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Publisher Informa Healthcare

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



International Journal of Audiology

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title-content=t713721994>

Early intervention in South Africa: Moving beyond hearing screening

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Online Publication Date: 01 January 2008

To cite this Article Störbeck, Claudine and Pittman, Paula(2008)'Early intervention in South Africa: Moving beyond hearing screening',*International Journal of Audiology*,47:1,S36 — S43

To link to this Article: DOI: 10.1080/14992020802294040

URL: <http://dx.doi.org/10.1080/14992020802294040>

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Key Words

Home-based early intervention
Family-centred early intervention
Informed choice

Abbreviations

DEAFSA: Deaf Federation of
South Africa
DM: Deaf mentor
EHDI: Early hearing detection and
intervention
HI HOPES: Home intervention:
Hearing and language
opportunities, parent education
services
HPCSA: Health Professions
Council of South Africa
JCIH: Joint Committee on Infant
Hearing
LDS: Language development scale
OAE: Otoacoustic emissions
PA: Parent advisor
SKI-HI: Sensory (kids) impaired
home intervention

Early intervention in South Africa: Moving beyond hearing screening

Abstract

Since little information is available on the outcome of early hearing intervention programs in South Africa, this article examines data on infants and families registered with a family-centred, home-based intervention program (HI HOPES) over a 12-month period in order to track the effectiveness of the holistic unbiased support to families of infants and toddlers with a hearing-loss. The aim of HI HOPES, which is based on the SKI-HI model of early intervention in the USA, is to ensure that families are enabled to make informed choices for their unique infant. Data were gathered on 32 infants ages birth to three years and their families using both qualitative and quantitative measures which included analysis of demographic data, quarterly language assessments, and parent satisfaction surveys. The report on the pilot year of this early intervention program shows that, though the sample is small, there is significant improvement in infant receptive and expressive language for infants identified before seven months of age, as well as a high level of satisfaction from families who have received services.

Sumario

Dado que existe poca información sobre los resultados de los programas de intervención temprana en Sudáfrica, este artículo examina datos sobre infantes y familias registradas en un programa centrado en la familia, con base en el hogar, de intervención (HI HOPES), durante un período de 12 meses. Se buscó rastrear la efectividad de un apoyo holístico no sesgado a las familias de infantes y niños con hipoacusia. El objetivo del HI HOPES, basado en el modelo SKI HI de intervención temprana en los EEUU, es asegurarse que las familias puedan hacer escogencias informadas para su niño único y singular. Los datos se colectaron de 32 niños con edades desde el nacimiento hasta los tres años y de sus familias, usando medidas cualitativas y cuantitativas, que incluyen análisis de datos demográficos, evaluaciones trimestrales de lenguaje y encuestas de satisfacción de los padres. El reporte del año piloto de este programa de intervención temprana muestra que, aunque la muestra es pequeña, existe una mejoría significativa en el lenguaje receptivo y expresivo de los niños identificados antes de los siete meses de edad. Igualmente, existen altos niveles de satisfacción entre las familias que han recibidos los servicios.

Without intervention, hearing loss in early childhood can have a profound effect on language development (Marschark, 2001; Mauk et al, 1995; Yoshinaga-Itano & Apuzzo, 1998), as well as speech, cognitive, perceptual, psycho-social, and the subsequent academic and vocational development (JCIH, 2007; Olusanya et al, 2007; Olusanya et al, 2006; Ross, 1990). Once a child is identified with a hearing loss, access to early intervention services and amplification and assistive technology through well trained early interventionists is critical (Bess, 1998; Yoshinaga-Itano & Apuzzo, 1998; Yoshinaga-Itano et al, 1998) and research indicates that the earlier identification and habilitation occur, the greater the level of linguistic competence achieved by children during their early years of life will be (Marschark, 2001; Ramkalawan & Davis, 1992; Yoshinaga-Itano & Apuzzo, 1998). In addition to language and communication skills development, early intervention ensures enhanced opportunities to maximize infants' abilities and increased support and information for

parents (Diefendorf, 1996; Goldberg, 1996; Meadow-Orleans et al, 1997; Moeller et al, 1996). With such resounding evidence Marschark (2001: ii) thus states, 'that enrollment in an early intervention program is one of the single best predictors of positive development and education outcomes for children who are deaf'.

While the importance of early hearing detection and immediate access to effective early intervention services has been well documented by researchers in the United States over the past several years (Moeller, 2000; Yoshinaga-Itano, 2003), early hearing detection and intervention has just recently come under the spotlight in South Africa and the rest of Africa (Olusanya et al, 2006; Swanepoel, 2006; Swanepoel et al, 2007). The focus in all of this research referred to above has been on the screening and diagnosis of the hearing loss with intervention viewed primarily as medical and therapeutic in nature. While there is some success documented for children who are in purely

therapeutic and center-based programs (Van der Spuy & Pottas, 2008), which are run by therapists and are usually focussed on an either-or approach in terms of what language and modality of communication is presented to families, intervention of this kind is often not accessible to many of the families in South Africa due to lack of awareness of services, limited funds to access services, and limited or no access to transportation due to the geographic location of the center-based program.

With strong documentation of the success of home-based, family-centered early intervention services in the USA that yielded positive results (Yoshinaga-Itano & Apuzzo, 1998; McBride & Peterson, 1997), the need for a similar program in South Africa became apparent. In 2006, HI-HOPES (home intervention – hearing and language opportunities parent education services) was launched at the Wits Centre for Deaf Studies in South Africa in Gauteng. The program is based on the SKI-HI model of early intervention which was established in the United States in 1971 as a model educational program for infants (birth to three years) with any form of hearing loss.¹ Efficacy of the SKI-HI model used within the USA is well established (Bodner-Johnson & Sass-Lehrer, 2003; SKI-HI Institute, 2004; Strong et al. 1994; Strong et al, 1994) however, the efficacy of this model in a developing country, with the complex social and economic intricacies present in South Africa, has never been examined.

Within the early hearing detection and intervention (EHDI) process there are three key phases: firstly the screening for hearing loss, secondly referral for diagnosis and confirmation of the hearing loss (if any), and thirdly, the subsequent referral to intervention services (HPCSA, 2007; JCIH, 2007). To date, most practice and research related to EHDI in South Africa has focused on detection of the hearing loss and the subsequent medical and therapeutic intervention (Swanepoel et al, 2006, 2007a, 2007b). Intervention has been equated with obtaining appropriate amplification for the child diagnosed with a hearing loss, be that hearing aids or a cochlear implant, along with the concomitant support by the pediatric audiologist and speech therapist to effectively use the technology to develop the child's potential for auditory and speech development. While effective early amplification is one essential component to achieving the ultimate goal of early intervention designed for children who are deaf or hard of hearing, research has shown that effective early intervention is multifaceted (HPCSA, 2007; JCIH, 2007; Moeller, 2000; Yoshinaga-Itano & Apuzzo, 1998; Yoshinaga-Itano & Arehart, 1999) with family-centered services delivered by highly trained early interventionists at the core (SKI-HI, 2004; Yoshinaga-Itano et al, 1998). Such services provide the entire family with support and present information and strategies to families in open and unbiased ways, encouraging informed-choice (ASHA, 2008; Young et al, 2004). While medical and therapeutic intervention is reasonably well established in South Africa, HI HOPES was started to enhance the range of current services that are being provided by the medical professionals in South Africa to complete the vision of a truly successful EHDI program for the entire country (Health Professions Council of South Africa, 2007). This paper serves as the first phase of this monitoring process as we track the establishment and implementation of systems in this pilot program along with the development of the infants/toddlers we serve, and the satisfaction rating of families regarding these services.

Method

A descriptive research design was used to explore and report on the first year of the HI HOPES early intervention program in South Africa, in order to establish a baseline of data for the program as a whole. In addition to a thick description of the intervention program (Ponterotto, 2006), data were gathered on the following aspects of the program: (1) family/child demographic data via registration forms and HI HOPES data sheets; (2) age of children at diagnosis, referral, and entrance into HI HOPES early intervention services via parent surveys and referral documentation from referral agencies; (3) child language development via the criterion referenced language assessment for deaf infants, the SKI-HI language development scale; and (4) parent satisfaction of program services via a parent survey.

The early intervention program: HI HOPES

The HI HOPES model of early intervention advocates a comprehensive, multidisciplinary approach to supporting families and their infants and toddlers who are deaf or hard of hearing, with the central aim of informing and equipping parents to make their own decisions based on the particular needs of their infant without any bias in terms of communication approach or combination of communication approaches employed, or type(s) of amplification used. The support is provided to families in their homes through weekly visits that are approximately one to one and a half hours long, during which an individualized lesson is presented by a parent advisor using the comprehensive SKI-HI resource manual (SKI-HI Institute, 2004). A primary focus of these visits is to provide families with open, unbiased information, and to help them to recognize and respond to their child's communication and language needs appropriately, building language, communication, and listening skills within the child and family's daily routines and environments.

An essential feature of the HI HOPES program is to actively involve parents and all family members in each home visit, and to work as a sounding board for families as they make decisions that directly and powerfully affect their lives. HI HOPES recognizes parents as the 'expert' on their child's needs and, therefore, advocates the family's role in making 'informed choices' regarding their child (ASHA, 2008; HPCSA, 2007: 25; Young et al, 2006). Weekly lessons are subsequently driven by the needs of the child and family and their particular questions. Beyond home visits by the parent advisors, parents can choose to meet and receive services from a deaf mentor, a trained deaf adult to work with the family, providing families with insight into the life experiences of individuals who are deaf or hard of hearing (either oral or signing). Families may also choose to learn South African Sign Language (SASL) from the deaf mentor. In addition to the team of interventionists (parent advisor and deaf mentor), an interdisciplinary collaboration (Moodley et al, 2000, in HPCSA, 2007) and creation of partnerships is also promoted, such as partnerships between parents, members of the HI HOPES team, and other professionals and service providers who form part of the infant's individualized team.

The goal of HI HOPES is to serve every child who is deaf or hard of hearing and his or her family, regardless of skin colour, language, religion, or financial income. Subsequently great strides have been made through local community outreach and

presentations to various fora to ensure that people in every community within the Gauteng province are aware of these services.

Finally, one of the key areas of focus for HI HOPES is the area of quality control and assessment in order to ensure that all team members are supported and continue to develop their skills and knowledge base so as to ensure that families are getting effective support (Storbeck & Calvert-Evers, 2008), and to ascertain whether individual infant development is commensurate with his/her chronological and developmentally appropriate levels. By systematically assessing and documenting the progress of each infant/toddler enrolled in HI HOPES, tracking of the individual child's progress can be accomplished.

Participants

In year one of the HI HOPES program, 37 infants and toddlers aged birth to three and their families were referred for early intervention services. Thirty-three families registered for services, with four not registering for services for the following reasons: one child was referred to preschool almost immediately because of his age; one family was not located; one family chose not to receive services; and one of the children lived in another province and received support and information via telephone and e-mail. Sadly, one of the children that were enrolled in HI HOPES in year one passed away in a shack fire after the first few visits. This paper therefore reports on 32 infants and their families that registered and remained in the program throughout the first year.

Due to the cultural and linguistic diversity of the South African population, and the historical mismatch between families and interventionists as noted by Louw & Avenant (2002), the 15 parent advisors that were selected in the first year were a linguistically diverse group. Within the group, every one of the eleven official languages of South Africa was spoken with the majority (10) using three or more languages. When selecting parent advisors great efforts were made to ensure that early interventionists were selected from within each of the local communities, and as a result of this diversity the program has been able to serve families within their home community and in their home languages during home-visits.

Data collection

In addition to the demographic data and the diagnosis and referral statistics collected for each participant, primary data was also collected via quarterly language assessments of each infant's language development and family satisfaction survey questionnaires.

The language ability of all infants is assessed upon entry into the HI HOPES program using the SKI-HI language development scale (LDS), followed by quarterly re-evaluations in order to assess how the infant's receptive and expressive language skills are progressing (in either the oral-aural or manual modality). Such data provides a baseline for subsequent evaluation and may be used to help parents make informed decisions about the best intervention strategies for their child.²

Of the 32 infants registered with HI HOPES throughout the first year, 10 will be reported on in terms of their language development, as they each had two or more LDS assessment results. The other infants either only had baseline assessments or were not assessed yet due to registration timelines or severity of additional disabilities. Though 10 is a small sample to be

reporting on, some of the seminal pieces of early research in EHDI had small samples, e.g. $n = 14$, in Apuzzo & Yoshinago-Itano (1995); and $n = 5$, in Robinshaw (1995). Pilot programs, though small, are essential to report on in order to create baselines for future research and growth within the field.

Finally, a key part of the assessment was to gauge how parents experienced HI HOPES and what the level of satisfaction was with this pilot program. Families that had been in the program for six months or more ($n = 20$) were sent questionnaires on their experiences with the programme, and in a request for voluntary involvement eleven questionnaires (55%) were completed and returned.

Results and Discussion

The first year results will be presented and discussed in sections: (1) family/child demographic data; (2) age of children at diagnosis, referral, and entrance into HI HOPES early intervention services; (3) child language development; and (4) parent satisfaction of program services.

Demographics

The 32 families and their infants came from all over Gauteng, spread through five of the six Gauteng districts (though the large majority—23 of the 32 families (72%)—came from the greater Johannesburg metropolitan area). These 32 families were served by 15 parent advisors who were situated in three of the Gauteng districts, with seven (53%) situated in the greater Johannesburg metropolitan area.

Racially and linguistically the HI HOPES families reflect the rainbow nation of South Africa, with 66% Black families, 22% white and 9% and 3% Mixed race³ and Asian populations respectively. The largest number of families spoke an African⁴ language (63%) with English used by 16% of the families and Afrikaans spoken by 9% of the family population. One family reported using South African Sign Language (SASL) in the home and one family spoke Bulgarian. Of the Parent Advisors 53% are Black (speaking all eleven of the African languages), 33% are white and 13% are Asian (with 40% speaking English and 6% speaking Afrikaans).

An etiological analysis of the parent-reported⁵ hearing losses revealed that 69% of parents did not know why their child had a hearing loss, and that 25% of infants were reported as having acquired hearing losses. Despite only two parents indicating complications at birth, 5 of the 32 infants enrolled had been in the ICU either at or some time near birth, raising the possibility that the hearing loss could have been caused by a variety of risk factors (as identified by HPCSA, 2007) such as exposure to ototoxic medication, asphyxia, or exposure to viral infections that could have contributed to the hearing loss.

Diagnosis, referral, and intervention

The average age of infants/toddlers at the time of registration with the HI HOPES program was 25 months ($+/-10$ SD, range: 3 months to 43 months). Fifteen females and 17 male infants were enrolled in the program. Only two out of 32 infants/toddlers were diagnosed with a hearing loss within the first few days after birth (as one infant was born into a deaf family and was thus screened at birth with an OAE screening test, and the second infant had unilateral ear malformation). The average age

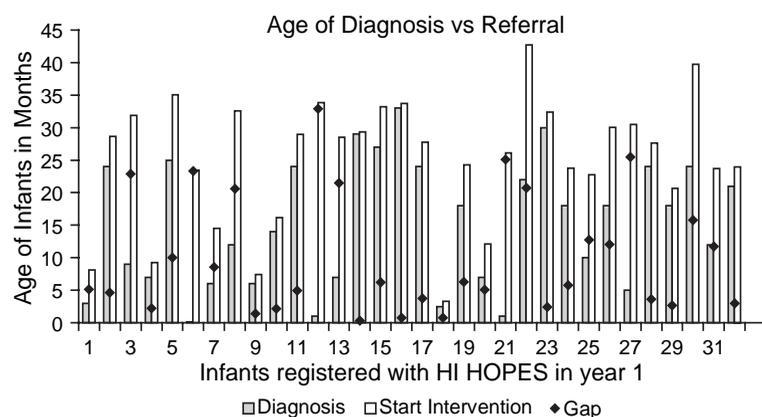


Figure 1. Age of diagnosis versus referral to early intervention services

of diagnosis for the remaining children was 15 months ($+/- 10$ SD, range: birth to 33 months) with an average age gap of 10 months ($+/- 9$ SD, range: 1 to 33 months) between diagnosis and referral to early intervention, which is plotted in Figure 1.

The results suggest that currently, professionals doing the diagnoses are not yet referring parents to the HI HOPES program immediately after diagnosis, resulting in a referral gap after diagnosis of almost a year. This may be due to a lack of awareness regarding this program or its benefits. Similarly in a study of referral by doctors and nurses Olusanya (2005, p. 737) confirms that until those 'who are likely to be consulted first by parents are convinced or even aware of the value of early detection and intervention, only minimal progress will be realised'.

The dominant referral agencies for infants registered to HI HOPES were public hospitals who referred 18 out of 32 infants (56%), and private practitioners who referred six infants (19%) along with one private hospital (3%). Word of mouth and media accounted for the remaining 22% of the referrals. These results indicate that the key relationships to be established are with the screeners and those who are the first point of contact for parents including hospital staff, clinic staff, or the private practitioner.

One of the basic tenets of a successful EHDI program is that children will be identified with a potential hearing loss by one month of age, diagnosed with a confirmed hearing loss by three months of age, and enrolled in an effective early intervention program before six months of age (JCIH, 2007; HPCSA, 2007), however until universal newborn screening is instituted and families are referred to early intervention at diagnosis (beyond amplification and therapeutic intervention) we have a long way to go until we reach the ideal as stipulated in the HPCSA (2007).

All but one of the 32 infants had bilateral hearing losses, and 84% of the infants used amplification (see Table 1), with 75% fitted with hearing aids (all digital) and 9% with Cochlear implants. One family (3%) declining any form of amplification, and one child (3%) was seen as unable to be amplified due to his ear malformation. Of the remaining three unaided infants one was awaiting hearing aids, one had lost his hearing aids, and one family was still making enquiries into forms of amplification. The majority of the infants have a profound hearing loss ($n = 15$, 47%) with seven infants (32%) with a severe to profound loss. The remaining nine infants have moderate (2), moderate to severe (4) and moderate to profound (3) hearing losses respectively.

The large majority of the HI HOPES families were within the public health sector (81%) with only 9% using private medical aids. A common frustration experienced by most of the families within the public health sector was the long waiting period for the hearing aids (the average gap between age of identification of hearing loss and amplification was 6.9 months, with the lowest gap being one month and the largest gap being 25 months). This

Table 1. Demographic characteristics of year 1 HI HOPES participants.

<i>Sample characteristics</i>	<i>N</i>	<i>%</i>
Gender		
Female	15	47
Male	17	53
Ethnicity		
Black	21	66
White	7	22
Mixed race	3	9
Asian/Indian	1	3
Multiple disabilities		
No other disabilities	21	66
Additional disabilities	11	34
Medical status		
Public health	26	81
Private health	6	9
Amplification		
Hearing aid (digital)	24	75
Cochlear implant	3	9
Declined amplification	1	3
Unable to amplify	1	3
Levels of hearing loss		
Moderate	2	6
Moderate to severe	4	13
Moderate to profound	3	9
Severe to profound	7	22
Profound	15	47

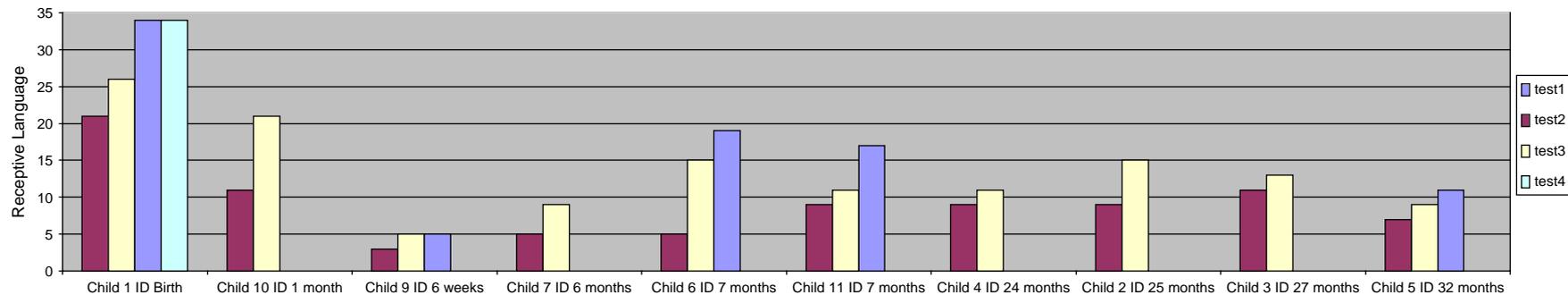


Figure 2. Receptive language development of year 1 HI HOPES participants. Y-axis: Receptive language scores. X-axis: Children sequenced in order of age of hearing loss identification. Test 1 to 4: sequence of language assessments conducted in four month intervals with Test 1 indicating the first assessment.

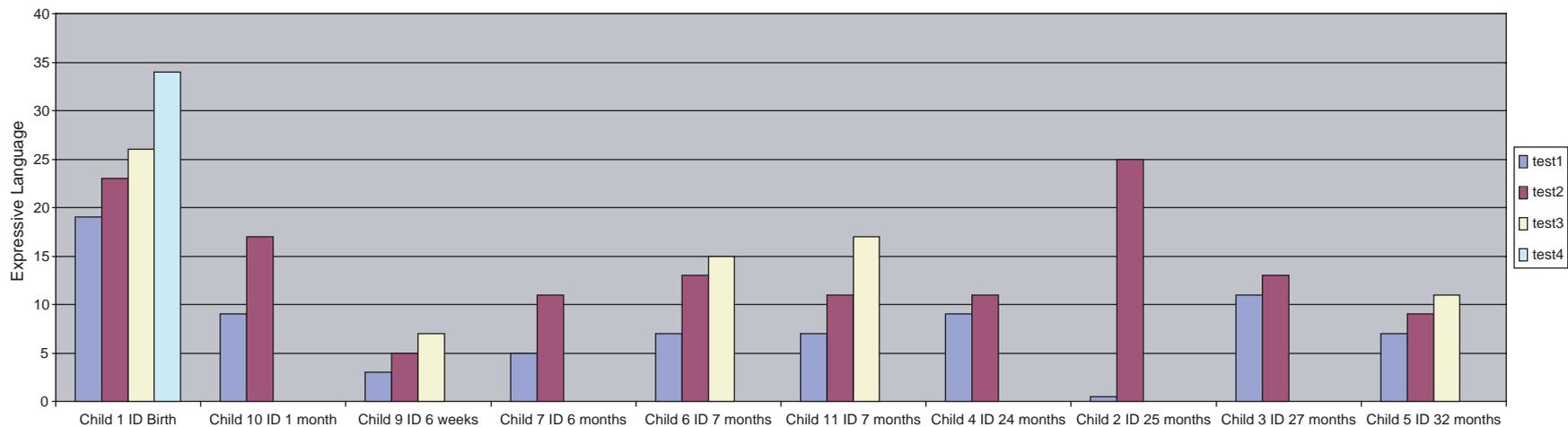


Figure 3. Expressive language development of year 1 HI HOPES participants. Y-axis: Expressive language scores. X-axis: Children sequenced in order of age of hearing loss identification. Test 1 to 4: sequence of language assessments conducted in four month intervals with Test 1 indicating the first assessment.

is clearly an area that must be improved in order to create an effective EHDI program in South Africa, and it is anticipated that the interdisciplinary approach of HI HOPES may contribute to an improvement in this area.

Language development assessment

An analysis of the language assessments reveal that these 10 children showed an average overall language increase of 4.66 months (± 3.07 SD) per quarter, with the average receptive language increasing 4.23 months (± 2.78 SD, see Figure 2), and the average expressive language increasing 5.1 months over the four-month cycles (± 4.04 SD, see Figure 3). Figure 2 and Figure 3 give a breakdown of the language development for each of the 10 infants and it is evident that all but one (Child 9's receptive language) shows an increase with each assessment.⁶

Despite the increase in both expressive and receptive language for all these infants, when investigating further there is a marked difference between the infants identified before 7 months ($n = 6$) and those late identified ($n = 4$). Five of the six (83%) developed typical language with an average quarterly increase of 5.73 months (± 1.86 SD) in comparison to three of the four late identified children's language increase of two months per quarter. Though a small sample in a pilot program, the year-one results of the LDS verify the groundbreaking findings of Yoshinaga-Itano et al (1998) that early identification and subsequent intervention have a significant impact on infants' language development. If typical language development is then the ultimate goal for each child with a hearing loss, we should thus aim for early identification along with the referral to early intervention as quickly after diagnosis as possible.

Parent satisfaction

Ten out of the eleven families (91%) rated the service offered by HI HOPES as excellent, with the eleventh family giving a rating of good. Emotional support and communication with their child were ranked the highest benefits of the program, with parent advisor characteristics such as respect, honesty, 'uplifting spirit' and ongoing knowledge greatly valued. Families also appreciated the fact that they felt their parent advisors genuinely cared for their child and family, and that they received support for the decisions they made.

Ten of the eleven families surveyed (91%) said they felt comfortable with their parent advisor visiting in their homes, and all of the families (100%) agreed that the parent advisor was suited to their family. All (100%) of the families surveyed said that they would recommend the program to other families because they appreciated 'learning information' which helped them to 'cope and understand more about hearing issues and how to support [their] child'. One family stated, 'when we were discover[ing] our child was deaf we realized that being made to feel normal and finding someone to understand is hard to find. HI HOPES is all of that and more. Overall, parents showed strong satisfaction with the HI HOPES program and the services their families received.

If this study and others like it can bring to the forefront the positive impact of early identification and early intervention (with evidence of the positive impact on infant development and family functionality and satisfaction) compared to the minimal cost of implementing screening programs (Swanepoel

et al, 2005), and long-term cost benefits of early intervention (Olusanya et al, 2007) it is hoped that professionals will start immediate referrals to programs such as HI HOPES. It is anticipated that continued research of the implementation of the HI HOPES early intervention program will reveal more conclusive benefits over time as the population size and data sample grows.

Conclusion

HI HOPES was piloted in South Africa as the first home-based, family-centered early intervention program that encourages all communication options through its unbiased, informative approach. Data were gathered on 32 infants aged birth to three years and their families, using both qualitative and quantitative measures which included quarterly language assessments and parent satisfaction surveys. In this first year HI HOPES sample one of the key aims of early intervention—one month of language gain for every month of life (HPCSA, 2007; JCIH, 2007)—was achieved with the expressive language increasing 5.1 months and receptive language increasing by 4.23 months over four-month language assessment cycles.

Though to date 'success stories for early intervention are still quite limited' (Olusanya et al, 2007:11) with there 'never before [being] a 'population' of children with significant hearing loss who have achieved average age appropriate language skills in the history of the research literature' (Yoshinaga-Itano, 2004), the preliminary data gathered from this small pilot program reveal the benefits of just one year of the family-centred home-based early intervention services to families and their deaf or hard of hearing infants. It is hoped that evidence-based studies such as this will assist in changing the face of early intervention in South Africa beyond amplification and private speech therapy service, toward a more holistic approach that recognizes and values parent education and support in the child's natural environment and the multidisciplinary, collaborative nature of early intervention in order to effectively address the needs of families and their infants and toddlers who are deaf or hard of hearing.

Notes

- [1] SKI-HI has developed over 37 years in the USA and has been validated as an early intervention program through the U.S. Department of Education, Office of Special Education Programs three times.
- [2] The LDS is a criterion-referenced test for infants with a hearing loss, developed by SKI-HI, which has been validated three times by the USA federal government especially for children of birth to three years with hearing loss.
- [3] The term 'coloured' is the contentious term for people of mixed race, usually black and white races mixed, living in South Africa
- [4] The term 'African' refers to the indigenous people of the African continent and reflects a variety of ethnic groupings, which nonetheless have a great deal in common in terms of background, culture, and descent.
- [5] Parents reported on what they had gleaned from their audiologist.

[6] Child 9 has been diagnosed with severe cerebral palsy making assessment of language development challenging.

Acknowledgements

The first year of the HI HOPES project was funded by The Nelson Mandela Children's Fund (grant code 3479/1) along with special assistance from HOPE, Inc. for training materials. Thanks to all the HI HOPES families, who have opened their homes to us as we come alongside them to inform and empower them on this journey. Thanks to all our early interventionists who go into homes weekly, to support and inform parents. A special thank you to our researcher Jenni Calvert-Evers who worked on the data throughout our first year, and to the HI HOPES team (especially Carla Zille and Kelly Naude) for assisting in getting the data updated and processed. A final thanks to our resident psychometrist, Hansini Dhana, who ensures all the tests and assessments are done along with data collation.

Declaration of interest: See acknowledgements section above. The authors alone are responsible for the content and writing of the paper.

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