

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 & 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 woman 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...
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- ✚ 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)?

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3 DEFINING THE CONCEPT...

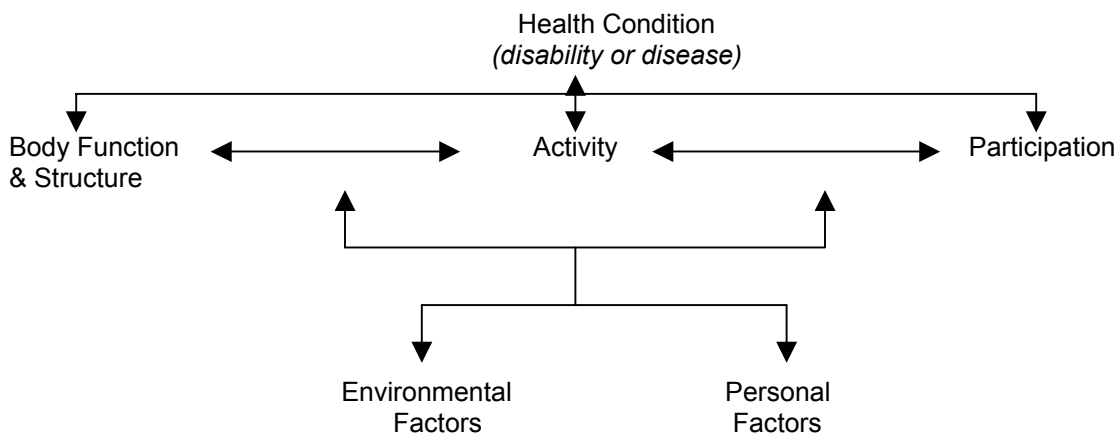
✎ What do CSDs have in common?

- 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
Level 1 Cross-training of basic patient care skills			This level of multi-skilling will not be addressed by the current training protocol.
Level 2 Cross-training of professional, non-clinical skills	Awareness	<ul style="list-style-type: none"> ▪ Create community awareness regarding the needs of CSDs ▪ Discuss community awareness with other professionals (e.g. school nurses and teachers) ▪ Make parents and teachers aware of the importance of adequate, effective and appropriate communication skills. 	<ul style="list-style-type: none"> ▪ Increased awareness of CSDs at both personal and community levels. ▪ Increased community understanding of needs of CSDs and the importance of providing them with appropriate effective communication means ▪ Reduced stigmatisation in community.
	Information	<ul style="list-style-type: none"> ▪ Provide information regarding CSDs ▪ Provide information regarding expectations ▪ Provide information regarding further communication needs (long-term plan) 	<ul style="list-style-type: none"> ▪ Demystify CSDs ▪ Empowerment of parents regarding their CSD by providing information about expectations and realistic goals. Parents will also feel supported.

	Referral	<ul style="list-style-type: none"> ▪ Initiate referrals to therapists ▪ Initiate referral for further medical management ▪ Assist therapists and teachers (particularly school nurses) in determining when a medical referral is necessary 	<ul style="list-style-type: none"> ▪ Increased understanding amongst professionals regarding the early referral and intervention of CSDs. ▪ Establishment of a clearer referral line that will not waste time, money and/or effort
	Feedback	<ul style="list-style-type: none"> ▪ Make caregivers aware of importance of providing feedback to referring nurse ▪ Encourage other professionals to provide feedback to referring nurse ▪ Provide feedback to caregiver regarding the changing communication skills after implementation of the protocol 	<ul style="list-style-type: none"> ▪ Encourage regular feedback from caregivers to monitor progress and meet changing needs and abilities of CSDs. ▪ Provide feedback to caregivers and other professionals. ▪ Feedback as reciprocal activity established.
	Follow-up	<ul style="list-style-type: none"> ▪ Encourage caregivers to bring their children for regular follow-ups to monitor progress. ▪ Assist caregivers to monitor the quality and quantity of communication (use the progress chart) 	<ul style="list-style-type: none"> ▪ Regular follow-up visits ▪ Caregivers become active observers of CSDs' progress. ▪ Increased motivation of caregivers as progress is noted.
Level 3 Cross-training of administrative skills	Prevention	<ul style="list-style-type: none"> ▪ 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) ▪ Refer high-risk mothers ▪ Educate on compliance with appointments (doctors, hospital, therapists, etc.), medication (e.g. epilepsy), periodic health visits (growth chart) and follow-ups. 	<ul style="list-style-type: none"> ▪ 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. ▪ Lower incidence of disability. ▪ Decreased impact of the disability on the child's functioning.

<p>Level 4 Cross-training of clinical disciplines</p>	<p>Identification and screening</p>	<ul style="list-style-type: none"> ▪ Identify children who are at risk of disability (e.g. twins, very low birth weight, poor nutrition, etc.) according to health history. ▪ Conduct health assessment on identified children (at risk and established risk). ▪ Use “<i>Progress Checklist</i>” to obtain baseline data. ▪ Assist in obtaining necessary medical evaluations. 	<ul style="list-style-type: none"> ▪ Obtaining relevant information about child in collaboration with caregiver to determine presence of disability so that child can be referred. ▪ Analyse and discuss results from progress checklist with the caregiver. ▪ Explore presence of risk factors further.
	<p>Planning services</p>	<ul style="list-style-type: none"> ▪ Initiate and implement the beginning communication intervention protocol (BCIP) ▪ Suggest modifications to present communication means, functions and opportunities (using principles from the BCIP) ▪ Reassuring caregivers of humanity and likeability of CSDs. ▪ Encouraging caregivers of CSDs to start a support-group while waiting at the clinics ▪ Sustaining families through support and being an anchor (willing to listen and help) 	<ul style="list-style-type: none"> ▪ Early participation and communication which will enable the CSD to reach his/her full potential. ▪ Realistic goals and expectations will be set by caregivers. ▪ Caregivers will adopt a positive attitude towards disability. ▪ Guide caregivers to adapt their environment to provide optimal opportunities for interaction and learning. ▪ Train caregivers in the use of different communication means and functions. ▪ Sustain families by offering continued support and interest.

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)

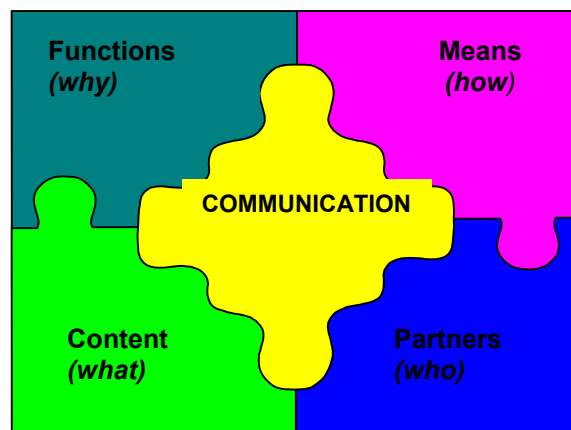
PROGRAMME

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.

Γ 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 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 you face or brush your teeth?”*
- Choice of partners, *“Must I help you, or can Ntebeng help you?”*

Γ 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”**

Communication functions	Requesting “help”
Communication opportunity	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

Communication functions	Draws attention to himself and signals his presence
Communication opportunities	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”

Communication functions	Protesting Concept of “no”
Communication opportunity	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 you 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**

Communication functions	Showing surprise and humour
Communication opportunities	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.

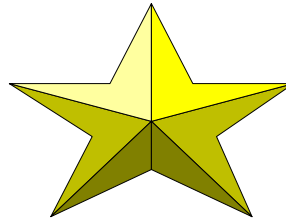
- ✎ Usually a strategy that elicits a lot of fun for both participants.
- ✎ Look for some reaction, e.g. a smile, a puzzled frown, a gesture, a vocalisation, speech or laughter.
- ✎ For some children this may be the start of communication interaction, as the child is actively responding, motivating the 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

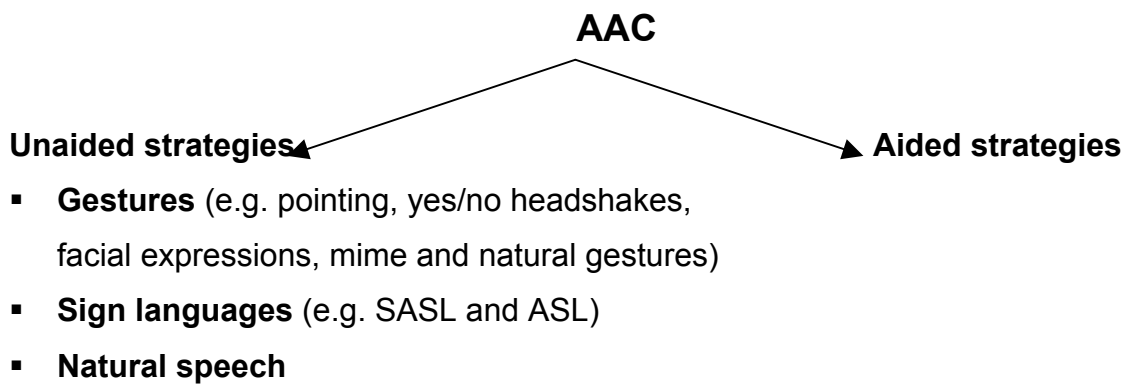
2.1 Introduction

- ✚ 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

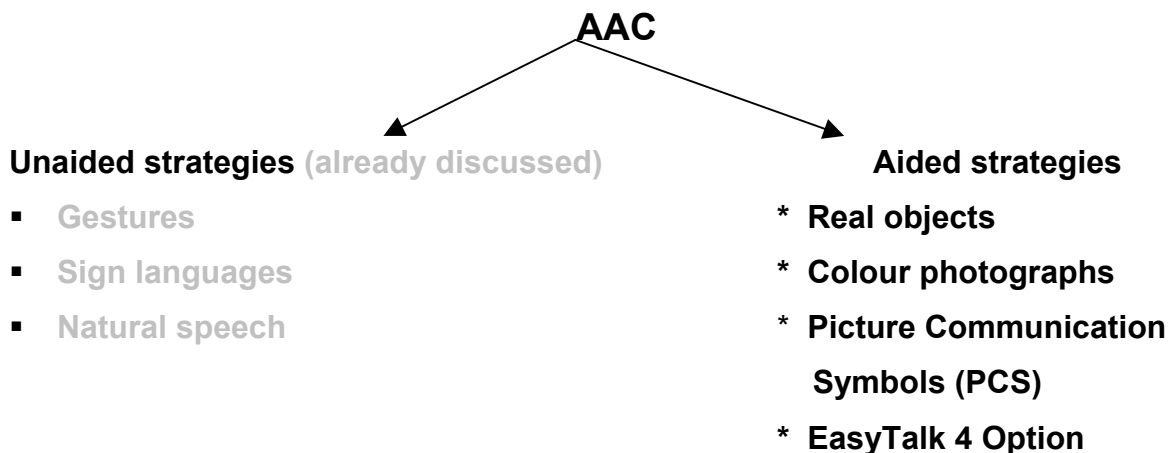
- Speech is obviously the most common form of communication.
- Easiest to produce, always accessible and usually understood by the majority of communication partners.
- Introduction to an AAC system does not imply that there has been “*given up*” on speech.
- When working with CSDs it is very important 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

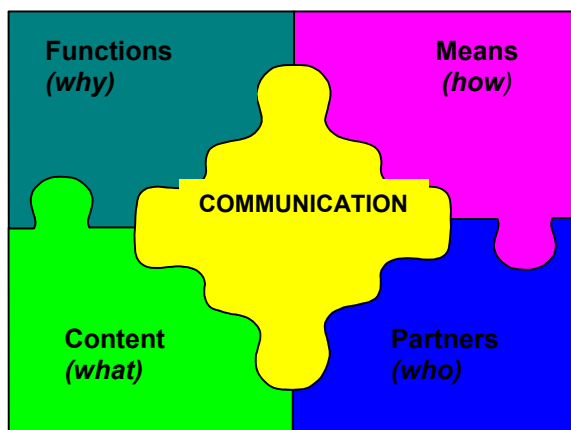
1 COMMUNICATION

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

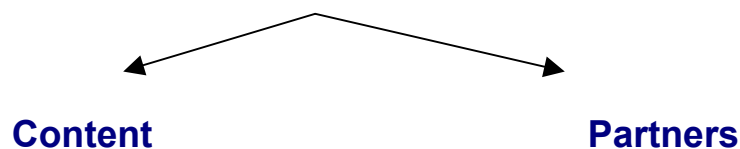
What is the communication environment and why is it important?

- ✚ 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: Providing opportunities	Communication modes: Objects & symbols	Procedure
1. Providing choices of <ul style="list-style-type: none"> ▪ Materials ▪ Tasks ▪ Partners <p><i>This teaches the child labels & choice-making</i></p>	<p>Objects: Spoon, plate, cup, food</p> <p>Pictures: Spoon, plate, cup,</p> <p>Signs: Milk, porridge, mother, I, grandmother, eat, drink</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ 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) ▪ Ask: “Do you want to eat or do you want to drink?” (task) ▪ Ask: “Must I help you or must Koko help you?” (partner)
2. Making desired items inaccessible <p><i>This teaches the concept of requesting “help”</i></p>	<p>Object: Cup</p> <p>Pictures: Cup, help, want</p> <p>Signs: Cup, want, help</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Place food in see-through container that the child can’t open independently. ▪ Place cup on top of cupboard (out of reach but in sight) ▪ Place food out of reach.
3. Providing small portions / brief turns <p><i>This teaches the concept of requesting “more”.</i></p>	<p>Objects: Cup, spoon, plate</p> <p>Pictures: Cup, spoon, plate</p> <p>Signs: More, want, help, eat, drink</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Pour only one mouthful of water into the child’s cup ▪ Feed one mouthful, and take plate away. If child feeds himself, follow same procedure.
4. Selecting materials that require assistance <p><i>This teaches the concept of requesting “help”</i></p>	<p>Objects: Cup, jug, mango</p> <p>Pictures: Cup</p> <p>Signs: Cup, jug, want, help, drink,</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Put water in jug that closes very tightly, so that child has to require assistance. ▪ Close tap tightly, so that child can’t open independently ▪ Put a fruit in a see-through container that the child can’t open independently
5. Withholding attention <p><i>This teaches the child to draw attention to himself and to signal his presence.</i></p>	<p>Objects: Cup, jug, mango</p> <p>Pictures: Cup, mango</p> <p>Signs: Cup, jug, want, help, drink,</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ 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”
6. Offering non-preferred items <p><i>This teaches protesting and the concept of “no”.</i></p>	<p>Objects: Water, mango, lemon</p> <p>Pictures: Mango, lemon</p> <p>Signs: Like, yuck, no</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ If you know that a child wants a mango, give him a lemon instead and see if he will reject it. ▪ If child wants milk, give water. ▪ If child wants to eat, first give a drink.
7. Violating expectations <p><i>This teaches protesting as well as surprise and humour.</i></p>	<p>Objects: Cup, spoon, plate</p> <p>Pictures: Cup, spoon, plate</p> <p>Signs: No, funny, mine</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ When you are feeding the child, do something totally unexpected like eating a mouthful yourself! ▪ When feeding the child, hold the spoon the wrong way round or upside down. ▪ Instead of giving the child something to eat, give him something like a stone / twig.
8. Asking yes/no questions <p><i>This teaches the child to confirm or negate information</i></p>	<p>Objects: Cup, spoon, food</p> <p>Pictures: Cup, spoon</p> <p>Signs: Head-nodding/head-shaking</p> <p>PCS Communication board</p> <p>EasyTalk 4 Option</p>	Ask questions such as <ul style="list-style-type: none"> ▪ Do you want milk? ▪ Do you want some chicken? ▪ Do you want something to drink? ▪ Are you hungry? ▪ Do you like pumpkin?

Content : Bathtime		
Context: Providing opportunities	Communication modes: Objects & symbols	Procedure
1. Providing choices of <ul style="list-style-type: none"> ▪ Materials ▪ Tasks ▪ Partners <p><i>This teaches the child labels & choice-making</i></p>	<p>Objects: Soap, water, sponge, towel, toothbrush Pictures: Soap, sponge Signs: Wash, pointing, dry PCS Communication board EasyTalk 4 Option</p>	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 <p><i>This teaches the concept of requesting "help"</i></p>	<p>Objects Soap, sponge Pictures: Soap sponge Signs: Want, help, wash, soap, water PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Place sink tub out of the child's reach (if he likes bathing) ▪ Place sponge out of reach. ▪ Place soap in plastic bag that the child cannot open independently ▪ Place anything that the child plays with in the bath in a container that he can't open
3. Providing small portions / brief turns <p><i>This teaches the concept of requesting "more".</i></p>	<p>Objects: Soap, sponge Pictures: Soap, arm, hands, face, foot Signs: More, wash, nice, point to different body parts. PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ 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. ▪ Stop, ask the child "Do you want more?" Yes, more wash. Let's wash your other leg." ▪ Continue with all body parts in same way.
4. Selecting materials that require assistance <p><i>This teaches the concept of requesting "help"</i></p>	<p>Objects Tap, shampoo bottle, soap, toothpaste Pictures: Soap, shampoo Signs: Want, help, open, nice, look! PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Close the tap very tightly. Ask the child to run the water. ▪ Put soap in a see-through container that he cannot open independently. ▪ Use an empty shampoo bottle that he can play with and close the lid very tightly. ▪ Close cap of toothpaste very tightly
5. Withholding attention <p><i>This teaches the child to draw attention to himself and to signal his presence.</i></p>	<p>Objects: Towel, soap Pictures: Soap Signs: Want, help, dry, putting up his hand PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ This is not a strategy that is recommended during the bathtime routine, as it has certain safety implications. ▪ 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.
6. Offering non-preferred items <p><i>This teaches protesting and the concept of "no".</i></p>	<p>Objects: Shampoo bottle, sponge, towel Pictures: Sponge, soap Signs: Want, help, no, wash, dry, head-shaking PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ During bathtime this activity is usually done by giving the child a bath toy (e.g. shampoo bottle, etc.) that he doesn't like. ▪ 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".
7. Violating expectations <p><i>This teaches protesting as well as surprise and humour.</i></p>	<p>Objects: Soap, bath, sponge Pictures: Soap, sponge Signs: Want, help, wash, funny, no, like, don't like PCS Communication board EasyTalk 4 Option</p>	Do something totally out of routine, e.g. <ul style="list-style-type: none"> ▪ Put the child in the bath without water and say "We are going to bath now!" ▪ Put the child in the bath with all his clothes on, and see if you get a reaction ▪ Put the sponge under his armpit ▪ Put the soap on his head -pretend not to see
8. Asking yes/no questions <p><i>This teaches the child to confirm or negate information</i></p>	<p>Objects: Water, sponge Pictures: Sponge, spoon Signs: Head-nodding / head-shaking PCS Communication board EasyTalk 4 Option</p>	Ask a number of questions to which the child can indicate yes or no, e.g. <ul style="list-style-type: none"> ▪ Must I wash your face? ▪ Are we going to wash your hair? ▪ Are you finished? ▪ Do you want some more?

Content : Dressing & Undressing		
Context: Providing opportunities	Communication modes: Objects & symbols	Procedure
<p>1. Providing choices of</p> <ul style="list-style-type: none"> ▪ Materials ▪ Tasks ▪ Partners <p><i>This teaches the child labels & choices-making</i></p>	<p>Objects: Pants, shirt, cap, socks Pictures: Cap, socks, shoes Signs: Want, dress, shoe, shirt, pants PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Give the child a choice of what he wants to wear, e.g. “Do you want your red T-shirt or do you want your striped T-shirt?” (materials) ▪ Give the child a choice of what to do first, e.g. “Must we first take off your shirt or first take off your pants?” (task) ▪ Give the child a choice of who must help him, e.g. “Must I help you or must Pauline help you?” (partner)
<p>2. Making desired items inaccessible</p> <p><i>This teaches the concept of requesting “help”</i></p>	<p>Objects: Socks, shoes, hanger, plastic bag, shirt Pictures: Socks, shoes, shirt Signs: Help, want, give, dress, sock, shoe, shirt PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Put his favourite clothes on a shelf where he can't reach. ▪ Put his shoes in a plastic bag that he can't open independently. ▪ Hang clothes on a hanger over the door where he cannot reach. ▪ Knot two socks together that he can't untie.
<p>3. Providing small portions / brief turns</p> <p><i>This teaches the concept of “more”.</i></p>	<p>Objects: Socks, shoe, pants, shirt Pictures: Socks, shoe, cap Signs: More, on, in, shoe, shirt, give PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ When putting on the child's shirt, put only one arm through the armhole and wait for him to indicate “more”. ▪ Put only one sock and pretend you are finished. ▪ Put on only one shoe. ▪ Pull on only one leg of the pants.
<p>4. Selecting materials that require assistance</p> <p><i>This teaches the concept of requesting “help”</i></p>	<p>Objects: Shirt, pants, shoe Pictures: Shoes, socks Signs: Help, you, shoe, close, difficult PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ Don't automatically start fastening the buttons of the shirt, give the child the opportunity to request assistance. ▪ Don't close the zip directly, but draw the child's attention by saying “Yes, fasten your zip” ▪ Ask the child to buckle/unbuckle his own shoes.
<p>5. Withholding attention</p> <p><i>This teaches the child to draw attention to himself and to signal his presence.</i></p>	<p>Objects: Shirt, dress Pictures: Shirt, dress Signs: Help, dress, put on, take off, difficult PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ 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. ▪ After undressing the child, start doing something else and pretend not to notice him
<p>6. Offering non-preferred items</p> <p><i>This teaches protesting and the concept of “no”.</i></p>	<p>Objects: Shirt, spoon, cap, pants Pictures: Shirt, cap, pants Signs: Head-shaking, give, help, want PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ While dressing the child, give a totally incorrect item. Say “Put on your shirt” but give him a spoon. ▪ If the child has selected his red T-shirt, deliberately give him the striped T-shirt. ▪ If the child wants to put pants on first, give him his cap.
<p>7. Violating expectations</p> <p><i>This teaches protesting as well as surprise and humour.</i></p>	<p>Objects: Socks, pants, shirt, shoe Pictures: Sock, pants, shoe, shirt Signs: No, funny, give, mine, finished PCS Communication board EasyTalk 4 Option</p>	<ul style="list-style-type: none"> ▪ After undressing, give the child the “dirty” clothes to put on again. ▪ Put a sock on the child's hand. ▪ Pull the pants over the child's head. ▪ Try to put his shirt on yourself. ▪ Put his shoe on your head. ▪ Give him your shoe to put on

<p>8. Asking yes/no questions</p> <p><i>This teaches the child to confirm of negate information</i></p>	<p>Object: Shoes, dress, jersey Pictures: Shoes, dress, jersey Signs: Head-shaking / head-nodding PCS Communication board EasyTalk 4 Option</p>	<p>Ask a number of questions to which the child can respond with a yes/no:</p> <ul style="list-style-type: none"> ▪ Do you want to wear shoes? ▪ Are you cold? ▪ Do you want your aeroplane shirt? ▪ Do you want to wear a dress today?
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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 procedures, 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*)