EARLY INTERVENTION FOR INFANT HEARING LOSS – CURRENT STATUS IN SOUTH AFRICA

Alison Hart, MPH
Child Health Program Coordinator
OZ Systems, Inc.
Acknowledgements

Co Authors

• Dr Claudine Störbeck
  – Co-Founder and Director of EHDI* SA
  – Centre for Deaf Studies, University of the Witwatersrand,
  – Email: claudine.storbeck@gmail.com

• Dr De Wet Swanepoel
  – Co-Founder and Director of EHDI* SA
  – Department of Communication Pathology, University of Pretoria, South Africa
  – Email: dewet.swanepoel@up.ac.za

* EHDI: Early Hearing Detection and Intervention
Outline

• Background and importance of Newborn hearing screening and EHDI Programs.
• Current status in South Africa
• Data information management partnership
• Challenges and Opportunities
WHY IS NEWBORN SCREENING IMPORTANT?

Because Out Of Every 100,000 Babies Born:

- Hearing Loss occurs in 300
- Sickle Cell Disease occurs in 76.9
- Congenital Hypothyroidism occurs in 33
- Galactosemia occurs in 13.3
- MCADD occurs in 10
- Congenital Adrenal Hyperplasia occurs in 6.67
- Phenylketonuria (PKU) occurs in 5.88
- Biotinidase occurs in 1.67

Source: www.savebabies.org • Source: http://www.infanthearing.org/screening/nhsresources.html
Evolution of Screening

1960-1970

1980-1990
2000 -
Present
Goals of EHDI

- Maximize linguistic and communicative competence and literacy development for children who are deaf or hard of hearing.
- Provide appropriate opportunities to learn language, so that these children will not fall behind their hearing peers in language, cognition, and social-emotional development.
Key Components of Newborn Screening Programs

1. Birth Admission Screening
2. Follow-up Screen & Diagnostic
3. Early intervention
4. Life Long Care
South Africa

- Hearing loss is the most common birth disorder
- Everyday 2000 babies are born with hearing loss globally
- Everyday 12 to 18 babies are born with hearing loss in South Africa
- Late identification (after 6 months) has severe consequences
- Early intervention has dramatic benefits on development

Source: [http://www.ehdi.co.za/](http://www.ehdi.co.za/)
HI Hopes Early Intervention Program

- In the pilot year of the program the average age of diagnosis of hearing loss was 15 months of age.
- The average age of referral to the HI HOPES early intervention program was 25 months.
- The average gap between diagnosis and referral to early intervention was 10 months.

From Detection to Connection

OZ Systems and South Africa EHDI Partnership
NBS Systems: Tonniges, 2000

• “To ensure that every newborn receives appropriate services…

• “Only public health using the authority to protect the public's health can implement systems that…
  • assess prevalence,
  • mandate screening,
  • ensure quality and availability of testing,
  • and provide follow-up”
eSP™

- Web-based
- Available Anytime, Anywhere
- Integrated Baby Record
- Screening, Assessment & Intervention
- Rule-based Care Paths To Assure Completion Of Critical Tasks
- Authorized Access For All Users
eSP™ Protocol

1. Add New Patient
2. Performing Screening
3. Passed Screening
4. Need More Care
5. Continuous Care
6. Communications
eSP™ in South Africa

- Cost effective development to customize for SA user needs
- Development of paper forms for users with limited or no access to internet.
Project Challenges

• Resources
  – Human
  – Equipment
  – Financial, project funding and pricing
  – Hearing aid affordability and accessibility

• Unconventional screening platforms

• Relatively high number of non-hospital births
Project Challenges (cont)

• Lack of government policy
  – Leading to a lack of standard practice

• Remote user training
  – Planning and implementation

• User acceptance
  – Paradigm shift, data collection tool is an investment
Benefits

• Secure state of the art information management system for EHDI program
  – Foundational electronic infrastructure allows program to grow while maintaining quality

• Early intervention already in place
  – Ensures that babies who are screened will have appropriate follow up.
Benefits (cont)

• Building capacity in South Africa:
  – Strengthening the network of providers involved in EHDI care
  – Coordinating communication across different sectors of care (audiologist, Speech pathologists, EI)
  – Empowering South African providers to take charge of screening programs.
Next Steps

- Systematic Training and Go live schedule for end users
- Monitoring and Evaluation of program progress/impact of data management on number of infants identified with hearing loss.
- Develop lessons learned for other pilot projects.
Resources

• South Africa EHDI Program:
  – http://www.ehdi.co.za/

• South Africa HI Hopes Early intervention program
  – http://web.wits.ac.za/Academic/Humanities/Education/DeafStudies/HiHopes.htm

• OZ Systems
  – www.oz-systems.com
Questions

Alison Hart, MPH
Child Health Program Coordinator
OZ Systems
ahart@oz-systems.com
214-631-6161 ext 750