

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
- 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

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

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 pepped 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