IN THIS ISSUE

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Being the parent of a child with hearing impairment

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Aino and Hilia are both deaf. They live near each other and play together.
NAMIBIA

CLaSH

The parents of a child with hearing impairment are usually hearing. Some parents will not have suspected a problem, assuming that their child will naturally be able to hear just like their parents. Others may have noticed that their child does not startle to loud sounds or is not starting to speak at the same age as their older siblings, or that the child's speech has deteriorated or changed after a severe febrile illness.

When parents are told that their child has a hearing loss, whether this comes as a surprise or confirms their suspicions, the news is most often a shock. Parents are faced with the loss of their expectations, hopes and plans for the hearing child they had anticipated. Many will go through a grieving process. Some will feel guilty thinking that it was their fault. For others, the news fosters a multitude of emotional responses and questions.

The response from parents who are deaf can vary: some may have hoped for a hearing child, others may 'take it in their stride' and be confident in their ability to raise a child with sign language – their 'mother tongue' – and within the deaf community.

Stigma and misunderstanding

There continues to be significant stigma and lack of understanding about disability in many countries. Families can easily feel shame and neglect their children with hearing impairment by hiding them away in villages, fearing old traditional beliefs and discrimination.

The parents of a child who is deaf or hard of hearing may not think that their child will have a future or is capable of living a full life ("I thought my child would be in a hole of darkness."*). Most parents may not have had any experience of hearing loss and can initially lose their confidence and be challenged about what to do and how to communicate with their child. They need specialist support as early as possible after diagnosis, to get information about their child's hearing loss and to learn how to best help their child to thrive.

Access to information, specialised services and education

Learning about their child's hearing impairment may reassure parents ("If I did not have this information, we could be running off to the witch doctor. But now I know my child is deaf. It is a normal thing, it is ok."*). Meeting other parents, as well as adults with hearing impairment, can motivate

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parents and help them see their child's potential ("You have opened my mind to what my child can do and to watch for all the little things he does."*).

It is important that parents receive as much support as possible to care for their child and are given information regarding educational options. The challenges of looking after a child who is deaf or hard of hearing are very real in low- and middle-income countries where many families face poverty-related issues on a daily basis. This is true in capital cities, but the struggle becomes even harsher and more complex for those in rural areas and very remote villages.

Quite often, there is no network supporting early identification and the recognition and diagnosis of a hearing loss often happens 'late', i.e. when children are brought to school. One of the reasons for this is that the number of specialised professionals is very limited and many primary healthcare workers know little about hearing loss.

For example, in Namibia, there is only one audiologist and one speech/language therapist in the Ministries of Health and Education respectively. A parent living in rural Namibia described the challenges of accessing specialised services: "It is tiring and a big trip to get to the hospital. I have to take the patient bus on a Monday and it takes seven or eight hours. I have to sleep at the hospital for two nights. Tuesday I get a hearing test and see the speech therapist and you [CLaSH, who run the only pre-school unit for deaf children in the country]. Wednesday I go back on the patient bus. It is a lot for me and my three-year-old. I would like to do this every three months but sometimes I cannot do it."*

In some countries, school places are limited and a child with hearing impairment is less likely than his/her hearing peers to get a place in a mainstream school. In addition, the limited number of schools for deaf children means that when children do get a place, they often have to travel many kilometres to attend. They may have to live in residential hostels and be separated from their families.

Communication challenges

It is important to support parents in communicating with their child. Many parents worry that they will not be able to communicate with a child who has a hearing impairment (see Box on the right). Some parents will not speak to their child – thinking that there is no point as the child does not hear – and this can affect their relationship. Parents who are deaf may sometimes have particular problems, e.g. they can have difficulty knowing that their baby is crying, especially at night. They may not have the same ability to stimulate speech without the help of others, if this is their choice of communication for their child. However, deaf parents very often accept sign language as the mother tongue of their deaf child and therefore confidently use sign language as the primary mode of communication.

If the child has the opportunity to be fitted with a hearing aid or cochlear implant, these devices can be worrying to parents who may lack confidence in their use. Sometimes, the residential school requires that hearing devices stay on the premises, so the parents have difficulty talking to and understanding their child when they are back at home. When children learn signing, hearing parents may find it difficult to achieve the same level of signing competence.


CLaSH

This mother of a deaf young son does all she can to support her family financially. NAMIBIA

Conclusion

We must spread messages about ear care, early intervention, education and equal opportunities for children with a hearing loss. Educating all health workers, parents and teachers, and developing specialist services can make an enormous difference to parents' and children's lives.

It is important to persist in challenging the expectations of parents of children with hearing impairment. One way to do this is to empower these parents to come together, share their experiences and learn from the life stories of deaf adults.

WHAT PARENTS WORRY ABOUT WHEN THEIR CHILD IS DEAF OR HARD OF HEARING

CLaSH is a non-governmental organisation (NGO) in Namibia working with children with language, speech and hearing impairments. Over the years the organisation has come into contact with many families. Below are some of the concerns expressed by parents during meetings and workshops:

- "How do I ask her if she is sick and what is wrong with her?"
- "It is hard for us to communicate in the dark at night. I have to tell him: 'it is dark now, no signing, go to sleep'." (Many of the families live in informal settlements and do not have access to electricity.)
- "I need help with his behaviour. He doesn't listen to me or watch me."
- "I see it is hard for her at big family gatherings like weddings and celebrations."
- "How will she communicate in a taxi?" (Local taxis are the most common form of transport in Namibia.)
- "How will he communicate at work, or at the hospital?"
- "It is important to learn sign language as it unites us with our children."
- "We need to make our children strong so they can make people accept them in their midst."
- "Meeting deaf adults makes me see their courage and motivation to prosper in life."
- "I thought my child would be in a hole of darkness. But now I know where they belong. They have a (deaf) community."
- "Having a deaf child makes me accept people as they are. I have learned that being deaf does not mean you have no future. One can prosper no matter what."

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* These quotes are taken from conversations between CLaSH and parents of deaf children in Namibia.