TOWARDS INTEGRATED PRACTICES IN EARLY DETECTION AND INTERVENTION FOR DEAF AND HARD OF HEARING CHILDREN

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INFANT HEARING LOSS

- Silent epidemic of developing countries
  - Silent …
    - invisible nature
    - non-life threatening
    - affected individuals “silent”
  - Epidemic …
    - 4-6/1000 bilateral hearing loss (>40 dBHL)
    - Significantly including mild and unilateral HL
    - As high as 2-6% in high risk group

Source: Friedland, Swanepoel and Storbeck, 2008
INFANT HEARING LOSS - INTERNATIONAL CONTEXT

- 120 million annual births in developing world
- 718,000 - permanent bilateral HL (25% from SSA)
- Everyday 1,972 born with HL in developing world vs. 146 per day in developed countries (>90% born in developing world)
- Annually 4,408 – 6,612 babies born with permanent bilateral HL in South Africa
- 1,135,000 babies were born in 2008 in SA (0.8% of world’s babies)

Sources: Friedland, Swanepoel and Storbeck, 2008
UNICEF, 2008
Olusanya and Newton, 2007
Smith et al. 2005
Everyday 17 babies born with some degree of hearing loss in SA (>0.5% of daily births), therefore almost 6 babies in 1,000

More infants suffer hearing loss due to meningitis, ototoxic medication, prematurity, jaundice, etc.

94% of children with hearing loss are born to hearing families … most of these families have never met a person with hearing loss

The primary impact of hearing loss is on language development, which in turn affects cognitive and socio-emotional development

Newborn hearing screening and referral to early intervention services not mandated

Minimal government funding for the EHDI sector
Early Hearing Detection & Intervention
CHANGING ROLES IN SERVICE DELIVERY

- Child
- Nurse Physician
- Social Worker
- Early Interventionists
- Audiologist/ENT
- OT
- PT
- SLI
CHANGING ROLES IN SERVICE DELIVERY

Audiologist/ENT  
Nurse Physician  
Family  
Child  
Social Worker  
Early Interventionists  
OT PT SLI
EHDI PATHWAY

EHDI DATABASE

*Tracking and follow-up of appointments

Monitoring of hearing and communication development
- 6 monthly hearing screen if risk factors present
- Annual hearing tests if no risk factors

Diagnostic Testing *
- ABR
- Behavioural
- Tympanometry and reflexes

Management
- Amplification
- Aural rehabilitation
- Family-centred, home based Early Intervention

Birth Hearing Screening (OAE)

Pass

Refer

Appointment for rescreen

2nd screen

Pass

Refer
CHALLENGES

- No policy for early hearing screening
- No universal newborn hearing screening – late age of identification = reduced effectiveness of early intervention
- Lack of understanding of financial impact of unidentified hearing loss / burden of disease
- Lack of a national database
- 90% of all children with hearing loss have no access to early identification and early intervention services
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HI HOPES is born and starts supporting the first family
WHAT IS HI HOPES?

- Partnering with families
- Weekly home-based visits (+/- 1 hour)
- Information and empowerment (informed choice)
- Unbiased
- Active involvement in decision-making process
- Close collaboration with team (multidisciplinary approach)
THE TEAM OF EARLY INTERVENTIONISTS

PARENT ADVISOR

- Understands and Assesses Child Needs
- Understands Family and Family Concerns/Strengths
- Offers the Family Information, Support, and Encouragement

DEAF MENTOR

- Interacts with child
- Interacts with parents
- Teaches about Deaf Culture/ be a role model

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ADVANTAGES OF HOME VISITS

- Home visits make it possible to reach isolated families
- Ideal for learning firsthand about the conditions the family faces day after day
- Learn about family structure, roles, and interrelationships
- Makes early intervention accessible to all
- Family doesn’t have to dress up, get organized, drive to get to the appointment (especially if no transportation)
ASSESSMENT OF LANGUAGE DEVELOPMENT

- SKI HI Language Development Scale (LDS)
  - Chronological vs Language Age
  - Expressive Lang
  - Receptive Lang
- Quarterly
- Normed for deaf infants
- Either modality
Improvement of 1.4 months in RECEPTIVE language and 1.1 months in EXPRESSIVE language for each month, however for children where intervention begins before 6 months of age there is an improvement of 1.5 months in receptive language and 1.2 months in expressive language.
QUALITY ASSURANCE

- Mentors
  - in home quality assurance
  - PA support and development

- Research
  - interview professionals
  - interview parents (service recipients)
  - longitudinal tracking of children’s development
HOLISTIC AND EQUITABLE OUTCOMES: 1. CHILDREN AND FAMILY OUTCOMES

- Relationships with members of the family
  - Parents
  - Siblings
  - Extended family
- Communication
- Language Development
- Overall development
HOLISTIC AND EQUITABLE OUTCOMES:
2. COMMUNITY OUTCOMES

- Awareness
- Informed
- Inclusive
- Undiscriminatory
Create awareness of urgency for Early Intervention
Professionalise Early Intervention
Establish National Benchmarks for E.I.
Longitudinal Research
National Statistics
Etc etc
PROGRAMME STATISTICS
Number of Families

- Year 1: 32
- Year 2: 48
- Year 3: 134
- Year 4: 188
- Year 5: 237

- 641% Growth from year 1 to year 5
- 50% Growth
- 179% Growth
- 40% Growth
- 26% Growth

178 (237 projected)
ADDITIONAL DISABILITIES
REFERRAL SOURCES
NATIONAL HEALTHCARE

83% Public
17% Private
HEALTHCARE – PROVINCIAL BREAKDOWN

![Bar Chart]

- **Public**
  - Gauteng: 86%
  - Natal: 67%
  - Western Cape: 87%

- **Private**
  - Gauteng: 14%
  - Natal: 33%
  - Western Cape: 13%
HOUSING

- Gauteng
- Natal
- WC

- House
- RDP housing
- Flat
- Room
- Informal Settlement
- Work Quarters
- Orphanage
- Foster Care
- Xenophobic camp
AMPLIFICATION

- BAHA
- CI
- Hearing Aids
- Refused Amplification

- 94.5%
- 1.0%
- 4.0%
- 0.5%
COMMUNICATION CHOICE

- Sign Language: 41%
- Spoken Language: 59%
- Total Communication: 37%
- Oral: 22%
THE IMPACT OF HI HOPES

- Families are supported and empowered
- The aim of ‘Typical Development’ is being achieved
- Children are school ready when transitioning into Education System
- Equipping & Empowering Local communities (sustainability)
THE IMPACT OF HI HOPES

CONT.

- Employing a large workforce (demographically representative)
- Democratisation in process
- Investment in early intervention – financial savings over the lifetime of the individual
- Creating awareness of paediatric hearing loss and leading the way in policy development