



Pupils outside a school for deaf children.
ZAMBIA

SIAN TESNI

Living with hearing impairment



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The modern world presents many challenges of very different types. Our senses are constantly being assailed with new sensations, environments, and experiences. We have to develop coping strategies that allow us to move with confidence and deal with these challenges without becoming overwhelmed. For many of us, that is a significant task. For others, particularly those with a disability, it is a monumental challenge. Deafness is often described as 'the silent disability' because it is not noticed, not visible and not discussed, yet it is a condition growing in importance and prevalence.

People who are hard of hearing have to cope with hearing impairment every day, in many challenging hearing environments. They face obstacles in most areas of their lives:

- In education settings, miscommunication can result in poor grades. Educators can be unaware that students have not heard the correct instructions, and mislabel children with hearing loss as 'lazy' or 'stupid.'
- In the workplace, people with hearing loss have more difficulty in finding employment and struggle with certain practical aspects, such as attending group meetings or answering the telephone.
- In social situations, hearing people cannot see that a person with hearing loss has difficulty hearing

others, and also forget that hearing aids and cochlear implants are only aids. They need to be constantly reminded to consider the hearing difficulty, which can be tiring, frustrating and embarrassing. It can become easier for a person with hearing loss to withdraw from social events and isolate themselves.

“People who are hard of hearing face obstacles in most areas of their lives”

For this and other reasons, people seldom admit they have a hearing loss and it usually takes them seven to ten years to do something about it. By the time they take action and consult a health worker, they have long struggled to keep up with what is being spoken about at home, socially and in the workplace.

This issue of *Community Ear and Hearing Health* aims to go beyond hearing impairment as a medical concern by highlighting the experience of people who are deaf or hard of hearing. It stresses in particular the obstacles they must face and overcome. It also aims to show that many of the difficulties experienced by people who are deaf or hard of hearing are not due to their hearing impairment alone, but are greatly compounded by social attitudes and lack of access. By considering the practical needs of people who are deaf or hard of hearing and acknowledging their potential, we can become a more inclusive society.

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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

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



CLaSH

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.

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.

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

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."

Going to school with a hearing impairment

Sian Tesni

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The positive impact of education

Education is a fundamental human right. It is central to achieving economic growth, increasing income and sustaining a healthy society. It helps to improve lives, break the cycle of poverty and ensure that all people have control over their destiny.

Education is a powerful tool for learners who are deaf or hard of hearing: it equips them with the knowledge, confidence and effective communication skills to break down institutional barriers.

Whilst there are special schools for children with hearing loss, the most widely advocated approach is inclusive education. This way a child can attend school with other children from the same community. However, this approach requires specialist support, resources and facilities, and the development of local skills and capacities. In some circumstances, other models may be more appropriate.

Lack of access to education

In low- and middle-income countries particularly, children with hearing loss or other disabilities have limited access to quality educational services.

For example, a study in Thailand demonstrated that 34% of children with physical disabilities had never attended school.¹ In Iraq, it was shown that 19% of children who were deaf or hard of hearing and 51% of children with psychosocial or developmental disabilities had never gone to school.¹

Some of the reasons why children who are deaf or hard of hearing often do not have access to education are:

- Parents may not believe that they can be educated.
- There is a stigma attached to hearing loss in the community.
- In the face of general difficulties such as distance and insufficient school places, these children may not be a priority.

Pupils at the Jerusalem inclusive school. ETHIOPIA



- There is a lack of educational services for children who are deaf or hard of hearing and/or a lack of specialist provisions to support inclusion.

Difficulties experienced at school

In mainstream education, communication difficulties may mean that learners who are deaf or hard of hearing have restricted access to the curriculum:

- Mainstream teachers are not aware of specific techniques and methodologies for including learners with hearing loss.
- There is a lack of access to appropriate communication support, for example sign language interpretation or amplification devices such as hearing aids.
- The impact of hearing loss can mean that learners miss subtle social cues and incidental language. They are at high risk for having difficulty with social skills. Teachers and other children may find it difficult to communicate fluently with them.

These difficulties can lead to or reinforce existing social and emotional problems such as:

- Bullying by other children: this is more likely if there are no other children who are deaf or hard of hearing in the class.
- Loss of confidence: mishearing instructions and doing the wrong thing can result in undeserved punishment. Impatience with indistinct speech may make the child self-conscious. The child may lose confidence and participate less.
- Lack of motivation: as a result of the above, the child may stop attending school.

Residential special schools may also present challenges:

- Children may find it hard to be away from family.
- If they are taught sign language or given hearing aids that must be left on the premises, they may be unable to communicate with their family when they go back home.
- They may no longer have access to their network of school friends when they go home.

What we can do to enable better access to education

In order for learners who are deaf or hard of hearing to learn and reach their full potential, there needs to be:

- An understanding of the impact of hearing loss for each individual.
- Early identification and early intervention with access to early years education.
- Specific adaptations to the curriculum when required, based on a clear identification of individual needs, with strategies and support systems designed to address and meet these needs.
- A sound understanding of and access to appropriate communication strategies.

- High-quality regular, specialist support to ensure access to the curriculum.
- Strong commitment to understanding and valuing deaf culture.
- Inclusion in all school life.
- Provision of hearing aids and/or communication support according to the needs of the individual.
- Adaptations to the classroom environment need to be considered individually for each learner and must be age-appropriate.

Listed below are changes that mainstream teachers may consider making to better meet the needs of children with hearing impairment:

- Keep background noise to a minimum.
- Avoid standing in front of a window so that your face can be seen without glare from the sun or outside distractions.
- Present all new directions, concepts and information from the front of the room, not when you are moving between desks or during noisy classroom transition times.
- Keep to a classroom routine; if a learner misses

something they will be better able to predict what they should be doing or what will happen next.

- During classroom discussions ask students to speak one at a time.
- Summarise students' answers or comments during class discussion.
- Write all assignments on the board, including the textbook page numbers the class will be turning to during each lesson.
- If a visual aid is used, like a map, graph or projected image, give students a chance to look at the visual, describe what they are seeing, and provide short silences so they can process the meaning of both the visual and what is being said.
- Encourage a 'buddy system' approach, in which two students are paired to help each other.

¹ EFA Global Monitoring Report, "Teaching and Learning: Achieving Quality for All" (Unesco, 2013–2014); page 56.

Resources to help include children with hearing impairment

- National Deaf Children's Society: Deaf-friendly Teacher Training Pack: www.ndcs.org.uk/professional_support/our_resources/deaf_friendly_schools_packs/teacher_training_pks.html
- Including Deaf and Hard of Hearing Children in the Classroom: <http://deafness.about.com/od/schooling/a/inclassroom.htm>

CASE STUDY PAKISTAN

“Teachers should pay special attention to special children”



Huda Zahid
Pharmacist,
Writer and
blogger, Lahore,
Pakistan

It is said that school is the first place where we acquire knowledge, make friends, socialise and develop the ambition to have a bright future.

Only my parents rectified my mistakes

When I was in third grade at school (at age 8–9), I realised, along with my parents, that I had a hearing problem. I often used to mispronounce words. For example, during the attendance call, I did not know how to pronounce 'present' and would say 'pasent' instead. Class fellows made fun of me a lot, but the teacher did not stop them and did not make me understand I was pronouncing the word incorrectly.

Only my parents rectified my mistakes in pronouncing words. With the passage of time, they made me understand words by face-to-face communication and by writing every part of the word on paper. They came to know that if I could hear properly, then I could speak words clearly. At that time, I did not use hearing aids because my parents were not aware about assistive technologies. They always took me to both allopathic and homeopathic doctors, hoping that I might be cured by taking medicines, but it did not work out.

I became timid and nervous at school

Few teachers understood my problem. In fourth grade (at age 9–10), we had to recite a few lines from a book one by one in front of the teacher. When my turn came up, the teacher realised that I did not speak well. She told me to quit and asked the next girl to recite. This kind of experience made me a timid and nervous type of child. I could not interact properly with others or express my fear of reciting in front of teachers. In addition, it made me reluctant to ask my teachers for help in communicating. Although I got good grades in written examinations, it was different in the case of verbal tests. Teachers had discouraged me.

In eighth grade (at age 13–14), all students had to make a science model and give a presentation. I made my model but was neglected because the teacher did not pay attention to preparing me for a presentation. So, I gave up my expectations of participating in extracurricular activities. In this way, life went on.

In the meantime, my parents were still helping me to pronounce words in their own way. For example, my father made me understand that 'b' is silent after some words like 'doubt', 'debt', and 'subtle'; that it is also silent after the words 'comb', 'womb', 'bomb', and 'climb'; and that 'l' is silent in the middle of words like 'talk', 'walk', 'calf', and 'half'. My mother found a trick to make me understand how to say the words 'retire' and 'comment' properly. She told me to pronounce '-tire' as 'ty-ere' and explained that one 'm' is silent in 'comment'. Until then, I had been unaware of how to pronounce all these words because neither my teachers nor my class fellows had made me understand this.

One teacher made all the difference

In ninth grade (at age 14–15), for the first time, my English teacher noticed my problem while I was reciting a few lines. She told me to come forward and to not hesitate in telling her what was wrong with me. Moreover, she told me to bring my parents the following day. My mother visited her and the teacher convinced her to make me use hearing aids. She said I should not feel embarrassed about using them. She added that it would develop my confidence and would help me to listen and to pronounce words.

I started using hearing aids and it brought enough improvement in my interaction with others and my confidence in myself. I went to college and university, where I made more friends.

In the end, I would like to say that teachers should pay special attention to 'special' children (children with disabilities), because teachers play a vital role in developing children's confidence, personality and ambition.

Finding employment when you have a hearing impairment



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Access to work is a fundamental human right. Employment enables people to participate in community life and to contribute economically to their households and their communities.

This article highlights some of the difficulties often faced by people with hearing impairment when seeking work.

Lack of education and training

In low- and middle-income countries, many people with hearing impairment do not achieve a high level of education, even if they have attended school for a few years.

They have limited access to mainstream education as well as technical and vocational education or training. Teachers in formal and non-formal training centres have often not been trained in inclusive education. Frequently, sign language and teaching methodologies have not been adapted to the needs of students with hearing impairment. This situation limits the quality of teaching and practical exchanges between students and teachers. The majority of training structures also lack training material, clear curricula, and tools linked to sign language.

Restricted access to the job market

Work mainly comes in two forms: waged employment (the person works for another person or for a company) and self-employment (the person has their own microbusiness).

Quite often in low- and middle-income countries, **self-employment** is the only way to earn a livelihood and a large proportion of the population work in the informal economy, including persons with disabilities. People with hearing impairment, like all entrepreneurs, often need financial services to start or expand their own income-generating activity and make savings for their future. They often have difficulty accessing financial services such as loans, whether through traditional or microfinance institutions.

These services are not accessible to their needs in terms of communication and loan criteria. Being poor, under-educated and lacking access to start-up funds is a constraint to many persons with disabilities.

Deaf people can also earn a living through **waged employment** though they often face barriers to access this type of work:



Razina Boubacar, a deaf hairdresser, tends to a customer. NIGER

ABDOURAMANE BARKÉ

- Obtaining waged work often requires completing an application form, producing a CV and attending an interview. Many people with hearing impairment have problems reading and writing as well as with speech and language.
- Because of the difficulties they experience with communication, people with hearing impairment have reduced access to the networks that usually help others find employment. There is a lack or absence of accessible employment services such as job centres, which could assist a deaf person to find work.
- Their choice of occupation is also restricted: some jobs require good hearing for the safety of others.
- People with hearing impairment are often excluded from programmes implemented in the country to help people find employment.

Negative perceptions of employability

- Employers, skills training centres and work creation schemes could be reluctant to employ a person who would have difficulty communicating and who would need special arrangements to perform their tasks and to ensure their safety.
- Employers often discriminate against persons with disabilities during recruitment, due to a lack of awareness of their abilities and potential.
- Family members and the community can hold limiting beliefs about what their relatives with hearing loss are capable of, which can lead to the social marginalisation of the person with hearing loss.

Difficulties experienced at work

Communication difficulties are common once a job has been acquired.

In most jobs, special equipment or provision would be needed for the worker with hearing loss to function optimally, even if they wear a hearing aid. Employers

“ Being poor, under-educated and lacking access to start-up funds is a constraint to many persons with disabilities ”

or employees may be reluctant to make these changes or not be aware of them. Even if employers are ready to invest in these changes, in the majority of developing countries there is a limited access to communication technologies for people with hearing impairment.

Many work colleagues are likely to leave out of their conversations anyone who does not hear well and, during meetings, it can be difficult to follow what is being said. A deaf person using signs would very likely have to depend upon the limited information coming from lip-reading. It can be exhausting trying to keep up: lip-readers automatically blink less, their eyes dry out, they cannot turn their heads fast enough to lip-read, so miss what is being discussed.

Mishearing or misunderstanding could lead a person who is deaf or hard of hearing to make an inappropriate remark, resulting in embarrassment. Over time, this person might become reluctant to participate, which could reflect badly on their performance.

In self-employment situations, potential customers can initially doubt the skills of a person with hearing impairment, which can lead to a slower build-up of customers.

Helping people with hearing impairment to find work

Governments can commit themselves to a proactive policy for the employment of persons with disabilities and draft legislation to support their right to work.

Governments and NGOs need to promote opportunities for persons with disabilities to learn different types of skills, such as a specific trade or entrepreneurship. Professional and technical training needs to be adapted to the individual needs of people with hearing impairment and the realities of the local markets, to ensure that they have access to the labour market.

Employers can raise awareness of the needs of employees with hearing impairment, undertake reasonable accommodations for them and adapt workstations where necessary. They can hire people with hearing impairment and keep them employed, accept trainees and/or interns with disabilities, and help include young people with hearing loss by being their first employer. When possible, training employees in basic sign language can be very helpful and easier than it seems.

Work colleagues can create a supportive work environment by making simple changes to their behaviour: for example, during meetings, they can ensure that only one person speaks at a time, that essential items are written up and there is an 'eye break' for lip-reading every 40 minutes.

Families can provide their relatives who are deaf or hard of hearing with crucial moral support and encouragement. They can also facilitate their communication with the employer.

Finally, **all of us**, along with organisations of persons with disabilities, can promote a positive perception of the skills, merits and aptitudes of people with hearing impairment and recognise that diversity is an asset in the labour market.

CASE STUDY NIGER

“Impairment doesn't mean incapacity”



Razina Boubacar
Manager of a
hairdressing
salon, Maradi,
Niger

I was born in Maradi, in Niger and I'm 24 years old. My father was a lorry driver and my mother, a housewife, supplemented our income by taking on small jobs she could do at home.

I helped my mother whilst my siblings continued their education

I lost my hearing when I was six years old, following an ear infection. I was able to get a primary school education from the Maradi School for the Deaf, one of the three deaf schools in Niger. After my sixth year in primary school, I failed my end-of-year exam. My family then decided that I would no longer attend school. Whilst my older siblings pursued an education, I spent my teenage years helping my mother with her housework and small jobs. During these years, I also taught myself to plait hair into traditional hairstyles. Thanks to these hairdressing skills, I was selected as a suitable candidate for a training programme run by an NGO (CBM) and the European Union.

Communication can be limited outside the company of deaf people

At home I communicate with my parents and siblings without difficulty, but our communication is very limited. It centres on everyday or household objects (garments, kitchen utensils, food items), on health (headache, stomach ache, cold, temperature), and on pets and livestock (chicken, goat, cow, dog, cat). We communicate through signs that were created when I was an infant and repeated all the time.

Outside home, unless I am in the company of people who are deaf like me, I sometimes find it difficult to make people understand me. I can feel isolated during ceremonies or community celebrations, when people form little conversation groups and I cannot communicate with them.

In my neighbourhood, however, I do have hearing female friends. Over time, I have taught them a lot of signs in the local sign language.

My apprenticeship strengthened my hairdressing skills

The training scheme offered me to train for eight months in modern hairdressing at a local hair salon. After I completed my apprenticeship, a hair salon promoter approached my family and offered me to manage her hair salon, *La Coquette*, in exchange for a monthly salary.

When I'm at the hair salon I communicate with my boss using basic signs from a local sign language. When we have to find a sign for a new object used in hairdressing, my boss shows me the object and I sign what I understand the object to be. If the meaning I have given the object is incorrect, my boss will demonstrate how to use the object and the expected result. Then we will create a new sign to designate this object.

Customers did not expect a deaf person to have these skills

I communicate with my customers by showing them pictures of hairstyles and a printed pricelist.

When I started out at the salon, things were not easy. Potential customers did not think I would have hairdressing skills, given my young age and my disability. When they saw the quality of the hairstyles I had created, customers were surprised. They did not expect a deaf person to be able to do this. Later these customers praised my services to others.

After a few months of hairdressing and managing *La Coquette*, my self-esteem increased. My family are proud of me. Members of my neighbourhood and my community are more considerate and respectful towards me.

Today I earn a small wage, which allows me to cover my basic needs and support my siblings a little bit.

My ambition is to inspire other deaf young women

Certainly, my boss and my customers are proud of the services I offer and *La Coquette* is doing well compared to other hairdressing salons. However, my ambition is to save as much money as possible in order to open my own salon, so as to show other young women, particularly deaf young women like me, that impairment does not equate incapacity.

CASE STUDY PAKISTAN

What I have learnt as a person with hearing loss looking for work



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When I was teenager I lost my hearing and became profoundly deaf. My family tried to find a cure for my deafness but nothing helped to restore my hearing. Afterwards, the first challenge was to find a way to re-start my studies. There were no 'accommodations' available for students with hearing loss in schools, colleges and universities, therefore I never went to college and missed that part of life. I re-started my studies at home and did a degree in commerce. Then I fell in love with computers and did a diploma in computer science from an institute. There too there was no concept of accommodation for students with hearing loss, but I found a few good teachers who helped me a lot. After that I continued to follow various information technology (IT) courses and to keep myself updated by self-study.

“I am trying my best to prove my talent and to prove that employees with disabilities are equally productive and responsible”

Finding a job

Pakistan is a developing country where there are more applicants than available jobs. Therefore finding a job is not easy even for people with no disability. I applied for many jobs but did not find any response.

Fortunately my brother's friend started his company and he hired me. There I worked for more than five years. Then I left that job, studied for more courses, and was again in search of a new job. I could have gone back to my old company but I took on the challenge of finding new horizons. Life became very difficult once again: I applied here and there but got no response despite the fact that I was well educated.

- **Tip:** I learned that you should not reveal your disability when applying for a job, otherwise your application may not get considered even at an initial level.

Building trust

There was an IT company near my home. I applied there and they refused to hire me. So I offered to volunteer – work for free – just to build their trust in my abilities. And after just one week, they hired me temporarily, though the salary was low. I kept working there and after two months the CEO of that company offered me to work with them on another project with a good salary. I accepted that offer and then worked with them on various projects for more than seven years.

- **Tip:** When you have a disability, getting hired by any company is difficult. But once you are in, you have a chance to grow and prove your skills and ability. So never mind if you have to start with a lower position or a lower salary.

My employment history so far

My first job was on a Unicef project, then I worked for many companies for long and short periods of time.

For around 2–3 years I worked as a web accessibility auditor with a US company. When this company sold out, I kept working as a freelancer but living expenses were becoming too high, especially during the tenure of the last government. This pushed me to search for a regular job. The story was the same again: I applied and even had interviews, but no good response. Then fortunately I met the country director of a big company (Al-Tuwairqi Steel Mills) during a flight and he hired me. So here I am trying my best to prove my talent and to prove that employees with disabilities are equally productive and responsible.

On the challenges of finding a job

- 1 Mostly, people do not trust in the skills of people with hearing loss.
- 2 They find it difficult and time-consuming to communicate with people with hearing loss, therefore they try to avoid including any person with hearing loss in their team.
- 3 Strangely, many people do not like to write things down on paper. Instead, they expect the person with hearing loss to lip-read. Sometimes this makes me angry and frustrated.
- 4 As people with hearing loss, we have fewer chances of getting promoted and of having a good position in the company, even if we are talented. This is because we cannot usually participate in important meetings and share our valuable input in time and in front of everyone.
- 5 Email and instant messaging are good tools for people with hearing loss if the company uses these tools properly.

Muhammad Akram making a presentation during a seminar on ear care. PAKISTAN



DANISHKADAH

Living in the community with a hearing impairment



Valerie E Newton
Professor Emerita in
Audiological Medicine,
University of Manchester,
United Kingdom



Sally Harvest
(Cochlear implant user),
Aural Rehabilitation
Therapist & Tinnitus
Retraining Therapist, CBM
Ear and Hearing Care
Advisory Group, National
Cochlear Implant Support
Programme Organiser
Ireland.

The impact of a hearing impairment on everyday life will depend not only on the type of hearing impairment but also on the community the person lives in. For example, in a big city where people are expected to keep to themselves, a deaf person may feel more isolated and more fearful than in a small community.

In the following paragraphs, we have highlighted some of the aspects of everyday life that may be affected when you have a hearing impairment.

Health

When going to see the doctor it is important to be able to describe what is wrong and problems with communication can have serious consequences. Bringing a family member to act as an interpreter can help but it could be that the problem is of a very personal nature and not one you would wish to share with others apart from the doctor. Very few clinics make provisions to facilitate communication with people with hearing impairment and not all doctors are aware of the need to check that these patients have understood instructions. Leaflets with health information may not be accessible to some deaf people who, through lack of appropriate education, may have poor reading skills.

Safety

Unexpected callers at the door may not be heard and a person intent upon crime could enter the house without the house-dweller being aware of the intrusion. Danger from fire could be experienced, as any alarm that may be present would not be heard. In the home, people who are deaf or hard of hearing can experience physical or sexual abuse more often than others, as their poor communication skills make it less likely that they will complain.

Marriage prospects

Marriage prospects for those with a hearing impairment may be reduced. The possibility of this being inherited by children deters potential suitors and in some communities deafness is a stigma.

Accessing services

People with hearing loss may have difficulty making their needs known and understanding the response of people whose speech is unfamiliar. Embarrassment can occur in the presence of other customers waiting to be attended to.

Isolation and social life

People who are deaf or hard of hearing can feel left out when groups get together for social activities. Going out to a public place with friends is less enjoyable when you cannot hear what is being said and if dim lighting prevents the additional clues afforded by lip-reading.

Even having a meal with family or friends at home is challenging because of sounds such as plates, cutlery, and people chatting away. When hearing aids are used, they capture all the sounds going on around the table. It is almost impossible to hear and keep up with conversations. Trying to eat a meal and lip-read at the same time means you lose out on whole sections of conversation around the table. This can be very frustrating and often the person with hearing impairment withdraws, slipping into the kitchen to wash the dishes.

Some people with hearing impairment will start to withdraw from social events, as mishearing causes embarrassment and a lowering of self-esteem, as does exclusion from the conversation. This can lead to feelings of isolation and depression.

Continues overleaf ➤

CASE STUDY PHILIPPINES

“I accept everything that I am and can do”



Maria Kathrina Lopez Yarza ('Kcat')
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In 2004, I was diagnosed with Neurofibromatosis Type 2 (NF2). I was told that I might turn deaf someday. Everything was sudden. I had just learned that I had brain tumours and was sick, and now I was also going deaf. Initially, my mum and I were in denial.

And then it happened. In 2006, I totally lost my hearing. An implant was not an option for people with NF2 at the time. It was not easy, but I learnt to accept my disability. I got used to living in a silent world. It is the same world as the one everyone is living in, just silent. I realised that after I became deaf, I was still chatting and communicating when someone talked to me. I could read lips.

In 2007, whilst surfing the Internet, I came across an implant specially designed for NF2 patients like

me (Auditory Brainstem Implant or ABI). After specialists evaluated my condition, I became a candidate for ABI.

I designed a tee shirt and conducted a fundraising campaign. With the help of many kind-hearted people, I was able to pay for my implant. I had my implantation in 2008. Up until now, I have only heard environmental sounds and do not understand words clearly.

Having the implant does not mean I hate being deaf. But I don't love being deaf either; I just accept everything that I am and everything that I can do. I can still do a lot of things. I can talk. I can see. I can eat. I can think. I can breathe. I can live. And I don't have to cover my ears when it's too noisy – I just need to turn off my hearing device.

Types of hearing impairment

The type of hearing impairment also needs to be considered. A person with bilateral hearing impairment from birth may have developed coping strategies by adult life, though it is a severe problem. People who develop a sudden bilateral hearing loss experience a complete change to their lives. Older persons who gradually lose their hearing over several years may not notice the problem themselves and think that others are mumbling when they speak; this can lead to arguments in families. Even a hearing loss in only one ear can cause difficulties, as it affects the ability to tell where a sound comes from and speech is less well heard when there is noise on the side of the good ear.

Conclusion

Being deaf or hard of hearing affects people in various ways, depending upon the nature of the hearing impairment, personal circumstances,



MONDI YOBIR KALIFA

additional medical problems and the presence or absence of support. However, in all cases, many communication problems can be reduced by ensuring the environment is acoustically friendly.

Laté Yao Tevi, a deaf shoemaker, in his workshop. **TOGO**

CASE STUDY TOGO

“It’s important to defend our rights and promote our culture”



Laté Yao Tevi
Shoemaker,
Lomé, Togo

I’m lucky my parents supported me

I became deaf at the age of one, following a fever. It was difficult for my parents. They didn’t know what to do. It was only when I went to a primary school for the deaf that they began to think that I would have a future. They

had to move and rent a house near the school. I come from a polygamous family; my father had eleven children in total and I feel very fortunate that he loved and supported me.

After primary school, I did an apprenticeship to become a shoemaker. This became my profession.

In my family, there were five children, although there are now only two of us. We communicated using mimes and ‘natural’, spontaneous signs. For example, we would mime a stool to indicate ‘sit down’, and we would mime ‘to eat’. Sometimes, we would not understand each other’s mimes. My mother and my younger brother went to my school to learn a bit of sign language, so with them I also used sign language. Some of my siblings went to school and as I can read and write – though not yet proficiently – we would communicate in writing.

I made an effort to connect with hearing people

I wanted to make friends outside my immediate family. I would approach hearing children using mime and natural signs. Some would run away because they did not understand deafness. Others made an effort because they wanted a playmate. I did not have a lot of hearing friends growing up, other than my parents’ neighbours. Today most of my friends tend to be deaf people and we communicate in sign language. With people who can hear, I communicate using signs if they have some notion of sign language; if not, I use natural signs and mime things. With those who know I can read and write, I communicate in writing as well.

I am 29 now and I work as a shoemaker in Lomé. I am a respected member of my community and I am able to

contribute to the household. I am very proud to have been accepted by hearing people. Although some customers are reluctant to tell a deaf person what they want, my good results earn their trust and repeated custom.

Society neglects people who are deaf

Some people are understanding when they find out we are deaf. Others make fun of us and imitate us. Some people, when they see us signing to each other, will pretend to do judo or karate, as if sign language was just a joke.

When shop owners don’t know that I am deaf, I mime that I can write. Once, a lady made me leave her shop when she realised I was deaf. After this I never went back. In another shop, they didn’t believe that I could read and write, so they asked me what level I had finished at school. When they found out I had graduated from primary school, they were happy for me and we started communicating through mime and writing.

Some people do not believe we are actually deaf, because we can walk, see, do everything. They tell us that we are liars and are trying to deceive people.

There is a real difference between deaf men and deaf women when it comes to prejudice. Generally, people prefer to interact with deaf men and if they do approach deaf women, it is out of self-interest. They want to use them and then leave them, because they are afraid that if they marry a deaf woman their children will also be deaf. For this reason, deaf women are wary of hearing men and prefer to marry deaf men. I would like to get married one day and have a family. I have the same feelings and wishes as everyone else.

I have belonged to the Togolese Association of Deaf People (AST or *Association des Sourds du Togo*) ever since I left school. I am an active member and attend all meetings. I have learnt a lot from the association. As deaf people, we are often neglected or bullied by society, by our community, and in some cases even by our parents. So it is important for us to belong to an association together with other deaf people, so that we can defend our rights and promote our culture.

Including people who have a hearing impairment



Paddy Ricard
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The impact of society on impairment

Recent years have witnessed the emergence of a social model of disability, which highlights that society can enable or further disable people who have an impairment. As illustrated by the testimonials featured in this issue, the negative effect of society is essentially twofold:

Prejudice. People with hearing impairment are often discriminated against. Those around them, including family, may not believe in their ability to learn and find employment. For example, both Razina Boubacar and Laté Yao Tevi (pages 7 and 10) mention in their testimonials that customers did not trust their abilities. Similarly, Muhammad Akram (page 8) had to offer free services to demonstrate his employability.

People with hearing impairment may often have the advantage of not looking different from hearing people,

but their invisible impairment has its own drawbacks. They must have the confidence to mention it, and this confidence can easily be crushed after a rejection, as in the case of Huda Zahid (page 5). Laté (page 10) also mentions that some people do not trust that a deaf person cannot hear and believe them to be lying.

Lack of access. Society does not take into consideration the needs of people with hearing impairment, thereby making the world less accessible to them and compounding their difficulties. For example, Muhammad (page 8) describes how he had to learn by self-study, because colleges could

not accommodate a student who was deaf.

The adjustments and facilities needed by people with hearing impairment vary in scale and cost. New technologies, such as instant messaging, can be a great help, though they are not yet accessible to all. However, improvements to face-to-face communication can be simple and cheap.

Communication

Hearing impairment presents a direct physical obstacle to communication. The inability to communicate well with others can lead to isolation and depression, and impacts everyday life in many ways (see pages 9–10).

Hearing people may not make the effort to communicate with a person who is deaf or hard of hearing, or exchanges may be very basic, which can also breed isolation. Hearing people may also not know how to communicate, as shown by the questions asked by parents of deaf children (page 3).

Communication fosters a sense of belonging, confidence, and independence. The testimonials in this issue have one thing in common: positive turning points are rooted in improved communication. Learning sign language, for example, enabled parents to

communicate with their child (page 3). The realisation that she could still communicate was a turning point in Kcat Yarza's acceptance of her diagnosis (page 9).

All of us can make small adjustments to improve communication with people who are deaf or hard of hearing.¹ The first step is always to treat the person with respect and to allow more time to communicate.

Education, training and employment

The acquisition of knowledge and employment are described as life-changing in the testimonials of Huda, Razina, Muhammad and Laté.

Education nurtures confidence and, by leading the way for employment, it also fosters independence. Including people with hearing impairment also means enabling them to learn, train and prove themselves at work.

What health personnel can do to be more inclusive

The objective of this issue was to focus on people with hearing impairment not as patients passing through a medical facility, but as individuals wishing to lead a full and interesting life.

In the testimonials featured here, medical care is only one of the factors that helped improve lives, and in some cases only plays a minor role.

The first thing health personnel can do, therefore, is what we can all do as individuals: improve communication with people who are deaf or hard of hearing. This means looking out for clues indicating that a person may have a hearing loss, encouraging people to volunteer this information and striving to communicate better with patients themselves, not just with their carers who will be easier to communicate with.

Health personnel should not focus solely on cure and prevention of hearing impairment. This limited focus excludes a large proportion of people who are deaf or hard of hearing, who need to be given information about living with hearing loss and maximising their communication skills.

Counselling will also help people with hearing loss reach their full potential by improving their confidence.

Inclusion also means participation

People who are deaf or hard of hearing should be included in decision-making processes, starting with those that affect them directly.

There has already been a shift in this direction. The disability movement – whose motto states 'nothing about us without us' – has grown in strength in recent years. The United Nations Convention on the Rights of Persons with Disabilities has been signed by 158 states. In 2011, the World Health Organization and the World Bank produced the first ever *World Report on Disability*.

Disability, and with it hearing impairment, is now a question of human rights. As stressed by Kcat (page 9), people with hearing loss live in the same world that everyone lives in. They must have equal access to it.



Children attending an inclusive pre-school.

CAMBODIA

Reference

¹ See poster on page 12 of this issue. One of our recent articles also offers simple, valuable tips: 'Improving communication with patients who have a hearing impairment', *Comm Ear Hearing Health* vol 9 issue 12 (2012): 10–11.

We can communicate better

Face me when you speak and do not hide your mouth

Do not stand or sit too far away and make sure I can see you clearly

Speak at a normal pace. Do not shout or exaggerate your speech

You can't see that I cannot hear unless I tell you

I cannot lip-read when I'm taking notes or looking away even briefly



I am deaf or hard of hearing

Minimise background noise: it is amplified by hearing devices and is generally an obstacle

Check that I have understood you

We can use sign language to communicate. We can also write things down

Good communication improves quality of life