

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

IT IS well documented that undetected hearing loss can have a profound effect on a child's holistic development, including communicative, language and cognitive development. It is crucial therefore that deaf and hard of hearing infants are detected as early as possible so that appropriate intervention services and support can be initiated. To assist parents in enabling their child's optimal growth and development, HI HOPES¹—the first South African home-based early intervention project—was launched in August 2006, offering families weekly home-based support that is both child-centred and family-directed. A critical overview of the pilot implementation of HI HOPES is presented, from inception to implementation, focusing on its innovative services and practices, and issues that influence the intervention process including a reflection on the challenges and areas for development.

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Studies show that undetected hearing loss can lead to irreversible language, speech and cognitive delays (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998; Morton & Nance, 2006; Swanepoel, Delport, & Swart, 2007). More pressing than the mere detection of the hearing loss is early diagnosis and subsequent early intervention before the age of 6 months, thus enabling the child to develop and maintain age appropriate development with particular focus on language development. This intervention before the age of 6 months has been found to have a significant impact on overall later development, whatever

the language modality, thus emphasising the power of accessible early intervention in any language (Yoshinaga-Itano et al., 1998).

Undetected hearing loss on the other hand has a profound effect on the language abilities and skills of the infant, which may result in persistent language delays of at least 2–4 years (Yoshinaga-Itano et al., 1998). There is now strong evidence that failure to detect hearing loss has far-reaching social and economic ramifications posing a threat to quality of life in such areas as education, employment, and societal integration (Moeller, 2000; Yoshinago-

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Itano, 2004; Olusanya, 2005) in particular in developing countries (Olusanya, 2007; Swanepoel et al., 2004). Consequently, much effort has been expended on implementing newborn hearing screening programs so that suitable interventions can be undertaken in the early formative years. Although early detection and intervention for infants with hearing loss is becoming the standard in developed countries such as the United States, the United Kingdom, and Australia, the same cannot be said of developing countries (Olusanya, Luxon, & Wirz, 2004; Yoshinago-Itano, 2004).

Although South Africa has not yet implemented a systematic hearing screening program for newborns, the Professional Board for Speech, Language and Hearing Professions of the Health Professions Council of South Africa (HPCSA) recently issued a position statement (2007) in which it proposed targeted infant screening, such as the screening of high-risk infants with either a family history of permanent childhood hearing impairment, or additional risk indicators such as in-utero infections such as CMV, rubella, Malaria, or HIV, postnatal infections requiring admission of 48 hours or greater in an intensive care unit, syndromes associated with sensorineural or conductive hearing loss, and craniofacial anomalies (Hearing Screening Position Statement Year, 2007, p. 28). Despite clusters of committed hospitals and clinics (in both private and public health sectors), formal implementation of this resolution is yet to be initiated, leaving a large number of infants with an undetected and hence disabling hearing impairment. Due to this hearing impairments are often detected only after 2 years of age when parents, without access to routine hearing screening for infants, notice speech and language delays in their young children, and sometimes

even as late as during adolescence (Olusanya et al., 2006; Swanepoel, Delpont, & Swart, 2004).

Timely detection of a hearing loss, however, is not sufficient to guarantee deaf and hard of hearing (d/hh) children full access to intervention and support services. We attest that infants with hearing loss within the South African context are not currently receiving adequate early intervention services after diagnosis and that newborn hearing screening will not achieve its goal unless a comprehensive early intervention program is in place. The data presented in this article are part of an ongoing needs assessment designed to identify priorities for improving service delivery to families of d/hh infants enrolled in an early intervention program called HI HOPES. Several implications for early intervention and service provision can be drawn from this study.

HI HOPES Early Intervention Program Background

Over the past 15 years of our involvement in deaf education, we have not found a home-based early intervention program aimed at supporting and empowering parents, which is not connected to either specific medical and therapeutic interventions or communicative biases. Due to this lack of support for the family of the infant with a hearing loss in South Africa, and a growing number of calls from this community, an early intervention program called HI HOPES (**H**ome **I**ntervention—**H**earing and **L**anguage **O**pportunities **P**arent **E**ducation **S**ervices) was launched in August 2006 by the Centre for Deaf Studies (CFDS) at the University of the Witwatersrand with seed funding from the Nelson Mandela Children's Fund.

The program provides home-based support for families of d/hh infants

(ages 0–3 years) and is open to all families (both within public and private healthcare sectors) at no cost. HI HOPES was developed on the model of SKI-HI, an internationally renowned early-intervention program that has been implemented for over 35 years in the United States. The central aim of HI HOPES is to partner with parents, informing and equipping them in their journey with their infant with a hearing loss, without any bias in terms of technological or communicative intervention preferences. In addition to the unique “nonbiased” philosophy of this parent-led, child-focused intervention, HI HOPES also introduces families to successful, confident D/deaf adults in the local community, thus introducing authentic role models and mentors to the family and infant with hearing loss.

One of the strengths of the program is the high level of investment—both intellectually and financially—that has been made into the program and material development by key experts in the various fields of early-childhood development and deafness over more than three decades. The HI HOPES program, though firmly established within this context, is being “South Africanized”—that is, support and services are continually tailored to meet the needs established from data collected on families enrolled in the program.

Implementation of the HI HOPES Program Inception and Planning

An essential feature of the inception phase was the active involvement and collaboration of other key stakeholders in the planning of the HI HOPES program. Through a process of consultation and open dialogue, the prevailing attitudes, interests and needs within the professional health care community as well as the deaf community

INTEGRATED PRACTICES IN EARLY INTERVENTION

were assessed. Other role players and stakeholders, including the Deaf Association of South Africa (DEAFSA), educational institutions and schools, hearing aid companies and donor funding organizations, health professionals such as ENT surgeons, speech therapists, and audiologists, were consulted and encouraged to become involved in the development of the program. Guidance and advice was also sought from leading overseas universities and organisations, recognized for their early-intervention programs and support services to children with disabilities, particularly that of hearing loss. Following this consultation process, a model for early intervention and support services that would be holistic, unbiased, and that requires integrated and interdisciplinary collaboration, was designed and developed. Subsequently HI HOPES was born.

The program recognizes the importance of working within the infrastructure of existing health care services and strives to develop networks that ensure coordinated effective use of available resources. The HI HOPES team works in close collaboration with health care workers, clinicians, pediatricians, audiologists, and other medical professionals within both the public and private health care sector. Individual home-based support, designed to best fit the child's needs and strengths is developed in consultation with parents with the aim of informing and empowering them. Progress is reviewed and revised regularly in light of the unique child's progress, development, and ongoing needs.

Recruitment and Training

For logistical reasons, the HI HOPES program was first implemented in Gauteng which is one of the top three provinces in terms of number of disabilities (Statistics South Africa, 2005)

and where the Centre for Deaf Studies is situated. Drawing on all the resources available in the media (print, television, and radio) as well as informal networks, individuals were invited to be trained as early interventionists (called Parent Advisors in the HI HOPES program) or deaf role models (deaf mentors). Selection criteria for Parent Advisors were determined primarily by the candidate's qualifications and motivation for working with families of d/hh infants. Ideally, candidates trained as Parent Advisors have a degree in deaf education, early childhood development, speech pathology and audiology, or specialized/inclusive education. A secondary selection criterion was the geographic spread of the candidates thus ensuring that HI HOPES does indeed become accessible to all families of d/hh infants across Gauteng. The average age of the Parent Advisor candidate was 40 years, and of the 15 selected for the first cohort of training, 13 were female. The majority (8 out of 15) resided in the Johannesburg metropolitan area with 4 in the Ekurhuleni region and 3 in the Tshwane district. Ten have their own transport. The first

or home language for most candidates (53%) was an African language, which was broken down further into XiTsonga (3), Sepedi (3) and 1 each for Zulu and SeTswana. The majority of Parent Advisors are multilingual. Additional demographic information on parent advisors is presented in Table 1.

The call for deaf mentors was advertised in the media and through deaf networks to schools for the deaf, Deaf clubs, and others. Criteria for training as a deaf mentor included confidence with own hearing status, good communication skills in home language/language of choice, and a willingness to work closely with families as a role model. The average age of candidates as deaf mentors was 37, and of the 8 selected for the first set of training, 7 were female. Half the candidates have their own transport and the majority (75%) reside in greater Johannesburg. Demographic characteristics and other information on deaf mentors are depicted in Table 2.

The first intake of parent advisors and deaf mentors were trained within the first month of launching the HI HOPES program. Although initial training was planned along international

Table 1.
Demographic Profile of HI HOPES Parent Advisors ($n = 15$)

<i>Characteristic</i>	<i>Number</i>
Ethnic group	
African	8
White	5
Indian	2
Home Language	
African ^a	8
English	6
Afrikaans	1
Profession	
Educator	10
Audiologist	1
Student	1
Unemployed	2
Not stated	1
a. Includes XiTsonga, SeTswana, and Zulu	

Table 2.
Demographic Characteristics of HI HOPES Deaf Mentors ($n = 8$)

<i>Characteristic</i>	<i>Number</i>
Ethnic group	
White	5
Indian	2
Black	1
First Language	
South African Sign Language	4
English	4
Profession	
Educator	5
Teacher assistant	1
Student	1
Not stated	1

criteria using material developed by Ski-Hi, it is acknowledged that specific aspects of the material will require adaptation for authenticity and to suit the South African context. Given the variety of experiences and the diverse cultures of the parent advisors and deaf mentors, the training and course material will be evaluated on a continuous basis, both before and after the program, to ensure that the materials remain relevant and appropriate for each group of learners.

Newly trained parent advisors were teamed up with more experienced HI HOPES team members who acted as mentors and provided further on-site training and workshops throughout the year. Parent advisors meet with each other and other members of the HI HOPES team on a regular basis to give feedback and to share their experiences and concerns. These meetings not only serve members to motivate, support, and encourage each other, they also provide valuable insight into the difficulties and complexities of problems that parent advisors face in offering home-based support and care within the South African context as well as a platform for the sharing of new information on a variety of topics. Once assessed as being competent and confident, the newly trained parent ad-

visor is suitably matched to a family with a deaf or hard of hearing infant.

Family Referral and Registration

Over a 12-month study period from September 2006 to August 2007, 37 families registered with the HI HOPES program.² Most families (78%) were referred to the program by hospitals and private professionals. Other families heard about the program through a relative or family friend, local organization or colleague (13%), or via the media in an article on HI HOPES appearing in a magazine or newspaper or a member of the HI HOPES team being interviewed on the radio or TV (9%). These different modes of exposure illustrate the importance of a high program profile in order to create an awareness of the newly established services offered to families of d/hh children, as currently this is not an area of great awareness in South Africa. A high proportion (34%) of registered d/hh infants are either orphans or come from single-parent homes. More mothers of d/hh infants than fathers have completed their

high school education (52% as compared to 46%).

The average age of d/hh infants at the time of registration is 25 months, with slightly more boys (17) than girls (15) being enrolled in the program. Only 2 out of 32 infants were diagnosed with hearing loss at birth; the average age of diagnosis for the remainder was 15 months, which is lower than other studies in which the typical age of detection in South Africa is reported to average about 2 years, depending on severity (Swanepoel et al., 2004; Olusanya, 2004). The average gap between diagnosis and referral to early intervention is 10 months, which indicates that professionals doing the diagnoses are not yet referring parents as a matter of procedure nor are they informing parents of the benefits of early intervention as soon as possible after diagnosis. Parents are thus without holistic support and intervention for a year after learning of their infant's hearing loss. Table 3 shows additional characteristics of families and infants registered with the HI HOPES program.

Family Support and Service Delivery

Initiation of intervention begins once the family of a d/hh child has accepted the service and been registered. Since ensuring age appropriate cognitive, language, and socioemotional development of the child requires commitment and close collaboration between parents and parent advisors, it is vital that when assigning parent advisors they are suitably matched to the family. Differences in communication styles, religious views, age, gender are taken into consideration when assignments are made. Parent advisors usually visit

2. Of the 37 families, this paper will only report on 32 due to family attrition: withdrawal from the program (1), immediate referral to school (1), not being able to locate the family (1), distance education via telephone to another province (1), death of the young deaf infant.

INTEGRATED PRACTICES IN EARLY INTERVENTION

Table 3.
Demographic Characteristics of Families and Infants ($n = 32$)

<i>Characteristic</i>	<i>Number</i>
Marital status of parent	
Married	10
Single or separated	9
Living with partner	11
No parents (i.e. orphans)	2
Type of dwelling	
Rented house/cluser/room/flat	16
Own house	7
Informal settlement	6
Orphanage	2
Government housing	1
Gender of d/hh infant	
Female	15
Male	17
Ethnic group	
Black	22
White	7
Mixed race	2
Indian	1
Home language	
African languages ^a	22
English	3
Afrikaans	3
Bilingual (English and Afrikaans)	2
South African Sign Language	1
Other-Bulgarian	1
a. Includes Sepedi, Shangaan, XiTsonga, Setswana, and IsiZulu	

each family weekly (with a minimum of three visits per month recommended). They spend 1–1½ hour sessions per week with the family in the home environment sharing information, giving guidance, counsel, and support to parents. Since families are at different stages in the intervention process, each week's lesson is carefully planned and designed to be responsive to the specific family's needs. An essential feature of the HI HOPES program is to actively involve parents in these sessions and to encourage their participation in decision-making processes that directly affect their lives. Some of the issues and decisions parents of d/hh children are faced with include choices on amplification and technology and

choosing a language development and communication approach in addition to deciding on such issues as on literacy, behavior, play, and general developmental issues. Parent advisors offer unbiased information about these various issues equipping parents to make "informed choices" regarding their child (Carr, Young, Hall, Hunt, McCracken, & Skipp, 2007). Once the family has reached a decision, parent advisors help families to effectively implement their chosen approach within the authentic home environment within everyday routines.

Systematically documenting the child's progress is another important function of parent advisors as such information is useful to ensure that the

infant's development is indeed occurring at an age appropriate level as well as for choosing an intervention strategy that is commensurate with the child's developmental level. Various forms of assessment are used to track development, including a 6-monthly assessment of holistic development (the Bayley scale of infant and toddler development) as well as 4-monthly assessments of language development (the Ski-Hi Language Development Scale takes place in the chosen language).

In addition to home visits by the parent advisors, parents can choose to meet a deaf mentor, who then visits the homes on a weekly basis and acts as language model (whatever the language of choice of the family), shares communication strategies with the family, and if they choose South African Sign Language (SASL) teaches sign language to both the infant and family. Additionally families learn about living as a deaf person, learn about deaf culture, and are able to ask the deaf mentor any question or concern they may have about their child's hearing loss and how this impacts upon daily life. To date, parents (of both the oral and signing families) have found this one of the most exciting aspects of the program.

Besides regular home visits by parent advisors and deaf mentors, the HI HOPES program offers "Parent-2-Parent" (P2P) meetings three to four times a year. P2P meetings bring families, members of the deaf community (both signing and oral), parent advisors, and members of the HI HOPES team together so that they can share their experiences and concerns. The meetings are designed to help parents understand their child's hearing loss and its impact on speech, language, and other related developmental areas. The central role of the P2P is how-

ever as an opportunity to network and socialize. A variety of approaches are used to encourage families to discuss their concerns, difficulties, and challenges and to share their views and opinions with other families. Insight gained from these meetings gives the HI HOPES team a good idea of the range of issues that may be better addressed in a workshop. For instance, a workshop may be organized to include talks by successful Deaf adults, counselors and experts on different types of hearing aids on subject such as enhancing the home environment to stimulate the child's listening and speech skills to the fullest potential and stimulating the child's cognitive development through natural interactions and play.

Language Development

Through the HI HOPES program, the overall developmental progress of the child is regularly monitored using widely approved assessment methods. The Ski-Hi Language Development Scale (a norm referenced test for infants with a hearing loss), which includes both receptive and expressive language (in either modality), is performed shortly after entrance into HI HOPES, after which language is monitored and reassessed on a 4-monthly basis. Additionally, each child undergoes a 6-monthly assessment using the Bayley Scale of Infant and Toddler Development. This is an individually administered instrument that assesses the developmental functioning of infants and young children in order to identify strengths and weaknesses. Although HI HOPES is still in its pilot phase, a longitudinal systematic assessment strategy has been put into place to assess and monitor the child's social, cognitive, and adaptive functioning as these objective data are required to provide a

baseline for subsequent intervention and evaluation and may be used to help parents make informed decisions about the best intervention strategies for their child.

Program Monitoring and Evaluation

Although the HI HOPES program is still in its pilot phase, the effects of intervention are currently being monitored both in terms of parent feedback as well as parent advisor quality assurance. Information on families of d/hh infants registered with HI HOPES is continuously being collected and analyzed and on graduating out of the program a termination interview is done. Such data not only provides the program with a reliable and accurate database, but also helps HI HOPES assess whether the intended intervention outcomes for infants and their families are being achieved, and to evaluate the program's effectiveness and efficiency. Home visits by both parent advisors and deaf mentors are also monitored through an intensive quality assurance strategy with the aim of ensuring the quality of the early intervention as well as to mentor the interventionists into this fairly new field in South Africa. As part of this research strategy, a summative evaluation will be conducted at the end of the program's third phase.

Lessons Learned

One of the primary objectives of the HI HOPES program is to provide an early intervention service that not only offers supportive counseling and information to families of d/hh infants but also advocates active family involvement in facilitating the child's language development and socioemotional well-being. At the end of this first phase of HI HOPES, we have

identified several key factors in the early intervention process.

Multidisciplinary Approach

Intervention begins with the early screening and diagnosis of hearing impairment by medical professionals and audiologists. However, successful sustained intervention requires the commitment of a team of health care professionals, primary health care services, hospitals, and early interventionists such as HI HOPES members. The program has shown how, despite differences, all role players can become valuable contributing members of a holistic early intervention program focusing on more than just medical intervention, but also on overall development (including language development, socioemotional development, and physical development). For instance, in the HI HOPES program, medical professionals and audiologists may conduct medical and therapeutic assessment and intervention; this is then reinforced in consultation with the parents of the d/hh infants and their parent advisor who assists the parent in understanding the implications within the home environment. Setting up an interdisciplinary communication strategy, though challenging for a variety of reasons, is the goal for an effective holistic intervention program.

Culturally Congruent Program

The HI-HOPES early intervention program has been developed with an appreciation of South Africa's characteristic linguistic, racial, and cultural diversity, and is aware that the acquisition of language and socioemotional development is deeply embedded in cultural values and practices. The importance of developing a culturally congruent early intervention program is reflected in the following statement by Louw and Avenant (2002):

INTEGRATED PRACTICES IN EARLY INTERVENTION

the majority (of) speech-language therapists and audiologists providing services to Black children with hearing loss and their families in South Africa are White, middle-class, and they cannot assume that the families whom they serve share their basic ideas and beliefs regarding disabling conditions and interventions. (p. 145)

With this in mind, HI HOPES specifically selected parent advisors and deaf mentors from within the various communities in Gauteng, thus families from Soweto, Midrand, and Lenasia will receive services from HI HOPES interventionists in those areas. Where necessary (if a cultural and linguistic match is not made) interventionists receive training on the ethnographic and cultural factors characteristic of the families they support. This issue is further explored in the HI HOPES training sessions, where interventionists represent all of the official languages of South Africa in addition to SASL (which is not yet official), thus ensuring that this intervention program remains contextually authentic.

Active Family Involvement

The HI HOPES program promotes a family-centred approach by encouraging parents to take the lead in decisions that will impact directly on their lives. Such participation however may not be easy or acceptable given the context of some families' lifestyle, values, and priorities. For instance, low-income, single-parent families with meager schooling may be unfamiliar with the concept of taking the lead in decision-making regarding their own child, nor would they always have the ability to articulate their needs to professionals. Additionally, after diagnosis medical professionals may not share the full spectrum of information about options and choices available to them as expensive interventions (such as

cochlear implants) are not seen as an option open to them. Lack of knowledge and advocacy often leads to an accepting, passive attitude to hearing impairment (Louw & Avenant, 2002). The HI HOPES program however has become a valuable platform for reaching and educating parents fully by establishing a "community of practice" for families of d/hh infants. By actively participating in the program, parents begin to establish an identity as the primary caregiver and decision-maker in their child's life as well as a member of an informal support group of fellow parents who share their experiences, support each other, and work together to help their infants develop to their full potential.

The Way Forward

While much attention has been given to the early detection and diagnosis of hearing loss in infants, a more pressing need is establishing and sustaining holistic support and intervention for families of d/hh infants. This is indeed beginning to occur through HI HOPES. However, since the HI HOPES program only caters for babies and infants up to 3 years of age, systematic integration between the early intervention program and transition to pre-school or to another educational setting is an area for development. This brief 1-year study period highlights the need for more effective organization and communication between primary health care practices (both public and private) and intervention agencies to improve coordination and implementation of services. Pragmatic and collaborative action plans involving key stakeholders need to be put in place to provide "safety nets" for those who are at risk of significant speech, language and cognitive delays if not detected early and appropriately assisted through intervention within the first year of life. In addition, one cannot

downplay the role of parents in the early detection and intervention process—more attention ought to be given to parental education since they may be more effective than professionals in facilitating their child's development and progress.

Improving intervention outcomes for d/hh infants is a challenging task. However, HI HOPES is in a unique position to build capacity and effectiveness by integrating early intervention practices within the health care system, the community and family. Although South Africa has a fairly well-developed infrastructure compared to the rest of Africa, the responsibility for coordinating health care services to families of d/hh infants is not clear. In addition, medical professionals and the health department may not be aware of emerging evidence on effective intervention programs beyond amplification and speech therapy, or have the support needed to coordinate such interventions.

By presenting these early findings, we hope to improve the way early intervention services are organized and delivered for all families with d/hh infants with particular attention to prevention outcomes for low income families of d/hh infants, and creating a renewed commitment to the implementation of such provision.

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