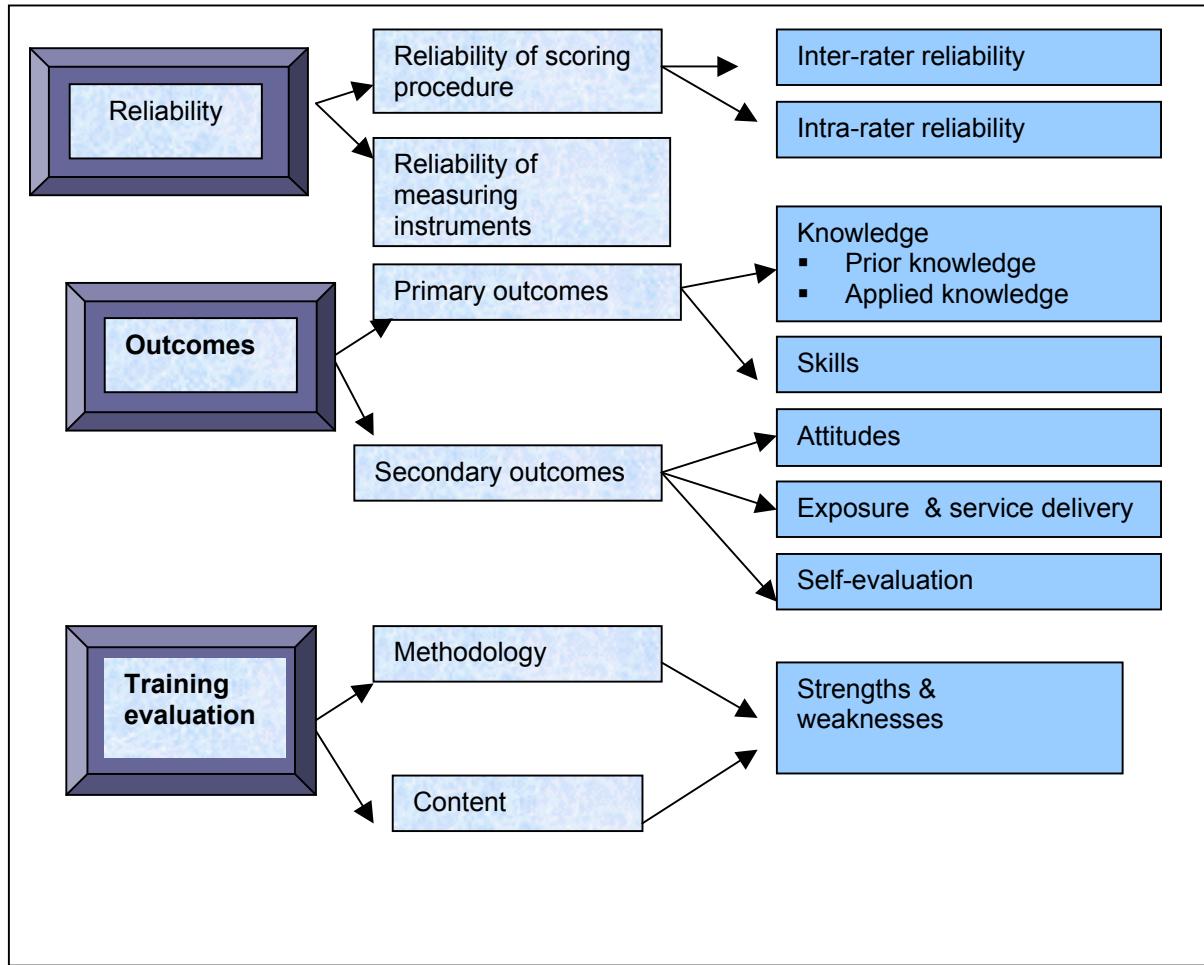
This chapter described the methodology of the research. It included the aim of the research and the objectives necessary to meet it. A description of the pilot study that indicated problem areas and deficiencies followed. Research phases, criteria for selection and a description of the participants, materials and equipment with respect to the main study followed. Finally data collection, recording and analysis were discussed.

## CHAPTER 5

## RESULTS

### 5.1 INTRODUCTION

The results described in this chapter focus on sub-aim four of the research, namely to determine the outcomes after having applied the BCIP to a group of 20 community health nurses. The other three sub-aims have already been met in the preceding chapters as they formed the basis for the methodology that was followed. Data will not only be organised and analysed but will also be summarised and interpreted so that conclusions can be drawn regarding the effectiveness and usefulness of the BCIP training in achieving specific outcomes. Three major components in the description of the results are important. Firstly, issues pertaining to reliability are discussed. The focus is mainly on the reliability of the scoring procedure and measuring instruments. Secondly, the outcomes of the BCIP training which includes primary outcomes (knowledge and skills pertaining to disability and beginning communication skills) and secondary outcomes (attitudes towards disability, exposure and service delivery to CSDs and a self-evaluation of knowledge and skills) are described. Finally, general comments regarding the training are made (including the methodology that was followed and the content) highlighting the strengths and weaknesses of the training. The general flow of the results is seen in Figure 5.1.



**Figure 5.1 Schematic presentation of the results of this research**

## 5.2 RELIABILITY

### 5.2.1 Reliability of the scoring procedure

Reliability is concerned with the consistency, stability and repeatability of the informants' accounts as well as the investigator's ability to collect and record information accurately (Brink, 1999). In order to account for this certain precautions were built into the measuring instruments and the methodology followed. Structured interviews (used to obtain the data for Response Form I) were video-recorded in order to ascertain if data

were collected and recorded consistently and accurately. Both inter-rater and intra-rater reliability measurement were included. Each will be described in detail.

### 5.2.1.1 Inter-rater reliability

Two raters (the researcher and an independent rater) independently scored Response Form I for all twenty participants in order to obtain inter-rater scores. For the first two measurements (namely pre- and post-training), both raters scored all of the 86 statements on the measuring instrument. However, it was then noted that no differences occurred for the first two sections of the measuring instrument (namely current abilities and recommendations). This was due to the fact that these sections of the measuring instrument involved verbatim transcriptions of the participants' responses. Differences did, however, occur for the third section of the measuring instrument, namely "*practical demonstration of skills*". Consequently only this section was recorded for the final three measurements. Inter-rater agreement was calculated with the following formula:

$$\frac{\text{Number of differences between Rater 1 \& Rater 2}}{\text{Number of items} \times \text{number of participants}} \times \frac{100}{1}$$

In addition, where the scores differed, Rater 1 was used as the standard, and it was calculated whether the score given by Rater 2 was bigger or smaller. A bigger difference would indicate greater tolerance from Rater 2 (the independent rater) whereas a smaller difference would indicate poorer performance (stricter measurement from Rater 2). It was decided to use this calculation as opposed to kappa statistics, which would not provide descriptive information, but merely a score. Across all measurements, the inter-rater agreement averaged 96%, with the majority of differences being greater, meaning that Rater 2 was more tolerant than Rater 1 or that Rater 1 was stricter than Rater 2. This might be due to the fact that Rater 2 viewed the skills demonstration on video and, in cases where uncertainty occurred, she tended to give participants the benefit of the doubt. However, these differences are insignificantly small and will not be further discussed. It

is also important to note that the score throughout never differed with more than one category. Table 5.1 shows the scores for each individual measurement.

**Table 5.1 Inter-rater reliability**

Score	Pre-training	Post-training	Follow-up 1	Follow-up 2	Follow-up 3
No difference in measurement	98%	95%	96%	93%	97%
Greater difference in measurement	2%	5%	4%	5%	3%
Smaller difference in measurement	0%	0%	0%	2%	0%

### 5.2.1.2 Intra-rater reliability

To test the stability of judgements made by the same rater, Rater 1 re-administered Response Form I five months later. The videos of five participants (20%) were randomly selected for this purpose. The rater watched the videos and scored all 86 items. An intra-rater score of 96% across all items was obtained with 3% of the scores being greater for the second rating and 1% being smaller. Ratings never differed with more than one category.

### 5.2.2 Reliability of participant responses

Traditional reliability coefficients were not applicable to this particular research for two major reasons. The first relates to the nature of the measuring instruments. Training was conducted and thus it was expected that the answers would change over time. However, biographic data (obtained from Response Form II) remained consistent during the five-month period. This consistency of responses indicates that the data were reliable and repeatable. Secondly, the sample size is relatively small ( $n=20$ ). Other methods were therefore included to increase the reliability of the measuring instruments, e.g. information obtained in Questions 11 and 12 (Response Form II) were compared to determine if the same nurses who reported that they never saw CSDs were also the ones

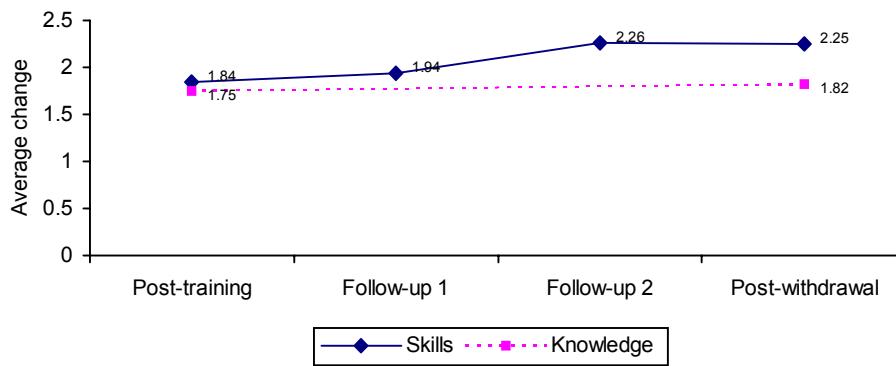
who marked that they spent no time with these individuals. Results indicated a precise comparison between these two data sets indicating that information obtained with the measuring instrument was reliable. In addition, frequencies were obtained for Question 8 (Response Form II) in order to determine whether nurses marked answers at random on the matrix. However, it became evident that the same option was never marked more than once, indicating careful consideration of each option in an attempt to provide the correct answer.

### **5.3 OUTCOMES**

Outcomes are described in terms of the primary outcomes that relate directly to the BCIP training, namely knowledge and skills. Secondary outcomes were not directly trained, and relate to attitudes, exposure, service delivery and self-evaluation. Each of these aspects will now be described in more detail.

#### **5.3.1 Primary outcomes**

In determining the primary outcomes, two aspects are described, namely the change in knowledge (including prior and applied knowledge) and skills of the participants after having completed the BCIP training. Results are presented in Figure 5.2.



**Figure 5.2 Global increase in knowledge and skills post-training**

In this graph knowledge and skills are expressed relative to the measurements obtained during pre-training, as this will clearly show how these aspects increased. This implies that the pre-training average in both cases were 0 and that knowledge thus increased from pre-training to post-training with an average of 1.5 and skills with an average of 1.7. Mention should also be made of the fact that skills were measured at five different intervals and knowledge thrice. It is noticeable that skills increased at a higher rate than knowledge. This is possibly due to the fact that the focus of training was on skills and the fact that skills were measured and emphasised more regularly than knowledge during the follow-ups.

These two primary outcomes will now be described in depth. Each section will start with a global summary followed by a detailed description.

### 5.3.1.1 Knowledge

The knowledge dimension was divided into two sections, namely prior knowledge and applied knowledge. The prior knowledge section included a set of 29 questions divided into three categories, comprising 15 true-false questions, 10 multiple choice questions and four ranking questions. Data were obtained by using Response Form II, which was administered at three different intervals, namely pre- and post-training and post-

withdrawal. Applied knowledge on the other hand, was obtained from data recorded in Response Form I, Section 1 (Questions 1.1 - 1.3) and Section 2 (Questions 2.1 – 2.5). Data were collected at five different intervals. An in-depth discussion of these sections will now follow.

### i) Prior knowledge

A Friedman test was employed to determine whether the change in prior knowledge was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.2 Friedman test of prior knowledge**

	R <sub>1</sub>	R <sub>3</sub>	R <sub>2</sub>
<b>Rank sum</b>	21.0	42.0	57.0
<b>Mean</b>	13.5	17.9	19.5
<b>Summary of results</b>	<hr/>		

For all the following multiple comparisons, it should be noted that values are in rank order from the lowest to the highest mean (x), and that the line indicates that measurements are essentially equal (i.e. there is no statistically significant difference). Table 5.2 indicates a statistically significant difference (increase) from prior knowledge at the 5% confidence level between the pre-training score (R<sub>1</sub>) and the post-training score (R<sub>2</sub>) and the post-withdrawal scores (R<sub>3</sub>) respectively.

Each of the specific questions that contributed to the prior knowledge domain will now be discussed in detail.

Regarding the true-false questions a frequency table of correct answers was compiled in order to determine what the trends were with each of these questions during the various

research phases. Results are displayed in Table 5.3. Further testing on individual questions was not done as the total score was used to form part of the prior knowledge section on which a Friedman test was done.

**Table 5.3 Number of nurses who answered the true-false questions correctly during the various research phases (n=20).**

No	Item description	Correct answer	Pre-training	Post-training	Post-withdrawal	Comments
V18	AAC refers to Abnormal Alphabetical Communication.	False	11	16	16	Knowledge maintained.
V19	Manual signs, facial expressions and pointing to pictures are different means of communication.	True	19	19	20	Slight knowledge increase. High pre-training score.
V20	Withholding attention is an example of a deliberate communication opportunity.	True	7	20	20	Sharp increase in knowledge – 100% maintained.
V21	The WHO defines disability from the perspective of the individual's participation in the environment.	True	10	13	11	Slight decline. Score better than pre-training.
V22	Multiskilling refers to many professionals (e.g. SLP, doctors, nurses, etc.) giving skills to disabled people.	False	2	9	5	Decline, but post-withdrawal score better than pre-training score.
V23	Teaching CSDs should not take place in the natural home environment.	False	14	17	18	Knowledge continued to improve slightly.
V24	Speech is an example of a communication function.	False	1	7	11	Knowledge continued to improve.
V25	“Dressing” does not provide many communication opportunities.	False	12	18	19	Knowledge continued to improve slightly.
V26	It is not necessary to train CSDs to make choices. This skill develops spontaneously.	False	19	20	19	High scores throughout. Slight decline.
V27	Protesting is one of the last communication skills that a child develops.	False	9	15	11	Decline, but post-withdrawal score better than pre-training score.
V28	Severe disability can be the result of peri-natal factors, e.g. rubella and malnutrition.	True	18	18	19	Knowledge continued to improve slightly.

No	Item description	Correct answer	Pre-training	Post-training	Post-withdrawal	Comments
V29	Environmental factors (e.g. family stress and lack of stimulation) do not cause disability.	False	13	18	13	Decline of knowledge to pre-training score.
V30	Unaided communication refers to the use of manual signs, natural gestures, fingerspelling and speech.	True	15	18	20	Knowledge continued to improve.
V31	Using objects, photographs and symbol systems for communication is known as unaided systems.	False	15	17	17	Knowledge maintained.
V32	The EasyTalk is an example of a voice output communication device.	True	14	18	20	Knowledge continued to improve slightly.

In summary, it can be seen that the aspects that were highlighted during the follow-ups resulted in knowledge increasing in 7 of the 15 areas (V19, V20, V23, V24, V25, V30 V32) and being maintained (V18, V31). Aspects not addressed during the follow-ups resulted in post-withdrawal knowledge declining, although the decline was mostly slight (V21, V22, V26, V27, V29) and not to a level below the pre-training score. When looking at each of these aspects in more detail, for questions V19 and V28 no changes were initially observed but a small gain was noted at the post-withdrawal. This might be due to the fact that such a high number of nurses had it correct pre-training, due to the fact that these concepts are familiar to them. The greatest knowledge improvement in this section was seen for V20 that dealt with the deliberate creation of communication opportunities. This improvement was sustained over the 5-months post-withdrawal phase which might be due to the fact that this is a new concept which was highlighted during training.

Afterwards the next knowledge question, namely the multiple-choice question was further examined. This question was presented in a matrix format, where nurses had access to the answers for all four questions. Firstly, a frequency analysis was done in order to look at all the different combinations that were given in an attempt to determine whether answers had been selected at random, indicating that nurses had guessed. In addition, this procedure also determined which coding system could be used, and if

marks had to be subtracted for incorrect answers. Results indicated that nurses did not mark answers at random, as a maximum of four was marked at any given time. This implies that there is not a dramatic overestimation of answers as there were three correct answers to the first two questions and two correct answers to the last two questions. A definite increase in the number of correct answers was seen during the post-training and post-withdrawal phases.

Results for the different correct multiple-choice answers across the different research phases are displayed in Table 5.4, providing information about the specific questions. Further testing on the individual questions was not done, as the total score was included in the prior section on which a Friedman tests was done. It is important to note that the first two questions (means and functions) had three correct answers while the last two (partners and temptations) had two correct answers each. A summary of the results is shown in Table 5.4.

**Table 5.4 Number of nurses who answered the multiple-choice questions correctly during the various research phases (n =20).**

No	Item description	Correct answer	Pre-training	Post-training	Post-withdrawal	Comments
M1	Communication means	Pointing	20	20	19	Slight decline. High frequency in all three phases.
M4	Communication means	Vocalisations / Sounds	19	10	15	Increase in post-withdrawal, but not to pre-training level.
M6	Communication means	Crying	13	13	13	No change in frequency throughout three phases.
F2	Communication function	Requesting interaction	6	14	9	Decline post-training, but not to pre-training level.
F3	Communication function	Requesting objects	3	16	10	Decline post-training, but not to pre-training level.
F9	Communication function	Indicating “ <i>thirsty</i> ”	4	1	1	Lower frequency post-training and post-withdrawal.
P5	Communication partner	Mother	14	18	19	Slight increase in post-withdrawal phase.
P10	Communication partner	Other children	15	20	19	Slight decline, but not to pre-training level.
T7	Communication temptation	Creative stupidity	-	8	3	Difficult aspect throughout.
T13	Communication temptation	Providing small portions	5	18	12	Decline post-withdrawal but better performance than pre-training.

In summary, it can be noted that with six of the ten items nurses performed better post-training; with two items no change was noted and with two items they performed, interestingly enough, poorer post-training. During the post-withdrawal phase scores remained consistent in some cases (M6, F9), increased in two cases (M4, P5) and slightly declined in other cases (M1, F2, F3, P10), but the decline was never to the level of pre-training. It is interesting to note that the post-withdrawal score was lower than the pre-training score for vocalisations (M4). This tendency is often seen when training individuals in the use of AAC strategies as they become so engrossed in the different AAC strategies that a tendency to “*forget*” about speech is often noted (Bornman & Alant, 1999; Bornman, Alant & Meiring, 2001). At the 5-month withdrawal phase, this score increased but not to the pre-training level. This might be indicative of the fact that

the focus is beginning to move towards including both speech (vocalisations) and AAC strategies when viewing communication means. Likewise, nurses performed poorer in the communication functions category of “*indicating thirsty*” during the post-training and post-withdrawal phases. This might be due to the fact that this aspect was not emphasised to the same extent during training as the other two functions mentioned in this question. It is therefore not surprising to note that major increases in knowledge are to be seen in this section. It is clear that post-training nurses were much more aware that requesting interaction (F2) and requesting objects (F3) were communication functions.

The term “*communication partners*” did not require as much demystifying as some of the other concepts. Pre-training, the majority of nurses were aware of the fact that the mother could be a partner (14) as could the other children (15). Despite this, the frequencies increased and all nurses were aware of the other children as partners (P10) and 18 were aware of the mother’s role (P5). Only a slight decline in both aspects was seen during the post-withdrawal phase.

Communication temptations remained the most difficult section to answer. It might be due to the fact that this concept was novel to participants and that more training regarding this aspect was required. Pre-training none could identify “*creative stupidity*” (T7), and only five could identify “*providing small portions*” (T13). These two concepts were practised at great length during training, consequently 18 could correctly identify “*providing small portions*” and 8 could identify “*creative stupidity*” post-training. Although a decline was seen during post-withdrawal, it was never to the pre-training level. It is interesting to note that these two items were trained to the same extent, but that the one yielded better results. This could possibly be because the term “*creative stupidity*” is more difficult (in spite of the fact the term was used during training) and the fact that “*providing small portions*” was trained first. In addition, “*providing small portions*” is very similar to its counterpart “*providing brief turns*” which in effect implies that nurses practised this strategy (albeit adapted) twice as much as they did “*creative stupidity*”.

The final phase in this section on prior knowledge deals with the ranking question aimed at determining the nurses' knowledge of representational levels. Four different elements were provided, i.e. identical objects, miniature objects, colour photographs and line drawings, e.g. PCS. Nurses had to rank these elements in terms of the level of representational difficulty, starting with the easiest and ending with the most difficult one. Results are summarised in Table 5.5.

**Table 5.5 Number of nurses who answered the ranking question correctly during the various research phases (n=20).**

Item description	Pre-Training	Post-training	Post-withdrawal	Comments
All four elements correct	-	7	6	Increase post-training, although only seven had it correct.
Two elements correct ( <i>Switching miniatures &amp; photographs</i> )	-	7	5	Tendency to change miniatures and photographs around frequently seen: as often as the correct answer.
Start with correct element ( <i>Identical objects</i> )	9	18	15	Better performance post-training. Majority knows what the easiest level of representation is.
First two elements correct ( <i>Identical objects &amp; miniatures</i> )	1	9	9	Better performance post-training. Almost half of participants have first two items correct. Knowledge maintained during post-withdrawal.
End with correct element ( <i>Line-drawings e.g. PCS</i> )	4	14	14	Improvement with training. Majority knows what the most difficult level of representation is. Knowledge maintained during post-withdrawal.

*These scores are not cumulative, and that each score is calculated out of 20.*

The ranking order that was used during training, and that was regarded as the “*correct answer*” (identical objects, miniature objects, colour photographs and line-drawings) is based on the typical practice of many AAC practitioners. This is based on the assumption that three-dimensional objects (3-D) are easier recognisable than two-dimensional objects (2-D) (Todd, 1993). As alluded to in Chapter 3, the levels of representation are complex and the assumptions made in developing programmes for CSDs should be examined in greater depth. However, in the present research nurses' correlation with the sequence used in training, was investigated. Results from Table 5.5

indicate that nurses gained from training, and were able to rank four different elements according to the level of representational difficulty. It should be noted that the number of nurses who could rank all four elements according to the taught sequence, is still low. The number who ranked it according to the taught sequence during the post-withdrawal phase remained fairly consistent. Todd (1993) suggests that 3-D elements are on a lower representational level (thus easier) than 2-D elements. However, it was interesting that in this research, just as many nurses as the ones who were in accordance with the taught sequence, changed miniature objects and photographs around. This might possibly be due to the fact that nurses were not as familiar with miniature objects as with photographs and the fact that the BCIP did not contain miniatures. As the 2-D element (photographs) might represent the real object more closely than a 3-D miniature element, the nurses might have assumed that photographs were on a lower representational level than miniatures. Due to the paucity of research in this area, and the fact that some researchers are beginning to question the hierarchical levels of these items, as highlighted in Chapter 3, this aspect should be further investigated (Fuller, Lloyd & Stratton, 1997). It is also recommended that the cultural impact on the ranking of representational skills should be further investigated. Post-training almost all the nurses knew what the easiest element was (in other words where training would start) and almost 50% could rank the first two elements in the taught sequence. This trend continued during the post-withdrawal phase. It is also evident that post-training, the nurses were more certain that line-drawings were on the highest level of representation of the available options.

In order to quantify the correctness of the answers provided, ranks of answers in the taught sequence were correlated with answers given, using Spearman's rank order correlation coefficient. This was done for the pre-training, post-training and post-withdrawal phases. Results are shown in Table 5.6.

**Table 5.6      Results obtained from the Spearman rank order correlation coefficient for each participant during the various research phases.**

PARTICIPANT	1	2	3	4	5	6	7	8	9	10
-------------	---	---	---	---	---	---	---	---	---	----

<b>Correlation pre-training</b>	-1.0	-0.8	0.6*	-0.4	-0.8	-1.0	0.6*	0.6*	-0.8	-0.4
<b>Correlation post-training</b>	0.6*	0.2*	-0.4	-0.4	-0.8	0.2*	0.2*	1.0*	1.0*	0.2*
<b>Correlation post withdrawal</b>	-0.8	1.0*	1.0*	-0.8	-0.5	0.2*	0.4*	1.0*	0.2*	0.2*
<b>PARTICIPANT</b>	<b>11</b>	<b>12</b>	<b>13</b>	<b>14</b>	<b>15</b>	<b>16</b>	<b>17</b>	<b>18</b>	<b>19</b>	<b>20</b>
<b>Correlation pre-training</b>	0.4*	-0.2	0.2*	-0.2	0.1	0.2*	-0.4	0.4*	-0.8	0.2*
<b>Correlation post-training</b>	1.0*	1.0*	1.0*	0.2*	1.0*	0.2*	-1.0	-0.8	0.2*	1.0*
<b>Correlation post withdrawal</b>	1.0*	0.8*	1.0*	1.0*	0.8*	0.2*	-0.2	0.8*	0.2*	-0.8

All variables indicating a positive correlation with the taught sequence were marked with an asterisk (\*)

The unusual correlation of 1.0 (indicating 100% correlation with the taught sequence) and -1.0 (indicating a total reversal of all elements) are due to the small number of items (four) which were ranked. Pre-training it is thus noted that two nurses had a score of -1.0, indicating a total reversal and none marked all the items correctly. However, during post-training seven nurses ranked the elements in agreement with the taught sequence while only one totally reversed the elements. This might possibly be due to the fact that the question was misread. During post-withdrawal six nurses ranked all the questions correctly with nobody totally reversing the elements.

A Friedman test was employed to determine whether the change in knowledge of representation levels was statistically significant over time. A p-value of 0.02 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.7 Friedman test of knowledge pertaining to representational levels**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>
<b>Rank sum</b>	29.5	44.5	46.0
<b>Mean</b>	-0.2	0.28	0.32
<b>Summary of results</b>			

Table 5.7 indicates a statistically significant difference (increase) of knowledge of representation levels at the 5% confidence level between the pre-training score (R<sub>1</sub>) and the post-withdrawal score (R<sub>3</sub>), as well as a statistically significant difference (increase) at the 10% confidence level for the pre-training (R<sub>1</sub>) and the post-training phase (R<sub>2</sub>). This implies that a greater difference was seen during the post-withdrawal phase, implying that knowledge continued to increase.

## ii) Applied knowledge

Apart from only determining the nurses' prior knowledge, their applied knowledge was also evaluated. This section is relevant to the present research as the nature of training was problem-based and thus directly impacted on their ability to apply knowledge to a particular case study. A Friedman test was employed to determine whether the change in global applied knowledge was statistically significant over time. A p-value of 0.001 was noted (p<0.05) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.8 Friedman test of applied knowledge**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	20.0	59.5	63.5	75.5	81.5
<b>Mean</b>	15.90	29.60	30.95	32.95	33.05
<b>Summary of results</b>					

Table 5.8 indicates a statistically significant difference (increase) of global applied knowledge at the 5% confidence level between the pre-training score (R<sub>1</sub>) and the post-

training score ( $R_2$ ), the two-week follow-up ( $R_3$ ), the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ) respectively.

The applied knowledge section consisted of two sections; the first pertains to the skills that nurses could identify in the particular case study and the second to recommendations they could make concerning this case. A description of these two sections with their detailed questions follows.

The first three questions of the applied knowledge dealt with a description of the current skills as displayed by the case study. A Friedman test was employed to determine whether the change in current skills was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.9      Friedman test of current skills depicted in the case study**

	<b><math>R_1</math></b>	<b><math>R_2</math></b>	<b><math>R_3</math></b>	<b><math>R_4</math></b>	<b><math>R_5</math></b>
<b>Rank sum</b>	24.0	56.0	64.0	79.5	76.5
<b>Mean</b>	6.55	9.20	9.60	10.25	10.35
<b>Summary of results</b>					

Table 5.9 indicates a statistically significant difference (increase) of current skills at the 5% confidence level between the pre-training score ( $R_1$ ) and the post-training score ( $R_2$ ), the two-week follow-up ( $R_3$ ), the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ) respectively.

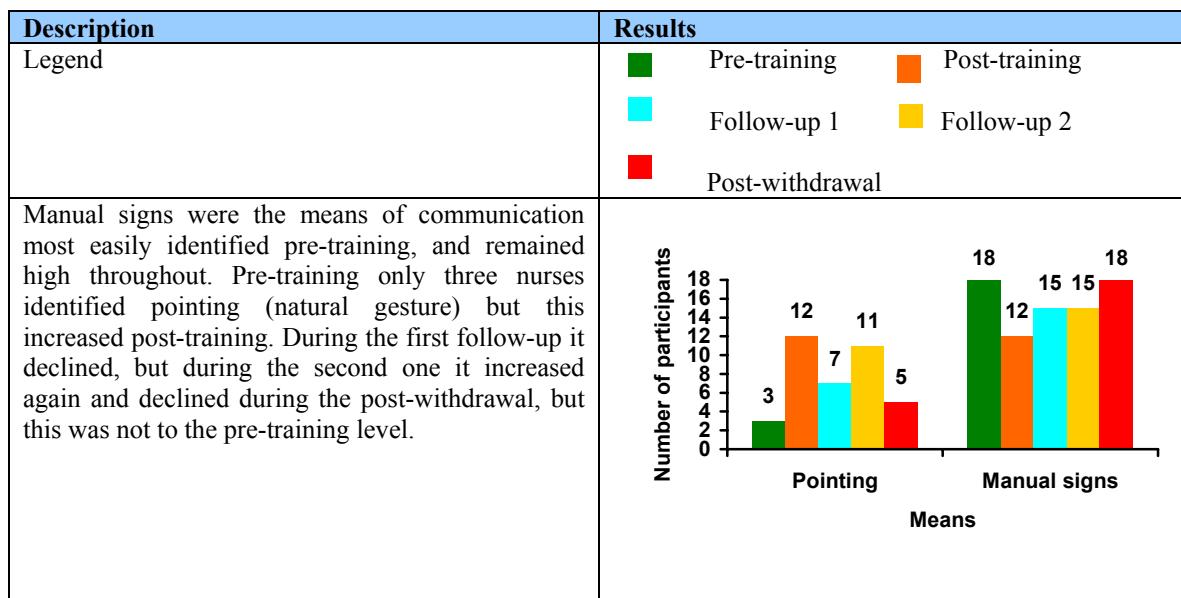
Each of these three questions will now be described in more depth. A Friedman test was employed to determine whether the change in communication means was statistically significant over time. A p-value of 0.007 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.10 Friedman test of identified communication means**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	36.0	54.5	65.5	67.5	67.5
<b>Mean</b>	2.55	3.35	3.60	3.65	3.95
<b>Summary of results</b>	<hr/>				

Table 5.10 indicates a statistically significant increase of communication means at the 5% confidence level between the pre-training score (R<sub>1</sub>) the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and post-withdrawal scores (R<sub>5</sub>) respectively.

In addition, frequencies were calculated for the different communication means over the various research phases. Results are shown in Table 5.11.

**Table 5.11 Frequency of communication means**

<p>The frequency of miming declined post-training. This is possibly due to the fact that nurses became more aware of other means of communication and they began to realise the limitations of miming. Participants' awareness of facial expressions decreased slightly, but then increased again. The frequency for both these communication means was noticeably lower than all the other means.</p>	<table border="1"> <thead> <tr> <th>Mean</th> <th>Green</th> <th>Orange</th> <th>Red</th> </tr> </thead> <tbody> <tr> <td>Miming</td> <td>5</td> <td>1</td> <td>2</td> </tr> <tr> <td>Facial expressions</td> <td>2</td> <td>1</td> <td>2</td> </tr> </tbody> </table>	Mean	Green	Orange	Red	Miming	5	1	2	Facial expressions	2	1	2						
Mean	Green	Orange	Red																
Miming	5	1	2																
Facial expressions	2	1	2																
<p>The greatest increase was seen in this section. Pre-training only six participants identified vocalisations as a communication means and during Follow-up 2 all the nurses had this correct. The increase in knowledge pertaining to speech increased in a step-like fashion, reaching its peak during the post-withdrawal phase.</p>	<table border="1"> <thead> <tr> <th>Mean</th> <th>Phase 1 (Green)</th> <th>Phase 2 (Orange)</th> <th>Phase 3 (Cyan)</th> <th>Phase 4 (Yellow)</th> <th>Post-withdrawal (Red)</th> </tr> </thead> <tbody> <tr> <td>Vocalisations</td> <td>6</td> <td>18</td> <td>19</td> <td>20</td> <td>18</td> </tr> <tr> <td>Speech</td> <td>10</td> <td>10</td> <td>14</td> <td>14</td> <td>20</td> </tr> </tbody> </table>	Mean	Phase 1 (Green)	Phase 2 (Orange)	Phase 3 (Cyan)	Phase 4 (Yellow)	Post-withdrawal (Red)	Vocalisations	6	18	19	20	18	Speech	10	10	14	14	20
Mean	Phase 1 (Green)	Phase 2 (Orange)	Phase 3 (Cyan)	Phase 4 (Yellow)	Post-withdrawal (Red)														
Vocalisations	6	18	19	20	18														
Speech	10	10	14	14	20														
<p>An increase in knowledge following training was seen. This knowledge continued to increase during the first follow-up, declined slightly during the second follow-up and increased again during the post-withdrawal phase.</p>	<table border="1"> <thead> <tr> <th>Mean</th> <th>Phase 1 (Green)</th> <th>Phase 2 (Orange)</th> <th>Phase 3 (Cyan)</th> <th>Phase 4 (Yellow)</th> <th>Post-withdrawal (Red)</th> </tr> </thead> <tbody> <tr> <td>Use of objects</td> <td>8</td> <td>13</td> <td>17</td> <td>13</td> <td>15</td> </tr> </tbody> </table>	Mean	Phase 1 (Green)	Phase 2 (Orange)	Phase 3 (Cyan)	Phase 4 (Yellow)	Post-withdrawal (Red)	Use of objects	8	13	17	13	15						
Mean	Phase 1 (Green)	Phase 2 (Orange)	Phase 3 (Cyan)	Phase 4 (Yellow)	Post-withdrawal (Red)														
Use of objects	8	13	17	13	15														

It is therefore clear that the total number of communication means correctly identified by the nurses increased from 52 (pre-training), to 67 (post-training), 72 (Follow-up 1) 73 (Follow-up 2) and 79 (post-withdrawal). It can thus be said that the BCIP training not only made nurses more aware of the different communication means, but also of the range of these means.

The second question dealt with **communication functions**. A Friedman test was employed to determine whether the change in communication functions was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.12 Friedman test of identified communication functions**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	29.5	58.0	64.0	79.0	69.5
<b>Mean</b>	2.00	2.90	3.20	3.70	3.40
<b>Summary of results</b>					

Table 5.12 indicates a statistically significant difference (increase) of communication functions at the 5% confidence level between the pre-training score ( $R_1$ ), the post-training score ( $R_2$ ), the two-week follow-up ( $R_3$ ), the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ) respectively.

When investigating the nature of the change that had taken place regarding the communication functions that community health nurses could correctly identify in the case study, interesting tendencies were noted. Frequencies are given in Table 5.13.

**Table 5.13 Communication functions identified by nurses**

No	Function	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
V15	Expressing wants and needs	6	9	15	12	2
V16	Expressing emotions	2	3	1	-	-
V17	Drawing attention to self	3	7	15	20	17
V18	Requesting interaction	4	4	1	-	2
V19	Requesting objects	3	6	5	5	7
V20	Protesting	2	-	-	1	-
V21	Affirmation	10	15	17	19	20
V22	Naming	-	3	-	3	1
V23	Showing politeness	-	-	1	-	-
No	Function	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
V24	Greeting	5	2	-	2	3
V25-1	Indicating "finished"	5	3	7	8	13

V25-2	Requesting help	2	3	1	4	2
V25-3	Requesting more	-	2	1	-	7
V25-4	Making choices	-	2	-	-	-
	<b>TOTAL</b>	<b>42</b>	<b>59</b>	<b>64</b>	<b>74</b>	<b>72</b>

From Table 5.13 it is clear that nurses became more aware of the different communication functions as the total number of responses increased from 42 to 74. The fact that this total score continued to increase could be possibly be attributed to the fact that communication functions were addressed throughout the BCIP training (including the follow-ups). Nurses also became much more aware of the range of communication functions. Low pre-training scores were noted throughout, with V21 (*affirmation*) and V15 (*expressing wants and needs*) most frequently mentioned. This might possibly be due to the fact that these are the two best-known communication functions. V15 (*expressing wants and needs*) decreased as did V16 (*expressing emotions*), as these aspects were not stressed during training. However, *requesting help* (V25-2), *requesting more* (V25-3), *drawing attention to self* (V17) and *affirmation* (V21) which were stressed during training, continued to increase.

Finally, the third question dealt with **communication partners**. A Friedman test was employed to determine whether the change in communication partners was statistically significant over time. A p-value of 0.0058 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

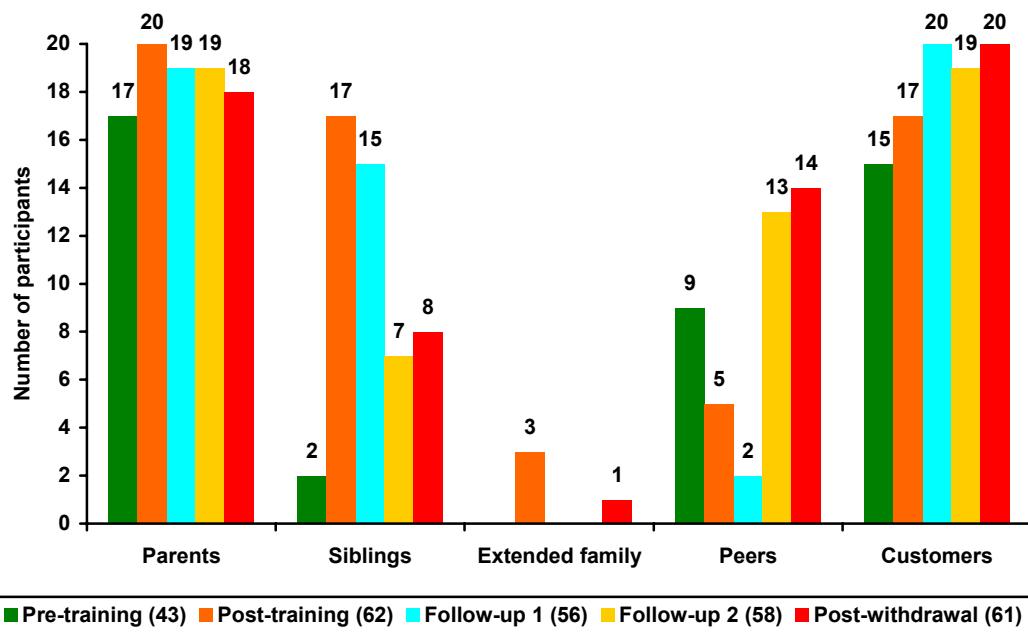
**Table 5.14 Friedman test of identified communication partners**

	R <sub>1</sub>	R <sub>3</sub>	R <sub>4</sub>	R <sub>2</sub>	R <sub>5</sub>
<b>Rank sum</b>	36.5	61.5	66.0	66.0	70.0
<b>Mean</b>	2.00	2.80	2.90	2.95	3.00
<b>Summary of results</b>					

Table 5.14 indicates a statistically significant difference (increase) of communication partners at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training

score ( $R_2$ ), the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ) respectively. No statistical significance between  $R_1$  and  $R_3$  (two-week follow-up), was noted.

Frequencies were then calculated in order to determine which communication partners were easier to identify in the given case study. Results are seen in Figure 5.3.



**Figure 5.3 Communication partners**

The two partners rated as highest throughout were the primary caregivers and the customers. Post-training it also became clear that the nurses were more aware of the importance of siblings as partners. Although this frequency decreased over time, the post-withdrawal score was still higher than the pre-training score. The role of peers also became more important, although a low frequency was noted during the post-training and Follow-up 1 phases. This might be due to the strong focus on siblings during these phases. The total number of responses increased from pre-training (43) to the post-training (62) and then declined again, but not to the pre-training level. Frequencies then increased again from Follow-up 1 (56), to Follow-up 2 (58) to post-withdrawal (61), but the highest score was seen directly post-training.

After having analysed and discussed the first section of the applied knowledge that dealt with the identification of current skills of the case study, the second section of applied knowledge that deals with recommendations for the particular case study will now be discussed. Five questions in this section were combined to obtain the combined recommendation score. A Friedman test was employed to determine whether the change in combined recommendations was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.15 Friedman test of combined recommendations**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	20.5	58.5	67.5	71.5	82.5
<b>Mean</b>	5.95	15.60	16.75	17.80	18.20
<b>Summary of results</b>					

Table 5.15 indicates a statistically significant difference (increase) of combined recommendations at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>) respectively.

Each of the five questions pertaining to communication means, functions, partners, communication opportunities and general advice was subsequently analysed in depth for the different research phases.

During the structured interview (Response Form I) nurses were asked which different communication means the particular child in the case study could still learn. It was clear from the range of answers that their knowledge in this regard had increased. See Table 5.16 for details.

**Table 5.16 Communication means**

No	Communication means	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
<b>1</b>	<b>UNAIDED COMMUNICATION MEANS</b>					
1a	Speech	11	8	3	9	13
1b	Crying	1	-	-	-	-
1c	Facial expressions	-	4	4	8	8
1d	Head-nodding and head-shaking	-	6	9	11	11
1e	Eye-gaze and pointing	2	9	9	13	11
1f	Body language and miming	3	2	7	6	5
1g	Manual signs	11	18	19	18	19
<b>2</b>	<b>AIDED COMMUNICATION MEANS</b>					
2a	Objects / Object communication box	3	11	10	13	15
2b	Miniature objects	-	5	1	-	-
2c	Photographs	-	11	4	7	8
2d	Pictures	1	-	2	4	9
2e	Line-drawings and communication boards	-	8	2	7	10
2f	EasyTalk 4 Option digital speaker	-	6	10	8	11
2g	Drawing / Writing	9	2	3	2	1
3	“Don’t know” or incorrect, unrelated answers	4				
4	More than five correct answers	-	2	-	10	11
	<b>TOTAL</b>	<b>46</b>	<b>90</b>	<b>83</b>	<b>66</b>	<b>121</b>

Table 5.16 indicates that nurses became much more aware of the different communication means that can be used as the total number of correct responses increased from 46 to 121! It is also evident that pre-training the focus was on more well-known unaided strategies (speech and manual signs). A few aided strategies were mentioned, with the emphasis on drawing and writing. Post-training a wider distribution of different means was noted. The communication means mentioned in 50% or more of the cases were speech, head-nodding, eye-gaze, pointing and manual signs, while the aided means were objects, communication boards and the EasyTalk 4 Option digital speaker. Drawing and writing decreased. This was possibly due to the fact that nurses became aware of the fact that these means are not appropriate for CSDs. Finally, it is also important to note that the number of incorrect answers disappeared and that the number of nurses who had five items or more correct increased to 50% during Follow-up 2 and 55% during the post-withdrawal phase.

These results were then further analysed to test for statistical significance. A Friedman test was employed to determine whether the change in recommended communication

means was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.17 Friedman test of recommended communication means**

	R <sub>1</sub>	R <sub>3</sub>	R <sub>2</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	27.5	57.0	68.0	74.5	73.0
<b>Mean</b>	2.25	4.20	4.70	4.90	4.85
<b>Summary of results</b>					

Table 5.17 indicates a statistically significant difference (increase) of recommended communication means at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>) respectively.

Secondly, the nurses were asked which different **communication functions** the particular child in the case study could still learn (Response Form I). It was clear from the range of answers that their knowledge in this regard had increased. See Table 5.18 for details.

**Table 5.18 Communication functions**

No	Communication functions	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
1	Don't know	4	-	-	-	-
2	Incorrect, unrelated answer e.g. "speech therapy"	9	-	1	1	-
3	Greeting	-	7	4	7	5
4	Expressing basic needs	8	1	6	1	-
5	Expressing emotions, e.g. pain	1	-	2	-	-
6	Requesting help	2	16	15	18	18
7	Requesting "more"	-	14	20	19	19
8	Labelling	4	7	5	10	13
9	Making choices	-	10	13	11	13
10	Protesting	1	11	11	18	17
11	Confirming	-	5	5	8	12
12	Asking yes/no questions	-	-	1	6	-
13	Drawing attention to self	2	9	5	11	9
14	Showing humour and surprise	-	7	-	7	12
15	Indicating finished	-	-	-	1	-
	<b>TOTAL</b>	<b>31</b>	<b>87</b>	<b>88</b>	<b>117</b>	<b>118</b>

As with the previous table, the number of “*don't know*” answers disappeared, the number of incorrect answers decreased and the number of correct answers increased from 31 (pre-training) to 118 (post-withdrawal). As previously mentioned, the range of correct answers also increased. In addition, answers also tended to be based on the BCIP training as the communication functions highlighted during training (e.g. no 6 – 14) increased whereas greetings (no 3), expressing basic needs (no 2) and expressing pain (no 5) decreased despite the fact that they were correct. The most noticeable difference was seen in number 7 (requesting more) which changed from 0 to 19, protesting (no 10), confirmation (no 11) and showing humour and surprise (no 14). Scores obtained during the post-training and Follow-up 1 phases correlate closely (there was an interval of two weeks between them). There was a noticeable increase between Follow-up 1 and Follow-up 2 (with an interval of four weeks), which was maintained over the five month period (post-withdrawal).

A Friedman test was employed to determine whether the change in recommended communication functions was statistically significant over time. A p-value of 0.001 was

noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.19 Friedman test of recommended communication functions**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	25.5	59.0	69.0	75.0	71.5
<b>Mean</b>	1.30	3.95	4.25	4.55	4.50
<b>Summary of results</b>					

Table 5.19 indicates a statistically significant difference (increase) of recommended communication functions at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>) respectively.

Thirdly, a question pertaining to recommendations regarding **communication partners** (Response Form I) when nurses were asked how the number of communication partners for the particular child in the case study could be increased. It was clear from the range of answers that their knowledge in this regard had increased. See Table 5.20 for details.

**Table 5.20 Communication partners**

No	Communication partners	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
1	Send CSD to a special school	4	1	2	3	3
2	Send CSD to a mainstream school/creche	10	16	16	15	16
3	Take CSD on outings, e.g. shops, sports, park, vacation	5	4	4	7	9
4	Take CSD to church / Sunday school	2	12	13	8	10
5	Take CSD to PHC clinic and therapists	2	3	3	2	2
6	Arrange parent support groups	1	-	1	1	1
7	Educate community about disability	2	-	-	1	-
8	Encourage social participation: invite children to come and play	11	18	17	16	16
9	Educate neighbours and customers to accept CSD	3	8	5	13	11
10	Educate extended family	4	8	7	6	7
11	Train siblings	1	3	4	1	2
12	Find helper to look after the CSD	-	3	1	-	-
13	Have an imaginary birthday party and invite friends	-	5	5	5	10

No	Communication partners	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
	<b>TOTAL</b>	<b>45</b>	<b>81</b>	<b>78</b>	<b>78</b>	<b>87</b>

During the various research phases nurses became more aware of methods that could be employed to increase the number of communication partners. This is evident from the total number of options that increased from 45 (pre-training) to 87 (post-withdrawal) as well as from the wider range of answers. Emphasis was placed on social inclusion (e.g. “invite other children to play”, “take CSD on an outing”, “take CSD to church” and “have an imaginary birthday party”). The latter aspect was mentioned during training and is indicative of the power of using examples in training to facilitate knowledge, provided that participants can identify with the example. Nurses also became more aware of the importance of training others (e.g. neighbours, customers, siblings and extended family) in order to enable them to act as communication partners.

As with the other questions, a Friedman test was employed to determine whether the change in recommended communication partners was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results are shown below.

**Table 5.21 Friedman test of recommended communication partners**

	R <sub>1</sub>	R <sub>3</sub>	R <sub>2</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	30.5	63.0	68.5	61.0	77.0
<b>Mean</b>	2.40	3.90	4.05	3.90	4.35
<b>Summary of results</b>					

Table 5.21 indicates a statistically significant change (increase) of recommended communication partners at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>) respectively.

The fourth question dealt with how the number of deliberate communication opportunities given to the child in the particular case study (Response Form I) could be increased. It was clear from the range of answers that their knowledge in this regard increased. See Table 5.22 for details.

**Table 5.22 Increasing communication opportunities**

No	Communication opportunities	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
1	Take CSD on outings, e.g. zoo, church, etc.	7	-	-	-	-
2	Informal social integration, e.g. play with friends, visit relatives	8	3	-	-	-
3	Take CSD to special school	2	-	-	-	-
4	Take CSD to mainstream school/crèche	1	1	-	-	-
5	Take CSD to health clinic	3	-	-	-	-
6	Provide stimulation e.g. books	4	2	1	-	-
7	Take part in daily household activities	6	-	-	-	-
8	Be patient and appreciate communication attempts	1	-	-	-	-
9	Provide materials in small portions	1	9	19	19	18
10	Provide brief turns in activity	1	4	7	9	6
11	Deliberately provide incorrect item	-	9	11	18	15
12	Select materials that require assistance	-	5	11	11	12
13	Make items inaccessible	-	12	16	17	15
14	Provide choices	-	5	11	13	14
15	Ask yes/no questions	-	2	3	8	9
16	Deliberately withhold attention	-	9	7	11	9
17	Violate expectations	-	6	7	11	13
18	Use different communication means	-	1	1	-	-
19	Teach greeting skills	-	2	-	2	-
<b>TOTAL</b>		<b>39</b>	<b>70</b>	<b>98</b>	<b>119</b>	<b>111</b>

Table 5.22 indicates that a shift had taken place from generalised statements that were provided pre-training (no 1 – 8) to more specific answers (no 9 – 19) post-training. It is also interesting to note that as nurses had the opportunity to practise using the BCIP (during the follow-up and post-withdrawal phases) their knowledge regarding the creation of deliberate communication opportunities through the use of communication temptations, continued to increase. Although all the communication opportunities addressed during the BCIP training were mentioned by participants, this was not done to the same extent. Some strategies were mentioned more frequently during all the phases

(e.g. “providing small portions” and “making items inaccessible”). This might possibly be due to the fact that nurses could identify better with these strategies, while others (e.g. “asking yes/no questions”) were more difficult.

A Friedman test was employed to determine whether the change in recommended communication opportunities was statistically significant over time. A p-value of 0.001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.23 Friedman test of recommended communication opportunities**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>5</sub>	R <sub>4</sub>
<b>Rank sum</b>	22.5	48.0	76.0	76.0	77.5
<b>Mean</b>	0.00	2.90	4.40	4.50	4.45
<b>Summary of results</b>					

Table 5.23 indicates a statistically significant difference (increase) of recommended communication opportunities at the 5% confidence level between the pre-training score (R<sub>1</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>) respectively, as well as between the post-training score (R<sub>2</sub>) and the post-withdrawal score (R<sub>5</sub>).

Finally, the nurses’ applied knowledge could also be seen in the advice that was given following the case studies as presented in Response Form I. Advice given to the mother of the particular child with a disability as depicted in the various case studies is shown in Table 5.24.

**Table 5.24 Advice given following a particular case study**

No	Advice	Pre-training	Post-training	Follow-up 1	Follow-up 2	Post-withdrawal
1	Referral (hospital, therapists, social worker, genetic counselling)	19	1	-	-	2
2	Refer to special school	7	3	1	3	2

3	Refer to mainstream school / crèche	1	5	7	11	9
4	Provide medical treatment	2	1	-	-	1
5	Counsel caregivers on acceptance	14	4	4	3	6
6	Discuss basic communication skills (e.g. talk slowly)	10	5	7	9	10
7	Expand on communication means	-	28	30	14	15
8	Stimulate communication functions	-	16	1	12	9
9	Use all possible communication opportunities (including toys, etc.)	1	3	4	8	6
10	Employ communication temptations	-	12	7	5	2
11	Increase social interaction, e.g. get other children to come and play	11	11	14	23	27
12	Employ helper so that mother has more time available	2	3	10	9	-
13	Increase independence	-	4	2	1	1
<b>TOTAL</b>		<b>67</b>	<b>96</b>	<b>87</b>	<b>98</b>	<b>90</b>

Please note that some scores are higher than 20. This is due to the fact that some aspects were grouped together, e.g. no 7 (manual signs, EasyTalk, objects, etc).

From Table 5.24 it is thus clear that nurses became more aware of advice that could be given, as seen in their total scores. Pre-training advice tended to be general (e.g. “*counsel caregivers on acceptance*”). Post-training the advice given tended to become more specific in nature (e.g. “*increasing communication means*” and “*increasing social interaction*”). Generally they also tended to become more aware of the importance of referral to a mainstream school (referral to special schools decreased). The decline in “*referral*” over the various research phases is also interesting. This could possibly be due to the fact that nurses became more empowered and confident in their service delivery to CSDs.

A Friedman test was employed to determine whether the change in advice given was statistically significant over time. A p-value of 0.0004 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.25 Friedman test of advice given**

	R <sub>1</sub>	R <sub>5</sub>	R <sub>3</sub>	R <sub>2</sub>	R <sub>4</sub>
<b>Rank sum</b>	34.0	57.0	64.0	71.5	73.5
<b>Mean</b>	3.40	4.52	4.60	4.81	4.93
<b>Summary of results</b>					

Table 5.25 indicates a statistically significant difference (increase) of advice given at the 5% confidence level between the pre-training score ( $R_1$ ), the post-training score ( $R_2$ ), the two-week follow-up ( $R_3$ ) and the six-week follow-up ( $R_4$ ), respectively. It is interesting to note that this was the only section in the complete applied knowledge section where there was no statistically significant difference between the pre-training score ( $R_1$ ) and the post-withdrawal score ( $R_5$ ). This might be due to the fact that this aspect was not directly trained, and that nurses had to integrate and apply knowledge in order to answer this question successfully.

### 5.3.1.2 Skills

Results for this section was obtained from data recorded on Response Form I, Section 3 (Questions 3.1 - 3.3). This questionnaire was administered at five different intervals, and was scored by two independent raters throughout. As already discussed in Section 5.2.1, a 96% inter-rater reliability was noted throughout and consequently only scores attributed by Rater 1, the main researcher, was used. A Friedman test was employed to determine whether the change in combined skills was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.26 Friedman test of combined skill areas**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	20.0	50.0	61.5	84.5	84.0
<b>Mean</b>	32.80	58.65	62.15	70.80	70.95
<b>Summary of results</b>					

Table 5.26 indicates a statistical significant difference (increase) of combined skills at the 5% confidence level between the pre-training score ( $R_1$ ), the post-training score ( $R_2$ ), the two-week follow-up ( $R_3$ ) and the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ), respectively. Results also indicated a statistical significant increase at the 5%

confidence level between the post-training score ( $R_2$ ) and the six-week follow-up ( $R_4$ ) and the post-withdrawal scores ( $R_5$ ), respectively. This implies that skills increased statistically significantly during the follow-up phases when compared to pre-training and post-training. This emphasises the importance of follow-ups in skills development. Each of the skills aspects will now be described in detail.

**i) Skill in representational level grading**

A Friedman test was employed to determine whether the change in representational level grading was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.27 Friedman test of skill in representational level grading**

	<b>R<sub>1</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>5</sub></b>	<b>R<sub>4</sub></b>
<b>Rank sum</b>	2.05	3.30	3.35	3.75	3.80
<b>Mean</b>	21.5	60.0	61.0	77.5	80.0
<b>Summary of results</b>					

Table 5.27 indicates a statistical significant difference (increase) of representational level grading at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively. This is viewed as an important skill as it indicates the level at which training should start.

## ii) Skill in using objects for communication

A Friedman test was employed to determine whether the change in using objects for communication was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.28 Friedman test of skill in using objects for communication**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	20.0	58.0	69.5	74.5	78.0
<b>Mean</b>	7.75	12.95	13.55	13.85	13.80
<b>Summary of results</b>					

Table 5.28 indicates a statistically significant difference (increase) in using objects for communication at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively.

### iii) Skill in using photographs for communication

A Friedman test was employed to determine whether the change in using photographs for communication was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.29 Friedman test of skill in using photographs for communication**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>5</sub>	R <sub>4</sub>
<b>Rank sum</b>	21.0	58.0	63.0	78.0	80.0
<b>Mean</b>	6.25	12.70	12.55	13.50	13.80
<b>Summary of results</b>					

Table 5.29 indicates a statistically significant difference (increase) in using objects for communication at the 5% confidence level between the pre-training score (R<sub>1</sub>), the post-training score (R<sub>2</sub>), the two-week follow-up (R<sub>3</sub>) the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively.

### iv) Skill in using communication boards

A Friedman test was employed to determine whether the change in using communication boards for communication was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.30 Friedman test of skill in using communication boards**

	<b>R<sub>1</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	31.5	49.5	55.0	80.5	83.5
<b>Mean</b>	5.65	8.70	9.15	12.20	12.25
<b>Summary of results</b>					

Table 5.30 indicates a statistically significant difference (increase) in using communication boards for communication at the 5% confidence level between the pre-training score (R<sub>1</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal score (R<sub>5</sub>), and also between the post-training score (R<sub>2</sub>) and the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively.

#### v) Skill in using manual signs for communication

A Friedman test was employed to determine whether the change in using manual signs for communication was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.31 Friedman test of skill in using manual signs for communication**

	<b>R<sub>1</sub></b>	<b>R<sub>2</sub></b>	<b>R<sub>3</sub></b>	<b>R<sub>4</sub></b>	<b>R<sub>5</sub></b>
<b>Rank sum</b>	26.5	52.0	60.0	77.0	84.5
<b>Mean</b>	6.00	10.15	11.55	13.35	14.00
<b>Summary of results</b>					

Table 5.31 indicates a statistically significant difference (increase) in using manual signs for communication at the 5% confidence level between the pre-training score (R<sub>1</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively, and also between the post-training score (R<sub>2</sub>) and the post-withdrawal scores (R<sub>5</sub>).

**vi) Skill in using the EasyTalk 4 Option digital speaker for communication**

A Friedman test was employed to determine whether the change in using the EasyTalk 4 Option digital speaker for communication was statistically significant over time. A p-value of 0.0001 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

**Table 5.32 Friedman test of skill in using the EasyTalk 4 Option digital speaker for communication**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>5</sub>	R <sub>4</sub>
<b>Rank sum</b>	24.5	52.5	65.5	79.5	78.0
<b>Mean</b>	5.10	10.35	12.50	13.80	13.65
<b>Summary of results</b>					

Table 5.32 indicates a statistically significant difference (increase) in using the EasyTalk 4 Option digital speaker for communication at the 5% confidence level between the pre-training score (R<sub>1</sub>), the two-week follow-up (R<sub>3</sub>), the six-week follow-up (R<sub>4</sub>) and the post-withdrawal scores (R<sub>5</sub>), respectively. In addition a statistically significant difference (increase) at the 10% confidence level was noted between the pre-training score (R<sub>1</sub>) and the post-training score (R<sub>2</sub>), as well as between the post-training score (R<sub>2</sub>) and the six-week follow-up score (R<sub>4</sub>).

**vii) Dependence on prompts**

A Friedman test was employed to determine whether the frequency of prompts given to nurses changed statistically significantly over time. A p-value of 0.076 was noted ( $p<0.05$ ) indicating no statistical significance. This implies that the number of prompts remained consistent over time despite the initial hypothesis that the number of prompts will be reduced as nurses' skills increased. It would thus appear that they were dependant

on prompts in order to demonstrate their skills. On the other hand, it is also reassuring to note that the increase in skills that was noted was not due to an increase in prompts.

### viii) Confidence in facilitating communication

A Friedman test was employed to determine whether the change in the nurses' confidence in facilitating communication was statistically significant over time. A p-value of 0.0154 was noted ( $p<0.05$ ) implying that multiple comparisons were required to test the nature of the significance. A summary of these results is shown below.

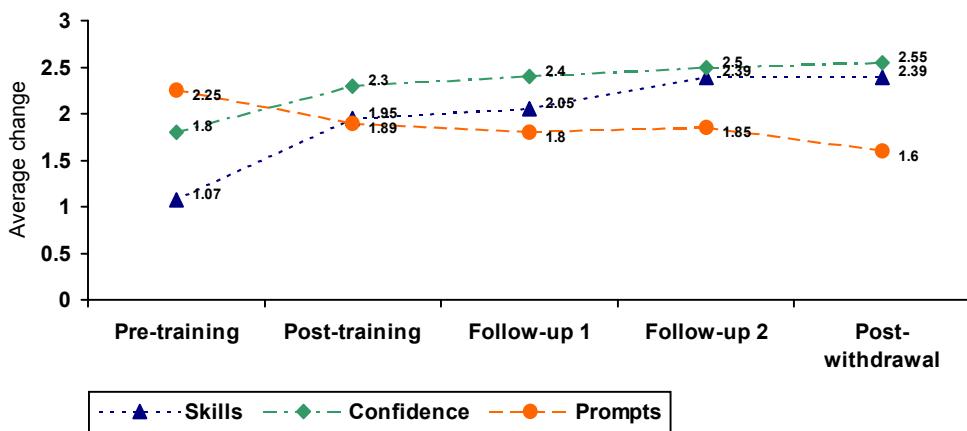
**Table 5.33 Friedman test of confidence in facilitating communication**

	R <sub>1</sub>	R <sub>2</sub>	R <sub>3</sub>	R <sub>4</sub>	R <sub>5</sub>
<b>Rank sum</b>	36.5	56.5	61.5	63.5	67.0
<b>Mean</b>	1.79	2.26	2.42	2.47	2.53
<b>Summary of results</b>	<hr/>				

Table 5.33 indicates a statistically significant difference (increase) in confidence at the 5% confidence level between the pre-training score (R<sub>1</sub>) and the post-withdrawal score (R<sub>5</sub>), and between the pre-training score (R<sub>1</sub>) and the six-week follow-up score (R<sub>4</sub>) at the 10% confidence level. This factor, as well as the increase in the rank sums and means, implies that the nurses' confidence continued to increase over time as their knowledge and skills increased.

### ix) Summary of skills

The statistically significant increase in the nurses' skills together with a description of their confidence in demonstrating these skills and the amount of prompting required to demonstrate these skills. Results are shown in Figure 5.4.



**Figure 5.4 Change in skills, confidence and prompts**

It is clear from Figure 5.4 that the nurses' skills initially increased noticeably and then remained consistent during the last two phases. After the noticeable first increase in confidence, the next increases were more gradual. A plateau was not reached, indicating that as skills continued to increase confidence also continued to increase. Regarding the amount of prompting that was initially required, nurses became less dependent on prompts. For the second follow-up, however, they required slightly more prompts than during the first follow-up but this declined again during the post-withdrawal period. During the pre-training phase nurses' dependence on prompts was higher than their confidence and skills, this changed post-training.

### 5.3.2 Secondary outcomes

Secondary outcomes pertain to those aspects not directly trained, but which changed during the course of the research, and that could possibly be attributed to the BCIP training. The aspects that will be described include attitudes, exposure and service delivery as well as a reflective self-evaluation by the nurses. These aspects were briefly described in Chapter 4, Table 4.17. The results pertaining to each of these aspects will now be described in detail.

#### 5.3.2.1 Attitudes

This section was compiled from data recorded on Response Form II, which was administered at three different intervals. Although it was not expected that attitudes would change over the weeklong training period, it was decided to keep the measuring instrument consistent and not to make any changes to it. Due to the “*halo effect*” where participants are aware of the high social desirability of certain answers, quantitative measurements are not always the most appropriate (Guy *et al.*, 1987). Consequently qualitative measurements were included to augment information about the participants’ attitude towards disability. A focus group was selected as the means of data collection as they allowed participants to share ideas and thoughts (Brink, 1999). A summary of this focus group is provided in Table 5.34.

**Table 5.34 Focus group with community nurses post-training and follow-ups**

Category	Description
Participants	Seventeen of the 20 community health nurses who participated in the research attended the focus group. Three were absent with valid excuses. As they had attended the training together and therefore knew each other, rapport was quickly established, and the group was experienced as non-threatening which was evident from the quality of the answers. The researcher/trainer facilitated the focus group. The audio recording was made by the research assistant who had been actively involved in the whole training period (five months), with the result that she was not seen as a threat to the group. It is also important to note that the research assistant did not actively participate in the discussion.
Aims	To determine how the BCIP training impacted on the attitudes of community nurses and the services rendered by them, three open-ended interview questions were used, namely: i) How did your experience in this training change what you do in the workplace

Category	Description
	<p>with primary caregivers and CSDs?</p> <p>ii) What in particular did you enjoy about the training?</p> <p>iii) What did you not enjoy about the training?</p>
<b>Method</b>	<p>The focus group was conducted in a semi-structured discussion of the questions and clarification was asked if concepts were unclear or open to misinterpretation (Krefting, 1991). Nurses were encouraged to participate actively, to share their experiences, to evaluate the training and to understand that no comments would discredit them. As the researcher knew what the three most important questions were and that flexibility was allowed in terms of sequence and discussion, she was able to listen, observe and respond to what she saw and heard, thereby maintaining structural coherence of the topic, increasing credibility (Krefting, 1991). In an attempt to enhance trustworthiness, member checks were included. This entailed that the researcher gave a short summary at the end of the discussion of each of the three questions, asking participants whether they agreed or disagreed and if any important issues raised were overseen.</p> <p>The researcher and the research assistant (who had gained substantial knowledge and insight into nursing and the field of severe disability over her five-months involvement period) spent some time debriefing directly after the focus groups to discuss interpretations and to note the major issues that were raised. No areas that needed additional probing or clarification were noted. As described in Chapter 4, debriefing is an important part of investigator triangulation and was included to heighten the credibility of the data obtained (Brotherson &amp; Goldstein, 1992).</p> <p>Audio recordings were used to make verbatim transcriptions of the focus group that lasted 54 minutes.</p>
<b>Analysis</b>	<p>The researcher delineated themes and came to tentative conclusions. Transcriptions were then handed to an independent expert in the field of severe disability and qualitative research and she was also asked to delineate themes (peer debriefing). This independent and separate coding and cross-checking of data increases analytic stability (Goldberg, 1993). In order to address this, both researchers received a set of coding guidelines pertaining to the content and the analytic procedure, e.g. the initial questions as well as the decision rules for determining the categories. This aspect is discussed in detail in Chapter 4. Following the development of the themes the researcher and the independent expert met to review the theme analysis with a request for verification, correction, clarification and/or elaboration of tentative conclusions drawn from the data analysis, ensuring credibility. Apart from only obtaining significant and consistent themes in the data it is also rich in providing illustrative examples.</p>
<b>Results</b> <b>Results (continued)</b>	<p>A summary of the themes delineated from this focus group is presented in <b>Appendix P</b>. Two main themes emerged, the first pertaining to service delivery and the second to an evaluation of the training. It is important to note that responses were genuine and honest. Some admitted to having tried to dodge the researcher initially and of being apprehensive about the course before it commenced. Nurses also spoke from their own experiences and were keen to relate the impact that the training had had on them as individuals.</p> <p>A number of issues related to service delivery were noted, namely attitudes, new knowledge that was gained, the role of the nurse and other multi-skilling issues, job satisfaction and a strong focus on social inclusion and caregiver involvement. It is noteworthy that a variety of outcomes were achieved, despite the fact that the training focus was on knowledge and skills. It was clear that the new knowledge and skills impacted positively on how they viewed their own skills and the way this pride impacted on their job satisfaction “<i>but now I know that I can work with them</i>”. It also became clear that they were more aware of the role the nurse, together with the caregivers, played in the training of CSDs. They also stated that they felt better equipped to work with caregivers and to provide them with training and guidance. In addition, a strong focus on the social inclusion of CSDs was noted, e.g. “<i>they</i></p>

Category	Description
	<p><i>should be included in the community and accepted.”</i></p> <p>Regarding the evaluation of training, a number of areas were covered. Firstly, the content of the training was discussed, and everyone felt that the most important aspects were covered during the BCIP training. It is also interesting that different nurses remembered different aspects that they particularly enjoyed, e.g. communication temptations or making object communication boards, etc. However, the two aspects that they all had in common was their enjoyment of using manual signs from SASL and the EasyTalk. On the whole nurses also enjoyed the particular training method that was used, and stated that they could identify with the case studies. In addition these case studies assisted them with a way of visualising a client and for practising their skills in cases where they did not have access to a patient. They also declared that the follow-ups formed a very important part of the training and that they did not experience them as threatening once they realised the importance of follow-ups in the revision and problem-solving areas. Nurses were keen to talk about all the positive outcomes of the training e.g. how empowered they felt, their new skills and knowledge, a positive attitude, increased confidence, a sense of achievement and pride and, finally, increased insight as they were also beginning to realise the potentially devastating effect of disability. Finally a few negative aspects were mentioned. These mostly related to time issues – nurses felt that a week was too short for training and that a whole day of interactive training was too tiring. In addition, they felt that hands-on experiences with live case studies would have improved the training.</p>
<b>Implications</b>	<p>Results from this focus group yielded important information regarding the nurses' attitudes and their evaluation of the training. A number of issues that could not be measured with the quantitative measuring instrument were brought to the foreground. Nurses experienced the training as very positive and commented that it had widened their horizons and opened up a whole new world to them. This impacted positively on the way they view CSDs, e.g. “<i>I don't regard disabled children as being disabled, I see them as normal kids who are unable to perform certain tasks</i>”, how they view the caregivers of CSDs “<i>the parents should also be given support that we can help the children</i>” and how they view themselves “<i>but now, after this training, I know I can work with them</i>”. The impact of the training was therefore wider than only the aspects that were trained. The content and method of the training proved to be effective and impacted positively on the nurses' knowledge and skills. The importance of using a problem-based format with follow-ups must be highlighted, and should form an important part of any future training.</p>

In summary, the focus group provided rich, honest and relevant data regarding the positive outcomes of the BCIP training. Information pertaining to attitudes, job satisfaction and service delivery (secondary outcomes of the training) as well as information pertaining to the primary outcomes (knowledge and skills) were obtained. As discussed, certain precautions were taken with the data in an attempt to increase its trustworthiness.

The final section of Question 10 (Response Form II) was used to obtain quantitative measurements. A Friedman test statistic was obtained with a p-value of 0.39 ( $p>0.05$ ) indicating no statistical significance, so that multiple comparisons were unnecessary. This

is supported by data from the frequency analysis where it can be seen that no nurses were “*very negative*” or “*negative*” towards disability. These results are given in Table 5.35.

**Table 5.35 Attitude towards disability during different research phases (n=20)**

Score	Description of motivation	Frequency pre-training	Frequency post-training	Frequency post-withdrawal
0 – 8	Very negative	-	-	-
9 – 16	Negative	-	-	-
17 – 24	Unsure	-	2	-
25 – 32	Positive	13	9	11
33 – 40	Very positive	7	13	9

As already mentioned the social desirability (Hawthorne effect) of the answers should be taken into account in Table 5.13, resulting in a ceiling effect (Babbie & Mouton, 2001). Despite the measurements included to reduce this effect, it was still noticeable. However, the positive and very positive attitudes that were noted pre-training, might also be due to the fact that nurses were selected who had indicated that they wanted to participate in the training. Post-training results are interesting. Two nurses recorded that they were “*unsure*” about their attitude towards disability. This might be due to the fact that they were more at ease with the procedure post-training and that they realised that they would not be penalised for answering honestly, thus reducing the social desirability effect. On the other hand it might also be because the training had made them more realistic, and that they realised that working with CSDs is challenging. During the post-withdrawal measurement no “*unsure*” measurements were recorded. However, it should be noted that post-training, two nurses had changed from being positive to very positive, and this was maintained during post-withdrawal. This might be because they felt better equipped to work with CSDs and less unsure about what was expected from them.

Two other important aspects that impact on attitudes, namely motivation and job satisfaction will now be described in more depth.

### i) Motivation

The reversal theory of motivation was used to determine this aspect, which holds that people are predominantly telic (goal-directed) or paratelic (more “easygoing” and “go with the flow”). As motivation is an aspect that impacts on attitudes, it was further investigated for descriptive purposes. Results were obtained from using six sub-questions from Question 10 (Response Form II) with a 5-point Likert scale. In order to rate the data some of the answers were reversed, e.g. “*I prefer to work independently and to choose my own tasks*”. By doing so, all nurses who were goal-directed would have a low score and all the nurses who were more “easygoing” would have a high score. Results for this question are shown in Table 5.36.

**Table 5.36 Nurses’ motivation as measured by using the reversal theory of motivation (n=20)**

Score	Description of motivation	Frequency pre-training	Frequency post-training	Frequency post-withdrawal
3 – 6	Very goal-directed	-	-	-
7 – 12	Goal directed	-	-	-
13 – 18	Unsure	7	9	7
19 – 24	Easy-going	10	6	8
25 – 30	Very easy-going	3	5	5

It is important to remember that this aspect was not directly trained during the BCIP training and is therefore a secondary outcome. Table 5.36 indicates that the majority of nurses are not very goal-directed, a tendency that prevailed throughout. This might be due to the fact that these nurses choose to work in community clinics because of this, as this is a workplace where not much planning can take place and where patients come at random. Friedman test statistics confirmed that the BCIP training had no significant influence on the nurses’ motivation, as a p-value of 0.49 was recorded ( $p > 0.05$ ). Consequently multiple comparisons were not done.

## ii) Job satisfaction

As with motivation, job satisfaction also impacts on attitudes, and although this aspect was not trained, it is important for descriptive purposes and was included for that reason

(See Chapter 4, Table 4.17). The next six sub-questions of Question 10 (Response Form II) evaluated job satisfaction, also using a 5-point Likert scale. Again some scores were reversed so that a nurse who was very satisfied with her job would have a high score, and a nurse who was very unsatisfied with her job would have a low score. Results are shown in Table 5.37.

**Table 5.37 Job satisfaction during the various research phases (n=20)**

Score	Description of motivation	Frequency pre-training	Frequency post-training	Frequency post-withdrawal
3 – 6	Very unsatisfied	-	-	-
7 – 12	Unsatisfied	-	-	-
13 – 18	Unsure	1	-	2
19 – 24	Satisfied	14	15	9
25 – 30	Very satisfied	5	5	9

From Table 5.37 it is evident that on the whole, nurses appeared to be satisfied and very satisfied with their jobs. Because the initial scores were high, a ceiling effect is seen (Babbie & Mouton, 2001). Only one nurse who appeared to be unsure pre-training also became satisfied with her job post-training, while two nurses became “unsure” during the post-withdrawal phase. This might possibly be due to the fact that they became more realistic because they had more exposure and hands-on experiences with CSDs. It can also be mentioned that at the end of the post-withdrawal phase, almost half of the nurses (9/20) felt very satisfied with their jobs. This factor is important as the fact that they felt satisfied with their jobs would impact on the way they viewed training and participated in it. It is also important to note that these high scores might be due to the “halo effect” as the nurses might have answered in a socially desirable manner (Guy *et al.*, 1987). As expected, Friedman test statistics indicated that training did not have a statistically significant impact on job satisfaction as a p-value of 0.49 ( $p>0.05$ ) was recorded. No multiple comparisons were thus done.

### 5.3.2.2 Exposure and service delivery

Results were obtained from using Questions 11, 12 and 13 (Response Form II) and Section 4 (Questions 4.1 and 4.2) of Response Form I.

Results from Response Form II were recorded on 4x4 contingency tables resulting in the frequencies in cells being very small, implying scarce data. Consequently data were regrouped in 2x2 contingency tables and chi-square tests were done. Results are shown in Table 5.38.

**Table 5.38 Nurses' exposure to CSDs and amount of time spent with them (n=20)**

No of children	Amount of time spent with children	Pre-training	Post-training	Post-withdrawal
0 children	Not applicable	6	9	7
1 child	<45 minutes	3	5	4
	>45 minutes	1	-	1
2 – 3 children	<45 minutes	7	4	4
	>45 minutes	1	-	-
4 – 5 children	<45 minutes	1	2	2
	>45minutes	1	-	1
> 5 children	<45 minutes	-	-	1
	>45 minutes	-	-	-

Results indicated that pre-training, four nurses saw one child each, while eight nurses saw between two and three children, and two nurses saw more than four children. During the post-withdrawal phases it appeared that a slight increase in service delivery to CSDs could be seen, as four nurses now see more than four children. This observation should, however, be treated with caution, as the number of participants was small.

A statistical analysis was done regarding the amount of time spent with CSDs. Pre-training eleven nurses spent 45 minutes or less with a CSD and three spent more than 45 minutes. Likewise, during post-withdrawal eleven nurses spent 45 minutes or less while two spent more than 45 minutes. This appears to be a very even distribution and thus it appears that training did not really impact on this aspect.

Fisher's Exact Test was done as it tests whether there is a positive or negative association between two aspects (in this case the number of CSDs seen and the amount of time spent with them). As expected, no statistical significance was found ( $p>0.05$ ) as the right-sided p-value was 0.6182 (which would have been indicative of a positive association) and the left-sided p-value was 0.8909 (which would have indicated a negative association). Nurses thus spent neither statistically more nor less time with CSDs in accordance with the number of CSDs to whom they provide services.

Nurses were also asked if they had used the BCIP with any of their clients. During Follow-up 1 five nurses (25%) reported that they had, during Follow-up 2 five nurses also (25%) reported that they had, and during the post-withdrawal phase nine nurses (45%) reported that they had. Reasons for either using, or not using the BCIP, are shown in Table 5.39.

**Table 5.39 Independent utilisation of the BCIP (n=20)**

No	Reasons	Follow-up 1	Follow-up 2	Post-withdrawal
<b>A</b>	<b>REASONS FOR NOT USING THE BCIP</b>			
A1	Other duties, e.g. night duty, labour ward, immunisation campaign	4	2	3
A2	No CSDs available	8	8	3
A3	No time as clinic was too busy	-	1	2
A4	Been on leave (1 month at a time)	3	3	3
A5	Been ill	-	1	
	<b><i>Subtotal</i></b>	<b><i>15</i></b>	<b><i>15</i></b>	<b><i>11</i></b>
<b>B</b>	<b>USE OF THE BCIP</b>			
B1	Seen 1 CSD briefly	2	-	2
B2	Seen 1 CSD extensively	1	3	3
B3	Seen 2 – 3 CSDs extensively	1	1	3
B4	Seen 4 – 5 CSDs extensively	1	1	1
	<b><i>Subtotal</i></b>	<b><i>5</i></b>	<b><i>5</i></b>	<b><i>9</i></b>
	<b>TOTAL</b>	<b>20</b>	<b>20</b>	<b>20</b>

Table 5.39 thus indicates that the number of nurses who utilised the BCIP increased, although still less than 50% used it at the end of the research. The extent to which it was used varied considerably as did the reasons for not using it. It is interesting to note that the one reason “no CSDs available” (A2) was the reason that decreased most noticeably. This might be due to a number of reasons, e.g. as the nurses held more health talks at the clinics targeting the community at large, more CSDs were referred to clinics by members of the community, and nurses might also have become more aware of CSDs who already visited the clinics as they could identify them better, or the nurses could have made a deliberate attempt to find a CSD as they wanted to practise their newly found skills.

After this nurses were asked if they had had contact with anybody regarding the BCIP (e.g. colleagues, friends, family, etc.). During the first follow-up 19 nurses (95%) reported that they had, as did 19 nurses (95%) in the second follow-up and 18 nurses (90%) during the post-withdrawal phase. The nature of this contact was then further investigated. Results are shown in Table 5.40.

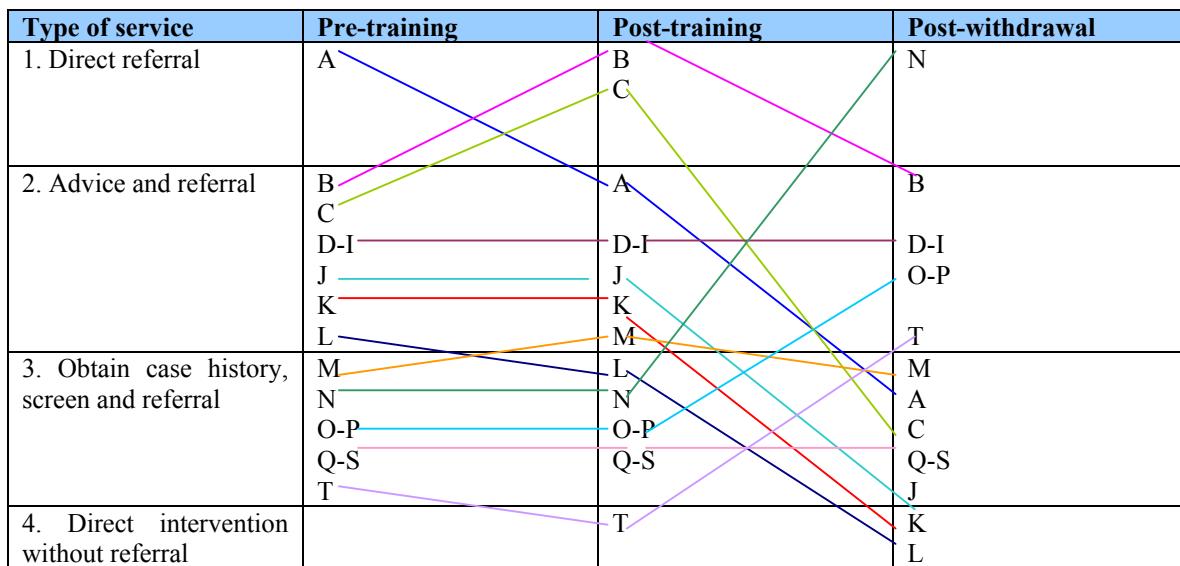
**Table 5.40 Nature of contact with others regarding the BCIP**

No	Description of contact	Follow-up 1	Follow-up 2	Post-withdrawal
----	------------------------	-------------	-------------	-----------------

No	Description of contact	Follow-up 1	Follow-up 2	Post-withdrawal
1	Informal discussions and demonstrations with own family	6	-	-
2	Informal talks with family and colleagues (nurses and/or teachers)	4	11	9
3	Formal talks and demonstrations to colleagues	5	6	-
4	Formal talks, demonstrations and health talks to community	4	2	7
5	In-service training of nursing assistant	-	-	2
<b>TOTAL</b>		<b>19</b>	<b>19</b>	<b>18</b>

Almost all the nurses had had contact with others regarding the BCIP. It is interesting to note that at the first follow-up (two weeks post-training) six nurses reported that the nature of the contact was mostly informal discussions and demonstrations with their own families. This aspect was not mentioned during the other two phases. It is also important to note that two nurses trained nursing assistants as they feared that no one would be able to render services to CSDs if they were not available, indicating how valuable they regarded the training to be. There was also an increase in health talks to the community at large.

Nurses were also asked what type of service they rendered at their respective clinics (Response Form II). This was compared during the various research phases. Data are presented visually in Figure 5.5.



**Figure 5.5 Type of service delivery rendered during the various research phases**

It is important to note that these four types of service delivery follow a hierarchical pattern in terms of how independently a nurse can provide training to a primary caregivers of CSDs. On the first level, there is no mention of direct intervention and the child is merely referred, whereas on the last level, the nurse is able to work more independently. Data indicate that seven nurses tended to become more independent as training progressed (participants A, B, C, J, K, L and M). Participants K and L marked the highest level of independence. This is significant, as no nurses had marked this level pre-training. Four nurses tended to regress (N, O, P and T). Nine nurses showed no change on these levels during the research phases.

### 5.3.2.3 Self-evaluation

Data for this section were obtained by using both open-ended questions (Question 15, 16 and 17) and close-ended questions (Question 14) from Response Form II.

The first open-ended question dealt with a general self-evaluation of their skills as a nurse, the second with their skills that positively impacted on their treatment of CSDs and

their primary caregivers and finally the skills that they would like to improve in order to enhance their service delivery to CSDs. In all instances nurses had to mention three skills, and so sixty observations for each of these aspects are recorded.

Combined frequencies for each of these questions were recorded for the different research phases and an item analysis was done. Table 5.41 depicts the nurses' self-evaluation of their general nursing skills during these phases.

**Table 5.41 Nurses' self-evaluation of general nursing skills during the various research phases (n=3x20=60)**

No	Description	Pre-training	Post-training	Post-withdrawal
1	Case history & interviewing	6	5	3
2	Communication & listening skills	10	11	11
3	Providing correct medical (nursing) treatment	10	7	11
4	Assessment	6	8	6
5	Education through health talks	13	9	10
6	Counselling caregivers on accepting CSDs and adopting a positive attitude towards them	8	4	3
7	Home visits to support caregivers and CSDs	2	-	-
8	Referrals	5	4	5
9	Follow-up visits	-	2	1
10	Showing primary caregivers how to communicate by using different communication means, functions, partners and opportunities	-	9	10
11	Provide information regarding school placement	-	1	-
<b>TOTAL</b>		<b>60</b>	<b>60</b>	<b>60</b>

From Table 5.41 it is clear that nurses became more aware of the importance of showing primary caregivers how to communicate with their CSD by using the BCIP principles. This was maintained during the post-training and post-withdrawal phases. In addition, they became aware of the importance of school placement and the provision of follow-up services post-training. The greatest decline was noted regarding counselling of primary caregivers on accepting their CSD and adopting a positive attitude. This is possibly due to the fact that nurses had a concrete way of achieving this post-training (e.g. using the BCIP as opposed to only talking and discussing – the traditional way of counselling). Some aspects received high scores throughout, e.g. general communication and listening

skills, providing correct medical treatment and education through health talks. Referrals remained fairly consistent over the three phases.

Secondly, nurses were asked to reflect on their skills that were particularly good when working with CSDs and their primary caregivers. As with the previous section, combined frequencies were calculated. As each nurse listed three skills, sixty responses were recorded. The results are shown in Table 5.42.

**Table 5.42 Nurses' self-evaluation of nursing skills specific to working with CSDs and their primary caregivers during the various research phases (n=3x20=60)**

No	Description	Pre-training	Post-training	Post-withdrawal
1	Using different unaided communication means (e.g. facial expressions, head-nodding and manual signs)	3	2	1
2	Using different aided communication means (e.g. real objects & photos).	-	3	2
3	Facilitating a positive attitude by giving advice	18	7	11
4	Demonstrating communication functions	-	4	2
5	Providing communication opportunities	-	4	5
6	Social integration by increasing communication partners & using play	2	2	4
7	Good communication and listening skills of the nurse	13	11	7
8	Service delivery:			
	▪ Case history & interviewing	6	4	8
	▪ Identification and screening	4	6	5
	▪ Referral	3	-	1
	▪ Teaching CSDs	7	-	1
	▪ Teaching feeding skills	-	1	-
	▪ Teaching primary caregivers to communicate with CSD	-	14	12
	▪ Health talk about hygiene	3	1	-
	▪ Information on disability grant	-	-	1
9	Professional secrecy	1	1	-
	<b>TOTAL</b>	<b>60</b>	<b>60</b>	<b>60</b>

For this question sixteen categories were formulated and Table 5.42 clearly shows that post-training nurses were aware of the specific skills which were required when working with CSDs and their primary caregivers, e.g. the highest score was obtained for “*teaching primary caregivers to communicate with CSD*”, which was maintained during the post-withdrawal phase. The other skills that were mentioned were specific in nature, e.g.

‘using real objects to communicate’, ‘demonstrating communication means and functions’ and ‘providing communication opportunities’. As noted in the previous table, (Table 5.41), skills mentioned pre-training were vague and general, e.g. “teaching CSDs” and “facilitate a positive attitude by giving advice”. These frequencies declined during post-training as attention was focused on specific aspects e.g. “providing communication opportunities”, “using aided communication” and “demonstrating communication functions”. During post-withdrawal, however, the frequencies for the general aspects increased again, but not to the pre-training level.

Finally a reflective, self-evaluation question pertaining to skills they would like to improve and/or receive training in was asked. An item analysis was constructed from the combined frequency counts of this open-ended question. Fifteen categories were extrapolated. Results are shown in Table 5.43.

**Table 5.43 Nurses’ self-evaluation of skills specific to working with CSDs and their primary caregivers that they would like to improve/receive training in, during the various research phases (n=3x20=60)**

No	Description	Pre-training	Post-training	Post-withdrawal
1	More information on communication means	4	7	13
2	Knowing more about communication functions	-	4	2
3	Creating communication opportunities by using communication temptations	-	5	-
4	Knowing more about multi-disciplinary teams, each member’s role and the referral route	3	4	4
8	Service delivery:			
	▪ Screening & measuring progress	-	5	4
	▪ Primary caregiver & sibling training	18	4	2
	▪ Providing primary health care & nursing	3	2	3
	▪ Basic training of CSDs e.g. providing exercises	10	1	3
	▪ Own nursing skills	4	2	-
	▪ Interviewing caregivers and communicating with them	13	4	3
	▪ Categorise CSDs according to disability types	3	-	-
	▪ Facilitating independence by functional skills	-	2	3
	▪ Teaching families to communicate with CSDs by using demonstrations	-	16	9
	▪ Know about schools for CSDs	2	3	3
	▪ How to form support groups	-	1	1
	<b>TOTAL</b>	<b>60</b>	<b>60</b>	<b>60</b>

Table 5.43 yields some interesting results. Pre-training eighteen, thirteen and ten nurses respectively required more training in “*training primary caregivers and siblings*”, “*interviewing caregivers and communicating with them*” and “*basic training of CSDs*”. It is clear that the training programme that was provided addressed these issues, as a noticeable decline was regarding these three aspects observed post-training. It is also interesting to note that “*categorising CSDs according to disability types*” was no longer an issue post-training. This is possibly due to the fact that the WHO’s ICIDH-II where the emphasis is placed on participation rather than disability types was discussed (WHO, 1999). Post-training, nurses identified a whole new set of needs, with “*teaching families to communicate with CSDs by using demonstrations*” as the most pressing. This could possibly be attributed to the emphasis placed on social inclusion during the training. The other training needs revolved around the specific issues addressed during training, e.g. expanding communication means and functions and creating communication temptations. During the post-withdrawal phase the highest reported frequency was for “*using different communication means*”. This could possibly be because they were already successfully using some manual signs and wanted to expand their current vocabulary.

Following the three open-ended questions, six close-ended questions (Question 14 on Response Form II) that employ a 4-point Likert scale were evaluated. A Friedman test was conducted in order to determine whether nurses viewed their own skills more positively during the post-training and post-withdrawal phases in a statistically significant manner. A p-value of 0.12 was obtained which is not statistically significant ( $p > 0.05$ ). Multiple comparisons were therefore not done.

#### **5.4 GENERAL TRAINING EVALUATION**

Results discussed in this section will be both qualitative and quantitative in nature. The qualitative data were obtained from the focus group that was discussed in Section 5.3.2.1.

The quantitative measurements were obtained from Response Form III that was administered twice, directly post-training and at the five-month withdrawal period. Firstly, nurses were asked if they thought that the training had helped them to improve their knowledge regarding severe disability. In order to determine whether any differences occurred post-training and post-withdrawal, 3x3 contingency tables were drawn. As none indicated that they did not gain any knowledge, this cell was empty and therefore omitted. Results are shown in Table 5.44.

**Table 5.44 Nurses' rating of the extent to which the BCIP training improved their knowledge regarding disability (n=20)**

POST-TRAINING	Frequency of nurses	POST-WITHDRAWAL			TOTAL
		Helped a little	Helped quite a lot	Helped very much	
	Helped a little	2	-	-	2
	Helped quite a lot	-	5	3	8
	Helped very much	-	6	4	10
	TOTAL	2	11	7	20

From this table it is evident that not many changes took place during the five-month withdrawal phase regarding the nurses' evaluation of the amount of knowledge they had gained in training. The same two nurses who initially stated that they had gained little knowledge continued to support this. Of the ten who felt that they had gained very much from training during the post-training phase, seven continued to think so. The three nurses who had changed their opinion, now stated that they had gained "*quite a lot*".

Nurses were also asked to give an overall rating of the training. None rated the training as "*very poor*" or "*poor*". Responses were recorded on a 3x3 contingency table and results are shown in Table 5.45.

**Table 5.45 Nurses' overall rating of the quality of the training.**

POST-TRAINING	Frequency of nurses	POST-WITHDRAWAL			TOTAL
		Good	Very good	Excellent	
	Good	3	3	1	7
	Very good	2	2	3	7

<b>Excellent</b>	1	1	4	6
<b>TOTAL</b>	<b>6</b>	<b>6</b>	<b>8</b>	<b>20</b>

From Table 5.45 it is clear that not much difference was noted between their rating of the quality of training during the post-training and post-withdrawal phases. One nurse each, who had respectively rated the training as “*good*” and “*very good*” during post-training, rated it as “*excellent*” during the post-withdrawal phase. In addition to these frequencies, it would add insight to look at some of the comments made by nurses during the post-withdrawal phase, to reflect their overall rating of the training: “*the course was an eye opener because after attending this course I see children with disability differently than before. I am able to deal with them and guide their parents. I think it is important and worthwhile to be included in the nursing curriculum*”. From this statement it is clear that the nurse was able to qualify the knowledge that she had gained and that an attitudinal change had also taken place. Another nurse commented that “*the course was interesting and I have gained a lot. Follow-up lessons made us participate actively. I have developed interest and a love of children with disability*”. This highlights the importance of the training methodology used (namely follow-ups and encouragement of active participation) as well as a change of attitude. The training methodology used was further emphasised when a nurse stated “*the lecturer is very good on teaching this, because she emphasised every little word she said. She knew that some of us are slow learners, so she was fluent enough to be heard by everybody*”.

Nurses were also asked if they had enjoyed the BCIP-training as a whole, to which everyone responded that they had (during the post-training and post-withdrawal phases). All of them also indicated during the post-training phase that they felt that all nurses should undergo this training, but during the post-withdrawal phase two nurses became unsure of this. On the other hand, eighteen nurses reported that this training had helped them adopt a positive attitude towards service delivery to CSDs (two were unsure), but during post-withdrawal all of them were sure about this. As expected, when obtaining a Wilcoxon score over these three aspects for the post-training and post-withdrawal phases,

a p-value of 1.00 was obtained ( $p>0.05$ ) indicating that no statistically significant changes had occurred over time.

The remaining section of the training evaluation will now be described in terms of the training methodology that was used and the training content.

#### **5.4.1 Training methodology**

Firstly, nurses were asked to comment on various aspects of the training in order to obtain a holistic view on the training methodology. Statements regarding the training methodology were made, and nurses had to state whether they agreed with the statement (“Yes”), disagreed (“No”) or whether they were uncertain (“Uncertain”). Results are shown in Table 5.46.

**Table 5.46 Nurses' evaluation of the training methodology (n=20)**

Aspect evaluated	Positive evaluation		Negative evaluation		Uncertain	
	Post-training	Post-withdrawal	Post-training	Post-withdrawal	Post-training	Post-withdrawal
Use of a problem-based format	19	20	-	-	1	-
Appropriacy of case studies used	20	20	-	-	-	-
Sufficient training time	9	7	10	11	1	2
Sufficient time for questions and answers	18	20	2	-	-	-
Sufficient time to practise BCIP application	13	14	5	5	2	1

Table 5.46 indicates that the use of a problem-based format and the appropriacy of the case studies proved to be particularly positive. The fact that the case studies were compiled from descriptions provided by primary caregivers during focus groups in the Moretele health district might be the reason why 100% of the nurses viewed the case studies as appropriate during both phases. On the other hand, the area where the nurses were most negative, were the ones pertaining to time, particularly the length of training and enough time to practise the use of the BCIP. However, they noted that the time for questions and answers was sufficient. As is clear from this table, nurses' views regarding these aspects did not change much during the post-withdrawal phase. Wilcoxon test statistic over all the aspects that pertain to the training methodology confirmed this observation and indicated a p-value of 0.6418 ( $p>0.05$ ) which implies that there was no statistical difference between the way nurses viewed the methodology during post-training and post-withdrawal.

This was followed by four open-ended questions regarding the training methodology, namely the three aspects of training that were most enjoyed, aspects more information were required on, suggestions to improve training and additional comments. Answers to the last three questions provided such similar answers that they were grouped together. Nurses could give any amount of information, thus the frequency scores do not add up to

twenty or any of its multiples. On analysing this information a differentiation was made between training methodology and content, of which only the former will be discussed in this section.

Results pertaining to the aspects that were most enjoyed relating to the training methodology are presented in Table 5.47.

**Table 5.47 Training methodology aspects that were most enjoyed**

Aspect	Post-training	Post-withdrawal	Comment
Use of case studies	7	5	Problem-based learning was a new concept. Highest frequency during both phases.
Use of videos	4	2	Less frequently mentioned in post-withdrawal phase as they were not exposed to this during the 5-month period.
Role-play and active participation	3	3	No difference between the various phases.
Hands-on workshops	3	3	No difference between the various phases.
Good & effective handouts	1	1	No difference between the various phases.
Follow-ups	-	1	This aspect was, as expected, only mentioned post-training.

From this table it becomes clear that nurses enjoyed a wide range of aspects pertaining to training methodology, of which case studies were most frequently mentioned. It also appeared that activities enjoyed post-training were the same ones enjoyed post-withdrawal, except for “*follow-up*”, which was only mentioned during the final phase.

Comments on how to improve the training were then categorised. Results are displayed in Table 5.48.

**Table 5.48 Training methodology that could be improved**

<b>Aspect</b>	<b>Post-training</b>	<b>Post-withdrawal</b>	<b>Comment</b>
Increase training time	11	10	Suggestions varied between two weeks and one month.
Use live case studies	14	16	As some had never had hands-on experiences with CSDs they would have liked this contact during training.
Increase use of videos	3	-	Two commented that the videos should be in one of the local languages, e.g. Setswana
Group nurses according to their qualifications & train one group at a time	-	2	Interestingly enough this aspect was only mentioned post-withdrawal. Might be due to the strong hierarchy in the nursing profession.
Follow-ups are fruitful and should continue	-	6	Enjoyed this aspect of training and did not experience it as threatening.

A number of aspects most enjoyed during training (Table 5.47) were also mentioned in Table 5.48 as possible ways to improve the training. During both phases 50% of the participants felt that the training period was too short, therefore it is recommended that the training period be extended. This is possibly because all the information provided during the BCIP training was new to them and the fact that 100% had reported that they had enjoyed the training. Nurses mentioned that they enjoyed the case studies, but from Table 5.48 it is evident that they would have preferred these case studies to be live. Likewise, the use of videos were also qualified as two nurses requested that the videos should be in one of the local languages, e.g. Setswana. All six nurses who mentioned “*follow-ups*” agreed that this was very fruitful and that they should continue as part of the training methodology.

#### **5.4.2. Training content**

As with the training methodology, nurses were asked to comment on various aspects of the training content in order to obtain a holistic view on the BCIP training. These questions were displayed in close-ended format where they had to indicate “Yes” “No” or “Uncertain” to the statements regarding the training content. Results are shown in Table 5.49.

**Table 5.49 Nurses' evaluation of the training content (n=20)**

Aspect evaluated	Positive evaluation		Negative evaluation		Uncertain	
	Post-training	Post-withdrawal	Post-training	Post-withdrawal	Post-training	Post-withdrawal
Usefulness of the handout	18	20	2	-	-	-
Completeness of information	14	12	3	3	3	5
Usefulness of BCIP	18	19	2	1		
Ease of application of BCIP	14	15	2	1	4	4
BCIP enables independent planning of training	15	19	-	-	5	1

The greatest change between the two phases in Table 5.49 is seen in the area that evaluates whether the BCIP enables independent planning of training for a primary caregiver of a CSD. This is possibly due to the fact that nurses had the opportunity to experiment with the BCIP and were able to judge this aspect more accurately during the post-withdrawal phase. Areas where a relatively high percentage of “*uncertain*” responses were recorded pertain to the ease of application of the BCIP and the completeness of information provided during training. This might be due to the fact that nurses had not had sufficient opportunities to practise using the BCIP independently and thus felt that it was difficult to use. The number of nurses who were “*uncertain*” regarding the completeness of the BCIP increased during the post-withdrawal phase. This could be because they had started implementing it, and found that some aspects were still difficult. The initial high score of negative and “*uncertain*” responses in this regard might be due to the fact that the areas of communication and disability were novel, and thus they were not equipped to judge whether important information had been omitted.

In order to determine whether statistically significant differences had occurred in the way nurses rated the training content during the two phases, a Wilcoxon test was used. The Wilcoxon test statistic was obtained with a p-value of 0.0872 ( $0.05 < p < 0.10$ ) indicating statistical significance at the 10% confidence level, but not at the 5% level. In order to determine the nature of this change, it is important to look at the mean scores. This had increased from 6.90 in the post-training phase to 6.50 in the post-withdrawal phase,

indicating that nurses had become more positive towards the training content. (The lower score comes from the fact that a 1 was given for “yes” answers and a 2 for “no” answers).

As with training methodology nurses then had to comment, in open-question format, on the three aspects of training that they most enjoyed, as well as on aspects more information was required on, suggestions to improve training and additional comments. The last three questions provided such similar answers that they were grouped together, as was done for training methodology. Results pertaining to the training content that was most enjoyed are shown in Table 5.50.

**Table 5.50 Training content aspects that were most enjoyed**

Aspect	Post-training	Post-withdrawal	Comment
Communication means (e.g. manual signs, EasyTalk and making communication boards)	24	23	This was by far the most frequent aspect. Specific aided and unaided communication strategies were mentioned.
Communication functions	6	9	More frequently mentioned in post-withdrawal phase as they had had the opportunity to practise it.
Using ADLs for communication	3	-	Aspect only mentioned pre-training when it was a new concept.
Creating communication opportunities	1	3	Mentioned more frequently in post-withdrawal as they became more familiar with this concept.
Other content			Interestingly, some aspects that were not the focus of the training and therefore not emphasised, were mentioned as the aspects most enjoyed. If training should be extended, these aspects may be included in more depth. In comparing these results to the focus group information, it is also evident that some aspects, such as the social inclusion perspective prevailed throughout. It is important to keep this perspective in training.
▪ Basic communication with CSDs	5	4	
▪ Handling challenging behaviour	1	-	
▪ Monitoring progress	1	-	
▪ Social inclusion perspective	-	1	
▪ Whole BCIP	-	3	
▪ Theory	1	2	

This table clearly shows that nurses enjoyed the four main focus areas regarding training content, with communication means being the most prominent. This could possibly be due to the fact that this is the aspect where their newly acquired skills were best seen (e.g. the use of manual signs and the EasyTalk). Communication functions and the creation of communication opportunities, on the other hand, were mentioned more frequently during post-withdrawal. This might be due to the fact that they had opportunities to practise

these two aspects during the 5-month post-withdrawal phase and became more skilled. However, using ADLs to provide the content and context for instruction was not mentioned during post-training. This may be attributed to the fact that nurses internalised this aspect; not regarding it as something that was trained. As seen in Table 5.50 some aspects that were not directly trained were also mentioned, and therefore it is important to keep this perspective. One aspect in particular, i.e. the social inclusion perspective, appeared to bring about the greatest mind shift and change of attitude as this aspect was mentioned throughout.

This section was followed by nurses' comments on possible ways to increase and enhance the training content. In addition some comments were made that referred neither to the training method nor the training content, and can best be described as "*outcomes*". It is important to also look at these aspects as they refer to aspects that already enhanced the training and that should be maintained. Results are shown in Table 5.51.

**Table 5.51 Training content that could be improved or enhanced**

Aspect	Post-training	Post-withdrawal	Comment
<b>TRAINING CONTENT</b>			
More information on communication means	16	13	Specific mention was made of manual signs and the use of the EasyTalk.
Increase information of communication functions	3	-	This aspect was not seen as a need during post-withdrawal.

Aspect	Post-training	Post-withdrawal	Comment
<b>TRAINING CONTENT</b>			
Intervention for specific disability categories, e.g. CP	4	4	This aspect remained a need. Aspects that were highlighted included feeding and physical management of children with CP.
Training primary caregivers	-	4	After implementing the BCIP nurses began to see this aspect as a need.
Planning a programme for CSDs and measuring outcomes	1	5	After implementing the BCIP nurses began to see this aspect as a need.
<b>OUTCOMES : ASPECTS THAT SHOULD BE MAINTAINED</b>			
Increased awareness of communication	3	3	Aspect mentioned during both phases. Main emphasis of the BCIP training.
Continue – should be part of curriculum for all nurses	11	11	More than 50% of the participants maintained this view throughout the training.
Want requirements for further study	1	-	One nurse wanted to continue studying in this area.
Greatly enjoyed training and the positive training atmosphere	11	8	Great enjoyment of training enhanced training and may be one of the factors why positive outcomes were obtained.

Interestingly, the aspect that was mentioned as most enjoyable, namely communication means, (Table 5.50) is also the one in which they would like to receive more training (Table 5.51). This may be due to the fact that they began to experience success and that they wanted to continue with the aspects that made them feel secure. Communication functions were only mentioned post-training as they probably began to feel more confident about this aspect when they began to implement it. As opposed to this, two aspects, namely training primary caregivers and planning a programme for a child with CSD and then measuring the outcomes, only became a priority post-withdrawal. What is important to note is that eleven of the twenty nurses stated during both phases that they felt this training should be incorporated into the general nursing curriculum. This is a positive indicator of how important they felt the training to be. A high percentage of nurses also mentioned that they had greatly enjoyed the training and the positive training atmosphere. This is possibly due to the fact that adult training principles were incorporated in the training and that a problem-based format was used, providing them with opportunities to use their prior knowledge.

## 5.5 CONCLUSIONS

Chapter 5 analysed and described data. The following key issues were noted:

### 5.5.1 Reliability

Reliability was high at 96% for both inter-rater and intra-rater reliability.

### 5.5.2 Outcomes

#### 5.5.2.1 Primary outcomes

- Prior knowledge increased statistically significantly at the 5% level of confidence over the five-month period.
- Applied knowledge (regarding communication means, functions, partners, opportunities and general advice) also increased statistically significantly at the 5% level. This increase in applied knowledge was not only seen more frequently in these respective aspects, but also in the identification of a wider range of aspects.
- Skills included skill in representational level grading, in using objects and photographs for communication, using communication boards, using manual signs and using the EasyTalk 4 option digital speaker. Friedman tests statistics indicated that all these skills increased statistically significantly over the five months period. In addition, the participants' dependence on prompts did not increase, while their confidence in demonstrating these skills began to increase statistically significantly at the 10% level during the second follow-up and at the 5% level during the post-withdrawal. This implies that confidence continued to increase over time.

### 5.5.2.1.1 Secondary outcomes

- From qualitative measurements it became clear that post-training nurses felt more positive about CSDs, their role as nurses and the services they were able to offer CSDs and their primary caregivers, despite the fact that attitude did not change statistically significantly on the quantitative measurements. Job satisfaction and motivation, two aspects which presumably impact on attitude also did not change statistically significantly.
- It appeared that although the number of CSDs receiving services from nurses increased slightly post-training, this change was not statistically significant. The number of children who received services also did not impact on the amount of time nurses spent with these children. However, regarding the type of service delivery it became evident that nurses were beginning to be more independent in service delivery and were less likely to merely refer the child.
- The nurses' self-evaluation revealed that they had become more specific and knowledgeable about service delivery to CSDs post-training. They were clear on which aspects they would address when training primary caregivers of CSDs and why they would do this. These results were confirmed during the focus group discussion.

### **5.3.3 General training evaluation**

#### **5.3.3.1 Training methodology**

- The use of problem-based learning with culturally relevant case studies facilitated knowledge and skill development and retention. The importance of follow-ups in providing practise opportunities was emphasised. Interactive, hands-on skill teaching was effective in involving all participants and optimising learning.

#### **5.3.3.2 Training content**

- The use of a variety of communication means (including manual signs, EasyTalk and communication boards) was greatly enjoyed during training. They also acknowledged that the BCIP was easy to use, and a useful tool in the independent planning of services for CSDs.

## **5.6 SUMMARY**

This chapter organised, analysed and described the results of the research as they relate to the main aim of the research (in particular Sub-aim 4). It commenced with a discussion of the reliability of the results, followed by an in-depth discussion on the primary and secondary outcomes of the research during the various phases. This was followed by a general evaluation of the training in terms of the methodology used and the content. This section concluded by highlighting the most important findings of the research, namely that knowledge, skills and attitudes of nurses' regarding CSDs increased significantly over the 5-month period, despite the fact that only knowledge and skills were trained. One factor that facilitated this consistent increase was the regular follow-ups and creative problem-solving during these sessions.

## CHAPTER 6

### DISCUSSION OF RESULTS

#### 6.1 INTRODUCTION

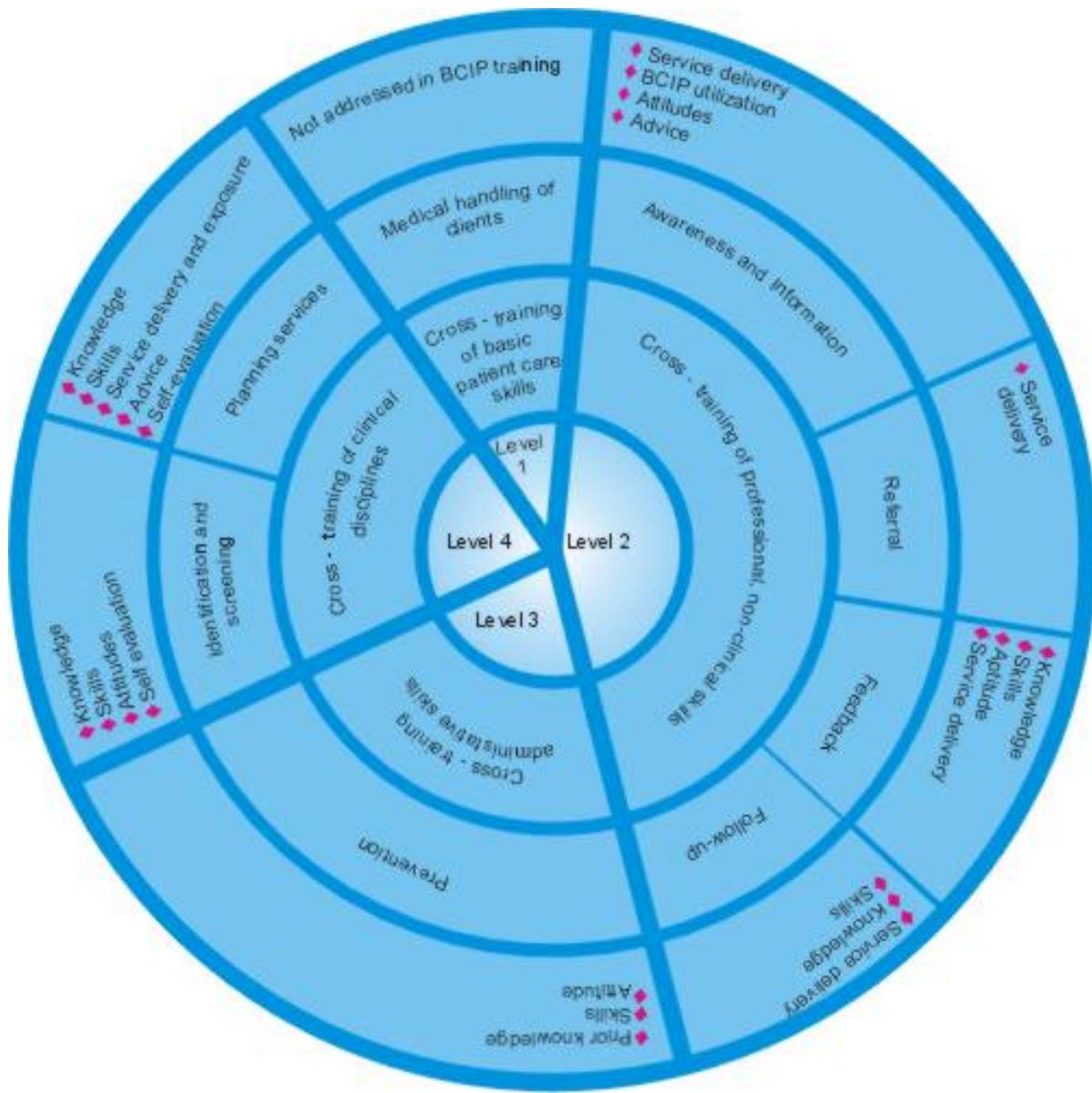
In the present research the aim of the BCIP training was to equip community health nurses with the knowledge and skills to function as transdisciplinary professionals, enabling them to train the primary caregivers of CSDs. It places multiskilling centrally in this research as this is one approach by which transdisciplinary skills are acquired.

The aim of this chapter is to discuss and integrate the results related to the primary outcomes (knowledge and skills) and the secondary outcomes (attitudes, exposure and service delivery, and self-evaluation) and their impact on the four multiskilling levels. Finally the specific training principles employed in the BCIP training that facilitated the achievement of these outcomes will be highlighted.

#### 6.2 MULTISKILLING LEVELS AND ACCOMPANYING OUTCOMES

Outcomes can be defined as clear learning results that participants in training should be able to demonstrate at the end of the learning experience (Spady, 1994). The Department of Education (1997, p.24) expanded this definition: “*The ‘outcome’ is the result of the learning programme; what the learner knows, can do, values and wishes to be like.*” This implies that all learning experiences should aim at integrating knowledge, skills and values. Multiskilling was selected as the approach by which community health nurses were trained to move beyond the boundaries of their specific discipline, enabling them to function as transdisciplinary professionals. They had to move beyond Level 1 which involves basic client care skills) to Levels 2 (involving professional non-clinical skills), 3 (administrative skills) and 4 (clinical skills). This was necessary in order to equip them with the skills to provide services to CSDs and their primary caregivers. Figure 6.1

depicts the outcomes achieved following the BCIP training on each of the nursing tasks within the four multiskilling levels.



**Fig 6.1: Multiskilling levels, nursing tasks and BCIP training outcomes**

Nursing tasks have been described in literature (ASHA, 1996; Wilkey & Gardner, 1999). In practice, however, it is very difficult to separate these specific nursing tasks as they impact on and influence each other, e.g. referral can only be effective in the

presence of raised awareness and information. It should also be noted that these four levels are hierarchical, so that a person will not be able to function on Level 4 (e.g. planning services) without having the skills to also function on Level 2.

Regarding outcomes, it should be noted that training programmes have specific foci, and some forms of teaching will result predominantly in skills enhancement, some predominantly in knowledge development and some in attitudinal change. As mentioned in Chapter 5 the BCIP training was deliberately planned and organised with the intention of changing knowledge and skills, and is not focused on changing attitudes. The outcomes achieved with the BCIP training were therefore separated in terms of primary outcomes (directly trained outcomes) and secondary outcomes (aspects that changed although they were not directly trained, e.g. attitudes). However, the impact of each of these outcomes on the other, should be acknowledged, e.g. increased knowledge impacts on all the different multiskilling levels (and nursing tasks). The fact that it is difficult to separate these outcomes therefore impacts on the construct validity of the present research. It also impacts on the content validity, e.g. what all the different variables that impact on service delivery are and how they were measured. The nursing tasks assigned to each of the multiskilling levels and the outcomes achieved within each of these nursing tasks following the BCIP training will now be described.

### **6.2.1 Level 1 Cross-training of basic client care skills**

This level refers to the medical handling of clients by providing specific nursing tasks and since the training focused on beginning communication skills for CSDs and their primary caregivers, this aspect was not addressed during training.

## 6.2.2 Level 2 Cross-training of professional non-clinical skills

Five nursing tasks that relate to this level were applied to disability (ASHA, 1996; Dublinske, 1983; Freeman & Heinrich, 1981). Specific outcomes were related to each of these nursing tasks, namely awareness and information, referral, feedback and follow-up. Each will now be described in more detail.

### 6.2.2.1 Awareness and Information

In this specific context it is difficult to separate these two nursing tasks. First of all nurses had to receive information to ensure that they became knowledgeable about CSDs and their needs and abilities before they could provide information to caregivers of CSDs, other professionals and the community at large which would lead to raised awareness of disability issues. Following the BCIP training, information dissemination (which is the start of raising awareness) began at the personal level with informal discussions and demonstrations with their own families (Table 5.40 and Appendix P).

However, raised awareness at the personal level is only the first step. This was followed by formal talks and demonstrations to colleagues and health talks to the community at large to expose the issue (disability) and to educate for action, demonstrating raised awareness at the professional level. Table 5.40 shows how the number of health talks to the community increased over time. During self-evaluation of their skills, community health nurses maintained their focus on education through health talks throughout the different research phases (Table 5.41). During the post-withdrawal period two nurses also reported that they had conducted in-service training of nursing assistants as they felt this information had to be available at times when they were unavailable themselves “*when we get that type of patient and I am not present, they can use these things*” (BCIP).

Afterwards information dissemination (and consequently raised awareness) became more specific in nature and was conducted at the level of the primary caregivers of CSDs. Nurses provided them with information (about disability and available services) and

training (about communication for CSDs) (Blumberg, 1987; Eggbeer, 1995; Lequerica, 1997; Meisels, 1992). During the BCIP training it became clear that awareness of disability and the needs of CSDs and their primary caregivers increased. This is evident from the fact that the number of children who received service delivery by community health nurses increased (Table 5.38 and 5.39). In addition, Table 5.39 shows that the number of nurses who stated that they could not use the BCIP independently due to the fact that no CSDs were available decreased from eight (during the first follow-up) to three (during the post-withdrawal). This might indicate that nurses became more aware of CSDs at their respective clinics and/or that the health talks had paid off and more CSDs were referred.

In addition, nurses became more specific on information that they would provide post-training, e.g. “*teaching parents to communicate with their CSD*”, “*information on a disability grant*” and “*demonstrating communication functions, means, partners and opportunities*” (Table 5.42 and 5.41). Homan (1999) states that good information is accurate, interesting, relevant and important. In the present research this implies that the focus is on the **abilities** of the child (as opposed to the **disabilities**) and to highlight the fact that all children **can** communicate (irrespective of how this is done). The information that nurses would provide to CSDs and their primary caregivers is reflected in the advice they would give (Table 5.24). It became clear that post-training nurses became clearer on how communication means and functions could be increased through the use of communication temptations, as well as the importance of increasing social interaction (by increasing communication partners). Nurses also highlighted the importance of increasing the independence of CSDs. The BCIP training thus facilitated a change in the nurses’ perceptions regarding CSDs as witnessed in the way they facilitated the interaction between primary caregivers and their CSDs.

Focus group discussions (Appendix P) showed that nurses became clearer on their role as it pertains to information dissemination and awareness raising of the needs and abilities of CSDs and their primary caregivers and that the new information facilitated a change in their perceptions “*it was an eye opener / affected me as a person.*” The nurses underlined

the importance of raising community awareness in disability issues and their role in this “*... and then we talk to the community at large.*” They also highlighted the importance of increasing awareness amongst typically developing children “*... teach these children to play with the disabled children.*” The importance of social inclusion and the training of the community at large in accepting these children also came to the forefront “*... they should be included in the community and accepted.*”

#### **6.2.2.2 Referral**

Pre-training, a high rate of referral of CSDs was seen without any direct services (Table 5.24). In some instances advice was given with the referral (Figure 5.5), although the nature of the advice is unknown. Providing information and support at the time of referral is a crucial element in effective service provision (Lequerica, 1997; Solomon *et al.*, 1994). Post-training, nurses verbalised the importance of support to these primary caregivers “*...the parents should also be given the support that we can help the children...*” (Appendix P).

Post-training, it became clear that nurses were able to be more autonomous during service delivery and that referral was accompanied by advice or by obtaining a case history and screening (Figure 5.5). This tendency continued during the post-withdrawal phase. As was seen from the quality of advice the community health nurses would give primary caregivers (Tables 5.24, 5.41 and 5.42) it was assumed that primary caregivers would be able to understand better why the particular referral was necessary and comply with it. During the focus group discussion nurses voiced their pre-training belief that they could only conduct referrals and their assumption that the BCIP training would focus on the referral process “*I thought we were just going to be taught how to refer these children...*”. They felt empowered because they could train the primary caregivers of these CSDs post-training “*...it helps me deal with them...*”

Despite the provision of services to CSDs and their primary caregivers, the availability of more extensive developmental assessment on referral basis will always exist (Eggbeer,

1995). Secondary health care provided at the Jubilee Community Hospital and tertiary health care provided at the Pretoria Academic Hospital for the particular health district was mentioned during the BCIP training. At the end of the BCIP training four nurses expressed the need for more information about the referral route and each team member's role while three requested more information about referral to special schools (Table 5.43).

#### **6.2.2.3 Feedback**

It has been noted that whereas primary caregivers take their children to PHC clinics regularly during the first year, there is a gradual fall-off in the attendance rate as the child gets older (Powell, 1984). This might be due to the fact that the need for feedback and reassurance declines as the immunisations are completed. However, this demand for feedback depends on the quality of the services provided and literature suggests that parents (primary caregivers) are more likely to attend community health clinics if they experience feedback to be sensitive and quick (Solomon *et al.*, 1994). Primary caregivers thus need to see and experience that the information they receive will make a difference, as discussed in Section 6.2.2.1.

During the BCIP training it was evident that the nurses' knowledge and skills empowered them regarding the feedback they could provide to CSDs and their primary caregivers "*I learnt that I could, that one could easily communicate with disabled children*" and "*it helps me to deal with them*" (Appendix P). The positive aptitude that nurses reflect towards CSDs and their caregivers will facilitate the feedback process. The number of children receiving services by means of the BCIP implementation almost doubled (from five to nine) from pre-training to post-withdrawal (Table 5.39). This could possibly indicate that primary caregivers felt that they had gained something from the feedback they were receiving and thus wanted to continue with the training.

#### **6.2.2.4 Follow-up**

In the past nurses were often seen as the “*experts*” who had all the answers, with the result that follow-ups were to some extent based on fears of primary caregivers (Jennings, 1984). However, with the move away from the medical model of service delivery to the social model, the importance of primary caregivers as “*partners*” in the rehabilitation process came to the fore (Buysse *et al.*, 1994; Meissels, 1992). Nurses and primary caregivers should jointly identify the problem and plan service delivery (Downs & Walker, 1996). This is followed by a process of continuous follow-up by both partners to monitor progress and to modify services (Buysse *et al.*, 1994). The extent to which caregivers thus attend follow-up visits is no longer driven by fear, but rather by empowerment as the community nurse is seen as a warm and sensitive partner in the rehabilitation process with empathy for the CSD and the family. In addition, for follow-ups to be successful, the nurses should be viewed as having specialised knowledge and expertise in the rehabilitation field. In other words, the caregivers should feel that the nurse has valuable information to share.

In the present research it was clear that nurses became aware of the importance of including primary caregivers as part of the team “... *to make them work together*” (Appendix P). In addition, nurses’ knowledge and skills increased, as described in Section 6.2.2.4, facilitating follow-up. During the pre-training phase none of the nurses highlighted the importance of follow-up visits as a general nursing skill (Table 5.41), but post-training two nurses included it. The increase in the number of CSDs receiving services (Table 5.39) is possibly also attributable to closer collaboration between nurses and primary caregivers. This could possibly in turn be related to the improved knowledge and skills of community health nurses and their sharing of these knowledge and skills.

### **6.2.3 Level 3 Cross-training of administrative skills**

On Level 3 of the multiskilling levels the nursing task that impacts on disability is prevention. Prevention can be defined as “*the elimination of factors which interfere with the normal acquisition and development of communication disorder*” (Stokes, 1997, p.139) which can be congenital (e.g. chromosomal abnormalities, hereditary conditions,

etc.), or acquired (e.g. trauma). Primary, secondary and tertiary levels of prevention should be available to families of CSDs, depending on how pervasive the problem is (Brandt & Magary, 1995; Roberts *et al.*, 1998). Although all team members (including the primary caregivers and professionals) are involved in prevention, the focus differs throughout the phases. In primary prevention the primary caregivers (parents) are the most prominent, in secondary prevention the community health nurse takes the lead, while tertiary prevention is the domain of the therapists (physiotherapist (PT), OT and SLP).

#### **6.2.3.1 Prevention**

The primary focus of the BCIP training was not on preventing disability in the given health care district (Moretele), but it had tangency with prevention at all three levels with a focus on secondary prevention.

Primary prevention involves providing caregivers with information that will enable them to make decisions that will promote their child's development prior to the development of problems (Freeman & Heinrich, 1981; Roberts *et al.*, 1998). In this research it involved explaining the concepts “*disability*” and “*communication*” and its four major components to primary caregivers, so that they can monitor their children and bring them to the clinic betimes should any problems arise. Primary prevention also aims at reducing an individual's susceptibility to disability by eliminating conditions contributing to disability. This should start early, even before the birth of a child (e.g. foetal screening) (Kaplan-Sanoff *et al.*, 1991; Stokes, 1997). As part of the BCIP training, nurses were made aware of peri-natal factors that can cause disability. Prior knowledge revealed that nurses were aware of these factors (18 of the 20 nurses had this question correct pre-training) and 19 during the post-withdrawal period (Table 5.3). Fewer nurses were aware of environmental factors that could cause disability.

Secondary prevention is aimed at achieving early identification and thus early referral for further assessment and treatment (Clark, 1996; Stokes, 1997). This implies that the

community health nurse adopts the role of early detector and referral source by directing primary caregivers to other possible resources, e.g. the social worker (for information on disability grants), genetic counselling (for family planning), OT (for seating and mobility), etc. This aspect will not be further discussed, as the information pertaining to early identification is further discussed in Section 6.2.4.1 while referral was discussed in Section 6.2.2.2. In addition, secondary prevention also highlights the community health nurse's role as information source and role model as it entails the modelling of appropriate behaviours to families as well as providing them with relevant information to enable them to make appropriate and knowledgeable decisions about their child's rehabilitation (Freeman & Heinrich, 1981; Roberts *et al.*, 1998). This aspect was discussed in detail in Section 6.2.2.1.

In the absence of available rehabilitation to CSDs by different professionals as seen in PHC clinics in South Africa, the need for community nurses to provide services to this population at a secondary level of prevention cannot be overlooked. The aim of the BCIP training, through multiskilling, was to enable community nurses to provide services to CSDs by means of training their primary caregivers in the utilisation of the BCIP. It should be highlighted that the aim is not for one professional (e.g. the community health nurse) to take over the role of another (e.g. OT, PT and/or SLP) but rather to provide them with the basic skills to facilitate service delivery. The outcomes of the BCIP training on service delivery will be described in more detail in Section 6.2.4.2.

Finally, tertiary prevention relates to the direct provision of rehabilitation services to CSDs and is aimed at restoring, as far as possible, the effective functioning of the individual (Roberts *et al.*, 1998; Stokes, 1997). This is usually conducted by therapists, and was consequently not the main focus of the BCIP training.

#### **6.2.4 Level 4 Cross-training of clinical disciplines**

Early identification and screening is defined as the implementation of a formal plan for locating and identifying a disability as early as possible in a child's life (Ralls, 1987).

Simply locating and identifying these children is not enough. Service delivery to minimise the effects of disability should be provided. The purpose of identification is thus action. These two aspects will now be described in detail.

#### **6.2.4.1 Identification and screening**

Implicit in all identification and screening procedures with children is the idea of “*the earlier, the better*” (Shonkoff & Meisels, 2000). The first step in the identification of disability can be regarded as the location of these children (Ralls, 1987). Perhaps one of the most effective ways of doing this continues to be the education of the community by raising awareness on disability issues. Nurses provide valuable information to the community by means of health talks. This aspect was described in detail in Section 6.2.2.1.

In addition, nurses need to attend workshops and training to learn more about disability and how it impacts and limits active participation in the community. Nurses should also be made more aware of the services available to CSDs and the ways in which they can assist the primary caregivers of CSDs to access these services. These aspects were addressed during the BCIP-training. The ICIDH-II classification which emphasises community participation was used as a classification system. In addition communication for CSDs (with emphasis on communication means, functions, partners and temptations) was covered. In Tables 5.3, 5.4 and 5.5 it is clearly shown that nurses’ knowledge increased statistically significantly between the pre-training phase and the phases that followed. Although the impact of increased knowledge on the identification of CSDs was not tested in the present research it is hypothesised that increased knowledge will impact positively on the location and consequent identification of CSDs.

Nurses also became more aware of the importance of obtaining a relevant and complete case-history as part of identifying a CSD. Pre-training, only six nurses regarded this as a nursing skill needed in working with CSDs (Table 5.42) but post-training eight nurses became aware of this. It is also important to note that pre-training thirteen nurses had

indicated that they would like to receive more training in interviewing primary caregivers and communicating with them (Table 5.43) but post-withdrawal this figure declined to only three. This might indicate that nurses felt that this need was addressed during the BCIP training.

Although the BCIP does not contain a formal screening tool, a progress checklist is included. This checklist covers the four most important aspects covered during the training, and nurses were instructed to use this as the first step of service delivery in order to obtain baseline data. Table 5.43 indicates that pre-training none of the nurses regarded screening and monitoring progress as important, but at the end of the training five nurses mentioned this aspect as did four at the end of the five month withdrawal period.

After this, community health nurses can refer the CSDs and primary caregivers if more specific information is required, e.g. on disability grants, sophisticated positioning equipment, etc. Nurses should be equipped to provide basic information regarding the disability and intervention for an interim period. Rural health clinics are often far from secondary or tertiary health care centres and transport difficulties are abundant, which may result in a long time lapse between the referral period and when the referral visit is actually done. Referral should thus never preclude the community health nurse offering the CSDs and primary caregivers advice and/or support (Jennings, 1984). Referral, and the way the BCIP training impacted on this aspect was described in detail in Section 6.2.2.2.

#### **6.2.4.2 Service delivery**

Once the disability has been identified, service delivery should commence. As CSDs and their families often live in remote rural areas community nurses are often the only persons available to provide services (Downs & Walker, 1996). Therefore CSDs and their primary caregivers should receive comprehensive holistic services “*on the spot*”(Lequerica, 1997). In order to achieve this, professional training should be expanded so that community health nurses become multiskilled enabling transdisciplinary service

delivery to primary caregivers of CSDs. This is the nursing task where community nurses required the most input as service delivery mostly focused on direct referral (discussed in Section 6.2.2.2). Consequently, this is where the emphasis of the BCIP training fell.

It is interesting to note that over the past two decades there has been a change from an unofficial taboo to official endorsement of primary caregiver involvement in the rehabilitation of their children as the positive effects of active caregiver involvement became clearer (Blumberg, 1987). A basic tenet of the BCIP training is that as primary caregivers are nurtured and receive more knowledge and skills through training, they become empowered to nurture and train their CSDs.

Two primary outcomes that impact directly upon service delivery were achieved with the BCIP training. The first pertains to the nurses' knowledge and the second to their skills. Figure 5.2 shows that there was a global increase in both of these aspects following the training, which continued to increase even after training had ended. When looking at knowledge specifically, it can be seen that prior knowledge regarding disability and communication increased over time (Tables 5.3, 5.4 and 5.5). It also became evident that nurses were able to apply their knowledge to specific case studies (Table 5.8). Applied knowledge was related to the identification of communication means (Table 5.11), communication functions (Table 5.13) and communication partners (Figure 5.3) as well as to the way communication opportunities for CSDs could be increased (Table 5.22). With all four these aspects it became clear that there was not only an increase in the frequency of responses (indicating that nurses identified these aspects easier and more regularly) but there was also an expansion of the range of all of the aspects they identified, i.e. pre-training only six communication functions were identified, which increased to ten post-training and to 12 during Follow-up 2 (Table 5.18).

However, in the PHC context, knowledge should be intertwined with skills. As expressed so aptly by Bruner "*It matters not what we have learned. What we can do with what we have learned; this is the issue...*" (cited in Brewer, 1985, p.3). During training the nurses received hands-on instruction in the utilisation of the BCIP. Results indicated that

statistically significant changes were obtained in their skills between the pre-training measurement and all the following research phases (Table 5.26). Specific skills that increased over time was the skill in representational level grading (Table 5.27) which indicates that nurses were aware of the appropriate level of representation at which to start training. Their skills in the use of the BCIP elements in providing the particular child described in the case study with choices during a mealtime activity also increased statistically significantly. This included elements such as using photographs for communication (Table 5.29), communication boards (Table 5.30), manual signs (Table 5.31) and skill in using the EasyTalk 4 Option digital speaker (Table 5.32).

It is also important to note that despite the increase in skills, nurses did not become more dependent on prompts. Figure 5.4 shows that the number of prompts required remained fairly consistent over time. Results also indicated that the nurses' confidence increased over time as there was a statistically significant improvement in confidence between the pre-training measurement and the fourth measurement (Follow-up 2) on the 10% level and a statistically significant difference between the pre-training and post-withdrawal period on the 5% level (Table 5.33). This indicates that confidence continued to increase over time as nurses became more familiar and skilled in using the BCIP.

### **6.3 IMPACT OF THE BCIP TRAINING ON ACHIEVING THESE OUTCOMES**

It is clear from the above discussion that the BCIP training significantly impacted on community health nurses' knowledge and skills regarding service delivery to CSDs and their primary caregivers. Possibly the single most important measurement of the effectiveness of the BCIP training lies in the fact that 11 of the nurses stated that this training should form part of the basic nursing curriculum (Table 5.51). This was also emphasised during the focus group discussions (Appendix P).

Due to the profile of the participants (Table 4.15), the BCIP training incorporated principles of adult teaching and learning. It is, however, crucial to determine what the

specific training principles were that facilitated this change in knowledge and skills. Although the training methodology and training content were separated in Chapter 5 for easier reference and clarity, it is important to integrate these aspects when discussing the results as content and methodology impacted jointly on and influenced each other in achieving the outcomes. Each of the important BCIP training principles will be described in turn.

### 6.3.1 Interactive nature of the BCIP training

The BCIP training is interactive and aims to provide community health nurses with knowledge and skills that will enhance their service delivery to CSDs and their primary caregivers. A number of specific strategies were used to facilitate interactivity, as it is well-documented that participants are more motivated when a variety of teaching methods are used (Caffarella, 1994). Firstly, case studies were used (this is discussed in more detail in Section 6.3.2.). Secondly, lectures were enhanced by the use of group discussions to facilitate the acquisition of knowledge. During the post-withdrawal period two nurses commented that the theory was one of the aspects that they most enjoyed (Table 5.50). Thirdly, role-play in small groups was used, during which time nurses were divided into groups of three, providing each nurse with the opportunity to take on the role of the nurse, the primary caregiver and the CSD. As there were twenty participants, the research assistant participated actively in one group to make up for the third person. This type of role-play requires the active involvement of each participant to fulfil a particular role during the activity. Three nurses commented that role-play was one of the aspects of training that they enjoyed most (Table 5.47). It should be noted that all of these techniques require high participant involvement (Caffarella, 1994). The nurses found this type of training demanding at first as they were not accustomed to it, but were later able to see the advantages (Appendix P). Fourthly, video observations with critical group discussions were included. Care was taken to ensure the authenticity of the videos, and during post-training four nurses commented that it was one of the aspects they most enjoyed (Table 5.47), while three nurses said that the use of videos could be increased

(Table 5.48). This comment was possibly made because the participants could see the advantage of using videos.

The fifth strategy that was incorporated into the BCIP training to ensure interactivity, relates to the relationship between the trainer and participants (nurses). This process should be characterised by facilitation and co-operation rather than control (Maehl, 2000). In addition, the trainer should also provide positive reinforcement (Heimlich & Norland, 1994). The presence of the trainer throughout the five-month training period impacted on the research, resulting in the so called Hawthorne effect as the participants wanted to please the trainer “*Let me not disappoint Juan*” (Appendix P). It can therefore be argued that the presence of the trainer throughout the training programme might be of value as it acts as a secondary motivation, while at the same time it might impact negatively on the sustainability of the programme as participants might only work for the praise of the trainer. A duplication of the training that does not use the same person as trainer and during the follow-ups will provide more information on this aspect. Directly post-training eleven of the nurses commented on the positive training atmosphere and the fact that they greatly enjoyed the training (Table 5.51). Finally, interactivity was underpinned by the logistical arrangements – a positive climate for learning was created from the moment the participants arrived with training orientation and appropriate introductions (Heimlich & Norland, 1994). All participants wore name labels on the first and second days to facilitate interaction, after which it was no longer necessary as everybody was on first-name terms.

### **6.3.2 Use of a problem-based approach**

One of the basic principles of problem-based learning includes the use of case studies based on real life experiences (Givens-King, Sebastian, Stanhope & Hickman, 1997; Savin-Baden, 1997). Care was taken to ensure authenticity of the case studies used in the BCIP and they were compiled after focus groups had been conducted with nurses, primary caregivers of typically developing children and primary caregivers of CSDs in the particular health district. All the nurses (100%) commented on the appropriacy of the

case studies (Table 5.46). This was further emphasised during the final focus group with nurses (Appendix P) when they commented that the case studies were relevant and that it “*makes us not to forget some of the things*”. However, 16 of the nurses stated that the use of live case studies would have further enhanced the quality of the training (Table 5.48).

### 6.3.3 Repetition and review

Each morning of the five-day in-service training started with a review of the most important concepts discussed the previous day. Complete handouts were given and during the focus group discussion nurses stated that the handouts enabled them to do independent review (Appendix P).

Case studies were revised in a creative way. As mentioned in Chapter 4, four different case studies were used for the different training periods to combat overfamiliarity and boredom and to stimulate creative thinking and problem-solving. The content of the case studies remained fairly consistent, with minor variations, e.g. the names of the CSD and the primary caregiver differed as did the CSDs gender and age (ranging between five and six), the objects used for communication (e.g. mug, spoon, plate) as well as the mother’s occupation (hairdresser from home, clothing alterations done from home, spaza shop from home and selling food from home). The same case study was used for the pre-training and post-withdrawal periods as it was assumed that with the five-month lapse, nurses would not remember the details.

### 6.3.4 Transfer of learning

Any effective training programme aimed at making a difference in current practices should assist with the transfer-of-learning (systematically think about how the programme can be applied in their own work context) (Caffarella, 1994). In the BCIP training this was achieved by means of follow-up sessions that involved case studies. These follow-ups provided interactive hands-on skills and practise opportunities which

optimised learning. Post-training six nurses said that the follow-ups were fruitful and should continue (Table 5.48). During the focus groups nurses spontaneously verbalised what the advantages of the follow-ups were without the facilitator probing for this information (Appendix P). Nurses felt that follow-ups helped them to problem-solve difficult cases, that it served a review role “*makes us not to forget some of the things*”, provided them with the opportunity to practise new knowledge and skills if they did not have any other exposure to a CSD “*helped us to visualise*” and it also acted as an independent trigger for review “*after the follow-up I started to recall them and I started to read*”. Due to the fact that the trainer was regarded as a partner in the training process and nurses were not threatened by the nature of the follow-up “*it wasn’t a big deal*”.

Transfer of learning is embedded within the content of learning and is usually identified by the specified learning objectives (Heimlich & Norland, 1994). Each of the handouts used in the BCIP training contained the objectives for the particular day (Appendices O1 – O5). These objectives were discussed at the beginning and end of each day. During the focus group discussion it was mentioned that the initial in-service training objectives had been met and that this impacted positively on their expectations during the follow-up phases (Appendix P).

Various sources were used to compile the content of the training. This was necessary in order to ensure that the training content was authentic and also to ensure that the most important theoretical concepts were covered. Authenticity was ensured by conducting focus groups with community health nurses and primary caregivers of typically developing children and primary caregivers of CSDs respectively in the particular area. A sound theoretical base was ensured by consulting the relevant, reputable literature and by discussions with experts in the field.

These strategies bore fruit as during the post-withdrawal phase 100% of the nurses felt that the handout was useful and 95% felt that the BCIP was useful and that it enabled the independent planning of services to CSDs and their primary caregivers (Table 5.49). Four nurses were still unsure of the ease of using the BCIP during the post-withdrawal phase

while one said that it was difficult to use. This might be because these nurses did not have the opportunity to practise using the BCIP, or the fact that they had started implementing it and became more aware of the pitfalls and difficulties involved in service delivery to CSDs and their primary caregivers. Aspects that nurses would have liked more information on related to communication means, working with primary caregivers, strategies to use with specific disability types and the planning of a service delivery programme for a CSD and monitoring progress (Table 5.51). It is interesting to note that during the post-training phase none of the nurses had commented on working with primary caregivers, but during post-withdrawal four nurses had regarded this as a need. This might possibly be due to the fact that they became more aware of the challenges when working with primary caregivers as partners in the training of their CSDs. Nurses also commented that the length of training was too short and suggested that it be expanded to at least two weeks (Appendix P). In addition they found the whole day training tiring. This might be due to the fact that they were mostly older and not used to spending a whole day in training. Despite the fact that half of the nurses felt that the training time should be increased (Table 5.48) all of them felt that there was sufficient time for questions and answers (Table 5.46). This possibly implies that they found the content to be overwhelming at first and that they needed more opportunities for role-play, videos and group discussions.

Apart from the specific techniques included in the BCIP training to enhance the nurses' acquisition and retention of new knowledge and skills, it should also be noted that learning is affected by a number of extrinsic factors. This includes the amount of past learning of the individual and his/her intrinsic motivation (Heimlich & Norland, 1994). Although years of experience and previous training in the disability field was asked in Response Form II, this information is difficult to quantify and control. These aspects impacted on the specific outcomes that were obtained.

#### **6.4 SUMMARY**

Chapter 6 interpreted and discussed the most important findings of the research. It clearly demonstrates the impact that the BCIP training had on the knowledge and skills of community health nurses. Although attitudes did not change statistically significantly, focus group's discussions indicated that community nurses perceived their role regarding services towards CSDs and their primary caregivers more positively. It was not anticipated that attitudes would change significantly, as this was not the focus of the BCIP training. Outcomes of the BCIP training were integrated with the various nursing tasks required from community health nurses working with CSDs and their caregivers. A final conclusion is that specific aspects of the BCIP training facilitated the process of knowledge and skills acquisition in adult learners, namely taking an interactive, problem-based approach to training that includes creative repetition and revision to facilitate the transfer of learning.

## CHAPTER 7

# SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

### 7.1 INTRODUCTION

This chapter contains a summary of the research and conclusions regarding the development and implementation of the BCIP with community health nurses. The purpose of this research was to equip community health nurses to function as transdisciplinary professionals by providing them with the skills (through multiskilling) to provide training to the primary caregivers of CSD's (training-the-trainer) at a PHC level. This is followed by a discussion of the clinical implications of the research. The research is also evaluated in terms of limitations and strengths. Finally, recommendations for further research are made.

### 7.2 SUMMARY OF RESULTS AND CONCLUSIONS

The purpose of this research was to develop and apply a protocol for training community health nurses who work in PHC settings to increase their knowledge and skills about beginning communication skills (i.e. informational and social communication functions using aided and unaided communication means, creating content for interaction by using ADL and fostering adult and peer communication partners). This protocol is intended to assist community health nurses when training primary caregivers of CSDs to facilitate interaction with their children. Data for the development of the BCIP were obtained through the use of questionnaires and focus groups with various stakeholders while data for the application of the BCIP were obtained through the use of questionnaires (to obtain information about knowledge), structured interviews during which nurses had to demonstrate their skills in the application of the BCIP, and a focus group during which the BCIP training was discussed. The BCIP training consisted of one week training with three

follow-up visits (two weeks, six weeks and five months post-training) during which time problem areas were identified and problems solved.

The BCIP was developed by consulting relevant literature, experts in the field as well as stakeholders in the Moretele Health District to ensure authenticity and cultural sensitivity. This ensured that the content was applicable to the context (e.g. not play-based but based on ADL), terminology used was familiar to participants (e.g. “*nurturance*” was replaced with “*care*”, “*tangible objects*” with “*real objects*” etc.), the communication means that were selected were appropriate (e.g. inclusion of a low cost digital speaker as well as manual signs and PCS that are relatively easy to reproduce), the communication functions that were selected were appropriate and viewed as important (e.g. establishing whether it was culturally appropriate for children in this area to initiate interaction) and also to determine if the communication temptations that were selected were easy to learn. In addition, the communication boards used in all three activities were translated into all 11 official languages. The languages that occurred most frequently in the particular environment were field tested on typically developing five and six-year olds. After the development of the BCIP a pilot study was conducted, revisions were made and the BCIP implemented.

Training as a whole contributed to a change in the community health nurses' behaviour - prior knowledge and applied knowledge (in terms of communication means, functions, partners, opportunities and general advice) increased statistically significantly at the 5% confidence level. Nurses were not only able to recognise different communication means, functions, partners and opportunities easier (as displayed in a higher frequency of these respective aspects) but they were also able to identify a wider range of aspects. This research also indicated that the nurses' skills in grading aspects according to representational levels, in using objects and photographs for communication, using communication boards, using manual signs and using the EasyTalk 4-Option digital speaker increased statistically significantly over the five months period. In addition, their dependence on prompts did not increase, while their confidence in demonstrating these skills increased.

This implies that the content and methodology of the training was successful in achieving the aims of the research, namely equipping community health nurses with the knowledge and skills to provide services to CSDs and their primary caregivers.

The changes related to the behaviours directly addressed in the training (namely knowledge and skills) increased significantly, while peripheral behaviours (namely attitudes, job satisfaction and type of service delivery provided) showed some form of improvement, but not significantly.

### **7.3 CLINICAL IMPLICATIONS**

The most important implication of this research is that a short training course (one week) with follows-ups can be used successfully in the in-service training of community health nurses. The other implications are as follows:

- The importance of case-orientated (problem-based) training confirmed the relevance of using adult training principles (e.g. an interactive approach that used

opportunities for role-play, group discussions, video observations and included creative repetition and revision) to facilitate the transfer of knowledge and skills.

- Follow-up visits formed a crucial part of the training to increase the relevance of the training principles in the particular settings where the respective nurses worked.
- Community health nurses can be effectively equipped with knowledge and skills to facilitate the communication training of CSDs and their primary caregivers.

## EVALUATION OF THE RESEARCH

- The BCIP is relevant in addressing the changes that were targeted in community health nurses, namely increasing their knowledge and skills related to the communication means, functions, opportunities and partners of CSDs.
- Knowledge and skills were mastered in the given timespan, namely a weeklong training with three follow-up visits.
- The research was conducted in a specific health district (Moretele), limiting the generalisation of findings.
- The participants were mostly older, experienced community health nurses. No nursing assistants were included. This limits the application of the findings to the total community health nursing profession.
- The sample (20 community health nurses) was selected by means of purposeful sampling (they were selected from a group of 74 who indicated that they were keen to receive this training). This implies that community health nurses were

already motivated when training commenced, with a possibility of skewing data to the positive side.

- A sleeping control group would have enhanced the reliability of the research findings. However, due to the way in which nurses interact with each other (in informal and structured ways) results could be contaminated.
- The research design included pre-training measurements, a weeklong training and three follow-up visits that were conducted in situ. In order to heighten the reliability and validity of the data, all structured interviews (Response Form I) were video recorded and rated by an independent rater.
- The measurement of certain constructs, e.g. job satisfaction and motivation was of limited use. In both instances the Hawthorne effect seemed to have prevailed, as scores were positive before training.

#### **7.4 RECOMMENDATIONS FOR FURTHER RESEARCH**

Recommendations for future research are follow:

- A comprehensive approach to PHC aims at equipping personnel (e.g. community health nurses in this research) with many different skills. This could lead to insecurity about their primary roles and responsibilities which, to a large extent could impact on job satisfaction and motivation. The relationship between multiskilling and job satisfaction, and between multiskilling and motivation to work with CSDs and their primary caregivers should be further investigated.
- In the present research nurses were mostly older and experienced resulting in greater maturity. They had therefore experienced a need for training in this regard in their workplace, providing them with the impetus to upgrade their knowledge

and skills. It would be interesting to apply the BCIP to a group of younger nurses with less experience and lower qualifications. Younger nurses with less experience might not have the same motivation to acquire these knowledge and skills.

- The focus of the present evaluation was based on an external evaluation by the researcher. This focus should be broadened to include more opportunities for self-evaluation. A self-evaluation after each of the research phases will promote a reflection on practice and will guide participants to keep track of their own development. It will also enhance their awareness of the elements of the BCIP and the skills required to provide services to CSDs and their primary caregivers. Self-assessment is also in line with using a problem-based approach as it advocates that participants should provide information about their ability to solve problems, to retrieve information, to find new solutions to problems and to be creative.
- A comparison between the present methodology that was followed (e.g. interactivity, a problem-based format, creative repetition and revision) and distance training will yield interesting results.
- The validity of the BCIP could be formally investigated.
- The hierarchical developmental levels of representation of different AAC means (e.g. objects, miniatures, photographs and line-drawings) could be further investigated to obtain a sound research base regarding the ease of acquisition of each of these means. In addition, the cultural impact on the ranking of these representational levels could also be further explored.
- In evaluating the training, 80% of the nurses commented that the presence of real cases would have further enhanced the quality of training. This aspect should be explored further and alternatives investigated. Nurses could possibly be exposed

to real cases on the fifth (and final) day of the formal training after having had ample opportunity for role-play. Another alternative would be to make it compulsory for nurses to have a CSD and primary caregiver available on the days of the follow-up visits to demonstrate their skills and for the trainer/researcher to assist with problem-solving certain aspects.

- Reduplication of the same training procedures using an independent trainer would be interesting in view of the Hawthorne effect demonstrated in some of the data.
- Conducting a follow-up visit one year post-training to determine the long term retention of knowledge and skills.
- Regarding further development of the BCIP, a screening tool, based on the BCIP principles, could be developed to facilitate the identification of children in need of BCIP intervention.

## 7.5 SUMMARY

This chapter summarises the results of the research as described in Chapter 5 and discussed in Chapter 6. The implications of equipping community health nurses with the knowledge and skills to act as transdisciplinary professionals (through multiskilling) when delivering services to CSDs and their primary caregivers, are addressed. The clinical implications of the research were pointed out, which led to a critical evaluation. This, in turn, produced recommendations for future research.

In general this research attempted to describe multiskilling as an element of transdisciplinary training as embedded in PHC and necessitated by the diverse and complex needs of CSDs and their primary caregivers. In this process it answered some research questions, while at the same time creating some new questions from which to start future research.

## References

---

**Allerton, H.** Here to stay. *Training and development*, 51(3), 10-11.

**American Association of Colleges of Nursing.** (1996). Position statement: Interdisciplinary education and practice. *Journal of Professional Nursing*, 12(2), 119 – 123.

**ASHA.** (1989). Communication-based services for infants, toddlers and their families. *ASHA*, 31, 32-34.

**ASHA.** (1996). Technical report of the ad hoc committee on multi-skilling. *Supplement No 16 to ASHA*, 38(2), 53-61.

**Atkins-Burnett, S., & Allen-Meares, P.** (2000). Infants and toddlers with disabilities: Relationship-based approaches. *Social Work*, 45(4), 371-380.

**Babbie, E., & Mouton, J.** (2001). *The practice of social research*. Cape Town, South Africa: Oxford University Press Southern Africa.

**Bailey, D.B., Simeonsson, R.J., Yoder, D., & Huntington, G.S.** (1990). Preparing professionals to serve infants and toddlers with handicaps and their families: An integrative analysis across eight disciplines. *Exceptional Children*, 57(1), 26–35.

**Barrows, H.S.** (1985). *How to design a problem-based curriculum for the preclinical years*. New York: Springer-Verlag Publishing Company.

**Beckwith, L., & Sigman, M.D.** (1995). Preventative intervention in infancy. *Child and Adolescent Psychiatric Clinics of North America*, 4(3), 683–700.

**Beukelman, D.R., & Mirenda, P.** (1998). *Augmentative and alternative communication. Management of severe communication disorders in children and adults* (2<sup>nd</sup> ed.). Baltimore: Paul H. Brookes Publishing Company.

---

## References

---

- Bjäräs, G., Haglund, B.J.A., & Rifkin, S.B.** (1991). A new approach to community participation assessment. *Health Promotion International*, 6(3), 199–206.
- Blacklin, J., & Crais, E.R.** (1997). A treatment protocol for young children at risk for severe expressive output disorders. *Seminars in Speech and Language*, 18(3), 213–237.
- Blackman, J.A.** (1995). *Training and continuing education in early intervention*. Rockville, MA: Aspen Publishers.
- Blackstone, S.** (1995a). AAC teams. How do we collaborate? *Augmentative Communication News*, 8(4), 1–8.
- Blackstone, S.** (1995b). AAC outcomes: Definitions and the WHO. *Augmentative Communication News*, 8(1), 1-3.
- Bless, C., & Higson-Smith, C.** (1995). *Fundamentals of social research methods. An African perspective*. Cape Town, South Africa: Juta & Company Ltd.
- Blischak, D.M., Loncke, F., & Waller, A.** (1997). Intervention for persons with developmental disabilities. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and alternative communication. A handbook of principles and practices* (pp. 299-339). Needham Heights, MA: Allyn & Bacon, Inc.
- Bluma, S., Shearer, M., Frohman, A., & Hilliard, J.** (1976). *Portage guide to early education*. Portage, MI: Portage Printers.
- Blumberg, T.L.** (1987). Parent counselling and training. In M.M. Esterson & L.F. Bluth (Eds.), *Related services for handicapped children* (pp. 69-77). Boston: College-Hill Press.

## References

---

- Bornman, J., & Alant, E.** (1997). A school-based demographic survey of non-speaking children's communication and functional literacy skills. *South African Journal of Education*, 17(1), 15–20.
- Bornman, J.** (1998). It takes two to interact and also a few other skills... *Clinica: Applications in Clinical Practice of Communication Pathology*, 3, 37–48.
- Bornman, J., & Alant, E.** (1999). Training teachers to facilitate classroom interaction with autistic children using digital voice output devices. *South African Journal of Education*, 19(4), 364–373.
- Bornman, J. Alant, E., & Meiring, E.** (2001). The use of a digital voice output device to facilitate language development in a child with developmental apraxia of speech: A case study. *Disability and Rehabilitation*, 23, In Press.
- Bortz, M.A., Jardine, C.A., & Tshule, M.** (1996). Training to meet the needs of the communicatively impaired population of South Africa: A project of the University of the Witwatersrand. *European Journal of Disorders of Communication*, 31(1), 465-476.
- Bradley, V., & Knoll, J.** (1995). Shifting paradigms in services to people with disabilities. In O.C. Karan & S. Greenspan (Eds.), *Communication rehabilitation services for people with disabilities* (pp. 5-19). Boston: Butterworth-Heinemann.
- Bradshaw, P.L.** (1989). Educating Adults. In P.L. Bradshaw (Ed.), *Teaching and assessing in the clinical nursing practice* (pp. 38-63). New York: Prentice-Hall.
- Brandt, P.A., & Magyary, D.L.** (1989). Preparation of clinical nurse specialist for family-centred early intervention. *Infants and Young Children*, 1(3), 51–62.
- Brandt, P.A., & Magyary, D.L.** (1995). Preparation of clinical nurses specialists for family centred early intervention. In A. Blackman (Ed.), *Training and continuing*

## References

---

*education in early intervention. Infants and young children series* (pp. 49-63). Rockville, MA: Aspen Publishers.

**Brayfield, A.H., & Rothe, H. F.** (1951). An index of job satisfaction. *Applied Psychology*, 35(October), 307–311.

**Brewer, I.M.** (1985). *Learning more and teaching less. A decade of innovation in self-instruction and small group learning*. Surrey, England: SRHE & NFER-NELSON.

**Bricker, D.** (1992). The changing nature of communication and language intervention. In S.F. Warren & J. Reichle (Eds.), *Causes and effects in communication and language intervention. Volume 1* (pp. 361-375). Baltimore: Paul H. Brookes Publishing Company.

**Bricker, D.** (1997). *AEPS measurement for birth to three years. Volume 1*. Baltimore: Paul H. Brookes Publishing Company.

**Brink, H.I.** (1999). *Fundamentals of research methodology for health care professionals* (2<sup>nd</sup> ed.). Cape Town, South Africa: Juta and Co Ltd.

**Bronfenbrenner, U.** (1977). Towards an experimental ecology of human development. *American Psychologist*, 32, 513-531.

**Brotherson, M.J., & Goldstein, B.L.** (1992). Quality design of focus groups in early childhood special education research. *Journal of Early Intervention*, 16(4), 334-342.

**Brown, R.I., Baine, D., & Neufeldt, A.H.** (1996). *Beyond basic care: Special education and community rehabilitation in low income countries*. Ontario, Canada: Captus Press Inc.

**Bruno, J., & Dribbon, M.** (1998). Outcomes in AAC: Evaluating the effectiveness of a parent training program. *Augmentative and Alternative Communication*, 14(3), 59-70.

---

## References

---

- Bryman, A.** (1994). The Mead/Freeman controversy: Some implications for qualitative researchers. In R.G. Burgess (Ed.), *Studies in qualitative methodology: Issues in qualitative research. Volume 4* (pp. XXXXXX). Midlesex, England: Jai Press Incorporated.
- Burd, L., Hammes, K., Bornhoeft, D.M., & Fisher, W.** (1988). A North Dakota prevalence study of nonverbal school-age children. *Language Speech and Hearing Services in Schools*, 19(4), 371-383.
- Butterfield, N.** (1995). Getting started. Procedures to assess communicative interactions. In N. Butterfield, M. Arthur & J. Sigafoos (Eds.), *Partners in everyday communicative exchanges. A guide to promoting interaction involving people with severe intellectual disability* (pp. 13-30). Baltimore: Paul H. Brookes Publishing Company.
- Buyssse, V., Schulte, A.C., Pierce, P.P., & Terry, D.** (1994). Models and styles of consultation: Preferences of professionals in early intervention. *Journal of Early Intervention*, 18(3), 302–310.
- Bynner, J., & Sibley, K.M.** (1979). *Social research: Principles and procedures*. London: Longman Group Ltd.
- Calculator, S.N.** (1999). AAC outcome for children and youths with severe disabilities: When seeing is believing. *Augmentative and Alternative Communication*, 15(1), 4-12.
- Calculator, S.N.** (1997). Fostering early language acquisition and AAC use: Exploring reciprocal influences between children and their environments. *Augmentative and Alternative Communication*, 13(3), 149-157.
- Caffarella, R.S.** (1994). *Planning programmes for adult learners. A practical guide for educators, trainers and staff developers*. San Francisco: Jossey-bass Publishers.

## References

---

- Case-Smith, J.** (1997). Clinical interpretation of the efficacy of an early prevention program facilitated by occupational therapists: A follow-up study. *The American Journal of Occupational Therapy*, 51(4), 252-255.
- Chapman, L., & Ware, J.** (1999). Challenging traditional roles and perceptions: Using a transdisciplinary approach in an inclusive mainstream school. *Support for Learning*, 14(3), 104–109.
- Clark, M.J.** (1996). *Nursing in the community* (2<sup>nd</sup> ed.). Stamford, CA: Appleton & Lange.
- Coats, D.L., & Lewis, M.** (1984). Early mother-infant interaction and infant cognitive predictors of school performance and cognitive behaviour in six-year-olds. *Child Development*, 55, 1219–1230.
- Coupe, J., & Goldbart, J.** (1998). *Communication before speech: Development and assessment* (2<sup>nd</sup> ed.). London: Chapman & Hall.
- Cress, C.J., Havelka, S., Dietrich, C., & Linke, M.** (1998, August). *Augmentative Communication Skill Development Checklist: Case examples of young children*. Paper presented at the International Society for Augmentative and Alternative Communication Conference, Dublin, Ireland.
- Croxford, J., & Viljoen, D.** (1999). Alcohol consumption by pregnant women in the Western Cape. *South African Medical Journal*, 89(9), 962-965.
- Culp, D.M., & Carlisle, M.** (1988). *Partners in augmentative communication training. A resource guide for interaction facilitation training for children*. Tucson, AZ: Communication Skill Builders Inc.

## References

---

- Department of Education.** (1997). *Building a brighter future*. Pretoria, South Africa: Department of Education.
- Department of Health.** (1998). *Policy guidelines on the prevention of conditions leading to disability. Draft 5*. Pretoria, South Africa: Department of Health.
- Department of Health.** (1999). *The primary health care package for South Africa – A set of norms and standards*. Pretoria, South Africa: Department of Health.
- Dixon, L.S.** (1981). A functional analysis of photo-object matching skills of severely retarded adolescents. *Journal of Applied Behavior Analysis*, 14(4), 465-478.
- Dochy, F.J.R.C.** (1996). Assessment of Domain-specific and domain-transcending prior knowledge. In M. Birenbaum & F.J.R.C. Dochy (Eds.), *Alternatives in assessment of achievements, learning processes and prior knowledge* (pp. 227-264). Boston: Kluwer Academic Publishers.
- Downs, S., & Walker, D.** (1996). Family support while you wait: Lessons from the Detroit family project. *Zero to Three*, 16(6), 25–32.
- Dublinske, S.** (1983). The nurse and communication disorders in the schools. In S.J. Shanks (Ed.), *Nursing and the management of communication disorders* (pp. 5-53). San Diego, CA: College-Hill Press.
- Dunbar, S.B., & Reed, C.N.** (1999). A Developmental screening program in primary health care: Meeting the challenges of children in low-income families. *Infant-Toddler Intervention. The Transdisciplinary Journal*, 9(2), 195-202.
- Dunst, C.J., Trivette, C.M., & Deal, A.G.** (1994). *Supporting and strengthening families. Volume 1: Methods, strategies and practices*. Cambridge, MA: Brookline Books.

## References

---

- Durand, V.M.** (1990). *Severe behaviour problems. A functional communication training approach*. New York: The Guilford Press.
- Dworkin, P.H.** (2000). Preventative health care and anticipatory guidance. In J.P. Shonkoff & S.J. Meisels (Eds.), *Handbook of early childhood intervention* (2<sup>nd</sup> ed.) (pp. 327-338). Cambridge, England: Cambridge University Press.
- Eayrs, C.B., & Jones, R.P.** (1992). Methodological issues and future directions in the evaluation of early intervention programs. *Child Care, Health and Development*, 18, 15-28.
- Eggbeer, L.** (1995). Expanding the boundaries of paediatric primary health care to support the development of infants, toddlers and their families. *Zero to Three*, 16(1), 1-7.
- Falvey, M.A., Forest, M., Pearpoint,, J., & Rosenberg, R.L.** Building connections. In J.S. Thousand, R.A. Villa & A.I. Nevin (Eds.), *Creativity and collaborative learning. A practical guide to empowering students and teachers* (pp. 347-368). Baltimore: Paul H. Brookes Publishing Company.
- Ferguson, J.** (1996). Something of value to the community. *Indian Life*, 17(4), 13-16.
- Fink, A.** (1995). *How to report on surveys*. London: Sage Publications.
- Fowler, F.J., & Mangione, T.W.** (1990). *Standardized survey interviewing. Minimizing interviewer-related error*. Newbury, England: Sage Publications.
- Frattali, C.M.** Outcomes measurement: Definitions, dimensions and perspectives. In C.M. Frattali (Ed.), *Measuring outcomes in speech-language pathology* (pp. 1-27). New York: Thieme.

## References

---

- Freeman , R.B., & Heinrich, J.** (1981). *Community health nursing practice* (2<sup>nd</sup> ed.). Philadelphia: WB Saunders Company.
- Frey, J.H., & Fontana, A.** (1993). The group interview in social research. In D.L. Morgan (Ed.), *Successful focus groups. Advancing the state of the art* (pp. 20-34). Newbury, England: Sage Publications.
- Fuller, T.D., Edwards, J.N., Vorakitphokatorn, S., & Sermsri, S.** (1993). Using focus groups to adapt survey instruments to new populations: Experience from a developing country. In D.L. Morgan (Ed.), *Successful focus groups. Advancing the state of the art* (pp. 89-104). Newbury, England: Sage Publications.
- Fuller, D.R., & Lloyd, L.L.** (1997). AAC model and taxonomy. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and alternative communication. A handbook of principles and practices* (pp. 299-339). Needham Heights, MA: Allyn & Bacon, Inc.
- Gerber, S., & Kraat, A.** (1992). Use of a developmental model of language acquisition: Applications to children using AAC systems. *Augmentative and Alternative Communication*, 8(1), 19-31.
- Geyer, N.** (1997). The National Qualifications Framework (NQF) – How will nursing education fit in? *Heath SA Gesondheid*, 2(1), 10-16.
- Goldberg, B.** (1993). Translating Data into Practice. *ASHA January 1993*, 45-47.
- Gibson, E.J.** (1969). *Principles of perceptual learning and development*. New York: Appleton-Century-Crofts.

## References

---

**Gilien, N.** (1999). Developmental Disabilities. In J.E. Hitchcock, P.E. Schubert & S.A. Thomas, S.A. (Eds.), *Community Health Nursing: Caring in action* (pp. 535-563). Albany, NY: Delmar Publishers.

**Givens-King, M., Sebastian, J.G., Stanhope, M.K., & Hickman, M.J.** (1997). Using problem-based learning to prepare advanced practice community health nurses for the 21<sup>st</sup> century. *Family Community Health*, 20(1), 29–39.

**Glassman-Feibusch, B.** (1984). The nurse's role with mentally retarded clients: teacher, advocate, listener, doer. *Journal of Community Health Nursing*, 1(4), 225–226.

**Glennen, S.L.** (1998a). Augmentative and alternative communication systems. In S.L. Glennen & D.C. DeCosta (Eds.), *The handbook of augmentative and alternative communication* (pp. 59-96). San Diego, CA: Singular Publishing Company.

**Glennen, S.L.** (1998b). Introduction to augmentative and alternative communication systems. In S.L. Glennen & D.C. DeCosta (Eds.), *The handbook of augmentative and alternative communication* (pp. 1-20). San Diego, CA: Singular Publishing Company.

### Goodman, M. Katz, B., & Greene, V. START REFERENCE

**Goossens', C., Sapp-Crain, S., & Elder, P.S.** (1994). *Communication displayes for engineered pre-school environments*. Solana Beach, CA: Mayer Johnson Company.

**Gordon, J.** (1994). The team troubles that won't go away. *Training*, 31(8), 25.

**Gouws, R.** (1993). *Kommunikasie-interaksie patronen tussen supervisors en studente in die spraakheelkunde* [Communication interaction patterns between supervisors and students in speech-language pathology]. Unpublished MLog thesis, University of Pretoria, Pretoria, South Africa.

## References

---

- Government Gazette No 17910** (1997). *White paper for the transformation of the health system in South Africa. No 17910. Vol. 382.* Pretoria: Government Printers.
- Graham, N.** (1981). Introduction. In J.A. Fox (Ed.), *Primary health care of the young* (pp. 1-5). New York: McGraw-Hill Book Company.
- Granlund, M., & Blackstone, S.** (1999). Outcomes measurement in AAC. In F.T. Loncke, J. Clibbens, H.H. Arvidson, & L.L. Lloyd (Eds.), *Augmentative and alternative communication. New directions in research and practice* (pp. 207-227). London: Whurr Publishers.
- Granlund, M., & Ollson, C.** (1999). Efficacy of communication intervention for presymbolic communication. *Augmentative and Alternative Communication*, 15(1), 25–37.
- Grebin, M.** (1981). Down syndrome. In J.A.Fox (Ed.), *Primary health care of the young* (pp.772-774). New York: McGraw-Hill Book Company.
- Griffel, G.** (1991). Walking on a tightrope: Parents shouldn't have to walk it alone. *Young Children*, 46(3), 40–42.
- Griffith, H.M.** (1994). Nursing's role in the delivery of clinical preventative services. *Journal of Professional Nursing*, 10(2), 69.
- Grissom, B.M.** (1992). Fostering adult learning : Principles for your staff. *Adult Learning*, September/October, 15.
- Guy, R.F., Edgeley, C.E., Arafat, I., & Allen, D.E.** (1987). *Social research methods. Puzzles and solutions.* Boston: Allyn & Bacon, Inc.

## References

---

- Hamel-Bissell, B.P.** (1992). Mental health and illness nursing in rural Vermont: Case illustrations of a farm family. In P. Winstead-Fry, J.C. Tiffany & R.V. Shippee- Rice (Eds.), *Rural health nursing* (pp. 55-78). New York: National League for Nursing Press.
- Hardy, N., & Sturmey, P.** (1994). Portage guide to early education: A rapid training and feedback system to teach and maintain mothers' teaching skills. *Educational Psychology*, 14(3), 345-359.
- Hart, B.M., & Risley, T.R.** (1975). Incidental teaching of language in the preschool. *Journal of Applied Behavior Analysis*, 8, 411-420.
- Heimlich, J.E., & Norland, E.** (1994). *Developing teaching style in adult education*. San Francisco: Jossey-bass Publishers.
- Hesketh, A., & Hopcutt, B.** (1997). Outcome measures for aphasia therapy: It's not what you do, it's the way that you measure it. *European Journal of Disorders of Communication*, 32(3), 189 - 202.
- Hitchcock, J.E.** (1999) Frameworks for assessing families. In J.E. Hitchcock, P.E. Schubert & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 410-446). Albany, NY: Delmar Publishers.
- Hochberg, J.E.** (1962). The psychophysics of pictorial perception. *Audio-Visual Communication Review*, 10(5), 22-54.
- Hoffart, N.** (1991). A member check procedure to enhance rigor in naturalistic research. *Western Journal of Research Practice*, 13(4), 522–534.
- Homan, M.S.** (1999). *Promoting community change. Making it happen in the real world* (2<sup>nd</sup> ed.). Pacific Grove, CA: Brooks/Cole Publishing Company.

## References

---

**House, H., McAlister, M., & Naidoo, C.** (1990). *Zimbabwe: Steps ahead*. London: Catholic Institute for International Relations.

**Huer, M.B.** (2000). Examining perceptions of graphic symbols across cultures: Preliminary study of the impact of culture/ethnicity. *Augmentative and Alternative Communication*, 16(3), 180-185.

**Hurst, K.** (1999). Educational implications of multiskilled health carers. *Medical Teacher*, 21(2), 170-174.

**Humphry, R.** (1995). Families who live in poverty: Meeting the challenge of family-centred services. *The American Journal of Occupational Therapy*, 49(7), 687–693.

**Integrated National Disability Strategy (INDS).** White paper. (November, 1997). Office of the Deputy President, T.M. Mbeki (On-line).  
<http://www.independentliving.org/LibArt/SANatlDisStat3.html>

**Jacobs, T.** (1997). Developing integrated education programmes for occupational therapy: The problem of subject streams in a problem-based course. *British Journal of Occupational Therapy*, 60(3), 134-138.

**Jarvis, P.** (1995). *Adult and continuing education theory and practice* (2<sup>nd</sup> ed.). London: Routledge.

**Jarvis, P., & Gibson, S.** (1997). *The teacher practitioner and mentor in nursing, midwifery, health visiting and the social services* (2<sup>nd</sup> ed.). Cheltenham, England: Chapman & Hall.

**Jennings, K.** (1984). The role of the health visitor. In G. Lindsay (Ed.), *Screening for children with special needs* (pp. 43-62). Kent, England: Croom Helm Ltd.

## References

---

- Jephson, M.B.** (1992). The purposes, importance and feasibility of programme evaluation in community-based early intervention programs. *Journal of Early Intervention*, 16(3), 252–261.
- Johnson, J.M., Baumgart, D., Helmstetter, E., & Curry, C.A.** (1996). *Augmenting basic communication in natural contexts*. Baltimore: Paul H. Brookes Publishing Company.
- Kaiser, A.P., Yoder, P.J., & Keetz, A.** (1992). Evaluating milieu teaching. In S.F. Warren, & J. Reichle (Eds.), *Causes and effects in communication and language intervention. Volume 1*. Baltimore: Paul H. Brookes Publishing Company.
- Kalmanson, B., & Seligman, S.** (1992). Family-provider relationships: The basis of all interventions. *Infants and Young Children*, 4(4), 46-52.
- Kangas, K.A., & Lloyd, L.L.** (1988). Early cognitive skills as prerequisites to augmentative and alternative communication use: What are we waiting for? *Augmentative and Alternative Communication*, 4(3), 211–221.
- Kaplan-Sanoff, M., Parker, S., & Zuckerman, B.** (1991). Poverty and early childhood development: What do we know and what should we do? *Infants and Young Children*, 4(1), 68-76.
- Kelly, J.F., & Barnard, K. E.** (2000). Assessment of parent-child interaction: Implications for early intervention. In J.P. Shonkoff & S.J. Meisels (Eds.), *Handbook of early childhood intervention (2<sup>nd</sup> ed.)* (pp. 258-289). Cambridge, England: Cambridge University Press.
- Kimchi, J., Polivka, B., & Stevenson, J.S.** (1991). Triangulation: Operational definitions. *Nursing Research*, 40(6), 364-366.

## References

---

**Kirk, J., & Miller, M.L.** (1986). *Reliability and validity in qualitative research. Qualitative research methods. Volume 1.* Beverly Hills, CA: Sage Publications.

**Kisanji, J.** (1995). Understanding CBR models. *CBR News*, 19(1), 4.

**Klopper, H.** (1995). Vertrouenswaardigheid strategieë in kwalitatiewe navorsing. [Trustworthiness strategies in qualitative research] *RAUCUR*, 1(1), 25-28.

**Krefting, L.** (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, 45(3), 214-222.

**Krogh, K.S., & Lindsay, P.H.** (1999). Including people with disabilities in research: Implications for the field of augmentative and alternative communication. *Augmentative and Alternative Communication*, 15(4), 222-233.

**Krueger, R.A.** (1988). *Focus groups: A practical guide for applied research.* Newbury, England: Sage Publications.

**Krueger, R.A.** (1993). Quality control in focus group research. In D.L. Morgan (Ed.), *Successful focus groups. Advancing the state of the art* (pp. 65-88). Newbury, England: Sage Publications.

**Leahy, M.M.** (1989). Philosophy in intervention. In M.M. Leahy (Ed.), *Disorders of communication: The science of intervention* (pp. 3-13). London: Whurr Publishers.

**Leedy, P.D.** (1993). *Practical research: Planning and design.* New York: Macmillian Publishing Company.

**Lerner, H., & Ross, L.** (1991). Community health nurses and high risk infants: The current role of Public Law 99-457. *Infants and Young Children*, 4(1), 46–53.

---

## References

---

- Lequerica, M.** (1997). Towards a one-stop model of service for low-income preschoolers: insights from clinical practice and research. *Infant-Toddler Intervention. The Transdisciplinary Journal*, 7(4), 285–300.
- Light, J.C.** (1997). “Let’s go star fishing”: Reflections on the contexts of language learning for children who use aided AAC. *Augmentative and Alternative Communication*, 13(3), 158-171.
- Light, J.C.** (1999). Do augmentative and alternative communication interventions really make a difference? The challenges of efficacy research. *Augmentative and Alternative Communication*, 15(1), 13-24.
- Light, J.C., & Kelford-Smith, A.** (1993). The home literacy experiences of preschoolers who use augmentative communication systems and of their nondisabled peers. *Augmentative and Alternative Communication*, 9(1), 10-25.
- Lincoln, Y.S., & Guba, E.G.** (1985). *Naturalistic inquiry*. London: Sage Publications.
- Lockhart, C.A.** (1999). Health care delivery in the United States. In J.E. Hitchcock, P.E. Schubert. & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 41-62). Albany, NY: Delmar Publishers.
- Louw, B., & Weber, I.** (1997). Attitudes and perception of nurses regarding early communication intervention. *Health SA Gesondheid*, 2(2), 16–22.
- Lloyd, L.L., Fuller, D.R., & Arvidson, H.H.** (1997). Introduction and overview. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and alternative communication. A handbook of principles and practices* (pp. 1-17). Needham Heights, MA: Allyn & Bacon, Inc.

## References

---

- Lloyd, L.L., Quist, R.W., & Windsor, J.** (1990). A proposed augmentative and alternative communication model. *Augmentative and Alternative Communication*, 6(3), 172-183.
- Lowenthal, B.** (1984). Classroom classics: Natural language stimulation for language delayed children. *ICEC Quarterly*, 33(2), 13-15.
- Lundgren-Linquist, B., & Nordholm, L.** (1993). Community-based rehabilitation: A survey of disabled village children in Botswana. *Disability and Rehabilitation*, 15(3), 83-89.
- Maehl, W.H.** (2000). *Lifelong learning at its best. Innovative practices in adult credit programs*. San Francisco: Jossey-bass Publishers.
- Manolson, A.** (1985). *It takes two to talk. A Hanen early language parent guide book*. Toronto, Canada: Hanen Resource Centre.
- Mast, D.L.** (1983). Selecting and implementing augmentative communication methods for children. In S.J. Shanks (Ed.), *Nursing and the management of communication disorders* (pp. 225-250). San Diego, CA: College-Hill Press.
- Matas, J.A., Mathy-Laikko, P., Beukelman, D.R., & Legresley, K.** (1985). Identifying the non-speaking population; A demographic study. *Augmentative and Alternative Communication*, 1(1), 17–31.
- Mavrogenes, N.A., Bezruczko, N., & Hagemann, M.** (1996). Cognitive and family-support mediators of preschool effectiveness: A confirmatory analysis. *Child Development*, 67(3), 1119-1140.

## References

---

- McConachie, H., & Pennington, L.** (1997). In-service training for schools on augmentative and alternative communication. *European Journal of Disorders of Communication*, 32, 277-288.
- McConkey, R.** (1996). *Innovations in evaluating services for people with intellectual disabilities*. Chorley, England: Lisieux Hall Publishers.
- McCormick, L., & Schiefelbusch, R.L.** (1984). *Early language intervention. An introduction*. Columbus, OH: Charles E. Merrill Publishing Company.
- McDaniel, S., Campbell, T.L., & Seaburn, D.B.** (1990). *Family-oriented primary care. A manual for medical providers*. New York: Springer-Verlag Publishing Company.
- McGivern, D.** (1995). Re-entry of students. In D. M. Modly, J.J. Fitzpatrick, P. Poletti & R. Zanotti (Eds.), *Advancing nursing education world-wide* (pp. 139-150). New York: Springer-Verlag Publishing Company.
- McGregor, G., Young, J., Gerak, J., Thomas, B., & Vogelsberg, R.T.** (1992). Increasing functional use of an assistive communication device by a student with severe disabilities. *Augmentative and Alternative Communication*, 8(3), 243–250.
- McLaren, P., Philpott, S., & Hlophe, R.** (1997). *Assistive devices in KwaZulu-Natal*. Howick, South Africa: DPSA.
- Meisels, S.J.** (1992). Early Intervention: A matter of context. *Zero to Three*, 12(3), 1-6.
- Meisels, S.J., & Atkins-Burnett, S.** (2000). The elements of early childhood assessment. In J.P. Shonkoff. & S.J. Meisels (Eds.), *Handbook of early childhood intervention (2<sup>nd</sup> ed.)* (pp. 231-257). Cambridge, England: Cambridge University Press.

## References

---

- Merriam, S.B., & Caffarella, R.S.** (1991). *Learning in adulthood. A comprehensive guide*. San Francisco: Jossey-bass Publishers.
- Mertens, D.M.** (1998). *Research methods in education and psychology. Integrating diversity with quantitative and qualitative approaches*. Thousand Oaks, CA: Sage Publications.
- Miles, S.** (1996). Engaging with the disability rights movement; the experience of community-based rehabilitation in southern Africa. *Disability and Society*, 11(4), 501–517.
- Mitchell, D.R.** (1991). Designing and evaluating early intervention programmes. In D.R. Mitchell & R.I. Brown (Eds.), *Early Intervention studies for young children with special needs*. (pp. 297-326). London: Chapman & Hall.
- Moodley, L., Louw, B., & Hugo, S.R.** (2000). Early identification of at-risk infants and toddlers: A transdisciplinary model of service delivery. *The South African Journal of Communication Disorders*, 47, 25-39.
- Morse, J.M.** (1996). What is a method? *Qualitative Health Research*, 6(4), 467–468.
- Murgatroyd, S., Rustiton, C., Apter, M.J., & Ray, C.** (1978). The development of the telic dominance scale. *Journal of Personality Assessment*, 42, 519-528.
- Murray, M.** (1980). *Fundamentals of Nursing (2<sup>nd</sup> ed.)*. Englewood Cliffs, NJ: Prentice-Hall.
- National Programme of Action (NPA).** (1999). *National programme of action for children in South Africa: 2000 and Beyond*. Pretoria, South Africa: The Presidency.

## References

---

- Newell-Withrow, C.** (1992). A church-based program for the homeless. In A. Graubard (Ed.), *Perspectives in Nursing: 1991 – 1993* (pp. 77-81). New York: National League for Nursing Press.
- O'Grady, C.** (1996). Home is where the start is. *Times Educational Supplement*, 4177, 1-2.
- Orelove, F.P., & Sobsey, D.** (1996). Designing transdisciplinary services. In F.P. Orelove & D. Sobsey (Eds.), *Educating children with multiple disabilities. A transdisciplinary approach*(3<sup>rd</sup> ed.) (pp. 1-33). Baltimore: Paul H. Brookes Publishing Company.
- Orem, D.E.** (1995). *Nursing: Concepts of practice* (5<sup>th</sup> ed.). Baltimore: Mosby.
- O'Toole, B.** (1988). A community-based rehabilitation programme for pre-school disabled children in Guyana. *International Journal of Rehabilitation Research*, 11(4), 323-334.
- Parker, G.M.** (1994). *Cross-functional teams: Working with allies, enemies and other strangers*. San Francisco: Jossey-bass Publishers.
- Parush, S., & Hahn-Markowitz, J.** (1997). The efficacy of an early prevention program facilitated by occupational therapists: A follow-up study. *The American Journal of Occupational Therapy*, 51(4), 247-251.
- Peshkin, A.** (1993). The goodness of qualitative research. *Educational Researcher*, 22, 23–29.
- Piché, L., & Reichle, J.** (1991). Teaching scanning techniques. In J. Reichle, J.York & J. Sigafoos (Eds.), *Implementing augmentative and alternative communication. Strategies for learners with severe disabilities*. Paul H. Brookes Publishing Company: Baltimore.
- Pieterse, M., & Treloar, R.** (1989). *Small Steps. An early intervention program for children with developmental delays*. Sydney, Australia: Macquarie University Press.

## References

---

- Pietranton, A.A., & Lynch, C.** (1995). Multiskilling. A Renaissance or a Dark Age? *ASHA*, 37(6), 37-40.
- Powell, R.M.** (1984). Medical screening and surveillance. In G. Lindsay (Ed.), *Screening for children with special needs* (pp.12-42). Kent, England: Croom Helm Ltd.
- Provence, S.** (1985). On the efficacy of early intervention programs. *Developmental and Behavioural Pediatrics*, 6(1), 363-366.
- Punch, M.** (1986). *The politics and ethics of fieldwork. Qualitative research methods. Series 3*. Beverly Hills, CA: Sage Publications.
- Ralls, M.C.** (1987). Early identification. In M.M. Esterson & L.F. Bluth (Eds.), *Related services for handicapped children* (pp. 35-39). Boston: College-Hill Press.
- Ramey, C.T., Farran, D.D., & Campbell, F.** (1978). Predicting IQ from mother-infant interaction. *Child Development*, 50, 804-814.
- Ramey, C.T., & Ramey, S.L.** (1992). Effective Early Intervention. *Mental Retardation*, 30(2), 337-345.
- Reichle, J.** (1991). Defining the decisions involved in designing and implementing augmentative and alternative communication systems. In J. Reichle, J.York & J. Sigafoos (Eds.), *Implementing augmentative and alternative communication. Strategies for learners with severe disabilities* (pp. 39-60). Baltimore: Paul H. Brookes Publishing Company.
- Reichle, J., Mirenda, P., Locke, P., Piché, L., & Johnson, S.** (1992). Beginning augmentative communication systems. In S.F. Warren & J. Reichle (Eds.), *Causes and*

## References

---

*effects in communication and language intervention. Volume 1.* (pp. 131-156). Baltimore: Paul H. Brookes Publishing Company.

**Reynolds, A., Mavrogenes, N.A., Bezruczko, N., & Hagemann, M.** (1996). Cognitive and family-support mediators of preschool effectiveness: A confirmatory analysis. *Child Development*, 67(3), 1119–1140.

**Rifkin, S.B.** (1986). Lessons from community participation in health programmes. *Health Policy and Planning*, 1(3), 240-249.

**Rifkin, S.B., & Walt, G.** (1981). Why health improves: Defining the issues “comprehensive primary health care” and “selective primary health care”. *Soc Sci Med*, 23(6), 559-566.

**Roberts, R.N., Rule, S., & Innocenti, M.S.** (1998). *Strengthening the family-professional partnership in services for young children*. Baltimore: Paul H. Brookes Publishing Company.

**Romski, M.A., & Sevcik, R.A.** (1988). Augmentative and alternative communication systems: Considerations for individuals with severe intellectual disabilities. *Augmentative and Alternative Communication*, 4(2), 83-93.

**Romski, M.A., & Sevcik, R.A.** (1988). An analysis of visual-graphic symbol meanings for two nonspeaking adults with severe mental retardation. *Augmentative and Alternative Communication*, 4(3), 109-114.

**Rosenthal, N.** (1991). Learning techniques. *Adult learning*, 4, 17.

**Rowland, C., & Schweigert, P.** (1993). Analyzing the communication environment to increase functional communication. *Journal for the Association for Persons with Severe Handicaps*, 18(3), 161–176.

---

## References

---

- Rowland, C., & Schweigert, P.** (2000). Tangible symbols, tangible outcomes. *Augmentative and Alternative Communication*, 16(2), 61-78.
- Ryan, T.A., & Schwartz, C.B.** (1956). Speed and perception as a function of mode and representation. *American Journal of Psychology*, 69(1), 60-69.
- Salvage, J.** (1995). Global trends in nursing education: A World Health Organisation perspective. In D.M. Modly, J.J. Fitzpatrick, P. Poletti. & R. Zanotti (Eds.), *Advancing nursing education world-wide* (pp. 3-13). New York: Springer-Verlag Publishing Company.
- Salvatori, P.** (1997). Towards developing a flexible health workforce. *Canadian Journal of Occupational Therapy*, 64(2), 47–52.
- Sailor, W., & Guess, D.** (1983). *Severely handicapped students and instructional design*. Boston: Houghton Mifflin Company.
- Sameroff, A.J., & Fiese, B.H.** (2000). Transactional regulation: The developmental ecology of early intervention. In J.P. Shonkoff & S. Meisels (Eds.), *Handbook of early childhood intervention (2<sup>nd</sup> ed.)* (pp. 135-159). Cambridge, England: Cambridge University Press.
- Sameroff, A.J., Seifer, R., Barcas, R., Zax, M., & Greenspan, S.** (1987). Intelligence quotient scores of 4-year-old children: Social-environmental risk factors. *Pediatrics*, 79, 343-350.
- Savin-Baden, M.** (1997). Problem-based learning, Part 2: Understanding learner stances. *British Journal of Occupational Therapy*, 60(12), 531-536.

## References

---

- Schlosser, R.W., & Braun, U.** (1994). Efficacy of AAC interventions: Methodologic issues in evaluating behaviour change, generalisation and effects. *Augmentative and Alternative Communication*, 10(3), 207-222.
- Schubert, P., Hitchcock, J., & Thomas, S.A.** (1999). Visions for the future. In J.E. Hitchcock, P.E. Schubert & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 139-157). Albany, NY: Delmar Publishers.
- Sevcik, R.A., Romski, M.A., & Adamson, L.B.** (1999). Measuring AAC interventions for individuals with severe developmental disabilities. *Augmentative and Alternative Communication*, 13(3), 172-178.
- Shanks, S.J** (1983). Communication disorders specialists: Sharing professionals. In S.J. Shanks (Ed.), *Nursing and the management of communication disorders* (pp. 1-4). San Diego, CA: College-Hill Press.
- Shearer, M.S., & Shearer, D.E.** (1972). The Portage project: A model for early childhood education. *Exceptional Children*, 36, 210-217.
- Shine-Hoff, P.** (1995). Adult learning and the nurse. In B. Fuszard (Ed.), *Innovating teaching strategies in nursing* (2<sup>nd</sup> ed.) (pp. 3-8). Rockville, MA: Aspen Publishers.
- Shippee-Rice, R.V., & Mahoney, D.F.** (1992). Training family caregivers of rural elderly. In P. Winstead-Fry, J.C. Tiffany & R.V. Shippee-Rice (Eds.), *Rural health nursing* (pp. 79-125). New York: National League for Nursing Press.
- Shonkoff, J.P., & Meisels, S.J.** (2000). Early childhood intervention: A continuing evolution. In J.P. Shonkoff & S.J. Meissels (Eds.), *Handbook of early childhood intervention*. (2<sup>nd</sup> ed.) (pp. 3-31). Cambridge University Press, England: Cambridge.

## References

---

- Silliman, E.R., & Wilkinson, L.C.** (1991). *Communication for learning. Classroom observation and collaboration*. Rockville, MA: Aspen Publishers.
- Slajmer-Japeli, M.** (1995). Issues in developing a new model for nursing education. In D.M. Modly, J.J. Fitzpatrick, P. Poletti, & R. Zanotti, (Eds.), *Advancing nursing education world-wide* (pp. 105-107). New York: Springer-Verlag Publishing Company.
- Sobsey, D., & Thuppal, M.** (1996). Children with special health care needs. In F.P. Orelove & D. Sobsey (Eds.), *Educating children with multiple disabilities: A transdisciplinary approach (3<sup>rd</sup> ed.)* (pp. 161-216). Baltimore: Paul H. Brookes Publishing Company.
- Solomon, R., Clougherty, S.L., Shaffer, D., Hofkosh, D., & Edwards, M.** (1994). Community-based developmental assessment sites: A new model for pediatric “child-find” activities. *Infants and Young Children*, 7(2), 67-71
- South Africa (Republic).** (1995). *South African Qualifications Authority (SAQA) Act, Act no. 58 of 1995*. Pretoria, South Africa: Government Printer.
- South Africa (Republic).** (1996a). *Constitution of the Republic of South Africa, Act no. 108 of 1996*. Pretoria, South Africa: Government Printer.
- South Africa (Republic).** (1996b). *South African Bill of Rights. Chapter 2 in the Constitution of the Republic of South Africa Act no. 108 of 1996*. Pretoria, South Africa: Government Printer.
- South Africa (Republic).** (1996c). *South African Schools Act, Act no. 84 of 1996*. Pretoria, South Africa: Government Printer.

## References

---

- Spencer, J.C.** (1993). The usefulness of qualitative methods in rehabilitation: Issues of meaning, of context and of change. *Archives of physical medicine and rehabilitation*, 47(1), 119–126.
- Stanhope, M.K.** (1995). Primary health care practice: Is nursing part of the solution or the problem? *Family Community Health*, 18(1), 49–68.
- Steyn, A.G.W., Smit, C.F., du Toit, S.H.C., & Strasheim, C.** (1998). *Moderne statistiek vir die praktyk (6<sup>de</sup> uitgawe)* [Modern statistics for practice (6<sup>th</sup> ed.)]. Pretoria, South Africa: J.L. van Schaik.
- Stokes, S.F.** (1997). Secondary prevention of paediatric language disability: A comparison of parents and nurses as screening agents. *European Journal of Disorders of Communication*, 21(1), 139–158.
- Spady, W.G.** (1994). *Outcome-based education: Critical issues and answers*. Arlington, VA: American Association of School Administrators.
- Tiffany, J.C., & Hourigan, M.** (1992). The role of rural community hospitals: Opportunities and challenges for rural health nurses and nursing. In P. Winstead-Fry, J.C. Tiffany & R.V. Shippee-Rice (Eds.), *Rural health nursing* (pp. 203-227). New York: National League for Nursing Press.
- Thobaben, M., & Biteman, P.** (1999). Rural health. In J.E. Hitchcock, P.E. Schubert, & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 693-714). Albany, NY: Delmar Publishers.
- Thomas, S.A.** (1999a). Historical development of community health nursing. In J.E. Hitchcock, P.E. Schubert & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 17-38). Albany, NY: Delmar Publishers.

## References

---

- Thomas, S.A.** (1999b). Health care systems around the world. In J.E. Hitchcock, P.E. Schubert & S.A.Thomas (Eds.), *Community health nursing: Caring in action* (pp.733-744). Albany, NY: Delmar Publishers.
- Thorburn, M.J., & Marfo, K.** (1990). *Practical approaches to childhood disability in developing countries: Insights from experience and research*. XXXX, Newfoundland: Memorial University of Newfoundland.
- Todd, V.R.** (1993). Frames of reference: Visual perceptual frame of reference: An information processing approach. In P. Kramer & J. Hinojosa (Eds.), *Frames of reference for pediatric occupational therapy* (pp. 177-232). Baltimore: Williams & Wilkins.
- Viljoen, D.** (1999). Foetal Alcohol Syndrome. *South African Medical Journal*, 89(9), 958-960.
- Van Tatenhove, G.M.** (1987). Teaching power through augmentative communication: Guidelines for early intervention. *Journal of Childhood Communication Disorders*, 10(2), 185–198.
- Von Tetzchner, S., & Martinsen, H.** (1992). *Introduction to symbolic and augmentative communication*. San Diego, CA: Singular Publishing Group.
- Webb, C.** (1999). Analyzing qualitative data: Computerized and other approaches. *Journal of Advanced Nursing*, 29(2), 323-330.
- Werner, D.** (1987). *Disabled village children : A guide for community health workers, rehabilitation workers and families*. Palo Alto, CA: The Hesperian Foundation.
- Werner, E.E.** (2000). Protective factors and individual resilience. In J.P. Shonkoff & S.J. Meisels (Eds.), *Handbook of early childhood intervention (2<sup>nd</sup> ed.)* (pp.115-132). Cambridge, England: Cambridge University Press.

## References

---

- Westling, D.L., & Fox, L.** (2000). *Teaching students with severe disabilities* (2<sup>nd</sup> ed.). Columbus, OH: Charles E. Merrill Publishing Company.
- Wilkey, S.F., & Gardner, S.S.** (1999). The varied roles of community health nursing. In J.E. Hitchcock, P.E. Schubert & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 301-334). Albany, NY: Delmar Publishers.
- Willis, E.M., Biggins, A.L., & Donovan, J.E.** (1999). Population-focussed practice. In J.E. Hitchcock, P.E. Schubert. & S.A. Thomas (Eds.), *Community health nursing: Caring in action* (pp. 209-224). Albany, NY: Delmar Publishers.
- Wilson C.C., Lanza J.R., & Barton J.S.** (1988). Developing higher level thinking skills through questioning techniques in the speech and language setting. *Language, Speech and Hearing Services in Schools*, 19(4), 428-431.
- Wolfendale, S.** (1998). Involving parents in child assessment in the United Kingdom. *Childhood Education*, 74(6), 355-359.
- World Health Organisation (WHO).** (1995). *Disability prevention and rehabilitation in primary health care. A guide for district health and rehabilitation managers*. Genev , Switzerland: World Heath Organisation.
- World Health Organization (WHO).** (1998). *ICIDH-2. The International Classification of Functioning and Disability (ICIDH-2)*. (Online). <http://www.who.int/whosis/icidh/index.html>
- World Health Organization (WHO).** (1999). *ICIDH-2. International Classification of Functioning and Disability. Beta-2 draft. Full version*. Assessment, Classification & Epidemiology Group. Genev , Switzerland: World Health Organisation.

## References

---

**World Health Organisation (WHO).** (2001). *ICF. The International Classification of Functioning, Disability and health (ICF)*. (Online). <http://www.who.int/icidh/index.html>

**Year of the Disabled Persons Report (Co-ordinating Committee).** (1987). *Disability in the RSA: Intellectual handicap*. Volume 12. Pretoria, South Africa: Department of National Health and Population Development.

**Zangari, C., & Kangas, K.** (1997). Intervention principles and procedures. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and alternative communication. A handbook of principles and practices* (pp. 137-168). Needham Heights, MA: Allyn & Bacon, Inc.

## LIST OF APPENDICES

<a href="#"><b>APPENDIX A</b></a> (PDF 625KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities
<a href="#"><b>APPENDIX B</b></a> (MPEG video 68,949KB)	Demonstration of the BCIP
<a href="#"><b>APPENDIX C</b></a> (PDF 182KB)	Summary of themes delineated after two independent focus groups with nurses
<a href="#"><b>APPENDIX D</b></a> (PDF 191KB)	Nurses' information: Questionnaire used during needs analysis
<a href="#"><b>APPENDIX E</b></a> (PDF 78KB)	Differences in translations in focus group of caregivers of typically developing children
<a href="#"><b>APPENDIX F</b></a> (PDF 86KB)	Summary of themes delineated after focus groups with caregivers of typically developing children
<a href="#"><b>APPENDIX G</b></a> (PDF 57KB)	Differences in translation in focus group of caregivers of children with disabilities
<a href="#"><b>APPENDIX H</b></a> (PDF 100KB)	Summary of themes delineated after focus group with caregivers of children with disabilities
<a href="#"><b>APPENDIX I</b></a> (PDF 229KB)	Training of interviewers
<a href="#"><b>APPENDIX J</b></a> (PDF 323KB)	Comments on BCIP training in visitors book
<a href="#"><b>APPENDIX K</b></a> (PDF 95KB)	Description of in situ follow-ups
<a href="#"><b>APPENDIX L</b></a> (PDF 208KB)	Response Forms 1.1 to 1.4
<a href="#"><b>APPENDIX M</b></a> (PDF 467KB)	Response Form II
<a href="#"><b>APPENDIX N</b></a> (PDF 150KB)	Response Form III
<a href="#"><b>APPENDIX O1</b></a> (PDF 231KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities: Handout - Day 1
<a href="#"><b>APPENDIX O2</b></a> (PDF 254KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities: Handout - Day 2
<a href="#"><b>APPENDIX O3</b></a> (PDF 205KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities: Handout - Day 3
<a href="#"><b>APPENDIX O4</b></a> (PDF 318KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities: Handout - Day 4
<a href="#"><b>APPENDIX O5</b></a> (PDF 153KB)	Beginning communication intervention protocol (BCIP) for children with severe disabilities: Handout - Day 5

children with severe disabilities: Handout - Day 5

[\*\*APPENDIX P\*\*](#) (PDF 148KB) Summary of themes delineated after focus group with nurses post-training and follow-up

[\*\*APPENDIX Q\*\*](#) (PDF 15369KB) Translations of communication boards into the 11 official South African languages

## APPENDIX A

### BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES

#### An In-Service Training Protocol for Community Nurses

##### AIMS OF THE TRAINING

- To discuss the concept of multiskilling and to highlight the role of community health nurses in the process of training beginning communication skills.
- To discuss the different communication means (including aided and unaided strategies), functions and opportunities for interaction.
- To facilitate the development of skills related to
  - the implementation of unaided strategies (e.g. facial expressions and manual signs)
  - the implementation of aided strategies (e.g. objects, photographs, PCS displayed on communication boards and voice output devices)
  - The creation of ongoing communication opportunities
- To discuss and demonstrate basic augmentative and alternative communication (AAC) intervention principles
- To describe the importance of monitoring progress through the use of a progress matrix

## 1 TRAINING PHILOSOPHY

### 1.1 What is problem-based learning (PBL)?

PBL is a technique aimed at integrating theory and practice. This implies that the focus is not on memorising facts, but rather on how to apply relevant facts, i.e. it is not only important *what* is known, but also how this knowledge is applied (Brandon & Majumdar, 1997).

One of the basic principles of PBL includes the use of case studies based on real life experiences. Time should also be allocated for hands-on experiences.

### **1.2 What are the advantages of using PBL?**

- It uses existing nursing knowledge and skills
- It facilitates critical thinking and problem-solving skills, so that existing knowledge can be applied to new cases
- It facilitates the application of skills to own context at the end of the training (Blackman, 1995; Givens-King, Sebastian, Stanhope & Hickman, 1997; Jacobs, 1997; Savin-Bardin, 1997)

### **1.3 How does one go about answering a case study?**

When answering a case study, it is the process that is important, rather than the answer. This protocol suggests a 5-point plan, adapted from Berger (1980), when answering a case study.

#### **1 Step 1: Clarify the terms and concepts in the problem.**

Ensure that all the terms and concepts are understood. If unsure, consult a dictionary, other group members or the trainer.

#### **2 Step 2: Define the problem**

Determine exactly which aspect of the problem or case study must be addressed

#### **3 Step 3: Analyse the problem**

Brainstorming. Formulate ideas and make assumptions about the case, e.g. if the mother has a spaza shop the customers are potential communication partners. Write down all the ideas without criticism.

When all the ideas have been given, go through all of them and accept or reject them. Ideas might come from:

- Previous knowledge (“*I remember that...*”)
- Attempts to explain aspects of the problem (“*Perhaps what is happening here is...*”)

**4 Step 4: Prepare a systematic answer based on the points identified in**

**Step 3**

Search for possible solutions to the problem. Organise all the information in a systematic way.

**5 Step 5: Report back**

Present methods and findings in some way, e.g. oral feedback, written feedback, transparencies, posters, etc.

**2 INTRODUCTION**

(Start by showing three video cases: one of a child trying to communicate but who is totally unintelligible, one of a child with challenging behaviour and one of a passive child. Discuss the difficulties these children experience).

- Why is it so difficult to work with children with severe disabilities (CSDs)?
  - they cannot make themselves understood easily
  - they may be passive – either partially or completely
  - they may have challenging behaviour
  - they seem to understand more than they are able to communicate
  - they are often not motivated to communicate
  - they often do not have anything to communicate about
  - they often do not have anybody to communicate with

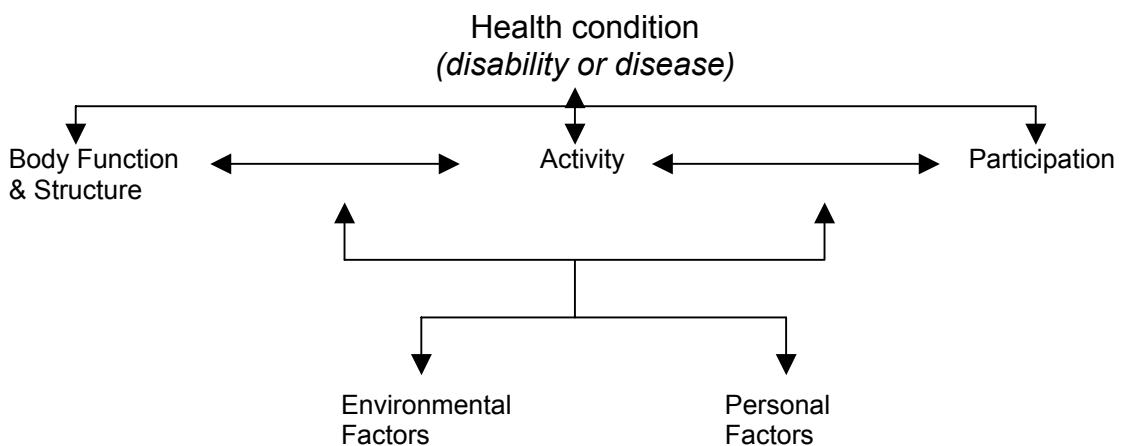
### 3 DEFINING THE CONCEPT...

- What do CSDs have in common?
  - there are no “*typical CSDs*” – they include children with Down Syndrome, intellectual impairment, cerebral palsy, etc.
  - they come from all age, socio-economic and ethnic groups
  - what they have in common is only their degree of dependence on services and support.
  - *“A severely disabled child is one who, because of the intensity of physical, mental or emotional problems, or a combination of such problems, needs educational, social, psychological and medical services beyond those which have been offered by traditional regular and special education programs, in order to maximise his full potential for useful and meaningful participation in society and for self-fulfilment. Such children include those classified as seriously emotionally disturbed (schizophrenic and autistic), profoundly and severely mentally retarded, and those with two or more serious handicapping conditions such as the mentally retarded deaf, and the mentally retarded blind”* (US Department of Education in Sailor & Guess, 1983,p5).
- This protocol uses the ICIDH-2 (International Classification of Functioning and Disability) developed by the World Health Organisation as framework (WHO, 1999)<sup>1</sup>.
- ICIDH-2 looks at functioning and disability from the perspective of an individual's life circumstances and does not attempt to “*label people*”.
- Looks at functioning and disability on three levels:
  - **Body level/ Body functions and structure** (The physiological and psychological functioning of body systems and the body structure, i.e. the anatomic parts such as the organs, limbs and their components)

---

<sup>1</sup> After the BCIP was developed and all the data collected, the WHO changed their interim terminology of the ICIDH-2 (WHO, 1998) to a finalised term: ICF: International Classification of Functioning, Disability and Health (WHO, 2001).

- **Individual level/ Activities** (the range of activities performed by an individual)
- **Society level/Participation** (opportunities and/or barriers that impact on the areas of life in which the individual is involved, or has access to)
  
- Contextual factors are an integral component of the classification and consist of:
  - **Environmental factors** (they have an external influence on functioning and can impact on all three levels. They are extrinsic (outside of the individual) e.g., the attitudes of society, architectural characteristics or the legal system. Environmental factors are organised from the immediate environment to the general environment)
  - **Personal factors** (they have an internal influence on functioning and may include gender, age, other health conditions, fitness, lifestyle, habits, coping styles, social background, education, past and current experience, overall behaviour patterns, individual psychological assets and other characteristics)
  
- **Functioning** is the umbrella term used to indicate positive aspects on all three levels
- **Disability** is the umbrella term used for the negative aspects (problems) on all three levels



From the above it is clear that functioning and disability are seen as a complex relationship between the health condition and the contextual factors (e.g. environmental or personal factors). Disability is thus seen as a multi-dimensional phenomenon resulting from the impaired interaction between people and the environment. The focus should not be on the **disability** but on the **ability** and how that can be used optimally to ensure full participation in everyday activities.

#### 4 WHAT CAUSES SEVERE DISABILITY?

The aetiology is not always clear, but may be caused by:

- **Genetic factors:** inborn metabolic errors, e.g. PKU, congenital factors (e.g. Fragile X Syndrome), chromosome deficiencies (e.g. Down syndrome), etc.
- **Peri-natal factors** (e.g. rubella, drugs, alcohol, malnutrition). Foetal Alcohol Syndrome is the most common preventable cause of intellectual impairment worldwide (Viljoen, 1999). In a study conducted in the Western Cape, 55% of the women in the sample admitted to varying degrees of alcohol ingestion during their current pregnancy, of which the drinking patterns and intake of 23,7% was sufficient to place their unborn children at high risk for Foetal Alcohol Syndrome (FAS)(Croxford & Viljoen, 1999).
- **Birth injuries** (e.g. anoxia).
- **Injuries, accidents and childhood diseases** (e.g. meningitis, poisoning, motor vehicle accidents, malnutrition, poor sanitation, poor water supplies, etc.).
- **Environmental factors:** factors that impact on this include the amount of stimulation, how stimulation is provided, teaching style of primary caregivers, expectations of primary caregivers, presence of a father, amount of family stress, poverty, etc.

#### 5 WHY SHOULD COMMUNITY NURSES KNOW ABOUT DISABILITY?

- Health care for CSDs offers a special challenge to community health nurses as they come into contact with children who are able to participate on different levels, depending on the degree and type of disability. In about 90% of cases intellectual impairment is moderate (IQ of 50 – 70) and with proper support and nurturing these children can live and learn in the community.
- Most of these children live at home with their primary caregivers (or extended families) and thus need to adapt to community living, making it mandatory that their needs be viewed within the context of the family and the community.
- The impact of disability is profound. It is permanent, placing high financial and caring demands on the family and on the community.
- The move is away from institutionalisation to “*inclusion*” of CSDs in all aspects of community living and learning (increased participation of CSDs).
- Nurses are part of the health care team and often act as the bridge between the primary caregivers and the medical team. Primary caregivers usually perceive the nurse as an approachable and concerned advisor who can identify with the problems that concern the family. They will thus discuss problems with her that they feel are too trivial to discuss with the doctor. In addition the nurse also contributes valuable knowledge to the rest of the team due to her particular training, expertise and function.
- Trans-disciplinary functioning in a team is necessary when implementing community-based, family-centred and co-ordinated health care to disabled children and their families (ASHA, 1989).
- In view of the shortage of qualified health care professionals in South Africa, the community nurse is ideally positioned to provide services to primary caregivers of young children with disabilities. She is equipped to perform this task as she is viewed as a sensitised professional who has the skills to observe behavioural patterns and environmental concerns and thus to make recommendations where necessary.
- In order to equip nurses for this task, the concept of “*multiskilling*” must be addressed. Multiskilling, a form of role diversification, refers to the cross-training of a service provider, in this case community nurses, to perform procedures and functions in two or more disciplines (Salvatori, 1997).

Multiskill level	Nursing task	Application to disability	Outcome
<b>Level 1</b> Cross-training of basic patient care skills			The current training protocol will not address this level of multiskilling.
<b>Level 2</b> Cross-training of professional, non-clinical skills	Awareness	<ul style="list-style-type: none"> <li>▪ Create community awareness regarding the needs of CSDs.</li> <li>▪ Discuss community awareness with other professionals (e.g. school nurses and teachers).</li> <li>▪ Make primary caregivers and teachers aware of the importance of adequate, effective and appropriate communication skills.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased awareness of CSDs at both personal and community levels.</li> <li>▪ Increased community understanding of needs of CSDs and the importance of providing them with appropriate effective communication means</li> <li>▪ Reduced stigmatisation in community.</li> </ul>
	Information	<ul style="list-style-type: none"> <li>▪ Provide information regarding CSDs.</li> <li>▪ Provide information regarding expectations.</li> <li>▪ Provide information regarding further communication needs (long-term plan).</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demystify concept of CSDs.</li> <li>▪ Empowerment of primary caregivers regarding their CSDs by providing information about expectations and realistic goals. Primary caregivers will also feel supported.</li> </ul>
	Referral	<ul style="list-style-type: none"> <li>▪ Initiate referrals to therapists</li> <li>▪ Initiate referral for further medical management.</li> <li>▪ Assist therapists and teachers (particularly school nurses) in determining when a medical referral is necessary.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased understanding amongst professionals regarding the early referral and intervention of CSDs.</li> <li>▪ Establishment of a clearer referral line that will not waste time, money and/or effort.</li> </ul>
	Feedback	<ul style="list-style-type: none"> <li>▪ Make caregivers aware of importance of providing feedback to referring nurse.</li> <li>▪ Encourage other professionals to provide feedback to referring nurse.</li> <li>▪ Provide feedback to caregiver regarding the changing communication skills after BCIP implementation.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Encourage regular feedback from caregivers to monitor progress and meet changing needs and abilities of CSDs.</li> <li>▪ Provide feedback to caregivers and other professionals.</li> <li>▪ Feedback as reciprocal activity established.</li> </ul>

	Follow-up	<ul style="list-style-type: none"> <li>▪ Encourage caregivers to bring their children for regular follow-ups to monitor progress.</li> <li>▪ Assist caregivers to monitor the quality and quantity of communication (use the progress chart).</li> </ul>	<ul style="list-style-type: none"> <li>▪ Regular follow-up visits.</li> <li>▪ Caregivers become active observers of CSDs' progress.</li> <li>▪ Increased motivation of caregivers as progress is noted.</li> </ul>
<b>Level 3</b> Cross-training of administrative skills	Prevention	<ul style="list-style-type: none"> <li>▪ Educate the community on causes of disability and how some conditions can be averted and prevented, e.g. pre-natal care, good nutrition etc.</li> <li>▪ Refer high-risk mothers.</li> <li>▪ Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-up.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Appropriate information and/or referral of mothers who are at risk of producing CSDs (e.g. women &gt;38 years or teenage mothers) so that early and informed decisions regarding childbearing can be made.</li> <li>▪ Lower incidence of disability.</li> <li>▪ Decreased impact of the disability on the child's functioning.</li> </ul>
<b>Level 4</b> Cross- training of clinical disciplines	Identification and screening	<ul style="list-style-type: none"> <li>▪ Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history.</li> <li>▪ Conduct health assessment on identified children (at-risk and established risk).</li> <li>▪ Use "<i>Progress Checklist</i>" to obtain baseline data</li> <li>▪ Assist in obtaining necessary medical evaluations.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Obtaining relevant information about child in collaboration with caregiver to determine presence of disability so that child can be referred.</li> <li>▪ Analyse and discuss results from progress checklist with the caregiver.</li> <li>▪ Explore presence of risk factors further.</li> </ul>

	Planning services	<ul style="list-style-type: none"> <li>▪ Initiate and implement the beginning communication intervention protocol (BCIP)</li> <li>▪ Suggest modifications to present communication means, functions and opportunities (using principles from the BCIP).</li> <li>▪ Reassuring caregivers of humanity and likeability of CSDs.</li> <li>▪ Encouraging caregivers of CSDs to start a support group while waiting at the clinics.</li> <li>▪ Sustaining families through support and being an anchor (willing to listen and help).</li> </ul>	<ul style="list-style-type: none"> <li>▪ Early participation and communication which will enable the CSD to reach his/her full potential.</li> <li>▪ Realistic goals and expectations will be set by caregivers.</li> <li>▪ Caregivers will adopt a positive attitude towards disability.</li> <li>▪ Guide caregivers to adapt their environment to provide optimal opportunities for interaction and learning.</li> <li>▪ Train caregivers in the use of different communication means and functions.</li> <li>▪ Sustain families by offering continued support and interest.</li> </ul>
--	-------------------	--	---

*(Applied and modified, based on ASHA, 1996; Dublinske, 1983, Freeman & Heinrich, 1981; Mast 1983 and job descriptions for community health nurses provided by the Assistant Director of Health in the Moretele district).*

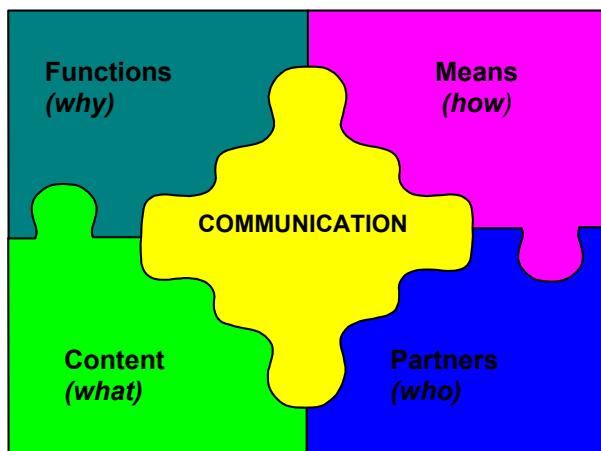
## **6 COMMUNICATION**

### **6.1 What is communication?**

Any act by which one person gives information to, or receives it from another person about that person's needs, desires, perceptions, knowledge or emotions. This can be done via gestural, signed, spoken, and/or written means. Communication is generally considered to be intentional and involves social interaction. The whole process is embedded in a specific context and environment (Beukelman & Mirenda, 1998; Johnson, Baumgart, Helmstetter & Curry, 1996; Zangari & Kangas, 1997).

From this definition four main areas arise

- 1) Communication functions (**why** the child communicates)
- 2) Communication means (**how** the child and others communicate)
- 3) Communication content (**what** the child and others communicate about – role of the environment)
- 4) Communication partners (**who** the child communicates with)



## 6.1 Main areas of communication

Each of the main areas will now be discussed in more detail.

### 6.1.1 Communication functions

Communication functions relate the **reasons for** communication. In the BCIP a few beginning communication functions will be addressed, namely:

- Making choices
- Naming / Labelling
- Requesting help
- Requesting more
- Getting or maintaining social attention: Draws attention to himself and signals his presence

- Protesting and the concept of “no”
- Confirmation and the concept of “yes”
- Showing surprise and humour.

Communication is powerful and efficient, with efficiency being reflected by the fact that a single message, e.g. “more” can function as a request in many different situations (e.g. “*I want more cookies*”; “*I want more bubbles*”; “*I want more play*”, etc. or can function as a comment (e.g. “*There are more cars.*”). Likewise “Mama” can be used to gain attention, to request “more”, to label or to protest. The first attempt at teaching beginning communication functions is the manipulation of certain aspects of the child’s environment to make things more conducive to meaningful communication. Due to their skills (including communication skills) typically developing children are able to engage in interaction, take turns, make their intentions known and indicate pleasure or protest. On the other hand CSDs, and in particular those with little or no functional speech, (LNFS) have fewer opportunities to communicate than their speaking peers.

Individuals with severe disabilities are sometimes passive - they have limited skills, or few reasons to communicate and few opportunities for meaningful interaction, making active participation difficult. This might be due to the fact that adults typically provide CSDs and in particular those with LNFS, with fewer opportunities to communicate than is the case with their speaking peers (Zangari & Kangas, 1997). Some communication partners also have little or no expectations that, because of their limited abilities, children with LNFS can or will participate in interaction. In addition, the main focus is often exclusively on the caring and nurturing of these children. Consequently no demands are placed on them, resulting in a reduced number of opportunities in which they are required or tempted to communicate (Silverman, 1995).

As stated in the definition of CSDs, these children experience problems with both communicative interaction and active participation, e.g., if Wendy is passive in

interaction, does this mean that she is unable to participate, unable to request objects, food or things? Does the problem lie with Wendy, or does it lie with her environment that is unable to make the appropriate adaptations to accommodate her particular abilities? The answer to this question will depend on whether she is given an opportunity to request something, e.g. favourite toy.

Very often the environment needs to be only slightly adapted in order to provide CSDs with the necessary communication opportunities. How can this be done?

A number of different strategies can be used, called **communication temptations** or "sabotage". There are different ways in which particular environments can be adapted or changed in order to provide deliberate opportunities for communication. This means that the environment has to be structured in such a manner as to deliberately provide opportunities (Westling & Fox, 2000).

The main aim of using communication temptations is to provide the CSD with more opportunities for interaction through deliberately creating opportunities for communication (Rowland & Schweigert, 1993). If no deliberate communication opportunities are created, two negative consequences follow. Firstly, the limited number of meaningful opportunities for interaction leaves the child with LNFS with very little motivation to develop more effective communication skills. If there is no reason to communicate, why work at better communication? Secondly, the number of communication opportunities children with LNFS need in order to practise their emerging communication skills are often limited (Blischak, Loncke & Waller, 1997). Children with LNFS should therefore not only acquire the desire to communicate, but also be provided opportunities to learn and practise new skills. This is necessary, as CSDs are often passive communicators who may respond to communication, but very rarely initiate interaction. Primary caregivers need to acquire skills to embed communication opportunities within the natural, functional activities of the child's entire day.

When assessing the skills of typically developing children, it is not necessary to pay special attention to the creation of opportunities for communication. This is

because these children are able to interact independently, e.g. they will walk to the refrigerator and take out the milk. On the other hand, a child with a physical disability may not have the ability to go to the refrigerator independently, while a child with a severe intellectual impairment may not have the skills to know that the milk is kept in the refrigerator. Therefore, deliberate opportunities for interaction must be created in order to develop and expand these children's skills.

An environment that contains few objects of interest, few reinforcers, or that meets all the needs of the child without requiring language is not conducive to developing the child's communication skills. Research has indicated that a number of strategies can be used very effectively to create opportunities for communication (Bornman & Alant, 1999; Rowland & Schweigert, 1993). Strategies that can be used to teach a specific function will now be discussed in more detail.

**a) Making choices and naming**

<b>Communication functions</b>	Making choices Naming / Labelling
<b>Communication opportunities</b>	Providing opportunities for making choices

Choice-making implies that an individual must have at least two available alternatives, either of which would meet at least some of the individual's chosen goals (Rourke, 1998). In order to train a child to make a choice, it is necessary to teach him/her to discriminate between a choice of at least two options as opposed to merely recognising each choice, e.g. "*Do you want the soap or do you want the toothbrush?*" Using materials that consist of known "likes" versus "neutrals" or "blanks" can do this, e.g. if it is known that the child has a strong desire for "Coca-Cola" as opposed to a neutral feeling regarding water, these two options can be given. In the past a lot of emphasis was placed on providing choices between a known, e.g. "Coca-Cola" and a known dislike e.g. milk. However, too much inappropriate behaviour was noted when the child accidentally made the wrong choice, and therefore the known dislike was

changed to a neutral/blank. It is essential that the child be guided to develop preferences, as preferences can be seen as an essential component of choice-making.

Choice-making can be conducted in a variety of ways, but often when considering choice-making, offering a choice of materials is the only one that comes to mind e.g., “*Do you want Coca-Cola or do you want milk?*” or “*Do you want the soap or do you want the facecloth?*” However, choices could also be given regarding tasks e.g., “*Must we wash your face or brush your teeth?*” as well as between partners “*Must I help you, or can Ntebeng help you?*” For example, Cindy’s primary caregivers could be encouraged to create opportunities for choice-making by asking her which dress she would like to wear. They should also be trained to wait expectantly before putting on the dress, as this will encourage Cindy to signal for the continuation of the activity.

Choices can also be presented on different levels, starting with the easiest choices and then moving to a more complex level. It is important to start with two options, using the real objects in the natural context. The child is then required to indicate his choice by pointing to the desired object or by reaching for it. It does not require a yes/no response from the child, nor does it require the labelling of the objects. On the next level, however, the same choices are provided, but now it is expected of the child to be able to give a yes/no response. On the last level multiple option choices are given where both yes/no responses and labelling responses are given. On this level, real objects are no longer used, but representational objects or symbols are used, e.g. empty packet of “*Simbas*” instead of real “*Simbas*” (Beukelman & Mirenda, 1998).

Providing CSDs with choices is something that should be consciously planned (Bornman, 1998). Primary caregivers of CSDs commented that, despite their children’s disability they can also be fussy about what they would like to eat (e.g. Samuel does not like salty foods), what they would like to wear (e.g. Spice girl takkies!) or even what they would like to do (e.g. play with the water in the bath).

Opportunities for indicating preferences and making choices should therefore always be a high priority.

**b) Requesting “help”**

Communication function	Requesting help
Communication opportunities	Making desired items inaccessible Selecting materials that require assistance

**Making desired items inaccessible**

CSDs very often do not have opportunities to request things, which causes them to become passive partners in interaction (Blackstone, 1991). Speaking partners (peers and adults) tend to dominate communication and only occasionally provide opportunities for children with LNFS to respond. In addition, very few to no opportunities are provided for CSDs to initiate interaction. In order to address the importance of providing CSDs with the opportunity to initiate interaction, requesting skills should be taught. This can be achieved through deliberately creating opportunities for requesting. A very effective method of doing this is by occasionally making desired items inaccessible to the child. It is, however, important to note that the desired items should not be taken completely out of the child's sight, as they may forget what it was that they were looking for, or they may lose interest. This strategy should not be used too often, as the idea is not to frustrate the child, but to provide an opportunity to request something.

Desired items could be made inaccessible by putting them in see-through plastic containers that the child is unable to open independently, thus providing him with the opportunity to request help. Desired items could also be placed out of reach, so that the child has to request the item. This could mean that the spoon is placed out of reach, or that a favourite shirt is placed out of reach.

If the child does not request the desired item, a prompt must be used in an effort to elicit communication. Start with a verbal prompt (“*Tell me what you want*”), followed by a gestural prompt if there is no response (e.g. a puzzled look, or a

vague sweep of the hand over the communication board) and finally a physical prompt (forming the child's hand into the needed gesture, e.g. "cookie"). Remember to allow the child enough time to respond before giving the prompt!

Requesting is a skill at which speaking children are very good. Think how easily they order us around with their voices "*Give me the spoon, please*", "*I want some ice-cream*" etc.

### **Select materials that require assistance**

A very important skill to teach a child is to request help. Think how often small children request help, e.g. by bringing their primary caregivers something that they cannot open themselves! CSDs on the other hand very often do not have the opportunity to develop these skills, as adults or peers tend to do everything for them! There is a general feeling that these children are already so disabled that life should not be made any more complicated for them! However, by doing so we are depriving CSDs of the opportunity to do things for themselves, fostering learned helplessness.

How can requesting help be taught? In order to create an opportunity for requesting assistance or "*help*", materials should be selected with care. Although it is of the utmost importance to create deliberate opportunities for requesting assistance, it is also important not to frustrate the child. The selected material should thus be of such motivational value that the child will request assistance, e.g. when making a sandwich, the bread can be placed in a plastic bag that the child cannot open independently, or a zip that the child cannot undo independently, or a Velcro shoe fastening, or even placing a fruit in a see-through container!

When the adult notices that the child is experiencing problems, and that the child is not requesting assistance, a prompt can be given, i.e. "*Must I help you?*" whilst the manual sign for "*help*" is also modelled. In this example a verbal as well as a visual prompt is given. If there is no response, a hand-over-hand prompt can be

given where the child's hands are moulded to form the manual sign for "help". Assistance is then provided. As the activity of making a sandwich continues, the margarine could be placed in a container that the child is unable to open independently. After pausing, observe the child before prompting. Prompts can gradually be faded until it would be sufficient to look at the child expectantly. In time the child should be able to request assistance without any prompts. Likewise, the jam or cheese, etc. could also be placed in containers that the child is unable to open independently.

As with requesting "more", requesting "help" is a very powerful interactional tool, as this request can be used across a number of activities.

### c) Requesting "more"

<b>Communication function</b>	Requesting more
<b>Communication opportunities</b>	Providing small portions Providing brief turns

#### Providing small portions or brief turns

When using this strategy, the adult does not give the child all the necessary materials at the same time (e.g. give clothing pieces one by one - give only one sock, and wait for the child to request the other) or offer small portions (e.g. when feeding, give only one mouthful, and then wait for the child to signal that he wants more). This strategy is another way of facilitating requesting skills as it provides children with ample opportunity for requesting to enable them to continue the activity. Other examples would be to pour only a tiny amount of milk, e.g. one mouthful into the child's cup. Give it to the child and wait expectantly. Likewise, if a child is very fond of "Jellytots" or "Smarties", do not give him the whole packet, but give the sweets one at a time. It should be stressed, however, that this strategy should only be used with objects of high motivational value, otherwise there is no incentive for requesting.

### **Providing brief turns**

When engaging in a particular activity the turns for participation could also be shortened, e.g., if a child is bouncing on the adult's lap and shows signs of enjoyment, bounce him once or twice, and then stop the activity and see if he will request "more". Remember that this need not be done verbally, but the child could also indicate/request "more" by using a body movement (e.g. showing a gross up and down movement of the body) or by using the manual sign or a symbol to request "more". This is a very powerful intervention strategy because teaching the child the manual sign or symbol for "more" opens up a great number of communication opportunities for him, as he is then able to request "more" of anything motivational in the environment.

#### **d) Getting or maintaining social attention: Drawing attention to himself and signalling his presence**

Communication function	Drawing attention to himself and signalling his presence
Communication opportunities	Deliberately withholding attention

Teaching children how to request attention from others appropriately can be a difficult task. Withholding attention can, however, be used as a very powerful strategy to elicit interaction, but should be used with caution. It requires the adult to occasionally withhold attention or interaction until the child attempts to gain attention. Think again of typically developing children. They have no problem in calling to get attention! And if they do not get a response immediately they make a fuss until they are taken notice of.

Although this strategy is highly effective with children with a strong desire to communicate, it is not effective with very passive children, as these children are happy to be left alone or ignored. If a child is strongly motivated to engage in interaction, attention can deliberately be withheld, e.g. while feeding the child pretend to ignore him by looking away. Specific times can also be selected for withholding attention, e.g. after lunch when everybody gets up to go and play,

you can “forget” to include him in the next activity and leave him at the cleared table until he does something to draw attention to himself. Of crucial importance, however, is to give the child your immediate attention at the slightest attempt from his side to indicate his presence. It is also important to equip the child with the necessary tools for calling attention, e.g. putting up his hand to call for attention, pressing a bell that rings to draw attention, or banging a spoon on the table for attention, etc.

**e) Protesting and the concept of “no”**

<b>Communication function</b>	Protesting Concept of “no”
<b>Communication opportunities</b>	Offering a non-preferred item Asking “yes/no” questions

Protesting is often one of the first communication functions that develops (Blischak *et al.*, 1997). Primary caregivers are always amazed to find that children at a very young age start showing preferences and start using the word “No!” CSDs often become very passive communication partners, as they often do not have the opportunity to indicate protest. Their diets and daily routines, for example, might be very strict, and therefore they are not allowed to indicate that they would not like to perform certain tasks, or eat certain food. Even if they do protest, these attempts are often ignored. This leads to these children not displaying protesting communication functions as frequently as their peer group. It is therefore important to deliberately create opportunities for these children to protest.

**Offering a non-preferred item**

A very effective strategy for doing this is by offering a non-preferred item, i.e. if you know that the child wants fruit, offer him porridge, or when bathing the child, instead of soap give him a spoon, or when feeding suddenly give him a comb and see if he will protest, or whether he will willingly accept the incorrect item. If no protest is noted the adult should intervene and say, “*No! This is the wrong*

*one! You actually asked for fruit!"* This strategy should, however, not be used if a child does not have good choice-making skills, as it will cause great confusion. When this strategy is introduced for the first time primary caregivers are often sceptical, as they fear major behavioural problems and temper tantrums. However, recent research with a group of autistic children showed the opposite to be the case (Bornman & Alant, 1999). The reactions of the children varied between total surprise ("What is this adult up to?") and vigorous head-shaking to indicate "no". During the whole course of the research project (almost three months) not one behavioural problem related to providing the incorrect item was noted.

### **Asking "yes/no" questions**

If a child has strongly developed protesting skills, one can move to a more sophisticated level of protesting, namely indicating "no". Sometimes CSDs are not challenged and all questions have a "yes" answer. It is important to not fall into a predictable routine when using this strategy.

#### **f) Confirmation and the concept "yes"**

Communication functions	Confirmation Concept of "yes"
Communication opportunities	Asking "yes/no" questions

Last, but definitely not least, the primary caregiver can ask yes/no questions for the child to confirm or deny e.g. "*Must I wash your hair?*" The ability to answer yes/no questions is, contrary to popular belief, an advanced skill. When referring back to the different levels of choice-making, the ability to indicate yes/no to a question, is on the advanced levels. It is also important to realise that initially both concepts are not taught simultaneously, but that one firm response is expected. Primary caregivers should ask yes/no questions for the child to confirm or deny, e.g. "*Do you want to have a bath?*" These strategies should, however, not be done at the expense of all other strategies as they are more directive in nature

and do not allow for as many opportunities for interaction and initiating communication on the child's side.

Furthermore, when working with children with LNFS it is important to steer away from the use of rhetorical questions e.g., "*That's a new dress, isn't it?*" (Blischak *et al.*, 1997). This leads to confusion, as the children do not learn the concept of when they are expected to communicate and when not. It also contributes to feelings of isolation and frustration as these children are rarely engaged in interaction as active participants, as no response is expected from them when they are asked rhetorical questions.

#### **g) Showing surprise and humour**

Communication function	Showing surprise and humour
Communication opportunity	Violating expectations

This strategy can only be used once the child is already engaging in certain routines, e.g. bathtime and is effective in eliciting a protest or a surprise reaction from a child. CSDs often have set routines that are conducted daily in almost exactly the same way. The primary caregiver may set up a familiar routine, and then violate the child's expectations by substituting the wrong items part way through to elicit protests or comments e.g., when dressing the child put a sock on his hand or his pants on his head. If the child is able to dress himself, one item can be substituted for another to elicit a response e.g., if he is putting on his shoes, give him a facecloth. If the primary caregiver always puts out spoons before meals, she can pretend to "forget" to give the child his spoon. The primary caregiver can then respond by saying "*I'm silly! Look what I've done... uh oh this is not right!*" When using a highly familiar routine like bathtime at home, the activity can continue as usual, but the primary caregiver can "forget" to fill the bath. This is usually an activity that elicits a lot of fun for both participants. The adult has to constantly remain creative (do not always violate expectations in the same way, as the child might later see it as part of the routine). The child, on the other hand, is bound to show some reaction, maybe through a smile, a puzzled

frown, a natural gesture, a vocalisation, speech or laughter. For some children this may be the start of communication interaction, as they are actively responding, motivating the adult to explore even more avenues of interaction.

### **Conclusions on communication functions**

Deliberately offering communication opportunities will enable CSDs to practise their communication skills (with regards to communication functions and means), optimising their interaction skills and learning experiences.

Care should however be taken to avoid “*communication temptations*” becoming “*communication frustrations*”. This will not happen if a primary caregiver is sensitive to the child and the way the child reacts to ensure that he does not get totally frustrated and angry because, e.g. he wants something to eat, but does not have the communication means to do so. In this case, the child needs to be taught how to request the food. The different communication means will be described later. The primary caregivers must also be careful not to miss or ignore the child’s communication attempts because they do not realise that a particular behaviour was used to request the object!

Often, when a child is learning how to communicate or learning how to use a specific AAC system, it is appropriate for the primary caregiver to offer many deliberate cues as this offers many learning opportunities. But as the child’s abilities improve, the primary caregiver may need to reduce the number of deliberate overt cues for communication in order to allow the interaction to become child-controlled instead of remaining adult-controlled. This is a very important element of communication for CSDs and in particular those with LNFS as they are often passive communicators who very rarely respond to communication. Primary caregivers thus have to learn the skills of how to embed communication opportunities within the natural, functional activities across the child’s entire day.

### 6.2.2 Communication means

In the definition of communication that is used for the BCIP, it is stated that the communication message can be transmitted from one person to another via gestural, signed, spoken, and/or written means. The communication means most frequently used is spoken language (talking). It is known, however, that this may often be the most difficult form of communication for CSDs. This does not imply that these children should be excluded from communication, but rather that a means other than traditional drill work should be used to get them participating and communicating. They therefore need a crutch to lean on while spoken language is developing. This crutch is called Augmentative and Alternative Communication (AAC). Some CSDs will learn to speak without using their crutch, some will sometimes need their crutch in certain situations, whereas others will always be dependent on their crutch.

What exactly do we understand by the term Augmentative and Alternative Communication (AAC)?

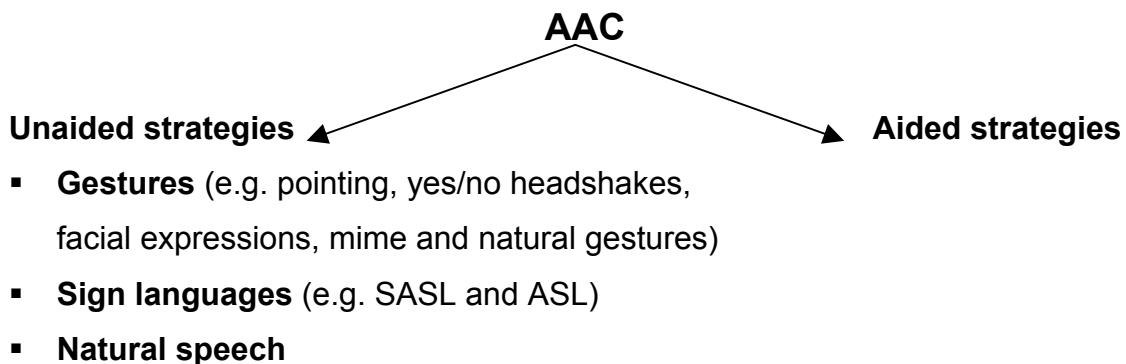
**Augmentative and alternative communication (AAC)** refers to the field or area of clinical/educational practice to improve the communication skills of individuals with little or no functional speech. It includes the supplementation or replacement of natural speech and/or writing, using aided and/or unaided symbols (Lloyd, Fuller & Arvidson, 1997).

The first important thing to note, is that **augmentative** communication is mentioned first, as this is the strategy that is used in the majority of cases. Most CSDs are able to produce a few vocalisations, and in some cases even a few words. For these individuals, AAC will never be used to replace the way they already communicate. Remember, a crutch is something we use to assist us, not something to replace what we already have! This means that if Thabang is able to communicate “no” by saying “uh..uh..” we will not attempt to modify this by giving him a symbol to say “no”, as we can understand his message. So if some natural speech is present, we use the term **augmentative**.

A few individuals, however, require an **alternative** system. This means that the strategy used will be a substitute (or alternative to) the natural speech of the individual. This might be used in cases where a person has a very high neck lesion and is unable to produce any sounds, or if there is damage to the vocal cords and no sounds can be made. An alternative system is, however, the exception rather than the rule.

All AAC strategies fall into two broad categories, namely unaided and aided communication systems. **Unaided communication systems** will be discussed first.

**Unaided communication:** This refers to communication symbols, strategies or techniques that use only the body or parts of the body to represent, select or transmit information (Lloyd et al., 1997, p.543).



#### a) Gestures

This refers broadly to non-linguistic communication and includes pointing, yes/no headshakes, mime, facial expressions and natural gestures (Loncke & Bos 1997).

**Pointing** is a gesture that occurs early in a child's development and is considered an essential part of communication development. It is usually used as a direct way of indicating or requesting a desired item. Although pointing is usually done by using the hand, it can also be done through eye-pointing in cases where a child has a severe physical disability. The child will indicate the

choice by looking at the desired item. Pointing is a very powerful interaction tool as it requires very little motor ability, is generally understood by unfamiliar communication partners and can be used in combination with other aided and/or unaided symbols.

**Yes/no headshakes** are a form of unaided communication that is widely used by speaking and non-speaking persons alike. They are usually easily understood and are highly useful and effective when used in combination with other AAC means. Their efficiency is, however, dependent upon the questioning skills of the communication partner. Headshakes only provide the child with access to one communication function, namely responding, and are therefore limited if not used in combination with other AAC means.

**Facial expressions** convey a vast amount of information, particularly regarding emotions. A smile can show happiness, a frown can show that you don't understand. The face can also be used to show anger, unhappiness, discomfort, etc. Never underestimate the use of facial expressions! The facial expression should always be in accordance with the rest of the message, e.g. do not say "*No! Don't do that!*" with a big smile on your face! It will either have no effect or confuse the child.

**Mime** is a more elaborate form of gesturing as it includes the use of the whole body and not only the hands, arms and face. It attempts to convey information or ideas through pantomime or simulation of an activity (Musselwhite and St. Louis, 1988). Mime can be effectively used as an initial technique before moving towards the use of gestures and/or signs (Loncke & Bos, 1997). It can also be used as a back-up system in some situations (e.g. showing a dog barking). Mime, on its own, is limited as a primary communication means.

**Natural gestures** are gestures that are mostly made spontaneously and are usually understood by the general public without any prior training. These natural gestures are culturally specific, so if you are not part of the community they can easily be misinterpreted! They are relatively easy to make, and are used by many

individuals e.g., your hands could be used to indicate “*come here*” or “*go away*”, or even to “*Watch it!*”

Sometimes natural gestures can take a slightly different form, and an object can be used for communication, e.g. Helen holds up her empty cup to indicate “*more juice*”, whilst Thembi holds out her foot with a shoe on to request “*Take off my shoes*”.

The major advantage of natural gestures is that non-disabled people also use them and many people understand them without needing any training. The movements usually require gross hand movements, and thus even children with a physical disability can usually form some gestures. Using and reinforcing natural gestures are usually good ways of introducing a person to the use of keyword signing (explained in detail in Section b). The greatest disadvantage is that they are very limited and do not allow for conveying more abstract or difficult messages.

### b) Sign language (e.g. ASL or SASL)

Sign language is a complete language on its own, used exclusively by the Deaf. It has its own sentence structure, grammar and rules, exactly like any other language, e.g. Tswana, Afrikaans or Pedi. A particular sign language, e.g. South African Sign Language (SASL) consists of a great number of formal learned manual signs. The aim of intervention with CSDs is not to teach them Sign Language but to teach them **keyword signing**, using the manual signs from SASL. We will therefore use the sentence structure of the oral language that we use, e.g. Thuso will use manual signs together with Tswana, Pieter will use his manual signs together with Afrikaans, and Lerato will use her manual signs with Pedi! None of them will suddenly start using the sentence structure of SASL! It is also important to note that there are different kinds of sign language, e.g. the United States of America uses ASL (American Sign Language) whereas SASL (South African Sign Language) is used in South Africa.

The emphasis of this protocol is on **keyword signing** which implies that signs are used to supplement the most relevant content words in a sentence. Signs from SASL are combined with speech and produced in the mother tongue word order, e.g. English or Setswana. Keyword signing has been reported to be most useful with hearing CSDs with LNFS. As messages are presented both auditorily and visually, they offer a reduced vocabulary that aids children with intellectual disabilities in processing information and it slows down the rate of spoken communication (Beukelman & Mirenda, 1998; Loncke & Bos, 1997).

SASL was developed to help people convey more abstract and difficult messages. This means that one does not automatically know what a manual sign means, but if trained, it would be understood and remembered. For example, if you were requested to sign “*help*”, how would you attempt it?



The SASL manual sign for “*help*” is not easy to guess. If, however, once trained and the sign is explained (i.e. the flat hand beneath the fist moves in an upwards direction to indicate “*I help you, because I lift up your burden*”) it becomes clearer and easy to remember. This BCIP will explore all the vocabulary needed for three activities of daily living, namely eating, dressing and bathing in more detail.

### c) Natural speech

Speech is obviously the most common form of communication. It is the easiest to produce, always accessible and usually understood by the majority of communication partners. It is therefore important to note that the introduction to

an AAC system does not imply that the development of natural speech does not remain a priority.

When working with CSDs it is very important not to stop talking! Remember that many CSDs can hear and that they need to get information from as many sources as possible to aid their learning. They not only have to see what you are talking about, but also hear what you are talking about and even physically experience it! As mentioned at the beginning of this section, facilitating speech is the main aim of communication intervention, but in addition, other methods are used to augment the speech, as it is known that speech production is sometimes very difficult for CSDs.

What are the **advantages** and **disadvantages** of unaided systems? Obviously any system has advantages and disadvantages. The most obvious advantage of unaided systems is the fact that the child does not have to carry anything around. The manual signs needed are always available, e.g. if you suddenly have to go to the bathroom, it is quicker to say by using a gesture than first having to take out a communication book, draw the listener's attention, and then select the correct symbol. By that time it might be too late! Unaided systems are also very effective for ambulatory CSDs as they do not have to carry additional communication displays, e.g. when Cindy is outside and she is thirsty and she wants to say "*Please give me something to drink*" the manual signs are readily available! To summarise, the biggest advantages of unaided systems are that they are portable (the body is used), always available, quick and easy to use... so that communication does not have to be a slow and laborious task.

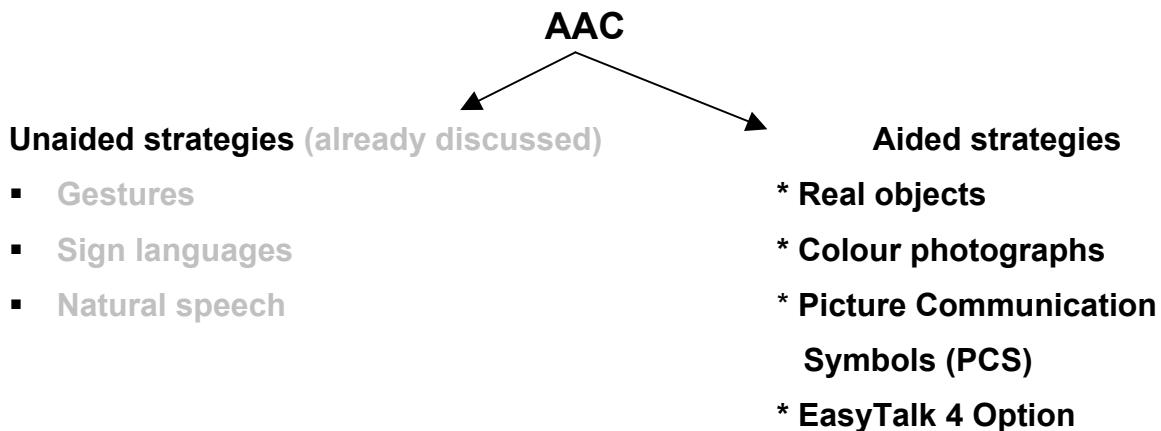
Regarding disadvantages, one the biggest problems with unaided systems is the fact that people who are unfamiliar with the system will not understand them, e.g. if you do not know the manual sign for "*black*", you would not be able to guess it! Unaided systems thus do not facilitate interaction with unfamiliar partners. Secondly, the user needs adequate motor skills as manual signs are formed using hands and arms. Furthermore, manual signs are not displayed on a board from which the child only has to select one. This means that the child has to be

able to think of the manual sign and remember how to make it, if he wants to use it.

That completes the section on unaided systems. **Aided communication systems** will now be discussed.

**Aided communication systems** refer to communication that uses some type of external aid, symbol or assistive communication device (Lloyd *et al.*, 1997, p523).

What all aided systems have in common is the fact that something additional is needed unlike unaided systems where the child needs only his own body. This would automatically highlight the main disadvantage of this type of system: the child has to take his aid or carry his device wherever he goes, e.g. Jennifer going to the beach, Zandile having to get into a taxi, Johnny wanting to take a bath, and Frankie playing outside.



Aided communication systems make use of symbols that are displayed either on communication boards or on communication devices. A symbol can be defined as something that is used to represent something else e.g. a spoon is used to represent mealtime. The way in which the different types of symbols are grouped in the above figure, shows broadly the hierarchy of difficulty, i.e. it is easier to understand the meaning of a real object than it is to understand a photograph (Beukelman & Mirenda, 1998). In teaching CSDs it is essential to start by using the easiest types of symbols while gradually moving to a more complex symbol.

A CSD can point to his plate to indicate that he wants to eat. Later a colour photograph can be used, followed by a line-drawing (e.g. Picture Communication Symbol) to indicate “eat”.

**a) Real objects**

This is the easiest type of symbol to use for communication, and can be very effective for beginning communicators as well as for children with severe intellectual disabilities. The similarity of the thing the child wants (concrete referent), to the object is initially very important, e.g. at first the object-symbol for plate has to look exactly like the plate the child is used to otherwise he might not recognise it.

Real objects can be used most effectively when providing a child with choices. Two objects (that represent different activities) are presented to the child, and he is then asked to indicate a preference or make a choice, e.g. while holding out a spoon and a cup, the child is asked *“Do you want to drink your milk first, or eat your porridge first?”* The three dimensional nature of objects also makes them ideally suited for children with visual impairments as they can easily manipulate the objects (Musselwhite & St. Louis, 1988). Providing beginning communicators and/or children with severe intellectual disabilities with a means of communicating ensures future communication control and prevents learned helplessness. The use of object-symbols may serve as a useful introduction to AAC. The greatest disadvantage of using objects is their size. For some concepts (e.g. bed, bath, chair) the use of full size real objects will be impractical. To overcome this problem use may be made of a small piece of blanket, miniature soap, etc.

It is important to think of how these real objects will be presented to the child. They can be placed in a box with different compartments, stuck on a piece of cardboard, or fastened to a car-mat with Velcro. Durability is important and the display must be designed to minimise damage to objects and to reduce the loss of objects (Musselwhite & St. Louis, 1988). Furthermore if object displays are not

kept in the designated place where the activity will take place, it will not be used. It is important to realise that some children might need more than one object display, e.g. an object display depicting food, one depicting toys, one depicting favourite activities, etc. Flexibility of objects must be kept in mind; thus objects should not be permanently fixed, but rather attached with Prestik or Velcro so that they can be added or replaced quickly. Finally one of the biggest advantages of an object board is the fact that it is a static display that cues the child to start looking at all the possible choices and to scan through the choices in the same sequence (e.g. right to left or top to bottom).

**b) Colour photographs**

Colour photographs are more easily understood than line drawings (e.g. PCS), as they provide more clues, e.g. the *red* mug can easily be recognised, and the extent to which the foreground stands out from the background (Beukelman & Mirenda, 1998). An advantage of photographs over real objects is the fact that they are smaller, making it easier to display them, to expand the system and to portability. The greatest concern in the use of photographs is the fact that they are limited in terms of the ideas that can be expressed as they mostly focus only on nouns and verbs (Fuller, Lloyd & Stratton, 1997).

Photographs, especially those that are highly representative of the referent are often viewed as an intermediate step between real objects and more abstract line-drawings (e.g. PCS) (Musselwhite & St. Louis, 1988). Pairing is important when attempting to teach a child to generalise from objects to photographs. Start with a previously learned object together with the photographs and gradually fade the real object.

**c) Picture Communication Symbols (PCS)**

Picture Communication Symbols (PCS) consist of some 3,000 black and white line drawings that cover a range of different categories, e.g. nouns, verbs, descriptives, prepositions, etc. Phrases used in typical communication, e.g. (“uh-

*uh!*" "*my turn*") are also included. The advantages of using PCS are that they are relatively easily learned by CSDs, they are appropriate for all age levels, simple drawings for visual clarity, easy to reproduce and plenty of teaching materials for using PCS is available.

PCS are used extensively in schools in South Africa and children will benefit greatly if they are exposed to these symbols before they enter school. Teachers can then spend time teaching more complex concepts as they will not need to spend time on basic ADL activities. The use of PCS not only stimulates CSDs' receptive language, but it also provides CSDs with LNFS with an expressive means of communication as they can "*tell*" certain things by pointing at the symbols.

PCS can be displayed either on communication boards, or on communication devices (e.g. EasyTalk). For the purpose of the BCIP, the PCS that are used will be presented in activity-based format. This means that the whole vocabulary for a specific activity is presented together. Activity-based boards for three ADLs, namely eating, dressing and bathing, developed by Goossens', Sapp-Crain & Elder (1994) are used as a basis and slightly adapted for the South African context. The selection of these three activities will be discussed in more detail later.

Some of the important elements of these boards are the fact that initially a total of 16 messages are depicted on the board, but that templating can be used to minimise the number of options in order to accommodate the ability of the particular child. Colour coding of word categories is used (e.g. nouns are yellow) in order to facilitate word recognition. Commonly used words (e.g. "*oh oh*", "*I*" etc.) are always placed in the same position on the board in order to facilitate quicker retrieval of messages (Goossens', Sapp-Crain & Elder, 1994).

#### d) EasyTalk 4 Option

As well as using the communication boards as discussed, the symbols can also be displayed on voice output devices. There are a variety of voice output devices available, ranging from very low to very high technology. The BCIP uses a digital speaker, namely the “EasyTalk 4 Option”.

Voice output devices have numerous advantages, e.g. intelligibility of communication is improved (unfamiliar partners are more likely to understand voice output than gestures or symbol systems), the speed and accessibility of communication is increased and there are more possible communication partners (Beukelman & Mirenda, 1998). Kannenberg, Marquardt & Larson (1988) also state that voice output devices provide greater communication independence, as the non-speaking person is able to use his own “*voice*” to communicate, rather than having to rely on gestures, pointing and symbols on communication boards or books. This leads to these people experiencing themselves as “*speaking*”. It has also been noted that users of voice output devices display better communication effectiveness, they initiate interaction more often, use more complex sentence structures and generally have more control during communication (Smith, 1994).

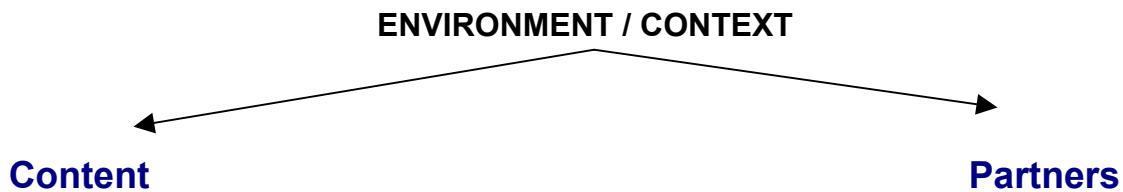
The two voice output devices generally used in the AAC field are digital speech (where speech is produced when the human voice is recorded and digitised) and synthetic speech (where speech is artificially produced by electronic means rather than by the human voice) (Quist & Lloyd, 1997). For the purpose of the BCIP emphasis will be placed only on digital speech, as a digital voice output device, namely the EasyTalk 4 Option is used. This device has been selected as it can be age, gender and language appropriate as speech is recorded, making it ideally suited to the multi-lingual South African context. Research has also shown that attitudes towards AAC users are more positive when the voice output is natural and easy to listen to (Gorenflo, Gorenflo & Santer, 1994).

When implementing the EasyTalk 4 Option, four different symbols for that particular activity will be selected and placed on the device. The child can then press on the photograph or PCS to activate the device and “speak” the message. Before using a voice output device, it is crucial that the child understands the meaning of the photographs/PCS that are placed on the device. If not, the device will not be used because the child does not understand the message, not because of lack of motivation to use the device.

### 6.2.3 Communication context / environment

The third communication aspect that needs to be addressed is that of communication environment. As previously mentioned, the communication context or environment refers to **where** the communication takes place. In order to interpret the meaning of a message, the context must be known. Context refers to where the child is, what the child is doing, whom the child is talking to, how he or she said something and what the partners had said, e.g. if the child says “*Daddy ball*” it can mean “*This is Daddy’s ball*”, “*Daddy get the ball*” or “*Daddy throw the ball*”. The context determines how this simple message will be interpreted.

Research has indicated that training of CSDs should be conducted in relevant and meaningful contexts (milieu teaching)(Blischak *et al.*, 1997). Teaching in the natural context thus allows the primary caregiver to take advantage of cues and consequences that are natural parts of the setting. In some situations the first step in teaching a CSD to actively participate and communicate, includes the manipulation of certain aspects in his environment to make those settings more conducive to meaningful communication (Beukelman & Mirenda, 1992). From this communication environment two things thus arise:



#### 6.2.3.1 Content

Content refers to **what** the child wants to communicate about. For the purpose of the BCIP, an ecological communication approach will be used as it is developmentally sound and clinically useful when dealing with CSDs (MacDonald, 1983). This approach states that for language to improve, major changes must occur in the child's communication, in communication of the partners and in the interactions between them. Secondly it states that language begins during the sensori-motor play activities and joint activities with others.

As play is the occupation of children, it is described as an excellent opportunity for discovering and learning new skills. During the early years of development play between an adult and a child is of particular importance, as this provides the content of learning experiences (Haring, 1993). Through joint play routines children observe adults and explore the world around them. However, during focus group discussions with primary caregivers in the Hammanskraal area, it was noted that primary caregivers do not regard play between a primary caregiver and child as culturally appropriate. Primary caregivers report that they do not generally play with their children but that a great deal of interaction occurs during activities of daily living (ADLs). As the aim of this protocol is to enhance participation and communication, three ADLs were selected, namely mealtime, bath/wash time and dressing/undressing. During these activities primary caregivers (caregivers) naturally interact with their children, which implies that in terms of intervention it is not something additional that they will have to do. These activities provide opportunities for joint attention and meaningful interaction between primary caregivers and children (McCormick & Schiefelbusch, 1984). The vocabulary used in these three ADLs also remains fairly consistent, providing opportunities for repetition and establishment of functional concepts.

On the downside it must be noted that the expansion of the vocabulary is limited when using ADLs. In addition, ADLs are activity-driven, i.e. they each have a set goal, and the primary caregivers try to achieve that goal, usually in the shortest time. Furthermore, ADLs have a fixed pattern, which is often difficult to change.

One of the biggest problems with CSDs is the selection of appropriate vocabulary in order to provide them with the necessary content to communicate a particular message.

Aided language stimulation (ALS) through the use of activity-based communication boards was designed specifically for CSDs and is based on milieu teaching (Goossens' *et al.*, 1994). The purpose is to provide the CSD with models for combining symbols in a flexible manner, and opportunities to do so. They are based on the premise that observing adults using the symbols extensively in natural interactions, the CSD will begin to establish a cognitive template of how to combine symbols to generate new messages (Beukelman & Mirenda, 1998). These activity-based boards are thus used in a very natural way.

ALS implies that the primary caregiver will highlight symbols on the child's communication board as she verbally interacts with the child during the activity, e.g. during mealtime the primary caregiver will say "*Uh oh! Look how dirty your face is! It is full of food*" while pointing to the symbols UH OH, DIRTY and FOOD. This means that the primary caregiver must know the symbols and have access to them. As discussed earlier, the primary caregiver should also provide numerous opportunities for interaction while conducting the activity.

According to Blischak *et al.* (1997) ALS serves at least three purposes: (1) it provides the user with a model of how the system must be used, (2) it allows the child to see the symbols used in everyday situations and (3) it suggests that the AAC system is an acceptable means of communication.

How can the three ADLs that provide the **content** for the participation and communication (what is communicated) be integrated with the communication

**contexts** (where communication takes place) and the **means** (how communication takes place).

Content : Mealtime		
Context: <b>Providing opportunities</b>	Communication modes: <b>Objects &amp; symbols</b>	Procedure
1. Providing choices of ▪ Materials ▪ Tasks ▪ Partners  <b>This teaches the child labels &amp; choice-making</b>	<b>Objects:</b> Spoon, plate, cup, food <b>Pictures:</b> Spoon, plate, cup, Signs: Milk, porridge, mother, I, grandmother, eat, drink <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>Before starting to feed, ask the child “<i>Do you want your porridge or your milk?</i>” Hold up both options so that child can see. Emphasise the particular one by holding it slightly more to the front.(material)</li> <li>Ask: “<i>Do you want to eat or do you want to drink?</i>” (task)</li> <li>Ask: “<i>Must I help you or must Koko help you?</i>” (partner)</li> </ul>
2. Making desired items inaccessible  <b>This teaches the concept of requesting “help”</b>	<b>Object:</b> Cup <b>Pictures:</b> Cup, help, want <b>Signs:</b> Cup, want, help <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>Place food in see-through container that the child cannot open independently.</li> <li>Place cup on top of cupboard (out of reach but in sight)</li> <li>Place food out of reach.</li> </ul>
3. Providing small portions / brief turns  <b>This teaches the concept of requesting “more”.</b>	<b>Objects:</b> Cup, spoon, plate <b>Pictures:</b> Cup, spoon, plate <b>Signs:</b> More, want, help, eat, drink <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>Pour only one mouthful of water into the child’s cup</li> <li>Feed one mouthful, and take plate away. If child feeds himself, follow same procedure.</li> </ul>
4. Selecting materials that require assistance  <b>This teaches the concept of requesting “help”</b>	<b>Objects:</b> Cup, jug, mango <b>Pictures:</b> Cup <b>Signs:</b> Cup, jug, want, help, drink, <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>Put water in jug that closes very tightly, so that child has to ask for assistance.</li> <li>Close tap tightly, so that child cannot open it independently.</li> <li>Put a fruit in a see-through container that the child cannot open independently.</li> </ul>
5. Withholding attention  <b>This teaches the child to draw attention to himself and to signal his presence.</b>	<b>Objects:</b> Cup, jug, mango <b>Pictures:</b> Cup, mango <b>Signs:</b> Cup, jug, want, help, drink, <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>When setting the table, or when giving food to the siblings, pretend to ‘forget’ the CSD. When he signals his presence, immediately react, and say “<i>I’m sorry! I forgot about you! I’m silly!</i>”</li> </ul>
6. Offering non-preferred items  <b>This teaches protesting and the concept of “no”.</b>	<b>Objects:</b> Water, mango, lemon <b>Pictures:</b> Mango, lemon <b>Signs:</b> Like, yuck, no <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>If you know that the child wants a mango, give him a lemon instead and see if he will reject it.</li> <li>If child wants milk, give water.</li> <li>If child wants to eat, first give a drink.</li> </ul>
7. Violating expectations  <b>This teaches protesting as well as surprise and humour.</b>	<b>Objects:</b> Cup, spoon, plate <b>Pictures:</b> Cup, spoon, plate <b>Signs:</b> No, funny, mine <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>When feeding the child, do something totally unexpected like eating a mouthful yourself!</li> <li>When feeding the child, hold the spoon the wrong way round or upside down.</li> <li>Instead of giving the child something to eat, give him something else, e.g. a stone</li> </ul>

<p>8. Asking yes/no questions</p> <p><b>This teaches the child to confirm or negate information</b></p>	<p><b>Objects:</b> Cup, spoon, food  <b>Pictures:</b> Cup, spoon  <b>Signs:</b> Head-nodding/head-shaking  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<p>Ask questions such as</p> <ul style="list-style-type: none"> <li>▪ Do you want milk?</li> <li>▪ Do you want some chicken?</li> <li>▪ Do you want something to drink?</li> <li>▪ Are you hungry?</li> <li>▪ Do you like pumpkin?</li> </ul>
<b>Content : Bathtime</b>		
<p><b>Context:</b>  <b>Providing opportunities</b></p> <p>1. Providing choices of</p> <ul style="list-style-type: none"> <li>▪ Materials</li> <li>▪ Tasks</li> <li>▪ Partners</li> </ul> <p><b>This teaches the child labels &amp; choice-making</b></p>	<p><b>Communication modes:</b>  <b>Objects &amp; symbols</b></p> <p><b>Objects:</b> Soap, water, sponge, towel, toothbrush  <b>Pictures:</b> Soap, sponge  <b>Signs:</b> Wash, pointing, dry  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<p><b>Procedure</b></p> <p>Hold out the soap and the sponge and ask, “<i>What do you want? Do you want the soap, or do you want the sponge?</i>”(Materials)</p> <p>Ask the child “<i>What must I wash? First you face or first your hands?</i>”(task)</p> <p>Ask the child: “<i>Must we first have a bath, or first brush teeth?</i>”(task)</p> <p>Ask the child “<i>Who can bath with you? Lesego or Mpumi?</i>”(partner)</p>
<p>2. Making desired items inaccessible</p> <p><b>This teaches the concept of requesting “help”</b></p>	<p><b>Objects</b> Soap, sponge  <b>Pictures:</b> Soap sponge  <b>Signs:</b> Want, help, wash, soap, water  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ Place sink tub out of the child's reach (if he enjoys bathing).</li> <li>▪ Place sponge out of reach.</li> <li>▪ Place soap in plastic bag that the child cannot open independently.</li> <li>▪ Place anything that the child plays with in the bath in a container that he can't open.</li> </ul>
<p>3. Providing small portions / brief turns</p> <p><b>This teaches the concept of requesting “more”.</b></p>	<p><b>Objects:</b> Soap, sponge  <b>Pictures:</b> Soap, arm, hands, face, foot  <b>Signs:</b> More, wash, nice, point to different body parts.  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ When bathing the child make foam with the soap on the sponge, and then only wash one body part at a time. Name the body part that you are currently washing.</li> <li>▪ Stop, ask the child “<i>Do you want more?</i>” <i>Yes, more wash. Let's wash your other leg.</i>”</li> <li>▪ Proceed with all body parts in the same way.</li> </ul>
<p>4. Selecting materials that require assistance</p> <p><b>This teaches the concept of requesting “help”</b></p>	<p><b>Objects</b> Tap, shampoo bottle, soap, toothpaste  <b>Pictures:</b> Soap, shampoo  <b>Signs:</b> Want, help, open, nice, look!  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ Close the tap very tightly. Ask the child to run the water.</li> <li>▪ Put soap in a see-through container that the child cannot open independently.</li> <li>▪ Use an empty shampoo bottle that he can play with and close the lid very tightly.</li> <li>▪ Close lid of toothpaste very tightly</li> </ul>
<p>5. Withholding attention</p> <p><b>This teaches the child to draw attention to himself and to signal his presence.</b></p>	<p><b>Objects:</b> Towel, soap  <b>Pictures:</b> Soap  <b>Signs:</b> Want, help, dry, putting up his hand  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ This is not a strategy that is recommended during the bathtime routine, as it has certain safety implications.</li> <li>▪ It can, however, be used when the child is washing his hands before lunch. Pretend not to notice him and do not offer him a towel to dry his hands.</li> </ul>
<p>6. Offering non-preferred items</p> <p><b>This teaches protesting and the concept of “no”.</b></p>	<p><b>Objects:</b> Shampoo bottle, sponge, towel  <b>Pictures:</b> Sponge, soap  <b>Signs:</b> Want, help, no, wash, dry, head-shaking  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ During bath time this activity is usually done by giving the child a bath toy (e.g. shampoo bottle, etc.) that he doesn't like.</li> <li>▪ When the child has to get out of the bath and it is time to dry himself, don't give him the towel, but give him a sponge and say “<i>Yes, It's time to dry yourself!</i>”</li> </ul>

<p>7. Violating expectations  <b><i>This teaches protesting as well as surprise and humour.</i></b></p>	<p><b>Objects:</b> Soap, bath, sponge <b>Pictures:</b> Soap, sponge <b>Signs:</b> Want, help, wash, funny, no, like, don't like <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<p>Do something totally out of routine, e.g.  <ul style="list-style-type: none"> <li>▪ Put the child in the bath without water and say "<i>We are going to have a bath now!</i>"</li> <li>▪ Put the child in the bath with all his clothes on, and see if you get a reaction</li> <li>▪ Put the sponge under his armpit</li> <li>▪ Put the soap on his head - pretend not to see</li> </ul> </p>
<p>8. Asking yes/no questions  <b><i>This teaches the child to confirm or negate information</i></b></p>	<p><b>Objects:</b> Water, sponge <b>Pictures:</b> Sponge, spoon <b>Signs:</b> Head-nodding/ head-shaking <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<p>Ask a number of questions to which the child can indicate a yes or a no, e.g.  <ul style="list-style-type: none"> <li>▪ Must I wash your face?</li> <li>▪ Are we going to wash your hair?</li> <li>▪ Have you finished?</li> <li>▪ Do you want some more?</li> </ul> </p>
<b>Content : Dressing &amp; Undressing</b>		
<p><b>Context:</b> <b>Providing opportunities</b></p>	<p><b>Communication modes:</b> <b>Objects &amp; symbols</b></p>	<p><b>Procedure</b></p>
<p>1. Providing choices of  <ul style="list-style-type: none"> <li>▪ Materials</li> <li>▪ Tasks</li> <li>▪ Partners</li> </ul>  <b><i>This teaches the child labels &amp; choices-making</i></b></p>	<p><b>Objects:</b> Pants, shirt, cap, socks <b>Pictures:</b> Cap, socks, shoes <b>Signs:</b> Want, dress, shoe, shirt, pants <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ Give the child a choice of what he wants to wear, e.g. "<i>Do you want your red T-shirt or do you want your striped T-shirt?</i>" (materials)</li> <li>▪ Give the child a choice of what to do first, e.g. "<i>Must we first take off your shirt or first take off your pants?</i>" (task)</li> <li>▪ Give the child a choice of who must help him, e.g. "<i>Must I help you or must Pauline help you?</i>" (partner)</li> </ul>
<p>2. Making desired items inaccessible  <b><i>This teaches the concept of requesting "help"</i></b></p>	<p><b>Objects:</b> Socks, shoes, hanger, plastic bag, shirt <b>Pictures:</b> Socks, shoes, shirt <b>Signs:</b> Help, want, give, dress, sock, shoe, shirt <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ Put his favourite clothes on a shelf out of reach.</li> <li>▪ Put his shoes in a plastic bag that he cannot open independently.</li> <li>▪ Hang clothes on a hanger over the door where he cannot reach.</li> <li>▪ Knot two socks together so that he is unable to untie them.</li> </ul>
<p>3. Providing small portions / brief turns  <b><i>This teaches the concept of "more".</i></b></p>	<p><b>Objects:</b> Socks, shoe, pants, shirt <b>Pictures:</b> Socks, shoe, cap <b>Signs:</b> More, on, in, shoe, shirt, give <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ When putting on the child's shirt, put only one arm through the armhole and wait so that he can indicate "<i>more</i>".</li> <li>▪ Put on only one sock and pretend you have finished.</li> <li>▪ Put on only one shoe.</li> <li>▪ Pull on only one leg of the pants.</li> </ul>
<p>4. Selecting materials that require assistance  <b><i>This teaches the concept of requesting "help"</i></b></p>	<p><b>Objects:</b> Shirt, pants, shoe <b>Pictures:</b> Shoes, socks <b>Signs:</b> Help, you, shoe, close, difficult <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ Do not automatically start fastening the buttons of the shirt; give the child the opportunity to request assistance.</li> <li>▪ Do not close the zip directly, but draw the child's attention by saying "<i>Yes, fasten your zip</i>"</li> <li>▪ Ask the child to buckle/unbuckle his own shoes.</li> </ul>
<p>5. Withholding attention  <b><i>This teaches the child to draw attention to himself and to signal his presence.</i></b></p>	<p><b>Objects:</b> Shirt, dress <b>Pictures:</b> Shirt, dress <b>Signs:</b> Help, dress, put on, take off, difficult <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ While child is undressing himself, help him to pull the shirt over his head, but do not pull it off completely. Pretend to ignore him and start picking up the other clothes.</li> <li>▪ After undressing the child, start doing something else and pretend not to notice him</li> </ul>

<p>6. Offering non-preferred items  <b><i>This teaches protesting and the concept of “no”.</i></b></p>	<p><b>Objects:</b> Shirt, spoon, cap, pants <b>Pictures:</b> Shirt, cap, pants <b>Signs:</b> Head-shaking, give, help, want <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ While dressing the child, give a totally incorrect item. Say “Put on your shirt” but give him a spoon.</li> <li>▪ If the child selected his red T-shirt, deliberately give him the striped one.</li> <li>▪ If the child wants to put pants on first, give him his cap.</li> </ul>
<p>7. Violating expectations  <b><i>This teaches protesting as well as surprise and humour.</i></b></p>	<p><b>Objects:</b> Socks, pants, shirt, shoe <b>Pictures:</b> Sock, pants, shirt <b>Signs:</b> No, funny, give, mine, finished <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<ul style="list-style-type: none"> <li>▪ After undressing, give the child the “dirty” clothes again to put on.</li> <li>▪ Put a sock on the child’s hand.</li> <li>▪ Pull the pants over the child’s head.</li> <li>▪ Try to put his shirt on yourself.</li> <li>▪ Put his shoe on your head.</li> <li>▪ Give him your shoe to put on</li> </ul>
<p>8. Asking yes/no questions  <b><i>This teaches the child to confirm or negate information</i></b></p>	<p><b>Object:</b> Shoes, dress, jersey <b>Pictures:</b> Shoes, dress, jersey <b>Signs:</b> Head-shaking / head-nodding <b>PCS Communication board</b> <b>EasyTalk 4 Option</b></p>	<p>Ask a number of questions to which the child can respond with a yes/no response:</p> <ul style="list-style-type: none"> <li>▪ Do you want to wear shoes?</li> <li>▪ Are you cold?</li> <li>▪ Do you want your aeroplane shirt?</li> <li>▪ Do you want to wear a dress today?</li> </ul>

## Conclusions about the communication content

According to MacDonald (1983) a few strategies are important when addressing the content of the interaction. In order to provide stimulating content, social contact is necessary, i.e. you need somebody with whom to communicate. That is why all three the activities discussed above involve the child and at least one other person (usually the caregiver). It is also important to provide opportunities for the child and to be in the child’s world. This highlights a number of proximity issues, namely the importance of being on the child’s level (be on the same level of eye contact and do not “talk down” to the child). It is also important to imitate the child, as this is the way in which he learns to imitate the adult. If the child puts a sock on his head, put the other sock on your own head. Apart from providing a rich opportunity for interaction, it is also great fun!

“Salt ‘n Pepper” contacts (interaction opportunities spread throughout the day that provide frequent, natural opportunities for interaction work best. (Beukelman & Mirenda, 1998). This is why these three ADLs were selected: mealtime happens at least three times a day, the child dresses and undresses at least

twice a day, and there are frequent opportunities to wash face and hands throughout the day. These are thus activities that occur frequently.

### **6.2.3.2 Communication partners**

This relates to **whom** the child communicates with. The communication partner is a vital part of the interaction process, because if you have something to say (content), you have the ability to say it, e.g. you know the manual sign for “*hello*”, but there is nobody to say it to, it all becomes futile. Communication partners, e.g. caregivers, siblings and peers also need to be taught how to communicate with the CSDs and what to expect of them in interaction. Partners should be taught to look for communication means that might not be very obvious. They also need to be aware of the different communication functions, e.g. the CSD is requesting “*more*” or requesting “*help*”.

Literature indicates that communication partners rate CSDs as competent communicators if they are able to do the following:

- (1) Portray a positive self-image to their partners (this can only be accomplished if the CSDs have a sense of self-esteem and they feel that they are also able to do something and can contribute to the interaction).
- (2) Show an interest in others and draw others into interaction. This implies that CSDs have the ability to ask questions, to convey compliments, etc. Although this is a very important aspect, it will not be addressed as such in the BCIP due to the specific activity-based nature of the communication content.
- (3) Actively participate and take turns during interaction. This aspect is highlighted in the BCIP as the CSDs will have ample opportunities to engage in turn-taking activities. The deliberate provision of communication opportunities is an attempt to facilitate turn-taking
- (4) Put their partners at ease, e.g. by commenting. Although this aspect will not receive direct attention in the BCIP, is expected to be a spin-off due to the particular method of training that is used. (Blischak *et al.*, 1997).

Providing CSDs with communication opportunities directly relates to the partners' perceptions of the children's ability to respond appropriately (Blischak *et al.*, 1997). Therefore, intervention that fails to examine and address the role of the partners' expectations has limited benefit for potential CSDs. Any intervention programme should therefore involve the raising of the partners' levels of awareness and by teaching them to expect the CSDs who use an AAC system to play an active role in interaction.

## **7 GENERAL INTERVENTION PRINCIPLES**

1. The intervention process should enhance participation in current and future integrated environments (Blischak *et al.*, 1997). Beukelman & Mirenda (1998) also stress that interventions should be relevant for both short- and long-term development ("for today and tomorrow"). This implies that the skills that the CSD learns should also be applicable once he enters school, and when he is interacting with people outside the immediate family. The critical communication messages that the child is taught during ADLs should also be applicable to other activities, e.g. if the child is taught to request help when dressing, he can also request help when he is at school and, for example, he is unable to open the paint.
2. The role of interaction is not only to facilitate interaction between the primary caregiver and the CSD, but also to generally increase social interaction (especially with peers and siblings). In the past this factor was overlooked, but as educational inclusion and social inclusion (integration into community activities) become more of a reality for CSDs, it is receiving more and more attention.
3. The skills taught to the CSDs should be essential components of further development. The cognitive skills that develop with the communication skills (e.g. object permanence) is a good example of this. Increasing a child's communication skills will lead to an increase of learning abilities once he

enters school. Literature has indicated that the first five years of a child's life is the critical period for learning, and this period has to be utilised to its full extent. Currently teachers are spending a lot of time teaching CSDs basic ADL skills and recognition of body parts – functions that could have been acquired in the pre-school years had the primary caregivers known how to facilitate them.

4. It is important that the development of functional communication should be a priority for the CSD and for the family. Although ADLs as such might not be highly motivational for CSDs, they might find the interactional component very enjoyable – this is the time when they have one-on-one interaction with their primary caregivers. During discussions with primary caregivers it was noted that they found ADLs very important in their daily routine, due to the high frequency. Their aim is to help their children to become as independent as possible in the pre-school years.
5. One of the golden rules of interaction with CSDs is a give-and-take balance. Primary caregivers should be cautious to not always give, give, and give. They have to be taught to **wait** for a response. This is one of the most difficult skills to acquire, as we become anxious if there is a silent period and try to fill it by talking. It is necessary to wait for at least 15 seconds, and when a child is busy discovering a new activity, the partner may have to wait for between 1 – 3 minutes. This is not a passive waiting period where the partner can do other things, but an active waiting period where she looks at the child and tries to understand what he wants to tell her! Waiting and observing are two sides of the same coin.
6. It is also important to actively facilitate conversational skills by keeping the interaction going. This can be done by chaining things together, e.g. “Yes, *that is your sponge. We wash your tummy with your sponge. This tummy is full!*” However, it is important to keep a balance and not to dominate the interaction – expect a response from the child! If the partner keeps on talking

and does not wait expectantly for a response the child will never learn to become an active communication partner taking turns during communication.

## **8 MONITORING PROGRESS**

### **8.1 Why is it important to monitor progress?**

Service provision to CSDs is an on-going process, and monitoring progress is part of it. This is largely due to the fact that CSDs' needs and abilities change over time, requiring adaptations to the intervention plan. Being able to monitor progress assists in the planning of new objectives and the setting of new goals. It is also a method of evaluating the effectiveness of the service provision heightening accountability. Finally, service providers (the nurse and caregivers in the case of the BCIP) gain self-confidence in performing their tasks if progress is seen.

**Progress checklist**

Name of child \_\_\_\_\_

Name of person completing the

form \_\_\_\_\_

Age \_\_\_\_\_

Date

**A THE CHILD**

**A-1 Which ways of communication did the child use? (communication means)**

Does the child use **pointing** to communicate?

1                  2                  3                  4

Does the child use **objects** to communicate?

1                  2                  3                  4

Does the child use **crying** to communicate?

1                  2                  3                  4

Does the child use **facial expressions** to communicate?

1                  2                  3                  4

Does the child use **manual signs** to communicate?

1                  2                  3                  4

Does the child use **photographs** to communicate?

1                  2                  3                  4

Does the child use **line-drawings** (symbols) to communicate?

1                  2                  3                  4

Does the child use the **EasyTalk** to communicate?

1                  2                  3                  4

Does the child use **vocalisations** to communicate?

1                  2                  3                  4

Does the child use **speech** to communicate?

1                  2                  3                  4

#### A-2 Why does this child communicate? (communication functions)

How well does the child **request help**?

1                  2                  3                  4

How well does the child **request objects**?

1                  2                  3                  4

How well does the child **request “more”**?

1                  2                  3                  4

How well does the child **protest**?

1                  2                  3                  4

How well does the child **confirm**?

1                  2                  3                  4

How well does the child **draw attention** to himself?

1                  2                  3                  4

How well does the child **label (name)** things?

1                  2                  3                  4

How well does the child **make choices**?

1                  2                  3                  4

How well does the child **indicate humour / teasing**, etc.?

1                  2                  3                  4

## B      COMMUNICATION PARTNERS & ENVIRONMENT

### B-1    How does the child communicate with people in the environment?

How frequently does the child communicate with **caregivers** / people in the house?

1                  2                  3                  4

How frequently does the child communicate with siblings and other **children**?

1                  2                  3                  4

How frequently does the child communicate with **unfamiliar adults** (strangers?)

1                  2                  3                  4

### B-2    Daily living information about the child

How **aware** is the child of the environment (interest in environment)?

1                  2                  3                  4

How much **enjoyment** is seen?

1                  2                  3                  4

How **active** is the child in interaction?

1                  2                  3                  4

How **independent** is the child during ADLs?

1                  2                  3                  4

**C NURSE'S OBSERVATION : Which strategies should I encourage the primary caregiver to use with her child?**

Providing opportunities for **choice-making**

Low priority              Medium priority              High priority

Providing **small portions** of materials or **brief turns**

Low priority              Medium priority              High priority

Making desired items **inaccessible**

Low priority              Medium priority              High priority

Selecting materials that require **assistance**

Low priority              Medium priority              High priority

Withholding **attention**

Low priority              Medium priority              High priority

Offering a **non-preferred** item

Low priority              Medium priority              High priority

**Violating expectations**

Low priority              Medium priority              High priority

Asking **yes/no** questions

Low priority              Medium priority              High priority

## D. RECOMMENDATIONS

---

---

---

### CODES

No	Description
1	No evidence at all.
2	Emergent use. (Skill is starting to develop, but it is not clear and inconsistent).
3	Correct use, but with low frequency.
4	Uses correctly when needed.

### CASE STUDY / VIGNETTE

Busi is a four-year-old girl brought to you by her mother. Her mother has noticed that she is reaching milestones at a slower rate than her brother who is two years younger. Her mother says that the brother is able to do things that Busi is still unable to do. Busi is the middle one of three children who live in an informal settlement in Hammanskraal. Her mother is not working, as she has to look after Busi. The father is a taxi-driver. Busi's mother feels that they are stigmatised due to Busi's disability. There is no family history of disability. At present Busi spends most of the day outside watching the other children play. The mother also has problems in dressing and feeding Busi as she is always on the move and becomes agitated easily. She mostly communicates using facial expressions, and makes sounds. She pushes things away when she does not want them.

**Answer the following questions**

**1. Current abilities**

- 1.1 Which different ways of communication does Busi use at present? (*communication means*)
- 1.2 What does Busi try to say with the things she does? (e.g. Which reasons for communication does she have?) (*communication functions*)
- 1.3 Who are the people Busi communicates with? (*communication partners*)

**2. Recommendations**

- 2.1 If you are the nurse working with Busi and her mother, what advice will you give her to help Busi?
- 2.2 Which different ways of communication do you think Busi should acquire? (*communication means*)
- 2.3 Which reasons for communication will you encourage Busi to learn? (e.g. what does she want to say with what she does?) (*communication functions*)
- 2.4 How can you increase the number of people Busi can communicate with? (*communication partners*)
- 2.5 How can you change things in Busi's environment in order to give her more opportunities to communicate? (*communication opportunities*)

## REFERENCE LIST

**American Speech-Language Hearing Association.** (1989). Communication-based services for infants, toddlers and their families. *ASHA, May*, 32-34.

**American Speech-Language Hearing Association.** (1996). Technical report of the ad hoc committee on multiskilling. *ASHA*, 38(2), 53-61.

**Berger, M.S.** (1980). Problem solving. In M.S. Berger., D. Elhart., S.C. Firshich., S.B. Jordan & S. Stone (Eds.), *Management for nurses*. (pp. 200-205). St Louis: Mosby.

**Beukelman, D.R. & Mirenda, P.** (1992). *Augmentative and alternative communication. Management of severe communication disorders in children and adults*. Baltimore : Paul H Brookes Publishing Company.

**Beukelman, D.R. & Mirenda, P.** (1998). *Augmentative and alternative communication. Management of severe communication disorders in children and adults*. (2<sup>nd</sup> ed.). Baltimore : Paul H Brookes Publishing Company.

**Blackman, J.A.** (1995). *Training and continuing education in early intervention*. Maryland : Aspen Publishers.

**Blackstone, S.** (1991). Intervention with partners of AAC consumers. *Augmentative Communication News*, 4(2), 1-6.

**Blischak, D.M., Loncke, F. & Waller, A.** (1997). Intervention for persons with developmental disabilities. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 299-339). Massachusetts : Allyn & Bacon.

**Bornman, J. & Alant, E.** (1999). Training teachers to facilitate classroom interaction with autistic children using digital voice output devices. *South African Journal of Education*, 19(4), 364-373.

**Bornman, J.** (1998). It takes two to interact but also a few other skills... *Clinical Applications in Clinical Practice of Communication pathology*, 3, 37-47.

**Brandon, J.E. & Majumdar, B.** (1997). An introduction and evaluation of problem-based learning in health professions education. *Family Community Health*, 20(1), 1-15.

**Croxford, J. & Viljoen, D.** (1999). Alcohol consumption by pregnant women in the Western Cape. *South African Medical Journal*, 89(9), 962-965.

**Dublinske, S.** (1983). The nurse and communication disorders in the schools. In S. Shanks (Ed.), *Nursing and the management of paediatric communication disorders*. (pp. 5–53). San Diego : College-Hill Press.

**Freeman, R.B. & Heinrich, J.** (1981). *Community health nursing practice*. (2<sup>nd</sup> ed.). Philadelphia : W.B. Saunders Company.

**Fuller, D.R., Lloyd, L.L. & Stratton, M.M.** (1997). Aided AAC Symbols. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 48-77). Massachusetts : Allyn & Bacon.

**Givens-King, M., Sebastian, J.G., Stanhope, M.K. & Hickman, M.J.** (1997). Using problem-based learning to prepare advanced practice community health nurses for the 21<sup>st</sup> century. *Family Community Health*, 20(1), 29-39.

**Goossens' C., Sapp-Crain, S. & Elder, P.S.** (1994). *Communication displays for engineered pre-school environments*. Solana Beach : Mayer Johnson Company.

- Gorenflo, C.W., Gorenflo, D.W. & Santer, S.A.** (1994). Effects of synthetic voice output on attitudes towards the augmented communicator. *Journal of Speech and Hearing research*, 37(1), 48-64.
- Haring, T.** (1993). Research basis of instructional procedures to promote social interaction and integration. In R.A. Gable, & S.F. Warren (Eds.), *Strategies for teaching students with mild to severe mental retardation*. (pp. 129-164). Wiltshire: Cromwell Press Ltd.
- Jacobs, T.** (1997). Developing integrated education programmes for occupational therapy: the problem of subject streams in a problem-based course. *British Journal of Occupational Therapy*, 60(3), 134-138.
- Johnson, J.M., Baumgart, D., Helmstetter, E & Curry, C.A.** (1996). *Augmenting basic communication in natural contexts*. Baltimore : Paul H Brookes Publishing Company.
- Kannenberg, P., Marquardt, T.P. & Larson, J.** (1988). Speech intelligibility of two voice output communication aids. *Journal of Communication Disorders*, 21(1), 11-20.
- Lloyd, L.L., Fuller, D.R. & Arvidson, H.H.** (1997). Glossary. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 522-543). Massachusetts : Allyn & Bacon.
- Loncke, F. & Bos, H.** (1997). Unaided AAC Symbols. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 80-106). Massachusetts : Allyn & Bacon.

**MacDonald, J.D.** (1983). A conversational approach to language delayed children: Problem-solving for nurses. In S. Shanks (Ed.), *Nursing and the management of paediatric communication disorders*. (pp. 103-164). San Diego : College-Hill Press.

**Mast, D.L.** (1983). Selecting and implementing communication methods for children. In S. Shanks (Ed.), *Nursing and the management of paediatric communication disorders*. (pp. 225-250). San Diego : College-Hill Press.

**McCormick, L. & Schiefelbusch, R.L.** (1984). *Early language intervention. An introduction*. Columbus : Charles E. Merrill Publishing Company.

**Musselwhite, C.R. & St. Louis, K.W.** (1988). *Communication programming for persons with severe handicaps. Vocal and augmentative strategies*. Texas : Pro-Ed.

**Quist, R.W. & Lloyd, L.L.** (1997). High technology. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 137-168). Massachusetts : Allyn & Bacon.

**Rourke, A.** (1998, August). *Introducing and developing choices*. Paper presented at the International Society for Augmentative and Alternative Communication Conference, Dublin, Ireland.

**Rowland, C. & Schweigert, P.** (1993). Analysing the communication environment to increase functional communication. *Journal for the Association for persons with Severe Handicaps*, 18(3), 161-176.

**Savin-Baden, M.** (1997). Problem-based learning, Part 2: Understanding learner stances. *British Journal of Occupational Therapy*, 60(12), 531-536.

**Sailor, W. & Guess, D.** (1983). *Severely handicapped students and instructional design*. Boston : Houghton Mifflin Company.

**Salvatori, P.** (1997). Towards developing a flexible health workforce. *Canadian Journal of Occupational Therapy*, 64(2), 47-52.

**Silverman, F.N.** (1995). *Communication for the speechless*. Englewood Cliffs : Prentice Hall.

**Smith, M.M.** (1994). Speech by any other name: The role of communication aids in interaction. *European Journal of Disorders of Communication*, 29(3), 225-240.

**Viljoen, D.** (1999). Foetal Alcohol Syndrome. *South African Medical Journal*, 89(9), 958-960.

**Westling, D.L. & Fox, L.** (2000). *Teaching students with severe disabilities*. Ohio: Charles E. Merrill Publishing Company.

**WHO** (1999). *ICIDH-2. International Classification of Functioning and Disability. Beta-2 Draft. Full version*. Assessment, Classification & Epidemiology Group. Geneva : World Health Organisation.

**Zangari, C. & Kangas, K.** (1997). Intervention principles and procedures. In L.L. Lloyd, D.R. Fuller, & H.H. Arvidson (Eds.), *Augmentative and Alternative Communication. A handbook of principles and practices*. (pp. 137-168). Massachusetts : Allyn & Bacon.

## APPENDIX C

### SUMMARY OF THEMES DELINEATED AFTER TWO INDEPENDENT FOCUS GROUPS WITH NURSES

---

#### THEME I            SUMMARY OF PROBLEMS EXPERIENCED BY PRIMARY CAREGIVERS OF CHILDREN WITH DISABILITIES

##### 1        DISEMPOWERMENT

###### 1.1    Lack of knowledge

- Disability
- Normal development, in particular sexual development : results in abuse and rape
- Medical issues and problems
  - poor compliance with appointments and medication : immunisations not up-to-date
  - “*shop around*” resulting in intervention starting very late
  - passive : “*don’t take action*”
  - no follow-ups are done
  - attitudes of nurses not always conducive to the establishment of rapport due to time constraints and staff shortages
- How to access a disability grant
- How to access services

###### 1.2    Poor parenting skills

- Unaware of seriousness / not concerned
- Impact on siblings, e.g. siblings have behaviour problems such as juvenile delinquency
- Focus on care, not training
- Lack initiative
- Overprotect or abandon children

- Deprivation
- Young mothers do not care for their typically developing children (come to school dirty, hungry, sick, etc.). This phenomenon is even more prevalent in the case of CSDs

### **1.3 Poverty**

- Transport
  - struggle to use public transport to school and clinic
  - some public transport does not take wheelchairs
- Clinic attended infrequently (cannot afford)
- Lack of own homes : live with relatives
- Malnourishment of pregnant mothers and children

### **1.4 Limited resources**

- Schools
  - limited and scattered : people unaware of them
  - expensive
  - long waiting lists
- Wheelchairs (acquiring and repairing)
- Untrained teachers
- Children stay at home : no or little stimulation
- No control of quality of services

### **1.5 Unemployment**

- No support, have to care for CSDs – cannot work
- Very young mothers – poorly qualified – low wages – battle to pay caregivers

### **1.6 Illiteracy**

### 1.7 Lack of support

- Rejection and blame from family
- Good prognosis if supported by partner

## 2 EXTERNAL INFLUENCES

### 2.1 Religion

- Acceptance
- Act of God
- Religious convictions do not allow them to attend clinic
- Pray at home
- Angry with God

### 2.1 Culture and tradition

- Rely on traditional healers : go there first
- Believe witchcraft caused disability
- Older people believe contraceptives cause disability and blame nurses who do family planning
- Customs

### 2.2 Family

- Impact on siblings : do not want to be identified
- Both primary caregivers work
- Single mother families
- New partners do not accept
- Unmarried mothers
- Big families, have many other children to attend to
- Rejection by family and in-laws
- Family disorganisation
- Very young mothers
- Elderly mothers

### **2.3 Community**

- Uneducated regarding disability
- Stigmatises family of CSD
- Rejects family of CSD
- Ostracises & blames
- Attacks integrity of profession – (impression: a nurse who has a CSD cannot really know what is what)
- Needs community outreach (especially into schools & churches)

## **3 EMOTIONAL PROBLEMS**

- 3.1 Denial
- 3.2 High stress levels
- 3.3 “*Give up*” – despondent
- 3.4 Fear : don’t know what to do / community reaction
- 3.5 Shock
- 3.6 Shame
- 3.7 Expectations for “*typically developing child*” is shattered
- 3.8 “*Breaks you*”
- 3.9 Worry
- 3.10 Anger (with God and with self)
- 3.11 Pride and status decline

## **4 IMPACT**

- 4.1 Lose status in the community
- 4.2 Hide / dump the child
- 4.3 Rejection by family / in-laws
- 4.4 Family members blame each other
- 4.5 Blame partners (especially in the case of an unwanted pregnancy)
- 4.6 Sexual abuse and sex for money (CSDs)

**THEME II            HOW DO NURSES PERCEIVE THEIR ROLE AND WHAT  
THEY CURRENTLY DO?**

- 1      Obtain case history and background information
- 2      Physical examination
- 3      Screen / Identify / Detect
- 4      Advice, comfort (support), counselling
- 5      Health promotion and co-ordination of CBR activities
  - Nutrition
  - Hygiene
  - Accident prevention
  - Awareness campaigns
  - Leadership
  - Co-ordination

Health promotion

CBR- activities
- 6      Treatment of minor ailments
- 7      Referral
  - Clinic
  - Hospital (secondary / tertiary)
  - Social worker
  - Therapist
  - School
  - Specialist
  - Religious support
  - Genetic clinic
  - Hospitals refer back to clinics
  - Referral line problematic
  - No feedback
  - Often primary caregivers do not attend referred service due to transport problems
- 8      Follow-up to monitor

App

### THEME III PROBLEMS EXPERIENCED BY NURSES

(*This information was spontaneously provided and not probed for*)

- Depressed : do not feel supported
- Incapable – not helping primary caregivers optimally – need knowledge and skills
- Attitudinal barriers due to limited staff and time constraints
- School nurses lack resources
- No follow-ups are done
- No co-ordination of staff

### THEME IV NURSES' EXPERIENCES

#### 1 Exposure

- Depends on setting (e.g. school nurses and nurses at the genetic clinic see CSDs more often)
- Some never see any CSDs

Appendix C

#### 2 Activities

- Look at roles

#### 3 Disability types

- Intellectual impairment
- Cerebral palsy
- Sensory deficits (deaf or blind)
- Epilepsy
- Hydrocephalic
- Micro-cephalic
- Physical appearance, e.g. strange or small for age
- Neglect, e.g. blind after running into a fence

- Abuse and sexual abuse
- At risk, e.g. twins

#### **4 How to identify**

- Developmental milestones (children younger than 2 years)
- Through schools (e.g. slow learner, repeated Gr. 1 three times)
- Neighbours inform nurse who then does home-visit
- Detect at birth
- If missed at birth, detect at baby clinic
- Go to traditional healers before clinics / hospitals
- Come to clinics when applying for a disability grant

#### **5 Problems at work**

- No follow-ups
- Lack of knowledge
- Lack of resources – deprived province (Northwest)
- Depression
- Shock "*nasty experience to deliver a baby with a disability*"

#### **6 Solutions**

- Training of nurses
- Co-ordination of services for CSDs (education and health sectors)
- Government to build an infra-structure

#### **FOOTNOTE**

- Although exposure might be limited, the impact is high as most nurses can recall details of clients even if they had not been seen for more than a year.
- Nurses are keen to know more about disability because they acknowledge the fact that although they do not frequently see CSDs at the clinics, they know that these CSDs are out there in the community.

## THEME V            WHAT DO NURSES NEED?

### 1       Knowledge / Education

- Disability
- Screening : “*What to look for*”
- At risk and established risk factors
- Identify, do case history and refer
- Referral skills
  - early referral
  - know referral line / route
  - also refer to church for support
  - refer to social worker for grant
- Family planning for CSDs to reduce number of pregnancies
- Guidance for primary caregivers on parenting skills for CSDs (currently overprotect, which leads to learnt helplessness or abandonment)
- How to treat primary caregivers
- What to **do** about problems (not only detect them!)
- Training of peers and siblings to understand disability
- Focus on **person** not on the **disability**
- Training by speech therapist
- Collaboration with other professionals, e.g. school health nurses, priests, social workers, teachers, midwives

### 2       Skills

- Rapport and empathy
  - comfort primary caregivers
  - how to deal with primary caregivers
  - how to put primary caregivers at ease
  - encourage acceptance
- Training of primary caregivers
  - parenting

- accident prevention
- guidance and nutrition
- hygiene
- household safety (e.g. paraffin and medicine)
- Establish and foster a support group
  - primary caregivers to “*break the silence*”
  - primary caregivers should support and provide suggestions
  - success stories are needed as role models
- Know what to look for / detection
- Handling CSDs: What to do. Bring skills to the people before referring!
- Foster feedback and follow-ups (at home and at school)
- Be able to provide examples and advice

### **3 Attitudes**

- Own acceptance of CSDs before teaching primary caregivers to accept
- Love CSDs : “*Have a big heart*”
- Interest
- Not irritable
- Feel supported and “*cared for*”
- Moral and spirit of nurses should be peped up
- Empathy (not sympathy)
- Address and change parental attitudes
- Focus on abilities and skills
- Focus on a person, not on a disability
- Peers – children do not have prejudices, adults instil them
- Motivated to help CSDs and their primary caregivers

### **4 Community awareness campaign**

- Drama / demonstration about severe disability
- Remove stigmatisation through education
- Empower community to supply own services

**APPENDIX D****NURSE'S INFORMATION**

1. Please answer all the questions
2. Answer all the questions as completely as possible
3. Mark with a cross in the appropriate block
4. All responses will remain highly confidential

**1 Where do you work?**

---

For official use

Respondent #

V1 

--	--	--

1-3

Card #

V2 

--

4

V3 

--	--

5-6

V4 

--

7

**2 Gender**

Female	Male
--------	------

**3 Birth date**

Day	Month	Year

V5 

--	--

8-9

V6 

--	--

10-11

V7 

--	--

12-13

**4 Highest nursing qualification obtained**

---

V8 

--	--

14-15

**5 Total number of years of experience as a nurse**

Years	Months

V9 

--	--	--

16-19

**6 How long have you worked in the present setting?**

Years	Months

V10 

--	--	--

20-23

**7 How often do you see children who have**

	Never	Every week	Every two weeks	Every month	Less than once a month
Mental retardation					
Cerebral palsy (CP)					
Deafness					
Blindness					
No speech					
Other (specify).....					

V11 

--

24

V12 

--

25

V13 

--

26

V14 

--

27

V15 

--

28

V16 

--	--

29-30

**8 How serious are the following problems in your opinion?**

	1 = Very serious	2 = Serious	3 = Average	4 = Mild	5 = No problem
Violence and trauma					
Mental retardation (MR)					
Cerebral palsy (CP)					
Deafness					
Blindness					
No speech					
Multiple disability e.g. CP & MR					
HIV/AIDS					
Tuberculosis					
Chronic diseases, e.g. asthma					

V17	<input type="checkbox"/>	31
V18	<input type="checkbox"/>	32
V19	<input type="checkbox"/>	33
V20	<input type="checkbox"/>	34
V21	<input type="checkbox"/>	35
V22	<input type="checkbox"/>	36
V23	<input type="checkbox"/>	37
V24	<input type="checkbox"/>	38
V25	<input type="checkbox"/>	39
V26	<input type="checkbox"/>	40

**9 How comfortable do you feel in coping with children who have**

	1 = Very uncomfortable	2 = Uncomfortable	3 = Comfortable	4 = Very uncomfortable
Mental retardation				
Cerebral palsy				
Deafness				
Blindness				
No speech				
Multiple disabilities				

V27	<input type="checkbox"/>	41
V28	<input type="checkbox"/>	42
V29	<input type="checkbox"/>	43
V30	<input type="checkbox"/>	44
V31	<input type="checkbox"/>	45
V32	<input type="checkbox"/>	46

**10 What do you usually do with these children?**

A child with mental retardation	<input type="checkbox"/>
A child who can't walk (cerebral palsy)	<input type="checkbox"/>
A child who can't hear (deafness)	<input type="checkbox"/>
A child who can't see (blindness)	<input type="checkbox"/>
A child who can't talk (no speech)	<input type="checkbox"/>
A child with multiple disabilities	<input type="checkbox"/>

V33	<input type="checkbox"/>	<input type="checkbox"/>	47-48
V34	<input type="checkbox"/>	<input type="checkbox"/>	49-50
V35	<input type="checkbox"/>	<input type="checkbox"/>	51-52
V36	<input type="checkbox"/>	<input type="checkbox"/>	53-54
V37	<input type="checkbox"/>	<input type="checkbox"/>	55-56
V38	<input type="checkbox"/>	<input type="checkbox"/>	57-58

**11 In your opinion, what are the things most children that you see, need?**

V39	<input type="checkbox"/>	<input type="checkbox"/>	59-60
-----	--------------------------	--------------------------	-------

## APPENDIX E

### DIFFERENCES IN TRANSLATIONS IN FOCUS GROUP OF CAREGIVERS OF TYPICALLY DEVELOPING CHILDREN

---

Translation 1	Translation 2
“...stays on my side...”	“...touches things that can fall on him, thus I keep him with me...” (safety issue)
“...helps me clean the house...”	“...when I clean the house and hold my broom like this, she holds hers the same...” (provides an example)
“...she fills her toys with sand...”	“... she brings her pots and cup toys and cooks porridge / pap...” (provides an example, child engages on higher level of play, namely imaginary play)
“... we watch TV...”	“... she comes to me and requests to watch her popular “Popeye” story...” (active activity with child initiating and requesting. Example provided)
Omitted fact	When child hears a sound he asks his mother what it is (child requesting information, example of a communication function)
“... I don't enjoy pushing him around on his bicycle...”	“... because I have a small baby inside, and I don't like him playing in the street...” (provided reason for action)
Omitted fact	“... he is one who doesn't like food, but wants chips, fruits and biscuits...” (child shows preferences : pre-cursor to choice-making which is an important communication function)
“doesn't like bathing...”	“... stands at the door and says, “Mama is killing me!” (example is provided. Shows intensity).
Omitted fact	“... if there are strangers in the house, he comes to ask who they are...” (child is inquisitive and initiates interaction).
“... playing with friends...”	“... playing “diketo” with friends (a game with stones thrown into holes and they add and subtract while throwing a bigger stone and pulling out the smaller stones and catching the bigger one before it falls)” (example provided giving rich contextual information).

## APPENDIX F

### SUMMARY OF THEMES DELINEATED AFTER FOCUS GROUPS WITH CAREGIVERS OF TYPICALLY DEVELOPING CHILDREN

---

#### THEME 1            ACTIVITIES TYPICALLY DEVELOPING CHILDREN ENGAGE                         IN

- Mealtimes
  - done individually – mother with child
  - allowed to choose food, e.g. oats, maltabella, tea, mealie porridge, bread, vegetables
  - social activity, all sit together and eat
- Bathtime
  - activity done frequently (sometimes only wash face and hands)
  - like playing with water
  - usually done when household chores are finished and while other children are still at school
- Music and dancing
- Literacy exposure
  - like drawing and colouring pictures
  - like tearing pictures from magazines
  - magazines, e.g. Bona
  - some have no exposure to books
- Toys
  - bicycle (other children push)
  - toy cars
  - sand play
- Playing with friends
  - interactive games with siblings, neighbours, etc.
- Helping with domestic tasks
  - sweeping the floor and dusting

**THEME II                    COMMUNICATION FUNCTIONS USED BY TYPICALLY DEVELOPING CHILDREN**

- Greeting - all mothers indicated that greeting is important. This is one of the indicators for being a “*good child*”.
- Commenting - make comments about what happened during the day, what they did, etc.
- Requesting - want to go and play with friends, ask people who come to visit what their names are, etc.
- Providing information - have to inform primary caregivers where they are going
- Choice-making
  - make choices in terms of what they want to eat, wear and do
  - persistent after choice has been made
  - usually occurs during feeding and dressing activities
  - strong preferences, e.g. jeans, macarena dance, takkies, etc.
- Protesting - walk away, cry, talk
- Indicating pleasure - show that they like/enjoy something indicate appreciation
- Signalling presence - request attention without interfering in adult communication and being rude  
Children should be seen, not heard!

**THEME III            GENERAL COMMENTS MADE BY CAREGIVERS**

- Mothers enjoy “*teaching*” their children, e.g. difference between good and bad, politeness and rudeness, animal sounds, etc.
- Household safety issues receive a lot of attention (e.g. fire, medicine, etc)
- Good manners, e.g. respect for elders, are a high priority.
- Mothers usually have all the responsibility for their children and have to take their children with them wherever they go. This has serious implications for children with disabilities (e.g. transport and mobility)

## APPENDIX G

### DIFFERENCES IN TRANSLATION IN FOCUS GROUP OF CAREGIVERS OF CHILDREN WITH DISABILITIES

---

Translation 1	Translation 2
“... I don't enjoy it when he plays with others...” Omitted fact	“... I don't enjoy it when he plays inside the house with others...” (providing more contextual data and qualifying of the answer). “... I enjoy teaching him the church songs...” (provides information regarding an enjoyable activity).
Omitted fact	“... she just sits with the other children although they know she cannot speak, but she understands their little games...” (provides information regarding an activity the child engages in as well as information about peers).

## APPENDIX H

### SUMMARY OF THEMES DELINEATED AFTER FOCUS GROUP WITH CAREGIVERS OF CHILDREN WITH DISABILITIES

---

#### THEME 1 ACTIVITIES CHILDREN WITH DISABILITIES ENGAGE IN

- Enjoy nothing
  - three participants stated that their children enjoy nothing, but continued to explain in which activities they do participate
- Games with friends
  - never at home, always play with friends
  - play with younger siblings' friends
  - some neighbourhood children take the CSDs toys and tease them
- Mealtimes
  - children eat with rest of family or they eat alone
  - allowed to choose food, e.g. tea, mealie porridge, bread, vegetables, fruits and meat (this depends on what is available). At times no choices are provided due to only one food type being available
- Bathtime
  - activity done very frequently (between two and three times per day). Sometimes only wash face and hands
  - like playing with water
  - do not like water over face and head
  - some try to be independent, but need help from primary caregiver or older siblings
  - some very dependent on primary caregiver to assist with the activity

- Music and dancing
  - primary caregiver teaches them songs (e.g. church songs)
  - primary caregiver does not like dancing, encourages younger peers to dance with the child
- Literacy exposure
  - three of the five participants said that their children had no interest in magazines or pictures
  - two paged through a magazine (Bona) and tried to scribble.
- Help with domestic tasks
- Wants continuous reinforcement
  - have to clap hands if she finishes her food
- One child runs away and sits alone on the rubbish dump all day

## THEME II            COMMUNICATION FUNCTIONS USED BY CHILDREN WITH DISABILITIES

- Greeting
  - all participants indicated that they felt greeting was very important. This is one of the indicators for being a “*good child*”
- Commenting
  - none of the participants perceived their children as commenting on activities
- Requesting
  - one participant said that her child requests to play with friends
  - do not request certain foods, activities or clothing
- Providing information
  - four of the five participants commented that their children never tell them where they are going. These children are perceived as naughty (no way of communicating message?)

- Choice-making
  - some make choices in terms of what they want to eat (particularly sweets and “*simbas*” chips)
  - mostly on level of indicating preferences (precursor to choice-making), e.g. milk
- Protesting
  - crying
- Indicating pleasure
  - no examples provided
- Signalling presence
  - should not request attention during adult communication, perceived as being rude
- Inappropriate interaction
  - participants commented that sometimes their children talk to strangers and visitors in an inappropriate way – causing shame for the family.

**THEME III            COMMUNICATION MEANS USED BY CHILDREN WITH  
DISABILITIES**

- Means frequently mentioned
  - crying
  - inappropriate talking
  - unintelligible speech
  - using objects to communicate, e.g. showing empty plate to indicate “*finished*”

**THEME IV            RECEPTIVE LANGUAGE SKILLS OF CHILDREN WITH  
DISABILITIES**

- Level
  - most participants commented that their children’s understanding is limited (e.g. days of the week).

- Participants struggle to understand communication intention, frustrates CSDs.
- Demands
  - children cannot cope with demands and try to avoid them through difficult behaviour or non-compliance. Leads to power struggles.

**THEME V            GENERAL COMMENTS**

- Participants generally perceive their children's behaviour as inappropriate. Also state that the children are uncooperative, highly irritable, short-tempered and stubborn, especially when demands are placed on them. One participant stated that her child is constantly tired (passivity to avoid demands?)
- Some children are well integrated into the community, e.g. play with neighbourhood children, go to the shops and go to church.
- One participant said that she did not want to encourage her child to play with other children, as they tease her child because they think she cannot understand.
- One participant said that she did not want to give her child with a disability any more toys (they used to make him wire-cars) as the other children take the toys.

## **APPENDIX I**

### **TRAINING OF INTERVIEWERS**

---

### **IN-SERVICE TRAINING OF COMMUNITY NURSES – BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES**

#### **Training of interviewers**

##### **Aims of the training**

1. To discuss practical aspects pertaining to the training
2. To provide interviewers with background information related to the training
3. To discuss the process of asking questions and the recording of results on Response Form I

##### **1 Practical aspects**

- Interviewers Juan Bornman (1), Munyane Mophosho (2), Kerstin Tönsing (3), Catherine van Dijk (4), Elaine Cobb (5), Elmarie van der Merwe (6) and Yasmin Opperman (7) Enid Moolman (8)
- Dates: Pilot study: Tuesday 20 June (whole day)  
Friday 23 June (13h00 – 15h00)  
Main study: Monday 10 July (7h30 – 10h30)  
Friday 14 July (12h00 – 14h00)
- Time Pilot study: Leave from Communication Pathology Building on 20 June at 07h00  
Main study: Leave from Communication Pathology Building On 10 July at 07h30 (arrange with Munyane).
- Video Each person must ensure that she knows how to operate the video camera. Sufficient video cameras, tapes and tripods will be provided.

- Materials      Take own stationary and clipboard  
Take a stopwatch  
Each interviewer will be supplied with enough forms  
(Response Form I)  
Each interviewer will be supplied with a BCIP, containing all the relevant equipment
- Dress           Please dress neatly and preferably wear navy or dark grey.  
No jeans or takkies. A dress is preferable.
- Tea & lunch    Will be provided

## 2 Background information

- Aim and basic content of the BCIP training:
  - 1 To discuss the concept of multiskilling and highlight the role of community nurses in the process of training beginning communication skills.
  - 2 To discuss the different means of communication (including unaided and aided strategies), functions, partners and opportunities for interaction.
  - 3 ***To facilitate the development of skills related to***
    - ***the implementation of unaided strategies (e.g. facial expressions and manual signs)***
    - ***the implementation of aided strategies (e.g. real objects, photographs, PCS communication board and digital speaker)***
    - ***the creation of communication opportunities during the day***
  - 4 To discuss and demonstrate basic augmentative and alternative communication (AAC) intervention principles
  - 4 To describe the importance of monitoring progress through the use of a progress matrix
- **Aim of the interview schedule – Response Form I**

- 1 To determine community nurses' skills in identifying basic communication skills in a case study (communication means, functions, partners and opportunities): Answers are ticked in table format. If you are unsure, write down the complete answer.
- 2 To determine the recommendations made to the caregiver regarding the case study: Open-ended questions. Write down the complete answer.
- 3 Practical demonstration of skills: rate the demonstration of practical skills on a 4 point Likert scale. Definition of each of these four points is provided at the end of this document.

- **Practical considerations**

- 1 Every interviewer is responsible for making a video of the interaction.  
Make sure that the demonstration of practical skills is clear.
- 2 Ensure that the lighting is good, so that the nurse can be seen clearly (i.e. do not take into the light).
- 3 For clear sound quality, make sure that the environment is silent.
- 4 Record only two interactions on each of the tapes provided, otherwise you will run out of tape!
- 5 If possible, operate the camera with power. Although the batteries will be charged, they tend not to be capable of taping the complete interaction.
- 6 Record the open-ended questions as completely as possible. Make sure that you answer **all** the questions
- 7 Time the practical demonstration – each participant has only seven minutes.
- 8 The activity that will be used throughout is mealtime.
- 9 Twenty nurses have to be interviewed: this means that each of us will have to do at least five (It should take roughly 30 minutes).
- 10 Once all the nurses have been interviewed, all of you will watch the 20 videos and rate them in order to increase the inter-rater

reliability. This will only be done for the pilot study. If necessary, more training will be conducted.

- 11 All responses will be coded on the provided form (Response Form I).
- 12 Read all the instructions on the form carefully.

- **Method**

- 1 Before commencing, give the nurse a friendly greeting and put her at ease. Ensure a comfortable, relaxed atmosphere. Clearly state that the aim is not to evaluate her skills, but to evaluate the effectiveness of the training programme.
- 2 Be seated opposite the nurse at a table.
- 3 Before commencing ask each nurse to state her date of birth.
- 4 Provide the nurse with a copy of the case study (to be handed back to you at the end).
- 5 Carefully read the case study with the nurse. Clarify any confusing terminology.
- 6 When asking the questions, constantly remind her to refer back to the case study.
- 7 After completing Sections 1 and 2 of Response Form I, take out the BCIP's mealtime activity (remember to also take out the digital speaker!), and proceed to Section 3.
- 8 After completing this section, put away the BCIP to avoid prompting of the next participant.

- **Guidelines for completing Response Form I**

- ➔ **General information**

- 1 Complete one Response Form I for each nurse.
- 2 Create a non-threatening environment by assuring her that this is not a test aimed at measuring her skills, but rather a tool to measure the programme.
- 3 The questions must be presented to each nurse in exactly the same way. Questions have to be put in exactly the wording used on

the form, in exactly the same order, and only examples provided on the form may be used.

- 4 Neutral prompts may be provided, e.g. "uh uh?" "mmm"
- 5 Provide sufficient time for each nurse to complete her answers. No time limit is provided, except for Section 3 (practical skills demonstration) where only seven minutes are provided.

## ↳ Specific information

- 1 Complete **birth date** is required, as respondent numbers will be allocated from this.
- 2 Carefully read through the **case study** with the nurse, and provide it to her in writing. Clarify any uncertainties and confusions regarding terminology. Ensure that she understands the case study well. She can have the case study in front of her for the duration of the interview.
- 3 **Current abilities** are obtained by asking the questions as they appear on Response Form I. If the nurse does not understand the question, you may rephrase in a neutral way, without giving leading examples, e.g. don't say, "*think of the people she communicates with like the neighbour's children*".
- 4 **Recommendations** are provided in open answer format with space to write the nurse's answer. Write down her complete response.
- 5 **Practical demonstration of skills.** Each nurse will have seven minutes (time with a stopwatch) to demonstrate "mealtime activity", using her BCIP. Read the instructions on the form carefully. Time checks can be provided halfway through the activity (e.g. "*You have three minutes left*".)
- 6 **Section 4** (number of clients and contact with colleagues) will only be conducted after the follow-ups. You will therefore not be required to complete this.

## Descriptions of the scores are as follows

	<b>Not attempted</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>
Correctness of perceptual grading	No attempt was made	Only one element correct (e.g. start with objects)	2 – 3 elements correct	All elements correct. Knows range of perceptual grading

<b>Objects &amp; Photographs</b>				
Type of messages selected	No observable attempt	Only naming of elements (e.g. <i>It's a cup, It's a spoon, etc.</i> )	Requesting of basic needs, e.g. <i>Give me the spoon ; Do you want-?</i> Matching objects and photos.	Abstract diverse messages, e.g. joking, teasing, requesting help, deliberately giving wrong choice. Includes 3 types of choices, viz. partner, object, activity.
Clarity on the use of objects and photographs	No observable attempt	Very unsure about what to do with objects or just move objects around.	Use objects to demonstrate functional use, e.g. <i>Cup is for drinking ; Spoon is for porridge.</i>	Use objects to facilitate skill development, e.g. give choices, request help, etc.
Incorporation of speech	No use of speech – only points to objects	Few single words used to name objects or functions, e.g. <i>Milk / Spoon? Eat / Drink?</i>	Use of phrases, e.g. <i>Maria wants milk? Maria drink?</i>	Complete grammatically correct sentences, e.g. <i>Do you want milk or do you want tea?</i> Inclusion of praise.
Incorporation of facial expressions	No observable attempt	Inappropriate use of facial expressions or no use of facial expressions (straight face)	Limited range of facial expressions	Optimal use of facial expression (extensive range), e.g. frown with “what questions” or raise eyebrows

<b>PCS communication board</b>				
Type of messages selected	No observable attempt	Points to PCS and names elements (e.g. <i>It's a cup, It's a spoon, etc.</i> )	Requesting objects (questions) e.g. <i>Give me the spoon; Where is the plate?</i>	Abstract diverse messages, e.g. joking, teasing, requesting help, providing choices, e.g. <i>Can I help you or do you want to help yourself?</i>
Clarity on the use of communication boards	No observable attempt	Very unsure about what to do with the communication board	Ask child to point at symbols, e.g. <i>Show me the spoon.</i>	Interaction between nurse and child. Nurse points while talking.
Incorporation of speech and intonation	No observable attempt	Few single words Monotone	Use of phrases. Very slow speed.	Complete grammatically correct sentences. Correct intonation
Incorporation of facial expressions	No observable attempt	Inappropriate use of facial expressions or no use of facial expressions (straight face)	Limited range of facial expressions	Optimal use of facial expression (extensive range), e.g. frown with “what questions” or raise eyebrows

<b>Manual signs</b>				
Type of messages selected	No observable attempt	Only naming of elements (e.g. <i>It's a cup</i> , etc. whilst making a sign)	Requesting (asking question) e.g. <i>Give me the plate</i> . Matching sign and objects.	Sign abstract concepts, e.g. <i>help, more</i> . Provide choices.
Clarity on the use of manual signs	No observable attempt	Only natural gestures, e.g. <i>drink</i> .	Knows a few signs, e.g. <i>milk, mug, more</i> . Only single words.	Keyword signing. Signs more than 1 word per sentence. Most signs correct.
Incorporation of speech	No use of speech – only manual signs	Whisper with signing. Only 1 word with signs.	Sign I a phrase, e.g. <i>Drink milk?</i>	Speaks full sentences whilst signing key words. Inclusion of praise.
Incorporation of facial expressions <b>Very important issue in signing!</b>	No observable attempt	Inappropriate use of facial expressions or no use of facial expressions (straight face)	Limited range of facial expressions	Optimal use of facial expression (extensive range), e.g. frown with "what questions" or raise eyebrows. Demonstrates understanding of the importance of facial expressions with manual signs.

<b>EasyTalk 4 Option Digital Speaker</b>				
Type of messages selected	No observable attempt	Only naming of elements (e.g. <i>It's a cup, It's a spoon, etc</i> )	Recording basic needs, e.g. <i>I want to eat; I want the porridge</i> .	Abstract messages, e.g. <i>Help me please! I want more. No, not that one!</i>
Clarity on the use of the digital speaker	No observable attempt	No idea how the device works. Ask questions e.g. <i>Show me blue</i> (colour of keys)	Knows how device works, but not 100% sure. Can record a message, but no symbol to cue. Records a question, e.g. <i>Do you want milk?</i>	Operational competence. Knows how to record and play messages. Puts symbols / pictures on the device.
Incorporation of speech and intonation	No observable attempt	Records single words. Monotone	Records phrases. Slow speech	Complete grammatically correct sentences, e.g. <i>I want more tea, please</i> . Correct intonation.
Incorporation of facial expressions <b>Difficult to score</b>	No observable attempt	Inappropriate use of facial expressions or no use of facial expressions (straight face)	Limited range of facial expressions	Optimal use of facial expression (extensive range), e.g. frown with "what questions" or raise eyebrows

<b>Question 3.2</b> How much prompting was required?	<b>Extensive</b> Requires significant amount of verbal and gestural prompts. >3 prompts	<b>Average</b> Requires verbal and little gestural prompts. 2 –3 prompts	<b>Minimal</b> Requires very little to no prompts. 0 - 1 prompts
<b>Question 3.3</b> Overall impression of nurse's confidence in facilitating communication	<b>Poor</b> Very unsure about all BCIP elements	<b>Average</b> Unsure about some BCIP elements	<b>Good</b> Confident in what to do with all BCIP elements

- Section 4 will only be completed after the follow-ups.
- 1) **General information** refers to the nurse's experience in the use of the BCIP. Although this section is included, the information will not be asked before or directly after training, as it is not applicable at this time. It will only be completed from the two week follow-up onwards.
  - 2) **Number of clients** refers to the total number of clients with whom the BCIP has been used since the onset of the training. This number is therefore cumulative. Although this section is included the information will not be asked before or directly after training. It will only be completed from the two week follow-up onwards.
  - 3) **Contact with colleagues** refers to any formal or informal contact with any member of the multi-professional team regarding the use of the BCIP, e.g. nurses, teachers, social workers, etc. Please specify the nature of the contact and the occupation of the colleague.

## **PRACTICAL DEMONSTRATION**

While watching the video record the results on Response Form I for the specific nurse.

# **Training of COMMUNITY nurses:**

**in the caring  
of children with...  
severe  
disabilities**





2000-07-10-  
2000-07-14



Juan Bornman from the CAAC with a group of very committed community nurses from the Mpondo Health District.

- The workshop was interesting but I needed more time.
- I wanted to visit the children with disability so that I can do its practical part of it.
- Meals were nice but the millet bread was not my favorite.
- The teacher was very excellent and is the person you can understand MOTSIE!

Thanks to the staff at the lovely Hammanskloof campus!

OH, JUAN.. 00.07.14  
THAT WAS A WONDERFUL IN-SERVICE ON CSO YOU PROVIDED US WITH. WE ARE DEFINATELY GOING TO COMMUNICATE WITH THESE CHILDREN.

Alma-Louise  
Moncreif



The workshop was very much interesting. I wish more time (day) could have been given. The kitchen staff were also wonderful. To Juan, you are great. I enjoyed every little time we spent with you. If only you could give us more.

Lishain

Just look at the communication boards we made!!



Lischa

- Thanks to the university staff for being so kind to us, especially the wheelchair people.  
- Thanks to Julian and Shabana again, very excellent you are, enjoyed the workshop very much and the donations you gave us. Please also note the other people who supported other groups just like you, the same amount.

M. Groot



• Centre for Augumentative &  
Alternative Communication.  
UNIVERSITY OF PRETORIA

**APPENDIX K**  
**DESCRIPTION OF IN SITU FOLLOW-UPS**

Clinic	Nurse	Follow-up 1	Follow-up 2	Follow-up 3
<b>Group 1</b>				
Mobile Clinic	M M M M A M M M K	31 July	28 August	27 November
Gateway	D L M J T	31 July	28 August	27 November
Kutlwanoong	S M R	31 July	1 September	27 November
Maubane	M M L	31 July	1 September	1 December
School health	M D M P F M G E N	31 July	28 August	27 November
Babelegi	L M	31 July	28 August	27 November
<b>Group 2</b>				
Bosplaas	M E K	1 August	29 August	28 November
Leseding	C M M	1 August	29 August	28 November
Mathibestad	S P P	1 August	29 August	1 December
Kgomo-Kgomo	M E M	1 August	1 September at 13h00	28 November
Moretele	A R M	1 August	29 August	28 November
<b>Group 3</b>				
Refentse	M N M	2 August	30 August	29 November
Ratjiepane	M C G	2 August	30 August	29 November
Ga-Motla	S S M	2 August	30 August	29 November
Kekanastad	M M K	2 August	30 August	29 November

## APPENDIX L

### Response Form 1.1

Information for this questionnaire will be obtained from answering questions pertaining to the case study from the practical demonstration of skills. Information pertains to skills, and will be gathered through a structured interview and observation.

**For official use**  
Respondent no

1-2

Batch no  1 3

Rater no  4

Card no  1 5

6-11

#### **SECTION A**

**1 What is your date of birth?**

Day	Month	Year

#### **Case study**

Mrs Serudu has brought her 5-year-old son, Sibusiso to you for help. She has noticed that he is developing slower than the neighbour's son who is about the same age. Although he can sit, walk and even run, these skills only developed at a late stage. Her major concern is that Sibusiso is not talking well. He can only say "Mama" and "Eee" to indicate "yes". He also shows her his empty plate when he has finished eating and wants her to clap hands for him. She thinks that he understands more than he is able to say. Mrs Serudu has a spaza shop at her house and she finds it difficult if he interferes when she has customers. She wants him to greet the customers properly.

#### **SECTION B**

**2 Current abilities**

Think of Sibusiso when you answer the following questions

**2.1 Which different ways of communication does Sibusiso use at present? (*communication means*)**

Pointing/Indicating with finger	<input type="checkbox"/>
Gestures, e.g. clapping hands, waving	<input type="checkbox"/>
Mime/Acting/Gross body movements/Actions	<input type="checkbox"/>
Facial expressions	<input type="checkbox"/>
Vocalisations (e.g. sounds, "eee")	<input type="checkbox"/>
Crying	<input type="checkbox"/>
Speech (e.g. words, Mama)	<input type="checkbox"/>
Use of objects, e.g. shows plate	<input type="checkbox"/>
Other	<input type="checkbox"/>

12  
13  
14  
15  
16  
17  
18  
19  
 20-21  
Appendix L 1

**2.2 What is Sibusiso trying to say with the things he does?  
(e.g. what reasons for communication does he have?)  
(communication functions)**

Expressing wants and needs, e.g. hungry		22
Expressing emotions, e.g. happy		23
Trying to draw attention to himself, e.g. call "Mama"		24
Requesting interaction, e.g. wants to play, seeking partners, socialising		25
Requesting objects, e.g. food		26
Protesting, e.g. not satisfied		27
Affirmation, e.g. rewards, appreciation, agreement, wants others to clap hands for him, say "yes"		28
Naming, e.g. this is a plate, names of family members		29
Politeness, e.g. "thank you" (please)		30
Greeting, e.g. making contact with others, hallo		31
Other		32-33

**2.3 Who are the people with whom Sibusiso communicates?  
(communication partners)**

Parents		34
Siblings		35
Other children, e.g. neighbourhood children, peers		36
Extended family		37
Unfamiliar adults		38
Customers		39
Other		40

**SECTION C**

**3 RECOMMENDATIONS**

- 3.1 If you were the nurse working with Sibusiso and Mrs Serudu, what advice would you give her?

		41-42
		43-44
		45-46
		47-48
		49-50

- 3.2 Which different ways of communication do you think Sibusiso should still learn? (*communication means*)

<input type="checkbox"/>	<input type="checkbox"/>	51-52
<input type="checkbox"/>	<input type="checkbox"/>	53-54
<input type="checkbox"/>	<input type="checkbox"/>	55-56
<input type="checkbox"/>	<input type="checkbox"/>	57-58
<input type="checkbox"/>	<input type="checkbox"/>	59-60

- 3.3 Which other reasons for communication will you encourage Sibusiso to learn? (e.g. what does he want to say with what he does) (*communication functions*)

<input type="checkbox"/>	<input type="checkbox"/>	61-62
<input type="checkbox"/>	<input type="checkbox"/>	63-64
<input type="checkbox"/>	<input type="checkbox"/>	65-66
<input type="checkbox"/>	<input type="checkbox"/>	67-68
<input type="checkbox"/>	<input type="checkbox"/>	69-70

- 3.4 How can you change things in Sibusiso's environment to give him more opportunities to communicate with? (*communication opportunities*)

<input type="checkbox"/>	<input type="checkbox"/>	71-72
<input type="checkbox"/>	<input type="checkbox"/>	73-74
<input type="checkbox"/>	<input type="checkbox"/>	75-76
<input type="checkbox"/>	<input type="checkbox"/>	77-78
<input type="checkbox"/>	<input type="checkbox"/>	79-80

Respondent no

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Card no  2  3

- 3.5 How can you increase the number of people with whom Sibusiso can communicate? (*communication partners*)

<input type="checkbox"/>	<input type="checkbox"/>	4-5
<input type="checkbox"/>	<input type="checkbox"/>	6-7
<input type="checkbox"/>	<input type="checkbox"/>	8-9
<input type="checkbox"/>	<input type="checkbox"/>	10-11
<input type="checkbox"/>	<input type="checkbox"/>	12-13

## **SECTION D**

## 4 PRACTICAL DEMONSTRATION OF SKILLS

*Each participant will be allowed seven minutes to demonstrate her skills pertaining to the different communication means. A stopwatch will be used to keep the length of time consistent.*

- 4.1 Show me how you would use each of the following things to encourage Sibusiso to make a choice. Start with the easiest, and move to the most difficult. (Objects, Photographs, Communication Board, Manual Signs and EasyTalk 4)

	Not attempted	Poor	Average	Good
Correctness of perceptual grading				
<b>OBJECTS</b>				
Type of messages selected				
Clarity on the use of objects				
Incorporation of speech				
Incorporation of facial expressions				
<b>PHOTOGRAPHS</b>				
Type of messages selected				
Clarity on the use of photographs				
Incorporation on speech				
Incorporation of facial expressions				
<b>COMMUNICATION BOARDS</b>				
Type of messages selected				
Clarity on the use of communication boards				
Incorporation of speech				
Incorporation of facial expressions				
<b>MANUAL SIGNS</b>				
Type of messages selected				
Clarity on the use of signs				
Incorporation of speech				
Incorporation of facial expressions				

<b>EASYTALK 4 OPTION</b>				
Type of messages selected				
Clarity on the use of the EasyTalk				
Incorporation of speech				
Incorporation of facial expressions				

4.2 How much prompting was required?

<b>Extensive</b>	<b>Average</b>	<b>Minimal</b>
------------------	----------------	----------------

4.3 Overall impression of nurse's confidence in facilitating communication

<b>Poor</b>	<b>Average</b>	<b>Good</b>
-------------	----------------	-------------

## **SECTION E**

### **5 GENERAL**

**5.1 Have you used the protocol with any of your patients?**

Yes/No

If Yes, please specify with how many \_\_\_\_\_ 37

**5.2 Have you had contact with any of your colleagues regarding the use of the protocol?**

Yes/No

If Yes, please specify how often \_\_\_\_\_ 40

31  
 32  
 33  
 34

35  
 36

37  
  38-39  
 40  
  41-42

## APPENDIX L

### Response Form 1.2

Information for this questionnaire will be obtained from answering questions pertaining to the case study from the practical demonstration of skills. Information pertains to skills, and will be gathered through a structured interview and observation.

**For official use**  
Respondent no

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Batch no  1 3

Rater no  4

Card no  1 5

6-11

#### **SECTION A**

##### **1 What is your date of birth?**

Day	Month	Year

#### **Case study**

Mrs Kekana has brought her 5-year-old daughter, Karabo to you for help. She has noticed that Karabo is developing slower than her 4-year-old brother. Although Karabo can sit, walk and even run, these skills only developed at a late stage. Mrs Kekana's major concern is that Karabo is not talking well. She can only say "uh" to indicate "yes" and "Mama". When she is thirsty she will show her cup. When she finishes any task she wants the family to clap hands. Mrs Kekana thinks that Karabo understands more than she is able to say. Mrs Kekana works from home and does repairs and alterations to clothing. She finds it difficult when Karabo interferes when she is busy with a client.. She wants Karabo to be polite and greet the clients properly.

#### **SECTION B**

##### **2 Current abilities**

Think of Karabo when you answer the following questions

##### **2.1 Which different ways of communication does Karabo use at present? (*communication means*)**

Pointing/Indicating with finger	<input type="checkbox"/>
Gestures, e.g. clapping hands, waving	<input type="checkbox"/>
Mime/Acting/Gross body movements/Actions	<input type="checkbox"/>
Facial expressions	<input type="checkbox"/>
Vocalisations (e.g. sounds, "eee")	<input type="checkbox"/>
Crying	<input type="checkbox"/>
Speech (e.g. words, Mama)	<input type="checkbox"/>
Use of objects, e.g. shows plate	<input type="checkbox"/>
Other	<input type="checkbox"/> <input type="checkbox"/>

12  
 13  
 14  
 15  
 16  
 17  
 18  
 19  
  20-21

**2.2 What is Karabo trying to say with the things she does?  
(e.g. what reasons for communication does she have?)  
(communication functions)**

Expressing wants and needs, e.g. hungry		22
Expressing emotions, e.g. happy		23
Trying to draw attention to herself, e.g. call "Mama"		24
Requesting interaction, e.g. wants to play, seeking partners, socialising		25
Requesting objects, e.g. food		26
Protesting, e.g. not satisfied		27
Affirmation, e.g. rewards, appreciation, agreement, wants others to clap hands for her, say "yes"		28
Naming, e.g. this is a plate, names of family members		29
Politeness, e.g. "thank you" (please)		30
Greeting, e.g. making contact with others, hallo		31
Other		32-33

**2.3 Who are the people with whom Karabo communicates?  
(communication partners)**

Parents		34
Siblings		35
Other children, e.g. neighbourhood children, peers		36
Extended family		37
Unfamiliar adults		38
Customers		39
Other		40

### **SECTION C**

### **3 RECOMMENDATIONS**

- 3.1 If you were the nurse working with Karabo and Mrs Kekana, what advice would you give her?

		41-42
		43-44
		45-46
		47-48
		49-50

- 3.2 Which different ways of communication do you think Karabo should still learn? (*communication means*)

<input type="checkbox"/>	<input type="checkbox"/>	51-52
<input type="checkbox"/>	<input type="checkbox"/>	53-54
<input type="checkbox"/>	<input type="checkbox"/>	55-56
<input type="checkbox"/>	<input type="checkbox"/>	57-58
<input type="checkbox"/>	<input type="checkbox"/>	59-60

- 3.3 Which other reasons for communication will you encourage Karabo to learn? (e.g. what does she want to say with what she does) (*communication functions*)

<input type="checkbox"/>	<input type="checkbox"/>	61-62
<input type="checkbox"/>	<input type="checkbox"/>	63-64
<input type="checkbox"/>	<input type="checkbox"/>	65-66
<input type="checkbox"/>	<input type="checkbox"/>	67-68
<input type="checkbox"/>	<input type="checkbox"/>	69-70

- 3.4 How can you change things in Karabo's environment to give her more opportunities to communicate with? (*communication opportunities*)

<input type="checkbox"/>	<input type="checkbox"/>	71-72
<input type="checkbox"/>	<input type="checkbox"/>	73-74
<input type="checkbox"/>	<input type="checkbox"/>	75-76
<input type="checkbox"/>	<input type="checkbox"/>	77-78
<input type="checkbox"/>	<input type="checkbox"/>	79-80

Respondent no

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Card no

2	3
---	---

- 3.5 How can you increase the number of people with whom Karabo can communicate? (*communication partners*)

<input type="checkbox"/>	<input type="checkbox"/>	4-5
<input type="checkbox"/>	<input type="checkbox"/>	6-7
<input type="checkbox"/>	<input type="checkbox"/>	8-9
<input type="checkbox"/>	<input type="checkbox"/>	10-11
<input type="checkbox"/>	<input type="checkbox"/>	12-13

**SECTION D****4 PRACTICAL DEMONSTRATION OF SKILLS**

*Each participant will be allowed seven minutes to demonstrate her skills pertaining to the different communication means. A stopwatch will be used to keep the length of time consistent.*

- 4.1 Show me how you would use each of the following things to encourage Karabo to make a choice. Start with the easiest, and move to the most difficult. (Objects, Photographs, Communication Board, Manual Signs and EasyTalk 4)

	<b>Not attempted</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>
Correctness of perceptual grading				
<b>OBJECTS</b>				
Type of messages selected				
Clarity on the use of objects				
Incorporation of speech				
Incorporation of facial expressions				
<b>PHOTOGRAPHS</b>				
Type of messages selected				
Clarity on the use of photographs				
Incorporation on speech				
Incorporation of facial expressions				
<b>COMMUNICATION BOARDS</b>				
Type of messages selected				
Clarity on the use of communication boards				
Incorporation of speech				
Incorporation of facial expressions				
<b>MANUAL SIGNS</b>				
Type of messages selected				
Clarity on the use of signs				
Incorporation of speech				
Incorporation of facial expressions				

- |                          |    |
|--------------------------|----|
| <input type="checkbox"/> | 14 |
| <input type="checkbox"/> | 15 |
| <input type="checkbox"/> | 16 |
| <input type="checkbox"/> | 17 |
| <input type="checkbox"/> | 18 |
| <input type="checkbox"/> | 19 |
| <input type="checkbox"/> | 20 |
| <input type="checkbox"/> | 21 |
| <input type="checkbox"/> | 22 |
| <input type="checkbox"/> | 23 |
| <input type="checkbox"/> | 24 |
| <input type="checkbox"/> | 25 |
| <input type="checkbox"/> | 26 |
| <input type="checkbox"/> | 27 |
| <input type="checkbox"/> | 28 |
| <input type="checkbox"/> | 29 |
| <input type="checkbox"/> | 30 |

<b>EASYTALK 4 OPTION</b>				
Type of messages selected				
Clarity on the use of the EasyTalk				
Incorporation of speech				
Incorporation of facial expressions				

31  
 32  
 33  
 34

4.2 How much prompting was required?

<b>Extensive</b>	<b>Average</b>	<b>Minimal</b>
------------------	----------------	----------------

35

4.3 Overall impression of nurse's confidence in facilitating communication

36

<b>Poor</b>	<b>Average</b>	<b>Good</b>
-------------	----------------	-------------

## **SECTION E**

### **5 GENERAL**

**5.1 Have you used the protocol with any of your patients?**

37

Yes/No

If Yes, please specify with how many \_\_\_\_\_

38-39

**5.2 Have you had contact with any of your colleagues regarding the use of the protocol?**

40

Yes/No

If Yes, please specify how often \_\_\_\_\_

41-42

## APPENDIX L

### Response Form 1.3

Information for this questionnaire will be obtained from answering questions pertaining to the case study from the practical demonstration of skills. Information pertains to skills, and will be gathered through a structured interview and observation.

**For official use**  
Respondent no

1-2

Batch no  1 3

Rater no  4

Card no  1 5

6-11

#### **SECTION A**

**1 What is your date of birth?**

Day	Month	Year

#### **Case study**

Mrs Mahlangu has brought her 6-year-old daughter, Maria to you for help. She has noticed that Maria is developing slower than her 4-year-old sister. Although Maria can sit, walk and even run, these skills only developed at a late stage. Mrs Mahlangu's major concern is that Maria is not talking well. She can only make a noise to say "yes" and she says "Mama". When she is hungry she will show her spoon. When she finishes her food she wants the family to clap hands. Mrs Mahlangu thinks that Maria understands more than she is able to say. Mrs Mahlangu has a hair salon at her house. She finds it difficult when Maria interferes when she is busy with a customer. She wants Maria to be polite and greet the customers properly.

#### **SECTION B**

**2 Current abilities**

Think of Maria when you answer the following questions

**2.1 Which different ways of communication does Maria use at present? (*communication means*)**

Pointing/Indicating with finger	<input type="checkbox"/>
Gestures, e.g. clapping hands, waving	<input type="checkbox"/>
Mime/Acting/Gross body movements/Actions	<input type="checkbox"/>
Facial expressions	<input type="checkbox"/>
Vocalisations (e.g. sounds, "eee")	<input type="checkbox"/>
Crying	<input type="checkbox"/>
Speech (e.g. words, Mama)	<input type="checkbox"/>
Use of objects, e.g. shows plate	<input type="checkbox"/>
Other	<input type="checkbox"/> <input type="checkbox"/>

12  
 13  
 14  
 15  
 16  
 17  
 18  
 19  
 20-21

**2.2 What is Maria trying to say with the things she does?  
(e.g. what reasons for communication does she have?)  
(communication functions)**

Expressing wants and needs, e.g. hungry		22
Expressing emotions, e.g. happy		23
Trying to draw attention to herself, e.g. call "Mama"		24
Requesting interaction, e.g. wants to play, seeking partners, socialising		25
Requesting objects, e.g. food		26
Protesting, e.g. not satisfied		27
Affirmation, e.g. rewards, appreciation, agreement, wants others to clap hands for her, say "yes"		28
Naming, e.g. this is a plate, names of family members		29
Politeness, e.g. "thank you" (please)		30
Greeting, e.g. making contact with others, hallo		31
Other		32-33

**2.3 Who are the people with whom Maria communicates?  
(communication partners)**

Parents		34
Siblings		35
Other children, e.g. neighbourhood children, peers		36
Extended family		37
Unfamiliar adults		38
Customers		39
Other		40

### **SECTION C**

### **3 RECOMMENDATIONS**

- 3.1 If you were the nurse working with Maria and Mrs Mahlangu, what advice would you give her?

		41-42
		43-44
		45-46
		47-48
		49-50

- 3.2 Which different ways of communication do you think Maria should still learn? (*communication means*)

<input type="checkbox"/>	<input type="checkbox"/>	51-52
<input type="checkbox"/>	<input type="checkbox"/>	53-54
<input type="checkbox"/>	<input type="checkbox"/>	55-56
<input type="checkbox"/>	<input type="checkbox"/>	57-58
<input type="checkbox"/>	<input type="checkbox"/>	59-60

- 3.3 Which other reasons for communication will you encourage Maria to learn? (e.g. what does she want to say with what she does) (*communication functions*)

<input type="checkbox"/>	<input type="checkbox"/>	61-62
<input type="checkbox"/>	<input type="checkbox"/>	63-64
<input type="checkbox"/>	<input type="checkbox"/>	65-66
<input type="checkbox"/>	<input type="checkbox"/>	67-68
<input type="checkbox"/>	<input type="checkbox"/>	69-70

- 3.4 How can you change things in Maria's environment to give her more opportunities to communicate with? (*communication opportunities*)

<input type="checkbox"/>	<input type="checkbox"/>	71-72
<input type="checkbox"/>	<input type="checkbox"/>	73-74
<input type="checkbox"/>	<input type="checkbox"/>	75-76
<input type="checkbox"/>	<input type="checkbox"/>	77-78
<input type="checkbox"/>	<input type="checkbox"/>	79-80

Respondent no

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Card no  2  3

- 3.5 How can you increase the number of people with whom Maria can communicate? (*communication partners*)

<input type="checkbox"/>	<input type="checkbox"/>	4-5
<input type="checkbox"/>	<input type="checkbox"/>	6-7
<input type="checkbox"/>	<input type="checkbox"/>	8-9
<input type="checkbox"/>	<input type="checkbox"/>	10-11
<input type="checkbox"/>	<input type="checkbox"/>	12-13

**SECTION D****4 PRACTICAL DEMONSTRATION OF SKILLS**

*Each participant will be allowed seven minutes to demonstrate her skills pertaining to the different communication means. A stopwatch will be used to keep the length of time consistent.*

- 4.1 Show me how you would use each of the following things to encourage Maria to make a choice. Start with the easiest, and move to the most difficult. (Objects, Photographs, Communication Board, Manual Signs and EasyTalk 4)

	<b>Not attempted</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>	
Correctness of perceptual grading					
<b>OBJECTS</b>					
Type of messages selected					14
Clarity on the use of objects					15
Incorporation of speech					16
Incorporation of facial expressions					17
<b>PHOTOGRAPHS</b>					
Type of messages selected					18
Clarity on the use of photographs					19
Incorporation of speech					20
Incorporation of facial expressions					21
<b>COMMUNICATION BOARDS</b>					
Type of messages selected					22
Clarity on the use of communication boards					23
Incorporation of speech					24
Incorporation of facial expressions					25
<b>MANUAL SIGNS</b>					
Type of messages selected					26
Clarity on the use of signs					27
Incorporation of speech					28
Incorporation of facial expressions					29
<b>EASYTALK 4 OPTION</b>					
Type of messages selected					30
Clarity on the use of the EasyTalk					31
					32
					33

Incorporation of speech				
Incorporation of facial expressions				

34

4.2 How much prompting was required?

<b>Extensive</b>	<b>Average</b>	<b>Minimal</b>
------------------	----------------	----------------

35

4.3 Overall impression of nurse's confidence in facilitating communication

<b>Poor</b>	<b>Average</b>	<b>Good</b>
-------------	----------------	-------------

36

## **SECTION E**

### **5 GENERAL**

**5.1 Have you used the protocol with any of your patients?**

37

Yes/No

If Yes, please specify with how many \_\_\_\_\_

38-39

**5.2 Have you had contact with any of your colleagues regarding the use of the protocol?**

40

Yes/No

If Yes, please specify how often \_\_\_\_\_

41-42

## APPENDIX L

### Response Form 1.4

Information for this questionnaire will be obtained from answering questions pertaining to the case study from the practical demonstration of skills. Information pertains to skills, and will be gathered through a structured interview and observation.

**For official use**  
Respondent no

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Batch no  1 3

Rater no  4

Card no  1 5

6-11

### **SECTION A**

**1 What is your date of birth?**

Day	Month	Year

#### **Case study**

Mrs Shibambu has brought her 5-year-old son, Joseph to you for help. She has noticed that Joseph is developing slower than the neighbour's son who is about the same age. Although Joseph can sit, walk and even run, these skills only developed at a late stage. Mrs Shibambu's major concern is that Joseph is not talking well. He can only make a "aaa" sound to say "yes" and he says "Mama". When he is thirsty he will show his mug. When he finishes his food he wants the family to clap hands for him. Mrs Shibambu thinks that Joseph understands more than he is able to say. Mrs Shibambu has a small catering business at her house where she makes "bunny chow". She finds it difficult when Joseph interferes when she is busy with a customer. She wants Joseph to be polite and greet the customers properly.

### **SECTION B**

**2 Current abilities**

Think of Joseph when you answer the following questions

**2.1 Which different ways of communication does Joseph use at present? (*communication means*)**

Pointing/Indicating with finger	<input type="checkbox"/>
Gestures, e.g. clapping hands, waving	<input type="checkbox"/>
Mime/Acting/Gross body movements/Actions	<input type="checkbox"/>
Facial expressions	<input type="checkbox"/>
Vocalisations (e.g. sounds, "eee")	<input type="checkbox"/>
Crying	<input type="checkbox"/>
Speech (e.g. words, Mama)	<input type="checkbox"/>
Use of objects, e.g. shows plate	<input type="checkbox"/>

12  
13  
14  
15  
16  
17  
18  
19

Other			
-------	--	--	--

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

 20-21

**2.2 What is Joseph trying to say with the things he does?  
(e.g. what reasons for communication does he have?)  
(communication functions)**

Expressing wants and needs, e.g. hungry			22
Expressing emotions, e.g. happy			23
Trying to draw attention to himself, e.g. call "Mama"			24
Requesting interaction, e.g. wants to play, seeking partners, socialising			25
Requesting objects, e.g. food			26
Protesting, e.g. not satisfied			27
Affirmation, e.g. rewards, appreciation, agreement, wants others to clap hands for him, say "yes"			28
Naming, e.g. this is a plate, names of family members			29
Politeness, e.g. "thank you" (please)			30
Greeting, e.g. making contact with others, hallo			31
Other			32-33

**2.3 Who are the people with whom Joseph communicates?  
(communication partners)**

Parents		34
Siblings		35
Other children, e.g. neighbourhood children, peers		36
Extended family		37
Unfamiliar adults		38
Customers		39
Other		40

## **SECTION C**

### **3 RECOMMENDATIONS**

- 3.1 If you were the nurse working with Joseph and Mrs Shibambu, what advice would you give her?

<input type="checkbox"/>	<input type="checkbox"/>	41-42
<input type="checkbox"/>	<input type="checkbox"/>	43-44
<input type="checkbox"/>	<input type="checkbox"/>	45-46
<input type="checkbox"/>	<input type="checkbox"/>	47-48
<input type="checkbox"/>	<input type="checkbox"/>	49-50

- 3.2 Which different ways of communication do you think Joseph should still learn? (*communication means*)

<input type="checkbox"/>	<input type="checkbox"/>	51-52
<input type="checkbox"/>	<input type="checkbox"/>	53-54
<input type="checkbox"/>	<input type="checkbox"/>	55-56
<input type="checkbox"/>	<input type="checkbox"/>	57-58
<input type="checkbox"/>	<input type="checkbox"/>	59-60

- 3.3 Which other reasons for communication will you encourage Joseph to learn? (e.g. what does he want to say with what he does) (*communication functions*)

<input type="checkbox"/>	<input type="checkbox"/>	61-62
<input type="checkbox"/>	<input type="checkbox"/>	63-64
<input type="checkbox"/>	<input type="checkbox"/>	65-66
<input type="checkbox"/>	<input type="checkbox"/>	67-68
<input type="checkbox"/>	<input type="checkbox"/>	69-70

- 3.4 How can you change things in Joseph's environment to give him more opportunities to communicate with? (*communication opportunities*)

<input type="checkbox"/>	<input type="checkbox"/>	71-72
<input type="checkbox"/>	<input type="checkbox"/>	73-74
<input type="checkbox"/>	<input type="checkbox"/>	75-76
<input type="checkbox"/>	<input type="checkbox"/>	77-78
<input type="checkbox"/>	<input type="checkbox"/>	79-80

no

Respondent

<input type="checkbox"/>	<input type="checkbox"/>	1-2
--------------------------	--------------------------	-----

Card no  2  3

- 3.5 How can you increase the number of people with whom Joseph can communicate? (*communication partners*)

<input type="checkbox"/>	<input type="checkbox"/>	4-5
<input type="checkbox"/>	<input type="checkbox"/>	6-7
<input type="checkbox"/>	<input type="checkbox"/>	8-9
<input type="checkbox"/>	<input type="checkbox"/>	10-11
<input type="checkbox"/>	<input type="checkbox"/>	12-13

**SECTION D****4 PRACTICAL DEMONSTRATION OF SKILLS**

*Each participant will be allowed seven minutes to demonstrate her skills pertaining to the different communication means. A stopwatch will be used to keep the length of time consistent.*

- 4.1 Show me how you would use each of the following things to encourage Joseph to make a choice. Start with the easiest, and move to the most difficult. (Objects, Photographs, Communication Board, Manual Signs and EasyTalk 4)

	<b>Not attempted</b>	<b>Poor</b>	<b>Average</b>	<b>Good</b>
Correctness of perceptual grading				
<b>OBJECTS</b>				
Type of messages selected				
Clarity on the use of objects				
Incorporation of speech				
Incorporation of facial expressions				
<b>PHOTOGRAPHS</b>				
Type of messages selected				
Clarity on the use of photographs				
Incorporation of speech				
Incorporation of facial expressions				
<b>COMMUNICATION BOARDS</b>				
Type of messages selected				
Clarity on the use of communication boards				
Incorporation of speech				
Incorporation of facial expressions				
<b>MANUAL SIGNS</b>				
Type of messages selected				
Clarity on the use of signs				
Incorporation of speech				
Incorporation of facial expressions				
<b>EASYTALK 4 OPTION</b>				
Type of messages selected				
Clarity on the use of the EasyTalk				

- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30
- 31
- 32

Incorporation of speech					<input type="checkbox"/> 33
Incorporation of facial expressions					<input type="checkbox"/> 34
4.2 How much prompting was required?					<input type="checkbox"/> 35
<b>Extensive    Average    Minimal</b>					<input type="checkbox"/> 36
4.3 Overall impression of nurse's confidence in facilitating communication					<input type="checkbox"/> 36
<b>Poor    Average    Good</b>					

## **SECTION E**

### **5 GENERAL**

#### **5.1 Have you used the protocol with any of your patients?**

Yes/No

If Yes, please specify with how many \_\_\_\_\_

37

38-39

#### **5.2 Have you had contact with any of your colleagues regarding the use of the protocol?**

Yes/No

If Yes, please specify how often \_\_\_\_\_

40

41-42

**APPENDIX M**  
**RESPONSE FORM II**

**Guidelines for completing the questionnaire**

1. Please answer **all** the questions.
2. Mark your choice with a cross (X) in the space provided.
3. All information will be treated confidentially and anonymity is assured.
4. The aim of this form is to gain insight into your experiences with children with severe disability and their parents.

**SECTION A**

- 1. What is your date of birth?**

Day	Month	Year

**For official use**  
 Respondent no

--	--

1-2

Card no


3

Batch no

--

4

--	--	--	--	--

5-10

**SECTION B**

- 2. Do you have a close relative with a disability?**

Yes/No

If Yes, please specify \_\_\_\_\_

11

- 3. What is your highest nursing qualification?**

Degree

--

Diploma

--

Other. Please specify:

--

12

- 4. Into which of the following categories do you fall?**

Auxiliary nurse (nursing assistant)

--

Senior auxiliary nurse

--

Staff nurse

--

Professional nurse

--

Senior professional nurse

--

Other. Please specify:

--

13

- 5 How long have you worked in a health clinic?**

Less than 1 year

--

2 – 3 years

--

4 – 5 years

--

6 – 10 years

--

11 – 15 years

--

16 – 20 years

--

More than 20 years

--

--

14

**6 Please specify if you have attended any training courses, lectures or workshops on disability, as well as the length of this training**

Kind of training	Yes	No	Length of training in hours
In-service training			
Lecturers/workshops (not for degree, diploma or certificate purposes)			
Diploma/certificate			
Special degree			

			15-17
			18-20
			21-23
			24-26

**7 Indicate with a cross (x) if the following statements are true or false**

Statement	True	False	Uncertain
AAC refers to Abnormal Alphabetical Communication.			
Gestures, facial expressions and pointing at pictures are different means of communication.			
Withholding attention is an example of a deliberate communication opportunity.			
The WHO defines disability from the perspective of an individual's participation in the environment.			
Multiskilling refers to many professionals (e.g. speech therapists, doctors, nurses etc.) giving skills to disabled people.			
Teaching children with severe disabilities should not take place in the natural home environment.			
Speech is an example of a communication function.			
"Dressing" does not provide many communication opportunities.			
It is not necessary to train the child with disability to make choices. This skill develops spontaneously.			
Protesting is one of the last communication skills a child develops.			
Severe disability can be the result of peri-natal factors (e.g. rubella and malnutrition)			
Environmental factors (e.g. family stress and lack of stimulation) do not cause disability.			
Unaided communication refers to the use of sign language, natural gestures, finger-spelling and speech.			
Using objects, photographs and symbol systems for communication are known as unaided systems.			
The EasyTalk is an example of a voice output communication device.			

	27
	28
	29
	30
	31
	32
	33
	34
	35
	36
	37
	38
	39
	40
	41

**SECTION C**

- 8 Emily is a 5-year old girl who has delayed developmental milestones. According to her mother she doesn't do much, except point at her mug when she is thirsty. Her mother never fills her mug, but only puts in one or two sips at a time. Emily also makes some noises when she wants the other children to play with her. She enjoys it when the other children put her mug on their heads. When Emily is left alone, she cries.

Respondent no  
  1-2  
 Card no  2 3

**Answer the following questions pertaining to Emily by marking your choice with a cross (X) in the relevant block. You can mark more than one option.**

Questions	Options											
	Pointing	Requesting interaction	Requesting objects	Vocalisations/Sounds	Mother	Crying	Creative stupidity	Protesting	Thirsty	Other children	Provide materials that require help	Delayed developmental milestones
Which means of communication does Emily use?												
Which communication functions are present?												
Name all Emily's communication partners												
Name the communication temptations that are present												

4-17  
18-31  
32-45  
46-59

- 9 In which order would you teach the following systems to a child? Mark the corresponding letter in the block provided. Begin on the easiest level. Look at the example provided on Level 5 (the most difficult level).

- A Line-drawings, e.g. PCS
- B Miniature objects
- C Normal writing
- D Identical objects
- E Colour photographs

Level 1	
Level 2	
Level 3	
Level 4	
Level 5	<b>C</b>

60  
61  
62  
63

**10 These statements refer to your current job. Indicate whether you agree or disagree with these statements.**

Question	Strongly agree	Agree	Un-decided	Dis-agree	Strongly disagree
I am the type of person who likes to know what is going to happen during the day and to have a fixed routine.					
I prefer to work independently and to choose my own tasks.					
I enjoy not having a fixed routine. I take every day as it comes.					
I prefer to have my tasks set for me.					
I enjoy coping with sudden issues that arise.					
I get upset when things happen that interfere with what I had planned for the day because I cannot finish what I had planned.					
I feel satisfied with my job.					
I have to force myself to go to work.					
My friends are more interested in their jobs than I am in mine.					
I am disappointed that I took this job.					
My job is interesting enough to keep me from becoming bored.					
Each day at work seems as if it will never end.					
Children with disabilities should participate in community activities.					
Children with disabilities can get hurt very easily and therefore should not mix with other children.					
Caring for children with disabilities is more important than teaching them.					
It takes a very long time for children with disabilities to learn new skills. Therefore it is more important to teach normal children.					
Teaching children with disabilities is the work of parents and teachers, not community health nurses.					

Respondent no

1-2

Card no

 3

3

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

Question	Strongly agree	Agree	Un-decided	Dis-agree	Strongly disagree
Many people who work in overpopulated clinics feel that they become impatient. I also become impatient when people give long case histories and want advice from me.					
Parents should bring their disabled children to the clinic regularly so that the nurses can provide guidelines and help in the handling of the children.					
Children with disabilities develop slowly and sometimes show little progress. This discourages many people who work with them, so that service delivery is not easily seen. For this reason I don't enjoy working with children with disabilities for a long time.					

**11 How many of your patients are disabled children?**

None	
1 child	
2 – 3 children	
4 – 5 children	
More than 5 children	

24

**12 How much time do you usually spend with a mother and a disabled child?**

15 minutes or less	
15 – 30 minutes	
30 – 45 minutes	
45 – 60 minutes	
More than 1 hour	

25

**13 What do you usually do with children with disabilities and their parents? Mark only one.**

Direct referral to hospital/therapists	
Direct referral to schools	
Give advice or counsel parents and refer	
Obtain case history, screen and refer	
Interact with the child and provide guidelines on how to handle the child <b>without</b> referral	

26

**14 Answer the following questions that relate to your own evaluation of the services you provide. Mark your answer in the appropriate block with a cross (X). There are no right or wrong answers.**

How comfortable do you feel in handling children with disabilities?	Very uncomfortable	Uncomfortable	Comfortable	Very comfortable
How effective do you feel your treatment of children with disabilities is?	Very effective	Effective	Ineffective	Very ineffective
How much do you enjoy working with children with disabilities?	Enjoy very much	Enjoy	Don't enjoy	Don't enjoy at all
How often do you have the opportunity to train parents of children with disabilities?	Never	Occasionally	Frequently	Very often
How do you feel when parents regularly bring their disabled child to you for assistance?	Very unhappy	Unhappy	Happy	Very happy
How do you feel when parents bring their child back to the clinic regularly after you have referred them to a hospital for services?	Very unhappy	Unhappy	Happy	Very happy

- |                          |    |
|--------------------------|----|
| <input type="checkbox"/> | 27 |
| <input type="checkbox"/> | 28 |
| <input type="checkbox"/> | 29 |
| <input type="checkbox"/> | 30 |
| <input type="checkbox"/> | 31 |
| <input type="checkbox"/> | 32 |

**15 When you think of your skills as a nurse, which three things do you do best?**

---



---



---



---

- |                          |       |
|--------------------------|-------|
| <input type="checkbox"/> | 33-34 |
| <input type="checkbox"/> | 35-36 |
| <input type="checkbox"/> | 37-38 |

**16 Which of your skills are particularly good when working with children with disabilities and their parents?  
Name three skills.**

---



---



---



---



---



---

- |                          |       |
|--------------------------|-------|
| <input type="checkbox"/> | 39-40 |
| <input type="checkbox"/> | 41-42 |
| <input type="checkbox"/> | 43-44 |

- 17 Which skills related to children with disabilities and their parents would you like to improve/receive training in?  
Name three skills.

---

---

---

---

---

---


45-46  
47-48  
49-50

## APPENDIX N

### RESPONSE FORM III: TRAINING EVALUATION

---

**The following questions relate to the in-service training programme in which you participated. This information will be used to help the planning of further programmes.**

**For official use**  
Respondent no

--	--

1-2

Batch no 



 3

--	--	--	--	--	--

4-9

#### **SECTION A**

**1 What is your date of birth?**

Day	Month	Year

#### **SECTION B**

**2 Did the training help you to improve your knowledge regarding children with severe disabilities?**

10

It didn't help	It helped a little	It helped quite a lot	It helped very much

**3 Please answer the following questions related to the training method and training materials.**

	Yes	No	Uncertain
I enjoyed working with a problem-based format			
I could identify with the case studies.			
The hand-out is helpful.			
I think that important information is missing.			
The Beginning Communication Intervention Protocol (BCIP) is useful.			
The BCIP is easy to use.			
I will be able to plan a programme for a child with a disability and his/her caregiver, using the BCIP.			
The length of the training was sufficient.			
There was enough time for questions and answers.			
There was enough time to practise using the BCIP.			
The training helped me to adopt a positive attitude towards service delivery for children with severe disabilities and their parents.			

- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23

I think all community nurses should undergo this training programme.			
I enjoyed the training.			

**4 Which 3 aspects of the training did you enjoy most?**

---

---

---

---

---

		24-25
		26-27
		28-29

**5 On which aspects would you have liked more information?**

---

---

---

---

---

		30-31
		32-33
		34-35

**SECTION C**

**6 Suggestions on how to improve the training**

---

---

---

---

---

		36-37
		38-39
		40-41

**7 Any additional comments**

---

---

---

---

---

		42-43
		44-45
		46-47

**SECTION D**

**8      Overall rating of the training**

48

Very poor	Poor	Good	Very good	Excellent
-----------	------	------	-----------	-----------

## APPENDIX O1

### BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES : Handout Day 1

#### An In-Service Training Protocol for Community Nurses

##### AIMS OF THE TRAINING : DAY 1

- To contextualise the training within the Primary Health Care system and the human rights of children with disabilities
- To highlight the importance of communication
- To explain the concept of “severe disability”
- To discuss the concept of multiskilling and to highlight the role of community health nurses in the process of training beginning communication skills.

#### PROGRAMME

08h30 – 08h45	Arrival and registration
08h45 – 09h00	Welcoming and introduction <i>Mrs P Mosupyoe: Acting Director: Moretele District Health Services</i>
09h00 – 10h30	Introduction to the training protocol. Establishment of training needs <i>Mrs Juan Bornman &amp; team from Centre for Augmentative and Alternative Communication (CAAC)</i>
10h30 – 11h00	Tea and sandwiches
11h00 – 12h30	Primary Health Care and Disability: How does this work? <i>Mrs Juan Bornman</i>
12h30 – 13h30	Lunch
13h30 – 15h00	What is the role of the community nurse in disability? <i>Mrs Juan Bornman</i>
15h00 – 15h30	Workshop

## 1 WHY IS THIS TRAINING IMPORTANT?

### 1.1 Primary Health Care (PHC)

- ➔ Department of Health: unified health system capable of delivering quality health care to all the country's citizens (including children with disabilities!) in a caring environment.
- ➔ The strategic approach that guides this process is that of Primary Health Care (Government Gazette, 17019, 1997).
- ➔ In South Africa 73% of the total population are women and children.
- ➔ Between 35 – 55% live in poverty and 53% live in rural areas.
- ➔ These factors put them at risk of disability.
- ➔ One component of PHC is that individuals should be equipped with the knowledge and skills to care for themselves.
- ➔ Clinical skills of all health workers should be advanced and further developed.

### 1.2 Human Rights of People with Disabilities

### 1.3 Importance of communication

- ➔ Communication is any act by which one gives to or receives from another person information about the person's needs, desires, perceptions, knowledge or emotions (Beukelman & Mirenda, 1998).



#### ***Communication...***

- B Puts us in touch with other human beings.
- B Provides environmental control
- B Enables us to “*manipulate*” the people in our environment
- B Facilitates social integration
- B Teaches us new skills
- B Assists us in gaining knowledge
- B Enables us to receive education
- B Helps us find and maintain employment
- B Enables us to lead full and rewarding lives...

- ➔ Why is communication sometimes not viewed as important?
- ➔ What happens if there is a severe communication problem?

## 2 INTRODUCTION TO SEVERE DISABILITY

### ► Why is it so difficult to work with children with severe disabilities (CSDs)?

- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_
- ☞ \_\_\_\_\_

## 3 DEFINING THE CONCEPT...

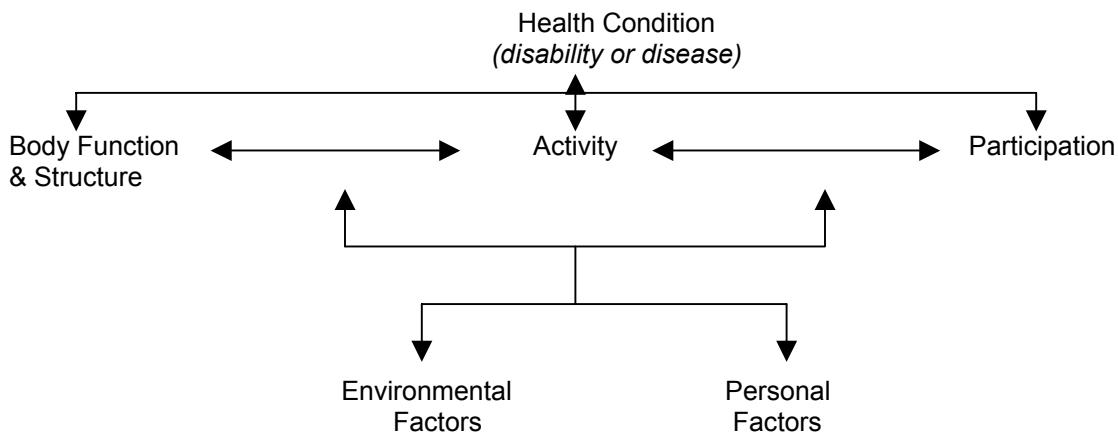
### ► What do CSDs have in common?

- There are no “*typical CSDs*” – they include children with Down Syndrome, intellectual impairment, cerebral palsy, etc.
- They come from all age, socio-economic and ethnic groups
- What they have in common is only their degree of dependence on services and support.
- “*A severely disabled child is one who, because of the intensity of physical, mental or emotional problems, or a combination of such problems, needs educational, social, psychological and medical services beyond those which have been offered by traditional regular and special education programs, in order to maximise his full potential for useful and meaningful participation in society and for self-fulfilment. Such children include those classified as seriously emotionally disturbed (schizophrenic and autistic), profoundly and severely mentally retarded, and those with two or more serious handicapping conditions such as the mentally retarded deaf, and the mentally retarded blind*” (US Department of Education in Sailor & Guess, 1983, p5).

### ► How can disability be classified?

- Framework of ICIDH-2 (International Classification of Functioning and Disability).
- ICIDH-2 looks at functioning and disability from the perspective of an individual's life circumstances and does not attempt to “label people”.
- Looks at functioning and disability on three levels:
  - **Body level/ Body functions and structure** (The physiological and psychological functioning of body systems and the body structure, i.e. the anatomic parts such as the organs, limbs and their components)

- **Individual level/ Activities** (The range of activities performed by an individual)
- **Society level/Participation** (Opportunities and/or barriers that impact on the areas of life in which the individual is involved, or has access to)
- Contextual factors are an integral component of the classification and consist of:
  - **Environmental factors** (They have an external influence on functioning and can impact on all three levels. They are extrinsic (outside of the individual) e.g. the attitudes of society, architectural characteristics or the legal system. Environmental factors are organised from the immediate environment to the general environment)
  - **Personal factors** (They have an internal influence on functioning and may include gender, age, other health conditions, fitness, lifestyle, habits, coping styles, social background, education, past and current experience, overall behaviour pattern, individual psychological assets and other characteristics)
- **Functioning** is the umbrella term used to indicate positive aspects on all three levels
- **Disability** is the umbrella term used for the negative aspects (problems) on all three levels



***The focus should not be on the DISability but on the ability and how it can be used optimally to ensure full participation in everyday activities.***

## 4 WHAT CAUSES SEVERE DISABILITY?

► The aetiology is not always clear, but may be caused by:

- **Genetic factors:** inborn metabolic errors, e.g. PKU, congenital factors (e.g., Fragile X Syndrome), chromosome deficiencies (e.g., Down Syndrome) etc.
- **Peri-natal factors** (e.g. rubella, drugs, alcohol, malnutrition). Foetal Alcohol Syndrome is the most common preventable cause of intellectual impairment worldwide (Viljoen, 1999). High incidence in South Africa : Western Cape study reported that 55% of the women admitted to varying degrees of alcohol ingestion during pregnancy, of which the drinking patterns and intake of 23,7% was sufficient to place their unborn children at high risk for Foetal Alcohol Syndrome (FAS)(Croxford & Viljoen, 1999).
- **Birth injuries** (e.g. anoxia)
- **Injuries, accidents and childhood diseases** (e.g. meningitis, poisoning, motor vehicle accidents, malnutrition, poor sanitation, poor water supplies)
- **Environmental factors:** factors that impact on this include the amount of stimulation, how stimulation is provided, teaching style of parents, expectation of parents, presence of a father, amount of family stress, poverty, etc.

## 5 WHY SHOULD COMMUNITY NURSES KNOW ABOUT DISABILITY?

- They come into contact with children who are able to participate on different levels, depending on the degree and type of disability. In about 90% of cases intellectual impairment is moderate (IQ of 50 – 70) and with proper support and nurturing these children can live and learn in the community!
- The majority of CSDs live at home with their parents (or extended families) and thus need to adapt to community living, making it mandatory that their needs be viewed within the context of the family and the community.
- The impact of disability is profound. It is permanent, placing high financial and caring demands on the family and on the community.
- The move is away from institutionalisation to “*inclusion*” of children with severe disabilities (CSDs) in all aspects of community living and learning (increased participation of CSDs).
- Nurses are part of the health care team. They often act as the bridge between the parents and the medical team.

- ➔ Trans-disciplinary functioning in a team is necessary when implementing community-based, family-centred, comprehensive and co-ordinated health care to disabled children and their families (ASHA, 1989).
- ➔ In view of the shortage of qualified health care professionals in South Africa, the community nurse is ideally positioned to provide services to parents of young children with disabilities. She is equipped to perform this task as she is viewed as a sensitive professional who has the skills to observe behavioural patterns and environmental concerns and thus to make recommendations where necessary.
- ➔ In order to equip nurses for this task, the concept of "***multiskilling***" must be addressed.

Multiskilling, a form of role diversification, refers to the cross-training of a service provider, in this case community nurses, to perform procedures and functions in two or more disciplines (Salvatori, 1997).

Multiskill level	Nursing task	Application to disability	Outcome
<b>Level 1</b> Cross-training of basic patient care skills			This level of multiskilling will not be addressed by the current training protocol.
<b>Level 2</b> Cross-training of professional, non-clinical skills	Awareness	<ul style="list-style-type: none"> <li>▪ Create community awareness regarding the needs of CSDs</li> <li>▪ Discuss community awareness with other professionals (e.g. school nurses and teachers)</li> <li>▪ Make parents and teachers aware of the importance of adequate, effective and appropriate communication skills.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased awareness of CSDs at both personal and community levels.</li> <li>▪ Increased community understanding of needs of CSDs and the importance of providing them with appropriate effective communication means</li> <li>▪ Reduced stigmatisation in community.</li> </ul>
	Information	<ul style="list-style-type: none"> <li>▪ Provide information regarding CSDs</li> <li>▪ Provide information regarding expectations</li> <li>▪ Provide information regarding further communication needs (long-term plan)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Demystify CSDs</li> <li>▪ Empowerment of parents regarding their CSD by providing information about expectations and realistic goals. Parents will also feel supported.</li> </ul>

	Referral	<ul style="list-style-type: none"> <li>▪ Initiate referrals to therapists</li> <li>▪ Initiate referral for further medical management</li> <li>▪ Assist therapists and teachers (particularly school nurses) in determining when a medical referral is necessary</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased understanding amongst professionals regarding the early referral and intervention of CSDs.</li> <li>▪ Establishment of a clearer referral line that will not waste time, money and/or effort</li> </ul>
	Feedback	<ul style="list-style-type: none"> <li>▪ Make caregivers aware of importance of providing feedback to referring nurse</li> <li>▪ Encourage other professionals to provide feedback to referring nurse</li> <li>▪ Provide feedback to caregiver regarding the changing communication skills after implementation of the protocol</li> </ul>	<ul style="list-style-type: none"> <li>▪ Encourage regular feedback from caregivers to monitor progress and meet changing needs and abilities of CSDs.</li> <li>▪ Provide feedback to caregivers and other professionals.</li> <li>▪ Feedback as reciprocal activity established.</li> </ul>
	Follow-up	<ul style="list-style-type: none"> <li>▪ Encourage caregivers to bring their children for regular follow-ups to monitor progress.</li> <li>▪ Assist caregivers to monitor the quality and quantity of communication (use the progress chart)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Regular follow-up visits</li> <li>▪ Caregivers become active observers of CSDs' progress.</li> <li>▪ Increased motivation of caregivers as progress is noted.</li> </ul>
<b>Level 3</b> Cross-training of administrative skills	Prevention	<ul style="list-style-type: none"> <li>▪ Educate the community on causes of disability and how some conditions can be averted and prevented, e.g. pre-natal care, good nutrition (already done to some extent)</li> <li>▪ Refer high-risk mothers</li> <li>▪ Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-ups.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Appropriate information and/or referral of mothers who are at risk of producing CSDs (e.g. woman over 38 years or teenage mothers). Enables early and informed decisions regarding childbearing.</li> <li>▪ Lower incidence of disability.</li> <li>▪ Decreased impact of the disability on the child's functioning.</li> </ul>

<b>Level 4</b> Cross-training of clinical disciplines	Identification and screening	<ul style="list-style-type: none"> <li>▪ Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history.</li> <li>▪ Conduct health assessment on identified children (at risk and established risk).</li> <li>▪ Use "<i>Progress Checklist</i>" to obtain baseline data.</li> <li>▪ Assist in obtaining necessary medical evaluations.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Obtaining relevant information about child in collaboration with caregiver to determine presence of disability so that child can be referred.</li> <li>▪ Analyse and discuss results from progress checklist with the caregiver.</li> <li>▪ Explore presence of risk factors further.</li> </ul>
	Planning services	<ul style="list-style-type: none"> <li>▪ Initiate and implement the beginning communication intervention protocol (BCIP)</li> <li>▪ Suggest modifications to present communication means, functions and opportunities (using principles from the BCIP)</li> <li>▪ Reassuring caregivers of humanity and likeability of CSDs.</li> <li>▪ Encouraging caregivers of CSDs to start a support-group while waiting at the clinics</li> <li>▪ Sustaining families through support and being an anchor (willing to listen and help)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Early participation and communication which will enable the CSD to reach his/her full potential.</li> <li>▪ Realistic goals and expectations will be set by caregivers.</li> <li>▪ Caregivers will adopt a positive attitude towards disability.</li> <li>▪ Guide caregivers to adapt their environment to provide optimal opportunities for interaction and learning.</li> <li>▪ Train caregivers in the use of different communication means and functions.</li> <li>▪ Sustain families by offering continued support and interest.</li> </ul>

## **WORKSHOP**

Divide into seven groups, and answer the following questions:

The Moretele District Department of Health wants to lessen the impact of disability in the area. You are required to assist. Explain how you would go about addressing the respective aspects of a disability campaign:

- Group 1: Awareness
- Group 2: Information
- Group 3: Referral
- Group 4: Feedback and follow-up
- Group 5: Prevention
- Group 6: Identification and screening
- Group 7: Planning services

## APPENDIX O2

### BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES : Handout Day 2

#### An In-Service Training Protocol for Community Nurses

##### AIMS OF THE TRAINING : DAY 2

- To describe the four major areas that impact on communication
- To discuss the development of different communication functions through the provision of deliberate communication opportunities
- To facilitate the development of skills related to:
  - the facilitation of different beginning communication functions
  - the creation of communication opportunities during activities of daily living (ADL)

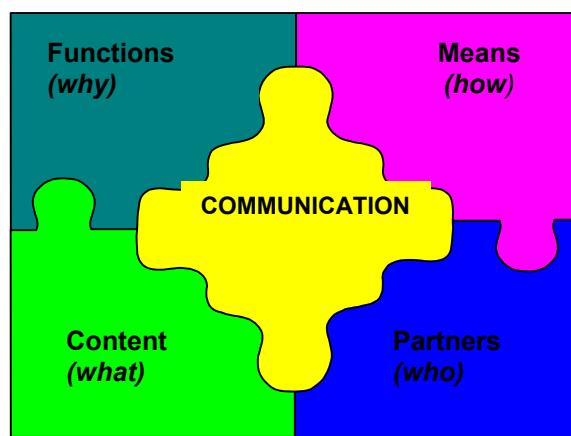
#### PROGRAMME

08h30 – 08h45	Revisiting the concept of “ <i>multiskilling</i> ” and the nurse’s role in disability.
08h45 – 10h30	Discussing the different beginning communication functions
10h30 – 11h00	Tea and sandwiches
11h00 – 12h30	Providing communication opportunities through the use of communication temptations
12h30 – 13h30	Lunch
13h30 – 15h00	Workshop and feedback

## 1 COMMUNICATION

### 1.1 What is communication?

- » Any act by which one person gives to, or receives from another person information about that person's needs, desires, perceptions, knowledge or emotions.
  - » This can be done via gestural, signed, spoken, and/or written means. Communication is generally considered to be intentional and to involve social interaction.
  - » The whole process is embedded in a specific context and environment. (Beukelman & Mirenda, 1998 ; Johnson *et al.*, 1996; Lloyd *et al.*, 1997).
- » From this definition four main areas arise:
- i) Communication functions (**why** the child communicates)
  - ii) Communication means (**how** child and others communicate)
  - iii) Communication content (**what** child and others communicate about – role of the environment)
  - iv) Communication partners (**who** the child communicates with)



## 2 COMMUNICATION FUNCTIONS

### 2.1 What does “communication functions” mean?

- Relates to the reasons why we communicate

## 2.2 Which are the main beginning communication functions?

- Main areas of communicative functions used in BCIP

- i) Making choices
- ii) Naming / Labelling
- iii) Requesting “**help**”
- iv) Requesting “**more**”
- v) Getting or maintaining social attention : draws attention to himself and signals presence
- vi) Protesting and the concept of “**no**”
- vii) Confirmation and the concept of “**yes**”
- viii) Showing surprise and humour

- Communication is powerful and efficient – efficiency is reflected by the fact that a single message, e.g. “*more*” can function as a request in many different situations or be a comment that there *is* more. “*Mama*” can be used to gain attention, to request “*more*”, to label, or to protest.
- First step in teaching communication functions is the manipulation of certain aspects of the child’s environment to make those settings more conducive to meaningful communication.
- Due to their skills (including communication skills) typically developing children are able to engage in interaction, take turns, make their intentions known and indicate pleasure or protest.
- CSDs, and in particular those with little or no functional speech (LNFS), have fewer opportunities to communicate than their speaking peers.
- Individuals with severe disabilities, however, are sometimes passive - they have limited skills, or few reasons to communicate and few opportunities for meaningful interaction, making active participation difficult.
- Low expectations of CSDs

- ➔ Main focus is often exclusively on the caring and nurturing of CSDs
- ➔ Little or no demands are placed on them, resulting in a reduced number of opportunities in which they are required or tempted to communicate

Γ If Wendy is passive in interaction, does this mean that she is unable to participate, unable to request objects, food or things? Does the problem lie with Wendy, or does the problem lie with her environment that is not able to make the appropriate adaptations to accommodate her particular abilities? The answer to this question will depend on whether she is given an opportunity to request her favourite toy.

### 2.3 Teaching communication functions by increasing communication opportunities

- ➔ Opportunities for communication are increased through the use of "*communication temptations*"
- ➔ These are different ways in which particular environments can be adapted or changed in order to provide deliberate opportunities for communication.
- ➔ The main aim of using communication temptations is to provide the CSDs with more opportunities for interaction through deliberately creating opportunities for communication.
- ➔ If no deliberate communication opportunities are created, two negative consequences follow.
  - i. Little motivation or desire to communicate
  - ii. Little opportunity to practise emerging communication skills
- ➔ CSDs are often passive communicators who may respond to communication, but very rarely initiate interaction.
- ➔ Primary caregivers need to acquire skills to embed communication opportunities within the natural, functional activities during the child's entire day.

**F** When assessing the skills of typically developing children, it is not necessary to pay special attention to the creation of opportunities for communication. This is due to the fact that these children are able to interact independently, e.g. they will walk to the refrigerator and take out the milk. On the other hand, a child with a physical disability may not have the ability to go to the refrigerator independently, while a child with a severe intellectual impairment may not have the skills to know that the milk is kept in the refrigerator. Deliberate opportunities must therefore be created in order to develop and expand these children's skills.

## 2.4 How do I teach communication functions?

### i & ii) Making choices & Naming

Communication functions	Making choices Naming / Labelling
Communication opportunity	Providing opportunities for making choices

- ➔ Indicating preference
- ➔ At least two available alternatives e.g. "*Do you want the soap or do you want the toothbrush?*"
- ➔ Use materials that consist of known "likes" versus "neutrals" or "blanks" can do this, e.g. if it is known that the child has a strong desire for "Coke" as opposed to a neutral feeling regarding water, these two options can be given.
- ➔ Choice of materials, "*Do you want Coke or do you want milk?*" or "*Do you want the soap or do you want the facecloth?*"
- ➔ Choice of tasks, "*Must we wash your face or brush your teeth?*"
- ➔ Choice of partners, "*Must I help you, or can Ntebeng help you?*"

**F** Cindy's primary caregivers could be encouraged to create opportunities for choice-making by asking her which dress she would like to wear. They should also be trained to wait expectantly before putting on the dress, as this will encourage Cindy to signal for the continuation of the activity.

- ➔ Different levels of choice-making: start with two options, using the real objects in the natural context. The child is then required to indicate his choice by pointing to the desired object or by reaching for it.
- ➔ After that, the same choices are provided, but now it is expected of the child to be able to give a yes/no response.
- ➔ On the last level multiple option choices are given where both yes/no responses and labelling responses are given. On this level, real objects are no longer used, but representational objects or symbols are used, e.g. empty packet of "Simbas" instead of real "Simbas"

*Providing CSDs with choices is something that we should consciously plan. Primary caregivers of CSDs commented that, despite their children's disability these children can also be fussy about what they would like to eat (e.g. Samuel does not like salty foods), what they would like to wear (e.g. Spice girl takkies!) or even what they would like to do (e.g. play with the water in the bath). Opportunities for indicating preferences and making choices should therefore always be a high priority.*

### iii) Requesting “*help*”

<b>Communication functions</b>	<b>Requesting “<i>help</i>”</b>
<b>Communication opportunity</b>	Making desired items inaccessible Selecting materials that require assistance

#### Making desired items inaccessible

- ➔ CSDs are passive partners in interaction, who do not request
- ➔ Speaking partners (peers and adults) tend to dominate communication and only occasionally provide opportunities for children with LNFS to respond.
- ➔ Very few to no opportunities are provided for CSDs to initiate interaction.
- ➔ How can deliberate opportunities for requesting be created? Occasionally **make desired items inaccessible** to the child.
- ➔ Do not take the desired items completely out of the child's sight, as he may forget what it was that he was looking for and lose interest.
- ➔ Do not overuse this strategy. The aim is not to frustrate the child, but to provide an opportunity to request something.

#### ➔ How can I do this?

- Put desired items in see-through plastic containers that the child is unable to open independently.
- Place desired items out of reach, so that the child has to request the item.
- ➔ Incorporating prompts. Start with a verbal prompt (“*Tell me what you want*”), followed by a gestural prompt if no response is seen (e.g. a puzzled look, or a vague sweep of the hand over the communication board) and finally a physical prompt (forming the child’s hand into the needed manual sign, e.g. “*cookie*”). Remember to allow the child enough time to respond before giving the prompt!

### **Select materials that require assistance**

- ➔ Requesting help is a very important skill.

Γ Think how often small children request help, e.g. by bringing their primary caregivers something that they cannot open themselves! CSDs, on the other hand, very often do not have the opportunity to develop this skill, as adults or peers tend to do everything for them! There is a general feeling that these children are already so disabled that life should not be made any more complicated for them! However, by doing so we are depriving CSDs of opportunities to do things for themselves, fostering learned helplessness.

- ➔ Careful selection of material as we do not wish to frustrate the child.
- ➔ The selected material should be of such motivational value that the child will request assistance, e.g. when making a sandwich the bread can be placed in a plastic bag that the child cannot open independently, or a zip that the child cannot undo independently, or a Velcro shoe, or even placing a banana inside a see-through container!
- ➔ Use of prompts can be given, i.e. “*Must I help you?*” while the manual sign for “*help*” is also modelled. In this example a verbal as well as a visual prompt is given. If there is no response, a hand-over-hand prompt can be given where the child’s hands are moulded to form the manual sign for “*help*”. Assistance is then provided. As the activity of making a sandwich continues, the margarine could be placed in a container that the child is unable to open independently. After pausing, observe the child before prompting.

- ➔ Prompts can gradually be faded until it would be sufficient to look at the child expectantly. In time the child should be able to request assistance without any prompts. Likewise, the jam or cheese, etc. could also be placed in containers that the child is unable to open independently.

#### **iv) Requesting “more”**

Communication functions	Requesting “more”
Communication opportunity	Providing small portions Providing brief turns

##### **Providing small portions**

- ➔ This is a strategy to facilitate requesting “more”
- ➔ Do not give the child all the necessary materials for the activity at the same time (e.g. give clothing pieces one by one - give only one sock, and wait for the child to request the other) or offer small portions (e.g. when feeding, give only one mouthful, and then wait for the child to signal that he wants more).
- ➔ Other examples would be to pour only a tiny amount of milk, e.g. one mouthful in the child’s cup. Give it to the child and wait expectantly. Likewise, if a child is very fond of “Jellytots” or “Smarties”, do not give him the whole packet, but give the sweets one at a time.
- ➔ Only use this strategy with objects of high motivational value, otherwise there is no incentive for requesting.

##### **Providing brief turns**

- ➔ This is also a strategy to facilitate requesting “more”
- ➔ Shorten the turns for participation, e.g. if a child is bouncing on the adult’s lap and shows signs of enjoyment, bounce him once or twice, and then stop the activity and see if he will request “more”.

- ➔ This is a very powerful intervention strategy as teaching the child the manual sign or symbol for “*more*” opens up a great number of communication opportunities for him, as he is then able to request “*more*” of anything motivational in the environment.
  
- v) **Getting or maintaining social attention : draws attention to himself and signals presence**

<b>Communication functions</b>	Draws attention to himself and signals his presence
<b>Communication opportunities</b>	Deliberately withholding attention

- ➔ Occasionally withhold attention or interaction until the child attempts to gain attention.
- ➔ Highly effective with children who have a strong desire to communicate; not effective with very passive children
- ➔ Specific times can also be selected for withholding attention, e.g. after lunch when everybody gets up to go and play, “*forget*” to include him in the next activity and leave him at the cleared table until he does something to draw attention to himself.
- ➔ Give the child your immediate attention at the slightest attempt from his side to indicate his presence. It is also important to equip the child with the necessary tools for calling attention, e.g. putting up his hand to call for attention, pressing a bell that will ring to draw attention, or banging the spoon on the table for attention, etc.

- vi) **Protesting and the concept of “no”**

<b>Communication functions</b>	Protesting Concept of “no”
<b>Communication opportunity</b>	Offering a non-preferred item Asking “yes/no” questions

- ➔ Protesting is often one of the first communication functions that develop (Lloyd *et al.*, 1997).

- ➔ CSDs often become very passive communication partners, as they often do not have opportunities to indicate protest.
- ➔ Even if they do protest, these attempts are often ignored. This leads to these children not displaying protesting communication functions as frequently as their peer group.

### **Offering a non-preferred item**

- ➔ A very effective strategy for eliciting protesting is by offering a non-preferred item i.e. if you know that the child wants fruit, offer him porridge, or when bathing the child, instead of soap give him a spoon, or when feeding suddenly give him a comb and see if he will protest, or whether he will willingly accept the incorrect item.
- ➔ If no protest is noted the adult should intervene and say, "*No! This is the wrong one! You actually asked for fruit!*"
- ➔ Never use this strategy if a child does not have good choice-making skills, as it will cause great confusion.

### **Asking “yes/no” questions**

- ➔ If a child has strongly developed protesting skills, one can move to a more sophisticated level of protesting, namely indicating "no"
- ➔ Sometimes CSDs are not challenged, and all questions have a "yes" answer. Also expand on "no" answers.
- ➔ Do not fall into a predictable routine

## **vii) Confirmation and the concept of “yes”**

Communication functions	Confirmation Concept of “yes”
Communication opportunities	Asking “yes/no” questions

- ➔ Asks yes/no questions for the child to confirm, e.g. "*Must I wash your hair?*"
- ➔ The ability to answer yes/no questions is an advanced skill.
- ➔ More directive strategy and do not allow for as many opportunities for interaction and initiating communication on the child's side.

- ➔ Never use rhetorical questions, e.g. “*That’s a new dress, isn’t it?*”

### viii) Showing surprise and humor

<b>Communication functions</b>	Showing surprise and humour
<b>Communication opportunities</b>	Violating expectations

- ➔ Effective if child is already engaging in certain routines, e.g. bathtime
- ➔ Used to elicit a protest or a surprise reaction from a child.

Γ When dressing the child put a sock on his hand or his pants on his head. If the child is able to dress himself, one item can be substituted for another to elicit a response e.g., if he is putting on his shoes, give him a facecloth. If the parent always puts out spoons before meals, she can pretend to “*forget*” to give the child his spoon. The parent can then respond by saying “*I’m silly! Look what I’ve done... uh oh this is not right!*” When using a highly familiar routine like “bathtime” at home, the activity can continue as usual, but the parent can “*forget*” to fill the bath.

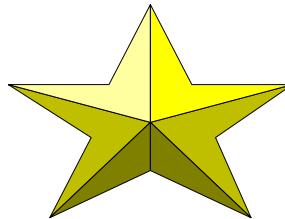
- ➔ Usually a strategy that elicits a lot of fun for both participants.
- ➔ Look for some reaction, e.g. a smile, a puzzled frown, a gesture, a vocalisation, speech or laughter.
- ➔ For some children this may be the start of communication interaction, as the child is actively responding, motivating the adult to explore even more avenues of interaction.

## 2.5 Conclusions

- ➔ Deliberately offering communication opportunities will enable CSDs to practise their communication skills (with regards to communication functions and means), optimising their interaction skills and learning experiences.
- ➔ Care should, however, be taken to avoid that “*communication temptations*” become “*communication frustrations*”.
- ➔ Primary caregivers must therefore learn the skills of how to embed communication opportunities within the natural, functional activities across the child’s entire day.

### 3 HOW DO I GO ABOUT ANSWERING A CASE STUDY?

- ➔ When answering a case study, it is the process that is important, rather than the answer.



- ➔ ***The 5-point plan to answering a case-study***

- i) **Step 1: Clarify the terms and concepts in the problem.**

Make sure that everybody understands all the terms and concepts. If unsure, consult a dictionary, other group members or ask the tutor

- ii) **Step 2: Define the problem**

Determine exactly what aspect of the problem or case study must be addressed

- iii) **Step 3: Analyse the problem**

Brainstorming. Formulate ideas and make assumptions about the case, e.g. if the mother has a spaza shop the customers are potential communication partners. Write down all ideas without criticism. When all the ideas have been given, go through all of them and accept or reject them.

Ideas might come from:

- ☺ Previous knowledge (“*I remember that...*”)
- ☺ Attempts to explain aspects of the problem (“*Perhaps what is happening here is...*”)

**iv) Step 4: Prepare a systematic answer based on the points identified in Step 3**

Search for possible solutions to the problem. Organise all the information in a systematic way.

**v) Report back**

Present methods and findings in some way, e.g. oral feedback, written feedback, making transparencies, posters, etc.

## **4 WORKSHOP**

- 4.1** Teboho is a 4-year-old who has very few opportunities to communicate. Her mother is very sceptical about Teboho's skills and feels that Teboho cannot do anything. Explain how you would assist this mother.
- 4.2** At present Cindy is not communicating effectively. She is withdrawn and never tries to interact with her primary caregivers or peers. They feel that Cindy is a burden and that she never helps in the house. Which important communication function will you teach Cindy? She is intellectually impaired and five years old.
- 4.3** Simon is a four-year old spastic boy. He cannot sit unsupported and although he can use his arms, he cannot use a finger to point. How will you go about teaching Simon to make choices?
- 4.4** Dorah is a six-year old who has behaviour problems. The mother thinks that one of the biggest problems is the fact that Dorah cannot indicate if she wants to continue with a specific activity. Which important concepts will you teach Dorah and how will you do it?
- 4.5** Daniel is a five-year old with an intellectual impairment. He gets very angry because his brothers forget to take him with them when they go out to play. Which important communication function will you teach Daniel?

- 4.6** Linah is a four-year old with a very strong will. She knows exactly what she wants. The biggest problem is that she does not know how to protest in a positive manner. Explain how you would go about teaching her better protesting skills and the concept of “no”
- 4.7** Rachel is a four-year old who loves it when her father bounces her on his knee. She is both deaf and blind, and it is unsure what her cognitive abilities are. Explain how you could use this activity to teach a specific communication function.

## **APPENDIX O3**

### **BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP)**

#### **FOR CHILDREN WITH SEVERE DISABILITIES : Handout Day 3**

---

#### **An In-Service Training Protocol for Community Nurses**

##### **AIMS OF THE TRAINING : DAY 3**

- To revisit the four major areas that impact on communication.
- To discuss the different communication means (aided and unaided strategies)
- To facilitate the development of skills related to:
  - the implementation of unaided strategies (e.g. facial expressions and manual signs)
  - the implementation of aided strategies (e.g. objects, photographs, PCS displayed on communication boards and voice output devices).

#### **PROGRAMME**

08h30 – 08h45	Revisiting the four major areas that impact on communication
08h45 – 10h30	Providing communication opportunities through the use of communication temptations
10h30 – 11h00	Tea and coffee
11h00 – 12h30	The use of aided and unaided communication strategies
12h30 – 13h30	Lunch
13h30 – 14h30	Exploring the communication means included in the BCIP (Beginning Communication Intervention Protocol)
14h30 – 15h30	Workshop

## 1 COMMUNICATION

### 1.1 What is communication?

- ➔ Any act by which one person gives to, or receives from another person information about that person's needs, desires, perceptions, knowledge or emotions.
- ➔ **This can be done via gestural, signed, spoken, and/or written means.**  
**Communication is generally considered to be intentional and to involve social interaction.**
- ➔ The whole process is embedded in a specific context and environment (Beukelman & Mirenda, 1998; Johnson *et al.*, 1996; Lloyd *et al.*, 1997).

## 2 COMMUNICATION MEANS

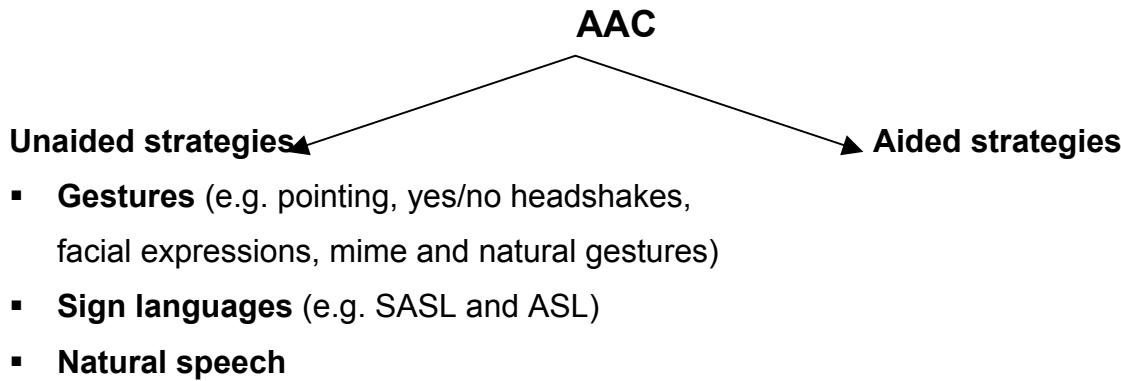
### 2.1 Introduction

- ➔ Spoken language (talking) is the most frequently used means of communication.
- ➔ This is the most difficult form of communication for CSDs!
- ➔ They need a crutch to lean on while spoken language is developing. This crutch is called ***Augmentative and Alternative Communication (AAC)***. Some CSDs will learn to speak without using their crutch, some will sometimes need their crutch in certain situations, whilst others will always be dependent on their crutch.

### 2.2 What is Augmentative and Alternative Communication (AAC)?

*Augmentative and alternative communication (AAC) refers to the field or area of clinical/educational practice to improve the communication skills of individuals with little or no functional speech. It includes the supplementation or replacement of natural speech and/or writing, using aided and or unaided symbols (Lloyd *et al.*, 1997).*

- ➔ Focus is on **augmentative** communication
- ➔ Most CSDs are able to produce a few vocalisations, and in some cases even a few words. AAC will never be used to replace the way they already communicate. Remember, a crutch is something we use to assist us, not something to replace what we already have! This means that if Thabang is able to communicate "no" by saying "uh..uh.." we will not attempt to modify this by giving him a symbol to say "no", as we can understand his message. So if some natural speech is present, we use the term **augmentative**.
- ➔ Sometimes an **alternative** system is required.
- ➔ This means that the strategy used will be a substitute (or alternative to) the natural speech of the individual. This might be used in cases where a person has a very high neck lesion and is unable to produce any sounds, or if there is damage to the vocal cords and no sounds can be made. An alternative system is, however, the exception rather than the rule.



**Unaided communication:** This refers to communication symbols, strategies or techniques that use only the body or parts of the body to represent, select or transmit information (Lloyd *et al.*, 1997:543).

### a) Gestures

- ⌚ This refers broadly to non-linguistic communication and includes pointing, yes/no headshakes, mime, facial expressions and natural gestures (Lloyd *et al.*, 1997).
- ⌚ **Pointing** occurs early in a child's development and is an essential part of communication development.

- Direct way of indicating or requesting a desired item.
- Usually hand-pointing but also eye-pointing.
- Powerful interaction tool as it requires very little motor ability, is generally understood by unfamiliar communication partners and can be used in combination with other aided and/or unaided symbols.

⌚ **Yes/no headshakes** are used widely by speaking and non-speaking persons alike.

- Usually easily understood.
- Highly useful and effective when used in combination with other AAC means.
- Efficiency depends upon the questioning skills of the communication partner.
- Headshakes only provide access to one communication function, namely responding.

⌚ **Facial expressions** convey a vast amount of information, particularly regarding emotions.

- A smile can show happiness, a frown can show that you do not understand. The face can also be used to show anger, unhappiness, discomfort, etc.
- Never underestimate the use of facial expressions!
- Use in accordance with the rest of the message, e.g. do not say “*No! Don't do that!*” with a big smile on your face! It will either have no effect or confuse the child.

⌚ **Mime** is a more elaborated form of gesturing as it includes the use of the whole body and not only the hands, arms and face.

- Attempts to convey information or ideas through pantomime or simulation of an activity.
- Effective as an initial technique before moving towards the use of gestures and/or signs
- Good back-up system in some situations (e.g. showing a dog barking).
- Limited as a primary communication means.

- ⌚ **Natural gestures** are gestures that are mostly made spontaneously and are usually understood by the general public without any prior training.
- Culturally specific, so if you are not part of the community, they can easily be misinterpreted!
  - Relatively easy to make, and are used by many individuals, e.g. your hands could be used to indicate “*come here*” or “*go away*”, or even to “*Watch it!*”
  - Major advantage is that non-disabled people also use natural gestures and many people understand them without needing any training.
  - Movements usually require gross hand movements, and thus even children with a physical disability can usually form some gestures.
  - Using and reinforcing natural gestures are usually good ways of introducing a person to the use of keyword signing.
  - The biggest disadvantage is that they are very limited and do not allow for conveying more abstract or difficult messages.

b) **Sign language (e.g. ASL or SASL)**

- ⌚ Sign language is a complete language on its own, used exclusively by the Deaf population.
- It has its own sentence structure, grammar and rules, exactly like any other language, e.g. Tswana, Afrikaans or Pedi. A particular sign language, e.g. South African Sign Language (SASL) consists of a great number of formal manual signs.
  - Focus remains on oral language

Γ Thuso will use gestures together with Tswana, Pieter will use his gestures together with Afrikaans, and Lerato will use her gestures with Pedi! None of these individuals will suddenly start using the sentence structure of SASL! It is also important to note that there are different kinds of sign language, e.g. the Americans use ASL (American Sign Language) whilst SASL (South African Sign Language) is used in South Africa.

- Emphasis is on **keyword signing** which implies that signs are used to supplement the most relevant content words in a sentence.

- Advantages are that messages are presented both auditorily and visually, they offer a reduced vocabulary that aids children with intellectual impairments in processing information and it slows down the rate of spoken communication
- SASL has been developed to help people convey more abstract and difficult messages.
- This means that one does not automatically know what a manual sign means, but if trained, one would be able to understand and remember it.

c) **Natural speech**

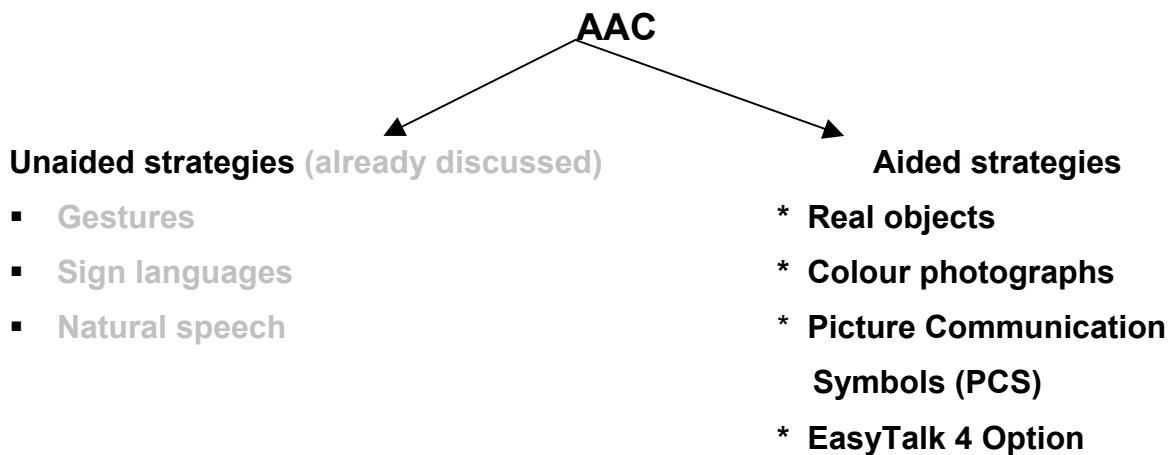
- Speech is obviously the most common form of communication.
- Easiest to produce, always accessible and usually understood by the majority of communication partners.
- Introduction to an AAC system does not imply that there has been “*given up*” on speech.
- When working with CSDs it is very important not to stop talking! Remember that many CSDs can hear and that they need to get information from as many sources as possible to aid their learning.

**2.3 What are the advantages of unaided systems?**

- ⌚ Child does not have to carry anything around : impact on ambulatory users
- ⌚ Always available, e.g. if you want to quickly say “*I need to go to the bathroom*” it is quicker to say it by using a manual sign than first having to take out a communication book, draw the listener’s attention, and then select the correct symbol.
- ⌚ Quick and easy to use

## 2.4 What are the disadvantages of unaided systems?

- ⌚ Unfamiliar people will not understand them, e.g. if you did not know the manual sign for “*black*”, you would not be able to guess it!
- ⌚ Do not facilitate interaction with unfamiliar partners.
- ⌚ Require motor skills as manual signs are formed using hands and arms.
- ⌚ Not displayed on a board from which the child only has to select one. This means that the child has to be able to think of the manual sign and remember how to make it, if he wants to use it.



**Aided communication systems** refer to communication that uses some type of external aid, symbol or assistive communication device (Lloyd *et al.*, 1997:523).

- Aided communication systems make use of symbols that are displayed either on communication boards or on communication devices.
- A symbol can be defined as something that is used to represent another thing, e.g. a spoon is used to represent mealtime.
- Hierarchical levels. Always start by using the easiest types of symbols while gradually moving to a more complex symbol

a) Real objects

- Easiest type of symbol to use for communication.
- Effective for beginning communicators as well as for children with severe intellectual impairments.
- The similarity of the thing the child wants (concrete referent), to the object is initially very important, e.g. at first the object-symbol for plate has to look exactly like the plate the child is used to, otherwise he might not recognise it
- Use real objects to provide choices.
- Start with two objects (that represent different activities)
- Because of the three-dimensional nature of objects they are ideally suited to children with visual impairments as they can easily manipulate the objects.
- Provides a means of communication and ensures future communication control.
- Prevents learned helplessness.
- Greatest disadvantage of using objects is their size. For some concepts (e.g. bed, bath, chair) the use of real objects will be impractical.
- Representation of objects, e.g. object communication boards, car-mats with Velcro, etc.
- Durability is important and the display must be designed to minimise damage to objects and to reduce the loss of objects.
- Keep in the designated place where the activity will take place.
- Flexibility of objects : thus do not fix permanently, but rather attach with Prestick or Velcro so that they can be added or replaced quickly.
- Stable display cues the child to start looking at all the possible choices and to scan through the choices in the same sequence (e.g. right to left or top to bottom).

b) Colour photographs

- Colour photographs are more easily understood than line-drawings (e.g. PCS), as they provide more clues; e.g. one can easily recognise the *red mug*.
- Advantage of photographs over real objects is the fact that they are smaller, making it easier to display them, to expand the system and also increased portability.
- Biggest concern of using photographs is the fact that they are limited in terms of the ideas that can be expressed as they mostly focus only on nouns and verbs.
- Intermediate step between real objects and more abstract line-drawings (e.g. PCS).
- Pairing is important when attempting to teach a child to generalise from objects to photographs. Start with a previously learned object together with the photographs and gradually fade the real object.

c) Line-drawings, e.g. Picture Communication Symbols (PCS)

- Picture Communication Symbols (PCS) consist out of some 3,000 black and white line drawings that cover a range of different categories, e.g. nouns, verbs, descriptive, prepositions, etc.
- Typical communication phrases, e.g. (“uh-uh!” “my turn”) are also included. The advantages of using PCS is that they are relatively easily learnable by CSDs, they are appropriate for all age levels, are easy, simple drawings for visual clarity, easy to reproduce and a lot of teaching materials for using PCS are available.
- PCS are used extensively in schools in South Africa and if children can be exposed to these symbols before they enter school, progress may be enhanced. Teachers can then spend time in teaching more complex concepts as they will not need to spend time on basic ADLs.
- Stimulates the CSDs receptive language, and expressive means of communication as they can “tell” certain things by pointing at the symbols.

- PCS symbols can be displayed either on communication boards or on communication devices (e.g. EasyTalk).
- Activity-based format. This means that all the vocabulary for a specific activity is presented together.
- Initially a total of 16 messages are depicted on the board, but templating can be used to minimise the number of options in order to suit the ability of the particular child.
- Colour coding of word categories is used (e.g. nouns are yellow) in order to facilitate quicker access.
- The same words (e.g. “oh oh”, “I” etc.) are always placed on the same spot in order to facilitate quicker retrieval of messages.

**d) EasyTalk 4 Option**

- Example of a Voice Output Communication Aid (VOCA).
- Can display symbols on technology.
- There are a variety of voice output devices available, ranging from very low to very high technology. The BCIP uses the “EasyTalk” voice output device.
- Advantages include
  - heightened intelligibility of utterances (unfamiliar partners are more likely to understand voice output than manual signs or symbol systems)
  - increased speed and accessibility
  - more potential communication partners
  - greater communication independence, as the non-speaking person is able to use his own “voice” to communicate and he experiences themselves as “speaking”
  - display better communication effectiveness
  - initiate interaction more often, use more complex sentence structures and generally have more control during communication
- Digital speech (where speech is produced when the human voice is recorded and digitised)
- Synthetic speech (where speech is artificially produced by electronic means rather than by the human vocal tract)

- Emphasis is on digital speaker, namely the EasyTalk as it can be age, gender and language appropriate as speech is recorded, making it ideally suited to the multi-lingual South African context. Attitudes towards AAC users are more positive when the voice output is natural, and easier to listen to, as is the case with digital speakers
- Implementation entails the following
  - Select symbol for that activity and place on the device.
  - The child can then press on the photograph or PCSs to activate the device and “speak” the message.
  - Before using a voice output device, it is crucial that the child understands the photographs/PCS that are placed on the device. If he does not, the device will not be used because the child does not understand the message, not due to a lack of motivation to use the device.

## 2.5 What are the advantages of aided systems?

- Increased receptive language
- Increase in expressive language
- Heightened expectations

## 2.6 What are the disadvantages of aided systems?

- Main disadvantage of this type of system is portability. The child will have to take his aid or carry his device wherever he goes, e.g. Jennifer going to the beach, Zandile having to get into a taxi, Johnny wanting to have a bath, and Frankie playing outside.

## 3 WORKSHOP

### 3.1 Hezekiel is three years old and blind. Which means of communication would you suggest for him? It is unsure on what cognitive level he functions.

- 3.2** Tumelo cannot rely on his speech to make his words known. He mostly uses his hands and arms to indicate things. He becomes frustrated when he wants something that he cannot point to. How will you go about helping him?
- 3.3** Simon has learnt that he can control his environment through using his arms and hands. How would you go about expanding Simon's current ways of communication?
- 3.4** Thandizile's mother feels that she can understand much more than she is able to say. She has spastic cerebral palsy. What would you consider as a means of communication for her?
- 3.5** You have advised one of the children in your clinic to start using manual signs as part of her communication. A teacher from the local school confronts you with this, and says that you are making the child "*lazy to talk*". How would you defend yourself?
- 3.6** When testing Naledi on a EasyTalk, it became very clear that she is a good candidate for a VOCA. Her primary caregivers cannot afford it. What arrangements could you make and how will you explain the importance of voice output for Naledi?
- 3.7** Lesego loves looking at pictures in a book. He can page through a book for hours. He makes sounds when he looks at the pictures. He is six years old and has an intellectual impairment. What communication means will you consider for him?

## APPENDIX O4

### BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES : Handout Day 4

#### An In-Service Training Protocol for Community Nurses

##### AIMS OF THE TRAINING : DAY 4

- To revisit the four major areas that impact on communication
- To discuss the different communication contexts / environments
- To discuss the inclusion of communication partners during the interaction process
- To highlight general communication intervention principles
- To facilitate the development of skills related to:
  - The implementation of AAC strategies in ADL
  - Basic AAC implementation strategies

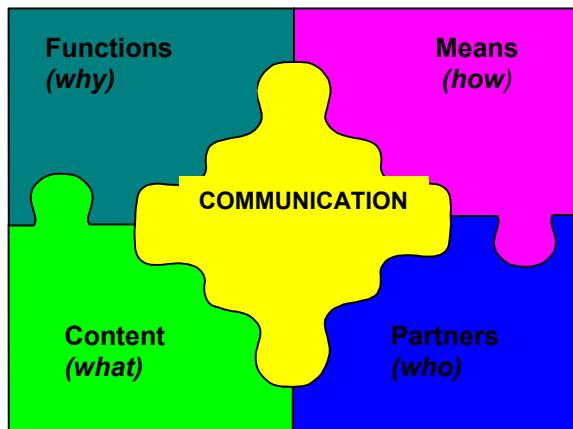
#### PROGRAMME

08h30 – 08h45	Revisiting the four major aspects that impact on communication
08h45 – 10h30	Implementing aided and unaided communication strategies during ADL
10h30 – 11h00	Tea and biscuits
11h00 – 12h30	Enhancing communication partners and general communication intervention principles
12h30 – 13h30	Lunch
13h30 – 15h00	Workshop and feedback

## 1 COMMUNICATION

### 1.1 What is communication?

- » Any act by which one person gives to, or receives from another person information about that person's needs, desires, perceptions, knowledge or emotions.
  - » This can be done via gestural, signed, spoken, and/or written means.  
Communication is generally considered to be intentional and to involve social interaction.
  - » The whole process is embedded in a specific context and environment.  
(Beukelman & Mirenda, 1998; Johnson *et al.*, 1996; Lloyd *et al.*, 1997)
- 
- » From this definition four main areas arise:
    - 1) Communication functions (**why** the child communicates)
    - 2) Communication means (**how** the child and others communicate)
    - 3) Content (**what** the child and others communicate about – role of the environment)
    - 4) Communication partners (**who** the child communicates with)



## 2 COMMUNICATION CONTEXT / ENVIRONMENT

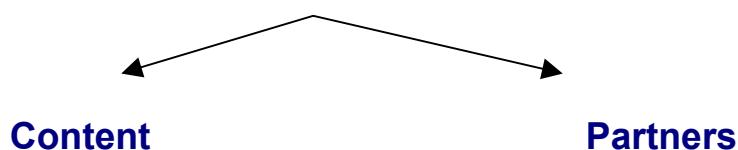
## What is the communication environment and why is it important?

- ➔ Context or environment refers to **where** the communication takes place.
- ➔ Interpretation of the meaning of a message is dependent upon the context
- ➔ Context refers to where the child **is**, what the child is **doing**, to **whom** the child is talking, **how** he or she is saying something and what the **partners** said

Γ If Teboho says "Daddy ball" it can mean "This is Daddy's ball", "Daddy get the ball" or "Daddy throw the ball". The context determines how this simple message will be interpreted.

- ➔ Milieu teaching : teaching in relevant and meaningful contexts.
- ➔ Advantage is that cues and consequences are natural parts of the setting.
- ➔ First step in active participation and communication includes the manipulation of certain aspects of the child's environment in order to make those settings more conducive to meaningful communication.
- ➔ Due to their skills (including communication skills) typically developing children are able to engage in interaction, take turns, make their intentions known and indicate pleasure or protest.
- ➔ CSDs, and in particular those with little or no functional speech (LNFS), have fewer opportunities to communicate than their speaking peers.
- ➔ Individuals with severe disabilities, are sometimes passive - they have limited skills, or few reasons to communicate and few opportunities for meaningful interaction, making active participation difficult.

**From the environment / context two important things arise**



## 2.1 CONTENT

- ➔ This refers to what the child wants to communicate about.
- ➔ Follow an ecological communication approach
  - i) For language to improve, major changes must occur in the child's communication, in communication of the partners and in the interactions between them.
  - ii) Language begins during the sensori-motor play activities and joint activities with others.
- ➔ Play is the occupation of children and provides excellent opportunities for discovering and learning new skills.
- ➔ Particularly important during early years of development when play is between an adult and a child as this provides the content of learning experiences.
- ➔ Through joint play routines children observe adults and explore the world around them.
- ➔ Cultural significance of play: primary caregivers in the Hammanskraal area noted that primary caregivers regard play between a parent and child as culturally inappropriate.
- ➔ BCIP uses three activities of daily living (ADLs), namely mealtime, bath/wash time and dressing/undressing.
- ➔ During these activities primary caregivers naturally interact with their children, which implies that in terms of intervention it is not something additional that they will need to do.
- ➔ ADLs provide opportunities for joint attention and meaningful interaction between primary caregivers and children.
- ➔ The vocabulary used in these three ADLs also remain fairly consistent, providing opportunities for repetition and establishment of these concepts.
- ➔ Disadvantages:
  - Expansion of the vocabulary is limited when using ADLs
  - ADLs are activity-driven, i.e. they each have a set goal, and the primary caregivers try to achieve that goal, usually in the shortest space of time.
  - ADLs have a fixed pattern, which is often difficult to change.

- ➔ Vocabulary selection to provide them with the necessary content to communicate a particular message is very difficult.
- ➔ Use activity-based communication boards that are based on milieu teaching.
- ➔ Purpose is to provide the CSDs with models for combining symbols in a flexible manner, and opportunities to do so. They are based on the premise that observing adults using the symbols extensively in natural interactions, the CSDs will begin to establish a cognitive template of how to combine symbols in order to generate new messages.
- ➔ Use activity-based communication boards in a very natural way.

#### ➔ How can I do this?

- Highlight symbols on the child's communication board as you verbally interact with him during the activity

Γ During mealtime the parent will say "*Uh oh! Look how dirty your face is! It is full of food*" while pointing to the symbols UH OH, DIRTY and FOOD. This means that the primary caregiver must know the symbols and have access to them.

- Caregiver should provide numerous opportunities for interaction while conducting the activity.

#### ➔ Functions of activity-based communication boards

- It provides the user with a model of how the system must be used
- It allows the child to see the symbols used in everyday situations
- It suggests that the AAC system is an acceptable means of communication.

Content : Mealtime		
Context: <b>Providing opportunities</b>	Communication modes: <b>Objects &amp; symbols</b>	Procedure
1. Providing choices of <ul style="list-style-type: none"> <li>▪ Materials</li> <li>▪ Tasks</li> <li>▪ Partners</li> </ul> <p><b>This teaches the child labels &amp; choice-making</b></p>	<b>Objects:</b> Spoon, plate, cup, food <b>Pictures:</b> Spoon, plate, cup, <b>Signs:</b> Milk, porridge, mother, I, grandmother, eat, drink <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Before starting to feed the child ask “Do you want your porridge or your milk?” Hold up both choices so that child can see. Emphasise the particular one by holding it slightly more to the front.(material)</li> <li>▪ Ask: “Do you want to eat or do you want to drink?” (task)</li> <li>▪ Ask: “Must I help you or must Koko help you?” (partner)</li> </ul>
2. Making desired items inaccessible  <b>This teaches the concept of requesting “help”</b>	<b>Object:</b> Cup <b>Pictures:</b> Cup, help, want <b>Signs:</b> Cup, want, help <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Place food in see-through container that the child can't open independently.</li> <li>▪ Place cup on top of cupboard (out of reach but in sight)</li> <li>▪ Place food out of reach.</li> </ul>
3. Providing small portions / brief turns  <b>This teaches the concept of requesting “more”.</b>	<b>Objects:</b> Cup, spoon, plate <b>Pictures:</b> Cup, spoon, plate <b>Signs:</b> More, want, help, eat, drink <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Pour only one mouthful of water into the child's cup</li> <li>▪ Feed one mouthful, and take plate away. If child feeds himself, follow same procedure.</li> </ul>
4. Selecting materials that require assistance  <b>This teaches the concept of requesting “help”</b>	<b>Objects:</b> Cup, jug, mango <b>Pictures:</b> Cup <b>Signs:</b> Cup, jug, want, help, drink, <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Put water in jug that closes very tightly, so that child has to require assistance.</li> <li>▪ Close tap tightly, so that child can't open independently</li> <li>▪ Put a fruit in a see-through container that the child can't open independently</li> </ul>
5. Withholding attention  <b>This teaches the child to draw attention to himself and to signal his presence.</b>	<b>Objects:</b> Cup, jug, mango <b>Pictures:</b> Cup, mango <b>Sigsn:</b> Cup, jug, want, help, drink, <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ When setting the table, or when giving food to the siblings, pretend to ‘forget’ the CSD. When he signals his presence, immediately react, and say “I'm sorry! I forgot about you! I'm silly”</li> </ul>
6. Offering non-preferred items  <b>This teaches protesting and the concept of “no”.</b>	<b>Objects:</b> Water, mango, lemon <b>Pictures:</b> Mango, lemon <b>Signs:</b> Like, yuck, no <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ If you know that a child wants a mango, give him a lemon instead and see if he will reject it.</li> <li>▪ If child wants milk, give water.</li> <li>▪ If child wants to eat, first give a drink.</li> </ul>
7. Violating expectations  <b>This teaches protesting as well as surprise and humour.</b>	<b>Objects:</b> Cup, spoon, plate <b>Pictures:</b> Cup, spoon, plate <b>Signs:</b> No, funny, mine <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ When you are feeding the child, do something totally unexpected like eating a mouthful yourself!</li> <li>▪ When feeding the child, hold the spoon the wrong way round or upside down.</li> <li>▪ Instead of giving the child something to eat, give him something like a stone / twig.</li> </ul>
8. Asking yes/no questions  <b>This teaches the child to confirm or negate information</b>	<b>Objects:</b> Cup, spoon, food <b>Pictures:</b> Cup, spoon <b>Signs:</b> Head-nodding/head-shaking <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	Ask questions such as <ul style="list-style-type: none"> <li>▪ Do you want milk?</li> <li>▪ Do you want some chicken?</li> <li>▪ Do you want something to drink?</li> <li>▪ Are you hungry?</li> <li>▪ Do you like pumpkin?</li> </ul>

Content : Bathtime		
Context: <b>Providing opportunities</b>	Communication modes: <b>Objects &amp; symbols</b>	Procedure
1. Providing choices of ▪ Materials ▪ Tasks ▪ Partners  <b>This teaches the child labels &amp; choice-making</b>	<b>Objects:</b> Soap, water, sponge, towel, toothbrush <b>Pictures:</b> Soap, sponge <b>Signs:</b> Wash, pointing, dry <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	Hold out the soap and the sponge and ask, "What do you want? Do you want the soap, or do you want the sponge?"(Materials) Ask the child "What must I wash? First you face or first your hands?"(task) Ask the child: "Must we first have a bath, or first brush teeth?"(task) Ask the child "Who can bath with you? Lesego or Mpumi?"(partner)
2. Making desired items inaccessible  <b>This teaches the concept of requesting "help"</b>	<b>Objects</b> Soap, sponge <b>Pictures:</b> Soap sponge <b>Signs:</b> Want, help, wash, soap, water <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Place sink tub out of the child's reach (if he likes bathing)</li> <li>▪ Place sponge out of reach.</li> <li>▪ Place soap in plastic bag that the child cannot open independently</li> <li>▪ Place anything that the child plays with in the bath in a container that he can't open</li> </ul>
3. Providing small portions / brief turns  <b>This teaches the concept of requesting "more".</b>	<b>Objects:</b> Soap, sponge <b>Pictures:</b> Soap, arm, hands, face, foot <b>Signs:</b> More, wash, nice, point to different body parts. <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ When bathing the child make foam with the soap on the sponge, and then only wash one body part at a time. Name the body part that you are currently washing.</li> <li>▪ Stop, ask the child "Do you want more?" Yes, more wash. Let's wash your other leg."</li> <li>▪ Continue with all body parts in same way.</li> </ul>
4. Selecting materials that require assistance  <b>This teaches the concept of requesting "help"</b>	<b>Objects</b> Tap, shampoo bottle, soap, toothpaste <b>Pictures:</b> Soap, shampoo <b>Signs:</b> Want, help, open, nice, look! <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Close the tap very tightly. Ask the child to run the water.</li> <li>▪ Put soap in a see-through container that he cannot open independently.</li> <li>▪ Use an empty shampoo bottle that he can play with and close the lid very tightly.</li> <li>▪ Close cap of toothpaste very tightly</li> </ul>
5. Withholding attention  <b>This teaches the child to draw attention to himself and to signal his presence.</b>	<b>Objects:</b> Towel, soap <b>Pictures:</b> Soap <b>Signs:</b> Want, help, dry, putting up his hand <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ This is not a strategy that is recommended during the bathtime routine, as it has certain safety implications.</li> <li>▪ It can, however, be used when the child is washing his hands before lunch. Pretend not to notice him and do not offer him a towel to dry his hands.</li> </ul>
6. Offering non-preferred items  <b>This teaches protesting and the concept of "no".</b>	<b>Objects:</b> Shampoo bottle, sponge, towel <b>Pictures:</b> Sponge, soap <b>Signs:</b> Want, help, no, wash, dry, head-shaking <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ During bathtime this activity is usually done by giving the child a bath toy (e.g. shampoo bottle, etc.) that he doesn't like.</li> <li>▪ When the child is to climb out of the bath and it is time to dry himself, don't give him the towel, but give him a sponge and say "Yes, It's time to dry yourself".</li> </ul>
7. Violating expectations  <b>This teaches protesting as well as surprise and humour.</b>	<b>Objects:</b> Soap, bath, sponge <b>Pictures:</b> Soap, sponge <b>Signs:</b> Want, help, wash, funny, no, like, don't like <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<p>Do something totally out of routine, e.g.</p> <ul style="list-style-type: none"> <li>▪ Put the child in the bath without water and say "We are going to bath now!"</li> <li>▪ Put the child in the bath with all his clothes on, and see if you get a reaction</li> <li>▪ Put the sponge under his armpit</li> <li>▪ Put the soap on his head -pretend not to see</li> </ul>
8. Asking yes/no questions  <b>This teaches the child to confirm or negate information</b>	<b>Objects:</b> Water, sponge <b>Pictures:</b> Sponge, spoon <b>Signs:</b> Head-nodding / head-shaking <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<p>Ask a number of questions to which the child can indicate yes or no, e.g.</p> <ul style="list-style-type: none"> <li>▪ Must I wash your face?</li> <li>▪ Are we going to wash your hair?</li> <li>▪ Are you finished?</li> <li>▪ Do you want some more?</li> </ul>

<b>Content : Dressing &amp; Undressing</b>		
<b>Context: Providing opportunities</b>	<b>Communication modes: Objects &amp; symbols</b>	<b>Procedure</b>
1. Providing choices of ▪ Materials ▪ Tasks ▪ Partners  <b>This teaches the child labels &amp; choices-making</b>	<b>Objects:</b> Pants, shirt, cap, socks <b>Pictures:</b> Cap, socks, shoes <b>Signs:</b> Want, dress, shoe, shirt, pants <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Give the child a choice of what he wants to wear, e.g. "<i>Do you want your red T-shirt or do you want your striped T-shirt?</i>" (materials)</li> <li>▪ Give the child a choice of what to do first, e.g. "<i>Must we first take off your shirt or first take off your pants?</i>" (task)</li> <li>▪ Give the child a choice of who must help him, e.g. "<i>Must I help you or must Pauline help you?</i>" (partner)</li> </ul>
2. Making desired items inaccessible  <b>This teaches the concept of requesting "help"</b>	<b>Objects:</b> Socks, shoes, hanger, plastic bag, shirt <b>Pictures:</b> Socks, shoes, shirt <b>Signs:</b> Help, want, give, dress, sock, shoe, shirt <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Put his favourite clothes on a shelf where he can't reach.</li> <li>▪ Put his shoes in a plastic bag that he can't open independently.</li> <li>▪ Hang clothes on a hanger over the door where he cannot reach.</li> <li>▪ Knot two socks together that he can't untie.</li> </ul>
3. Providing small portions / brief turns  <b>This teaches the concept of "more".</b>	<b>Objects:</b> Socks, shoe, pants, shirt <b>Pictures:</b> Socks, shoe, cap <b>Signs:</b> More, on, in, shoe, shirt, give <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ When putting on the child's shirt, put only one arm through the armhole and wait for him to indicate "<i>more</i>".</li> <li>▪ Put only one sock and pretend you are finished.</li> <li>▪ Put on only one shoe.</li> <li>▪ Pull on only one leg of the pants.</li> </ul>
4. Selecting materials that require assistance  <b>This teachers the concept of requesting "help"</b>	<b>Objects:</b> Shirt, pants, shoe <b>Pictures:</b> Shoes, socks <b>Signs:</b> Help, you, shoe, close, difficult <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ Don't automatically start fastening the buttons of the shirt, give the child the opportunity to request assistance.</li> <li>▪ Don't close the zip directly, but draw the child's attention by saying "<i>Yes, fasten your zip</i>"</li> <li>▪ Ask the child to buckle/unbuckle his own shoes.</li> </ul>
5. Withholding attention  <b>This teaches the child to draw attention to himself and to signal his presence.</b>	<b>Objects:</b> Shirt, dress <b>Pictures:</b> Shirt, dress <b>Signs:</b> Help, dress, put on, take off, difficult <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ While child is undressing himself, help him to pull the shirt over his head, but don't pull it off completely. Pretend to ignore the child and start picking up the other cloths.</li> <li>▪ After undressing the child, start doing something else and pretend not to notice him</li> </ul>
6. Offering non-preferred items  <b>This teaches protesting and the concept of "no".</b>	<b>Objects:</b> Shirt, spoon, cap, pants <b>Pictures:</b> Shirt, cap, pants <b>Signs:</b> Head-shaking, give, help, want <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ While dressing the child, give a totally incorrect item. Say "<i>Put on your shirt</i>" but give him a spoon.</li> <li>▪ If the child has selected his red T-shirt, deliberately give him the striped T-shirt.</li> <li>▪ If the child wants to put pants on first, give him his cap.</li> </ul>
7. Violating expectations  <b>This teaches protesting as well as surprise and humour.</b>	<b>Objects:</b> Socks, pants, shirt, shoe <b>Pictures:</b> Sock, pants, shoe, shirt <b>Signs:</b> No, funny, give, mine, finished <b>PCS Communication board</b> <b>EasyTalk 4 Option</b>	<ul style="list-style-type: none"> <li>▪ After undressing, give the child the "dirty" clothes to put on again.</li> <li>▪ Put a sock on the child's hand.</li> <li>▪ Pull the pants over the child's head.</li> <li>▪ Try to put his shirt on yourself.</li> <li>▪ Put his shoe on your head.</li> <li>▪ Give him your shoe to put on</li> </ul>

<p>8. Asking yes/no questions   <b>This teaches the child to confirm or negate information</b></p>	<p><b>Object:</b> Shoes, dress, jersey  <b>Pictures:</b> Shoes, dress, jersey  <b>Signs:</b> Head-shaking / head-nodding  <b>PCS Communication board</b>  <b>EasyTalk 4 Option</b></p>	<p>Ask a number of questions to which the child can respond with a yes/no:  <ul style="list-style-type: none"> <li>▪ Do you want to wear shoes?</li> <li>▪ Are you cold?</li> <li>▪ Do you want your aeroplane shirt?</li> <li>▪ Do you want to wear a dress today?</li> </ul> </p>
--	--	---

## Conclusions

- Stimulating content requires social contact, i.e. you need somebody with whom to communicate.
- Provide opportunities for the child and be in the child's world (e.g. through the use of ADLs).
- Proximity issues, namely the importance of being on the child's level (be on eye level and do not "talk down" to the child).
- Initially imitate the child, as this is the way in which he learns to imitate the adult. If the child puts a sock on his head, put the other sock on your head. Apart from providing a rich opportunity for interaction, it also is great fun!
- "Salt 'n Pepper" contacts (interaction opportunities spread throughout the day that provide frequent, natural opportunities for interaction work best. Relevance of ADLs.

## 2.2 COMMUNICATION PARTNERS

- Relates to **whom** the child communicates with.
- The communication partner is a vital part of the interaction process, because if you have something to say (content), you have the ability to say it, e.g. you know the manual sign for "*hello*", but if there is nobody to say it to, it all becomes useless.
- Teach communication partners, e.g. caregivers, sibling and peers how to communicate with the CSDs and what to expect of them in interaction.
- Teach partners to look for communication means that might not be very obvious, They also need to be aware of the different communication functions, e.g. CSD is requesting "*more*" or requesting "*help*".

- CSDs are rated as competent communicators if they are able to do the following:
  - i. Portray a positive self-image to their partners (this can only be accomplished if the CSD has a sense of self-esteem and if he feels that he is also able to do something can contribute to the interaction).
  - ii. Show an interest in others and draw others into interaction. This implies that the CSD has the ability to ask questions and to convey compliments, etc.
  - iii. Actively participate and take turns during interaction. The deliberate provision of communication opportunities is an attempt to facilitate turn-taking.
  - iv. Put their partners at ease, for example, by commenting.
- Providing opportunities for communication to CSDs directly relates to the partners' perceptions of the children's ability to respond appropriately
- Must examine and address the role of the partners' expectations
- Attempt to raise the partners' levels of awareness and teach them to expect that their CSDs who use an AAC system, play an active role in interaction.

### **3 A FEW GENERAL INTERVENTION PRINCIPLES**

1. The intervention process should enhance participation in current and future integrated environments. Interventions for today and tomorrow. This implies that the skills that the CSD learns should also be applicable once he enters school, and when he is interacting with people outside the immediate family. The critical communication messages that the child is taught during the ADLs should also be applicable to other activities, e.g. if the child is taught to request help when dressing, he can also request help when he is at school and he is, for example, unable to open the paint.
2. The role of interaction is not only to facilitate interaction between the primary caregivers and the CSD, but also to generally increase social interaction (especially with peers and siblings). In the past this factor has been overlooked, but as social and educational inclusion as well as integration into community

activities become more of a reality, this factor is beginning to receive more and more attention.

3. The skills taught to the CSD should be an essential component of further development. The cognitive skills that develop with the communication skills (e.g. object permanence) is a good example of this. Increasing a child's communication skills will lead to an increase of educational skills once he enters school. Literature has indicated that the first five years of a child's life is the critical period for learning, and this period has to be utilised to its full extent. Currently teachers are spending a lot of time teaching CSDs basic ADL skills and recognition of body parts – functions that could have been acquired in the pre-school years had the primary caregivers known how to facilitate them.
4. It is important that the development of functional communication should be a priority for the CSD and for the family. Although ADLs as such might not be highly motivational for CSDs, they might find the interactional component very enjoyable – this is the time when they have one-on-one interaction with their primary caregivers. During the discussions with primary caregivers it was noted that they found ADLs of great importance in their daily routine, due to the high frequency of these activities. Their aim is to get their children as independent as possible during the pre-school years.
5. One of the golden rules of interaction with CSDs is a give-and-take balance. Primary caregivers should be cautious to not always give, give, and give. They have to be taught to **wait** for a response. This is one of the most difficult skills to acquire, as we become anxious if there is a silent period, so we try to fill it by talking. It is necessary to wait for at least 15 seconds, and when a child is busy discovering a new activity, you may have to wait for 1 – 3 minutes. This is not a passive waiting period where you can go on with other things, but an active waiting period where you look at the child and try and understand what he wants to tell you! Waiting and observing are the two sides of the coin.

6. It is also important to actively facilitate conversational skills by keeping the interaction going. This can be done by chaining things together e.g. “*Yes, that is your sponge. We wash your tummy with your sponge. This tummy is full!*” However, it is important to keep a balance and not to dominate the interaction – expect a response from the child! If you keep on talking and do not wait expectantly for a response from the child, he will never learn to become an active communication partner taking turns during communication.

## 4 WORKSHOP

Nurses are required to work in pairs and role-play the application of the activity-based communication boards. Make sure that you have the opportunity to play the roles of the nurse, parent and child.

### WORKSHOP

1. Emily is a five-year-old girl with an intellectual impairment. She is cared for by her grandmother. There is a history of family violence and she has been abandoned by her mother. Her grandmother cares very well for her, and when seeing Emily for the first time it was noted that she is very dependent upon her grandmother. How would you start providing services?
2. Johnny is a lively six-year old. His mother complains that she has difficulty in getting him to sit down and pay attention. She says the only time when he is calm is when he plays with the water in his bath. How would you start providing services?
3. Maria is three years old and has severe spastic cerebral palsy. She does not have a wheelchair as her mother thinks that she is still young and will learn to walk. The mother is not concerned by her lack of speech. How would you start providing services?
4. Henry is five years old. He is intellectually impaired and when you saw him for the first time you noticed that he walked into things. He also touches

everything in his environment and tends to put new (unfamiliar) objects into his mouth. How would you start providing services?

5. Refilwe is six years old. She is a totally passive child who does not seem to pay any attention to her environment. The only time she seems to be interested is when her mother starts peeling a mango. The mother reports that at home Refilwe does nothing for herself, and that the mother has to do everything for her. How would you start providing services?
6. Nomsa is seven years old. Her grandmother of 90 cares her for. Although the grandmother is very loving and caring she is bedridden. Nomsa's only real toy is a broom that she pushes through the house aimlessly. The grandmother does not want to send Nomsa to a special school, as that will mean that she will be alone for most of the day.
7. Sally is a six year old who was typically developing until she was in a motor vehicle accident with her mother at the age of three. Although it appears that she understands more than what she is able to say, her developmental milestones are delayed. She appears to mostly use her right hand side of her body. Her left eye has a severe squint and it is unsure how much she sees with it.

## APPENDIX O5

### BEGINNING COMMUNICATION INTERVENTION PROTOCOL (BCIP) FOR CHILDREN WITH SEVERE DISABILITIES : Handout Day 5

#### An In-Service Training Protocol for Community Nurses

##### AIMS OF THE TRAINING : DAY 5

- ① To describe importance of monitoring progress
- ② To complete a checklist designed for monitoring progress
- ③ To apply knowledge gained to a case study

#### PROGRAMME

08h30 – 08h45	Revisiting the concepts of communication functions and partners.
08h45 – 10h30	Monitoring progress
10h30 – 11h00	Tea
11h00 – 12h00	Conducting a case study
12h00 – 12H30	Completing Response Form 1
12h30 – 14h00	Completing Response Form 2
14h00 – 15h00	Braai & certificate presentation

## 1 MONITORING PROGRESS

### 1.1 Why is it important to monitor progress?

- ☺ Service provision to CSDs is an on-going process, and monitoring progress is part of it.
- ☺ Helps to plan new objectives and set new goals.
- ☺ Method of evaluating the effectiveness of the service provision.
- ☺ Screening is never a once off procedure, has to be ongoing as the child's needs and abilities change over time.
- ☺ Service providers (nurse and the primary caregiver) gain self-confidence and perform their tasks if progress is seen.

**Progress checklist**

Name of child: \_\_\_\_\_

Name of person completing the

form: \_\_\_\_\_

Age: \_\_\_\_\_

Date: \_\_\_\_\_

**A. THE CHILD :**

**A-1 What ways of communication did the child use? (communication means)**

Does the child use **pointing** to communicate?

1                  2                  3                  4

Does the child use **objects** to communicate?

1                  2                  3                  4

Does the child use **crying** to communicate?

1                  2                  3                  4

Does the child use **facial expressions** to communicate?

1                  2                  3                  4

Does the child use **manual signs** to communicate?

1                  2                  3                  4

Does the child use **photographs** to communicate?

1                  2                  3                  4

Does the child use **line-drawings** (symbols) to communicate?

1                  2                  3                  4

Does the child use the **EasyTalk** to communicate?

1                  2                  3                  4

Does the child use **vocalisations** to communicate?

1                  2                  3                  4

Does the child use **speech** to communicate?

1                  2                  3                  4

## A-2 Why does this child communicate? (communication functions)

How well does the child **request help**?

1                  2                  3                  4

How well does the child **request objects**?

1                  2                  3                  4

How well does the child **request “more”**?

1                  2                  3                  4

How well does the child **protest**?

1                  2                  3                  4

How well does the child **confirm**?

1                  2                  3                  4

How well does the child **draw attention** to himself?

1                  2                  3                  4

How well does the child **label (name)** things?

1                  2                  3                  4

How well does the child **make choices**?

1                  2                  3                  4

How well does the child **indicate humour / teasing etc**?

1                  2                  3                  4

## B. COMMUNICATION PARTNERS & ENVIRONMENT

### B-1 How does the child communicate with people in the environment?

How frequently does the child communicate with **caregivers** / people in the house?

1                  2                  3                  4

How frequently does the child communicate with **siblings** and other **children**?

1                  2                  3                  4

How frequently does the child communicate with **unfamiliar adults** (strangers?)

1                  2                  3                  4

### B-2 Daily living information about the child

How **aware** is the child in the environment (interest in environment)?

1                  2                  3                  4

How much **enjoyment** is seen?

1                  2                  3                  4

How **active** is the child in interaction?

1                  2                  3                  4

How **independent** is the child during ADLs?

1                  2                  3                  4

C. **NURSES OBSERVATION : What strategies should I encourage the primary caregiver to use with her child?**

Providing opportunities for **choice-making**

Low priority      Medium priority      High priority

Providing **small portions** of materials or brief turns

Low priority      Medium priority      High priority

Making desired items **inaccessible**

Low priority      Medium priority      High priority

Select materials that require **assistance**

Low priority      Medium priority      High priority

Deliberately withholding **attention**

Low priority      Medium priority      High priority

Offering a **non-preferred** item

Low priority      Medium priority      High priority

**Violating expectations**

Low priority      Medium priority      High priority

Asking **yes/no** questions

Low priority      Medium priority      High priority

D. **RECOMMENDATIONS**

---

---

---

## CODES

No	Description
1	No evidence at all.
2	Emergent use. (Skill is starting to develop, but it is not clear and consistent).
3	Correct use, but with low frequency.
4	Uses correctly when needed.

## 2 WORKSHOP

Busi is a 4-year-old girl who is brought to you by her mother. Her mother has noticed that she is developing milestones at a slower rate than her brother who is two years younger. Her mother says that the brother is able to do things that Busi is still unable to do. Busi is the middle daughter of three children who live in an informal settlement in Lethlabile. Her mother is not working, as she has to look after Busi. The father is a taxi-driver. Busi's mother feels that they are stigmatised due to Busi's disability. There is no family history of disability. At present Busi spends most of the day outside watching the other children play. The mother is also having problems in dressing and feeding Busi as she is always on the move and becomes agitated easily. She mostly communicates using facial expressions, and makes sounds. She pushes things away when she doesn't want them.

### **Answer the following questions:**

#### **1. Current abilities**

- 1.1 What different ways of communication does Busi use at present? (*communication means*)
- 1.2 What messages does Busi try to say with the things she does? (e.g. what reasons for communication does she have?) (*communication functions*)
- 1.3 Who are the people with whom Busi communicates? (*communication partners*)

#### **2. Recommendations**

- 2.1 If you are the nurse working with Busi and her mother, what advice will you give her to help Busi?
- 2.2 What different ways of communication do you think Busi should acquire? (*communication means*)
- 2.3 What reasons for communication will you encourage Busi to learn? (e.g. what does she want to say with what she does?) (*communication functions*)

- 2.4 In which way can you increase the number of people with whom Busi can communicate with? (*communication partners*)
- 2.5 How can you change things in Busi's environment to give her more opportunities to communicate? (*communication opportunities*)

## APPENDIX P

### SUMMARY OF THEMES DELINEATED AFTER FOCUS GROUP WITH NURSES POST-TRAINING AND FOLLOW-UP

---

#### 1 SERVICE DELIVERY

- Attitude
  - Increased confidence due to increased knowledge and skills "*I learnt that I could, that one could easily communicate with disabled children*" / "*helps me to deal with them*"
  - Change in mindset "*eye opener*" / "*affected me as a person*"
  - Myths regarding children with severe disabilities were dispelled "*when I was at college, they say that the mentally retarded patients just keep quiet when they have a pain*"
  - Positive attitude "*now I don't regard them as being disabled, I see them as normal kids who are not able to do certain tasks*" / "*these children can be given a second chance in life*"
  - Proud : feel valued by patients, primary caregivers and other nurses)
  - Increased patience "... *it has made me practise patience and has made me understand them...*"
  
- New knowledge -
  - Increased understanding and knowledge about
    - Disability
    - Communication skills
  - Now have the ability to communicate with children with severe disabilities "... *now I can talk to patients who visit the clinics with signs...*"
  - Feel empowered : can teach children with severe disabilities as well as colleagues
  - Realise the importance of early intervention "... *it is easier for them to learn and teach them while they are still young...*"
  - Importance of milieu teaching "... *so I've realised the importance of home environment teaching after this in-service*"
  - Importance of providing children with severe disabilities with communication opportunities "*we must give them a chance to do so...*"
  - Pre-training belief: conducted only referrals, now equipped to provide training "*I thought we were just going to be taught how to refer these children...*"

- **Role of nurse / - Multiskilling**
  - Importance of team collaboration “*I can show them we are all a team.*”
  - See own role in team as important (pride in own profession) “*the nurses are the first people who come into contact with this child.*”
  - Importance of community and training and their role with this “*... and then to talk to the community at large...*”
  - Importance of collaborating with families “*... for us (nurses) to be with the primary caregivers...*”
  - Importance of training other nurses “*... I was using this sign of “help” and then the nurses were just all around myself... and then I started going on with all these signs teaching them...*”
  - Importance of teaching typically developing children about disability, and the nurse’s role “*teach these children to play with the disabled children ...*”
  - Knowledge and skills about the communication means and functions of children with disabilities
  - Know what they’ll teach (concrete knowledge) “*... I can advise the mother about exercising and teach about the functions of communication, also the signs and then advise them to take the child to a crèche and communicate with other children...*”
  
- **Job satisfaction -**
  - Increased job satisfaction “*... I enjoy this too much...*”
  - Pride in own abilities “*... but now, after this training, I know that I can work with them...*”
  - Enjoyment and fun of interactive teaching, using problem-based learning “*... and then I enjoyed this method.*”
  
- **Strong focus on - social inclusion**
  - Training of community in acceptance of disability “*they should be included in the community and accepted...*”
  - Importance of inclusion and community integration (e.g. take children with disabilities on outings) “*on a Sunday the child can also go to the Sunday school like the other children...*”
  - Importance of focusing on the ability and not the disability “*I don’t regard disabled children as being disabled, I see them as normal kids who are not able to do certain tasks...*”
  - Training of primary caregivers to facilitate social inclusion “*...they must not hide these children.*”
  
- **Relationship with primary caregivers**
  - Importance of including primary caregivers as part of the team “*to make them work together...*”
  - Necessity of providing support to these primary caregivers “*...the primary caregivers should also be given support that we can help the children...*”

- Educate primary caregivers on acceptance by focusing on ability “*take their children as they are and be with them.*”
- Increased knowledge about what to do with primary caregivers
  - *Listen to the problem*
  - *Talk to primary caregivers and ask about problems*
  - *Assist primary caregivers by showing them what to do*
  - *Teach mother signs (expand to family and then outsiders)*
  - *Referral to therapist if still necessary after having tried first*

## 2 TRAINING EVALUATION

- **Content**
  - **Communication means**
    - Manual signs: feel that they are equipped to use it, especially for greeting, to give instructions and to request basic needs.
    - EasyTalk (started at home by teaching own children and family members)
    - Real objects and the making of the object communication board
    - Communication board
  - **Communication functions**
    - Greeting
    - Requesting “help”
    - Requesting “more”
  - **Communication partners**
    - Importance of increasing number of communication partners through social inclusion
  - **Communication opportunities**
    - Importance of providing and creating communication opportunities
    - Violating expectations
- **Training method**
  - Follow-ups**
    - Helped to problem-solve difficult cases
    - Served revision role “*makes us not to forget some of the things.*”
    - Not threatened by the evaluative nature of follow-up “*it wasn't a big deal.*”
    - Provided an opportunity to practise new knowledge and skills if they have not had exposure to a child with severe disability “*helped us to visualise...*”
    - Acted as a trigger for independent revision “*after the follow-up I started to recall them and then I started to read.*”
    - Relevant case studies were selected for follow-ups

- **Training**
  - Could identify with the researcher and wanted to please her "*Let me not disappoint Juan.*"
  - Training was well-prepared
  - Lectures were good
  
- **Skills mastered**
  - Gained knowledge about what to do "*now I feel I can communicate with these children*"
  - Excited about new knowledge and skills. Eager to demonstrate them
  - More hands-on training with real cases will further enhance skills development.
  
- **Outcomes**
  - Empowerment. "*I never thought I would use that (signs) as an adult, but now I see it has a lot of purpose.*"
  - Positive attitude. Know what to do and how to do it.
  - In-service training of other nurses at clinic "*when we get that type of patient and I am not present, they can use these things* (BCIP)."
  - Enjoyment when working with children with disabilities "*it (BCIP and training) helps us to enjoy working with severe disability patients because really before that was a problem.*"
  - Apply skills to own profession to ease nursing problems "*teach him something to show us when he is feeling pain...*"
  - New knowledge and how to problem-solve in situ and where to start.
  - Sense of achievement and pride "*one patient who is deaf specifically asks for the nurse who knows how to talk!*" (herself)
  - Pride "*...how to communicate by using signs. That is something I never dreamt I would be able to do.*"
  - Feel valued and confident about new skills and knowledge
  - Horizons are widening (watching Deaf TV, interested in Para-Olympics, etc.)
  - Felt that initial course objectives were met – positive impact on expectations.
  - Increased insight. Thinking about the devastating effects of disability and realises it is emotionally draining.
  - Fun: training was enjoyable "*we were so laughing...*"
  
- **Negative aspects**
  - One week training was too short : should be extended to at least two weeks
  - Whole day training is tiring : should maybe be only mornings
  - Found interactive teaching and hands-on workshops demanding at first. Not accustomed to problem-based learning.

### 3 General comments

- Responses were genuine and deep, and nurses shared experiences on an emotional level.
- Honesty. Admitted to having tried to avoid the researcher initially during first follow-ups due to fear and anxiety of what would be expected of them.
- Initial anxiety was put at ease by researcher during first follow-up "*I was so relieved...*"

**Appendix Q: Translations of communication boards into the 11 official South African languages**

**Afrikaans**

**English**

**IsiNdebele**

**IsiXhosa**

**IsiZulu**

**Sepedi**

**Sesotho**

**Setswana**

**Siswati**

**Venda**

**XiTsonga**

## DRESSING / UNDRESSING

### AFRIKAANS

ek	skoon	nog	broek
nee	vuil	klaar	hemp
ô...ô	aantrek	uit trek	onderklere
help	pet	skoene	kouse

## MEALTIME

### AFRIKAANS

ek	wil hê	nog	beker
nee	skink	klaar	lepel
ô...ô	oop	vuil	langs
eet	drink	lekker	sleg

## WASHING

### AFRIKAANS

ek	wil hê	nog	water
nee	was	klaar	seep
ô...ô	afdroog	skoon	vuil
maak oop	maak toe	nat	in

## DRESSING / UNDRESSING

### ENGLISH

	clean 	more 	pants 
no 	dirty 	finished 	shirt 
uh oh 	put on 	take off 	underwear 
help 	cap 	shoes 	socks 

## MEALTIME

### ENGLISH

	want 	more 	mug 
no 	pour 	finished 	spoon 
uh oh 	open 	dirty 	beside 
eat 	drink 	good 	yuckie 

## WASHING

### ENGLISH

	want 	more 	water 
no 	wash 	finished 	soap 
uh oh 	dry 	clean 	dirty 
open 	close 	wet 	in 

## DRESSING / UNDRESSING

### isiNDEBELE

mina	ngifuna	godu	ibhrugu
awa!	feyila	siqedile	irhembe
Maye!	mbatha	hlubula	iimpahla zangaphasi
ngisiza	ikepisi	amanyathelo	amakowusu

## MEALTIME

### isiNDEBELE

mina	ndifuna ...	godu	ibhigiri
awa!	thela!	thelele	isigobho
Maye!	khamisa	kufeyila	hlanukwe...
dla	selo	kumnandi	akusimnandi

## WASHING

### isiNDEBELE

mina	ngifuna	godu	amanzi
awa!	hlamba	siqedile	isibha
Maye!	omisa!	hlanzekile	feyila
vula	vala	kumanzi	phakathi

## DRESSING / UNDRESSING

### isiXHOSA

mna	coekile	futhi	ibhulukhwe
hayi	gcolille	siquidile	ihempe
Maye!	nxiba	khulula	iingubo zangaphantsi
ndincede	ikyepusi	izihlangu	iikawusi

## MEALTIME

### isiXHOSA

mna	ndifuna ...	futhi	inkomityi
hayi	galela	siquidile	isipuni
Maye!	akhama	ngcolille	ecaleni
tya	selo	kumnandi	akumnandi

## WASHING

### isiXHOSA

mna	ndifuna...	futhi	amanzi
cha! / qha	hlamba	siquidile	isepha
Maye!	omisa!	coekile	ngcolille
vula	vala	kumanzi	phakathi

## DRESSING / UNDRESSING

### isiZULU

mina	hlanzekile	futhi	ibhulukwe
			
cha! /qha	ngcolile	ngithelele	ihembe
			
Mayel	embatha	khumula	izingubo zangaphansi
			
ngisize	ikepisi	izicathula	amasokisi
			

## MEALTIME

### isiZULU

mina	ngifuna ...	futhi	inkomishi
			
chal /qha	thela!	thelele	isipuni
			
Mayel	khamisa	kungcolile	eceleni
			
dla	phuza	kumnandi	akumnandi
			

## WASHING

### isiZULU

mina	ngifuna	futhi	amanzi
			
chal / qha	geza!	siqedile	insipho
			
Mayel	omisa!	esulal	ngcolile
			
vula	vala	kumanzi	phakathi
			

## DRESSING / UNDRESSING

### SEPEDI

nna	ke hlwekile	gape	borokgo
aowa	ditšhila	ke feditše	hempe
Jo! Jo!	apara	hlobola	diaparo tša ka gare
nthuše	mongatse	dieta	dikaušu

## MEALTIME

### SEPEDI

nna	ke nyaka...	gape	lebekere
aowa	tšhela	ke feditše	lelepolo
Jo! Jo!	ahlama	ditšhila	hleng go
ja	nwa	go bose	ga go bose

## WASHING

### SEPEDI

nna	ke nyaka...	gape	meetse
aowa	hlapa	ke feditše	sešepe
Jo! Jo!	iphumola	ke hlwekile	ditšhila
bula	tswalela	thapile	ka gare

## DRESSING / UNDRESSING

### SESOTho

nna	hlwekile	gape	borokwe
tjhee	tshila	feditse	hempe
A-e!	apara	apola	diaparo tsa ka hare
thusa	kepsi	djeta	dikausu

## MEALTIME

### SESOTho

nna	batla	gape	lebekere
tjhee	tshela	feditse	kgaba
A-e!	ahlama	tshila	haufi
-ja	-nwa	-lokile	ha di monate

## WASHING

### SESOTho

nna	batla	gape	metsi
tjhee	hlapa	feditse	sesepta
A-e!	omile	hlwekile	tshila
bula	kwala	kolobile	ka hare

## DRESSING / UNDRESSING

### SETSWANA

nna	phepa/skono	gape	borokgo
nnyaya/aowa	maswe/ditshila	Ke feditse	hempe
Aa! Oo!	apara	apola	diaparo tsa ka mo tlase
nthuse	kepisi	ditlhako	dikausu

## MEALTIME

### SETSWANA

nna	ke batla....	gape	lebekere
Nnyaya	tshela	ke feditse	leswana
Aa! Oo!	atlhama	maswe	fa thoko
ja	nwa	di monate	ga di monate

## WASHING

### SETSWANA

nna	ke batla...	gape	metsi
nnyaya	tihapa	ke feditse	sesepa
Aa! Oo!	Iphimole	phepa	maswe
bula	tswala	metsi	ka fa gare

## DRESSING / UNDRESSING

### SISWATI

mine	-hobile	lokunye	libhuluko
cha	-ngcolile	-cedzile	emashodo

nhinhlil	gcoka	khumula	imphahla yangephasi

lusito	likepisi	ticatfulo	emasokisi

## MEALTIME

### SISWATI

mine	funa	lokunye	imaki
cha	tsela	-cedzile	sipuno

nhinhlil	vula	-ngcolile	eceleni
dlani	natsa	kuhle	lokudlakubi

## WASHING

### SISWATI

mine	funa	lokunye	emanti
cha	geza	-cedzile	insipho

nhinhlil	-omile	-hlobille	-ngcolile
vula	vala	-manti	ekhatsi

## DRESSING / UNDRESSING

### VENDA

nne	kuna	engedza	vhurukhu
A thifuni	mashika	fhedza	hembe

E! E!	ambaxa	bvula	zwiambaro zwa nga ngomu

thusa	gebisi	zwienda	masogisi

## MEALTIME

### VENDA

nne	toda	engedza	bigiri
A thifuni	shela	fhedza	lebula

E! E!	atama	mashika	nga thungo

la	nwa	swavhudi	a si swavhudi

## WASHING

### VENDA

nne	toda	engedza	madi
A thifuni	tamba	fhedza	tthisibe

E! E!	oma	kuna	mashika

vula	vala	nukala	ngomu

## DRESSING / UNDRESSING

### XITSONGA

## MEALTIME

### XITSONGA

## WASHING

### XITSONGA