



# Family Friendly!



Working with deaf children and their communities worldwide

Deaf Child Worldwide (formerly the International Deaf Children's Society) is the only UK based international development agency dedicated to enabling deaf children to overcome poverty and isolation.

Our vision is a world without barriers for every deaf child.

We believe that:

- Every deaf child has the right to the same opportunities as a hearing child
- Every deaf child has the right to be included and valued by society
- Families have the right to make informed choices on behalf of their deaf child and for those choices to be implemented
- Families have the right to clear and balanced information and support, delivered in a way that is accessible to them

We work with partners in the countries where need is greatest throughout the world. We are the international development agency of the National Deaf Children's Society in the UK. Registered Charity: 1016532.

Copyright of this document is the property of Deaf Child Worldwide. Deaf Child Worldwide encourages others to copy, reproduce or adapt any or all parts of this book, provided that the parts are reproduced free or at cost and Deaf Child Worldwide is identified as the source. Please contact Deaf Child Worldwide for permission if you are interested in translating any section of the book or if you would like to reproduce this book for commercial purposes.

Written By: Kirsty Wilson, Susie Miles and Ian Kaplan.  
First published: February 2008.

Cover photograph: Loto Taumafai Society, Samoa.

The illustrations on pages 9, 22, 42, 64 and 118 are by Heidi Broner and were published in the book *Helping Children who are Deaf* (The Hesperian Foundation 2004)

Deaf Child Worldwide would like to thank all the contributors to this booklet and in particular, the Enabling Education Network, [www.eenet.org.uk](http://www.eenet.org.uk) for their contribution to the writing and editing of this book. EENET is an information sharing network which promotes the inclusion of marginalised groups in education worldwide. Its membership is open to all. Contact [info@eenet.org.uk](mailto:info@eenet.org.uk) for more information.



# About this book

This book aims to raise awareness of the important role that parents and families can play in the lives of their deaf children and in their communities. It is written for all those who want to know more about parental involvement in support for deaf children, but especially those who are involved in providing services for deaf children and their families.

It is not always easy for service-providing organisations to involve family members in their work, or in self-help activities. Often parents feel that they know too little in comparison to professionals, that they are too poor, that the distances to travel are too far or that they have little to contribute. However the inspirational case studies presented here show that it is possible for service providers, families and deaf people to work together to support deaf children.

The examples in this book show that families can be one of the most powerful forces for change in the lives of deaf children. They can change the lives of their own children and also work to change the future for many others.

Different people - both deaf and not deaf, parents and practitioners - have contributed to the book and we are very grateful for their willingness to take time in contributing to our project.

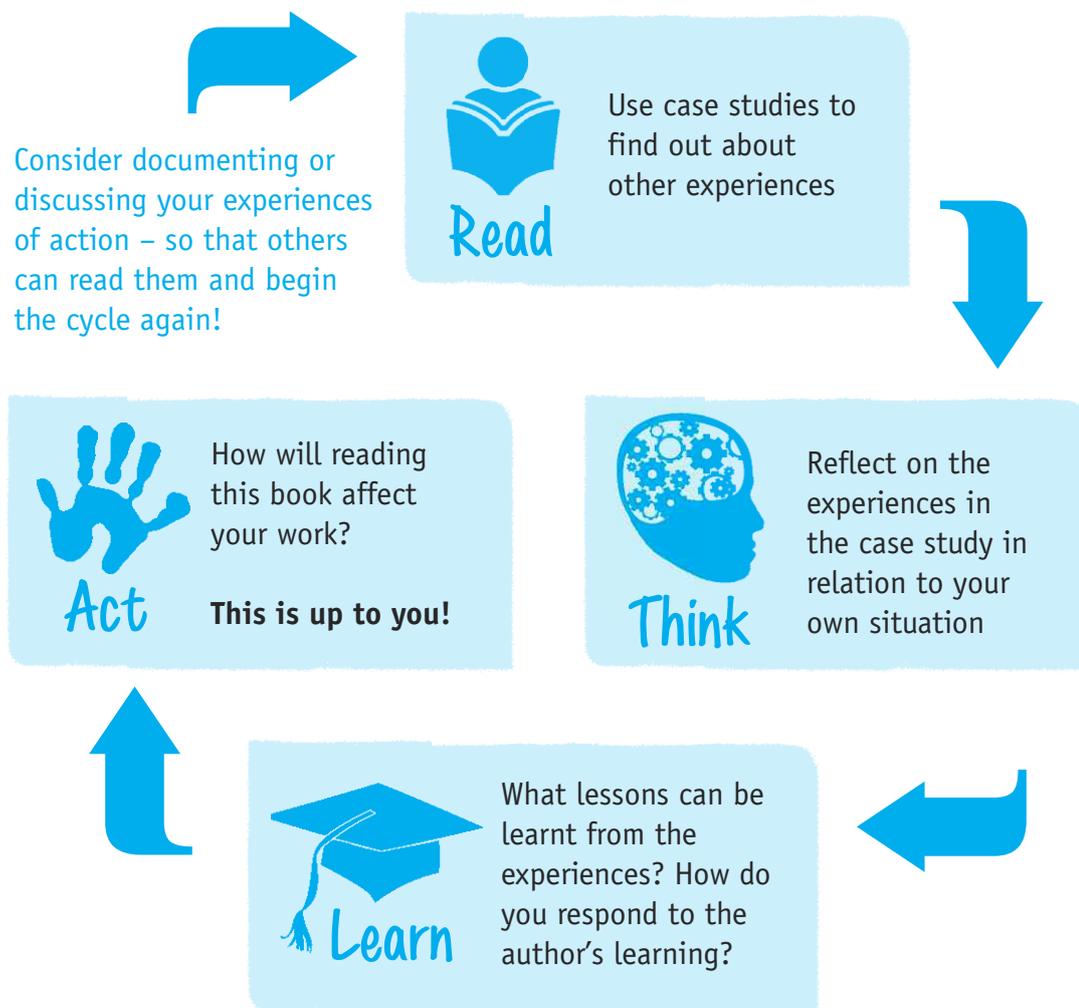
This book represents some of the core values of Deaf Child Worldwide and many important learning points from the work of our partners and friends.

**We have found producing this book inspiring and we hope that it inspires you, too!**

# Using this book

This book presents the experiences of others through case studies. It uses some principles from Action Learning to encourage readers to think about their own practice and to challenge themselves to act upon what they learn as a result.

## Action Learning Guide



Each stage of the cycle uses these symbols. In each chapter, you will find:



**Case studies** written by practitioners or family members. You can find all the case studies in full on our website – [www.deafchildworldwide.info](http://www.deafchildworldwide.info). If you don't have access to the internet, please write to us and we would be happy to send the case studies to you.

The case studies come from many countries, in which families have followed a range of different approaches for their children. On the whole, there are fewer case studies written about children with mild or moderate deafness or about those who became deaf later in their childhood. However, as this book is about strategies for

Continued

informing and empowering families, we hope that the examples will be relevant to all families with deaf children who have different levels of hearing loss.

On page 144, there is an index of all the people who contributed to the book and the page numbers where their contributions can be found. Some of the case studies have been published previously and the full references for those published stories are available after this index.



### Things to think about...

Taking time to reflect on your own practice can be very productive. The case studies may help you to see your own work situation differently. Some people call this “making the familiar unfamiliar”. The questions in these “think” boxes are designed to help you to reflect on your own work. They may help you to reflect on what is going well in your project. They may also help you to think creatively about changes that could be made. The questions can be used with individuals, with a team of colleagues, or with larger groups in workshops.



### Learning from...

The book does not propose a set approach to common challenges. Instead, it invites you to learn from the experiences of others and apply that learning to your own situation.

There is a summary of some of the learning at the end of each chapter and after some case studies. These are ideas which the authors of the book have picked out. You might find different aspects of the case studies important. Please contribute to the debate – tell us what you think some of the learning points are – we could publish your comments on the website or, perhaps, in future editions of the book.



## Basic principles for Deaf Child Worldwide

**On some issues, Deaf Child Worldwide uses these principles to guide its work. These may be useful for practitioners to consider in relation to their own work. These principles are, like everything else, open to critique, different interpretations, additions and amendments. Please let us know what you think.**

# Using this book

## Some notes on terminology used

Deaf Child Worldwide uses the term “deaf” to refer to all levels of permanent hearing loss. This includes mild, moderate and profound hearing loss. This includes people who use sign languages and spoken languages as their preferred language. It is important to note that children with different levels and types of hearing loss require different support.

As this book contains case studies written by people who do not work for Deaf Child Worldwide, you will notice that some authors use Deaf (upper case D) when specifically referring to the group of people who identify themselves as culturally and linguistically members of the Deaf community.

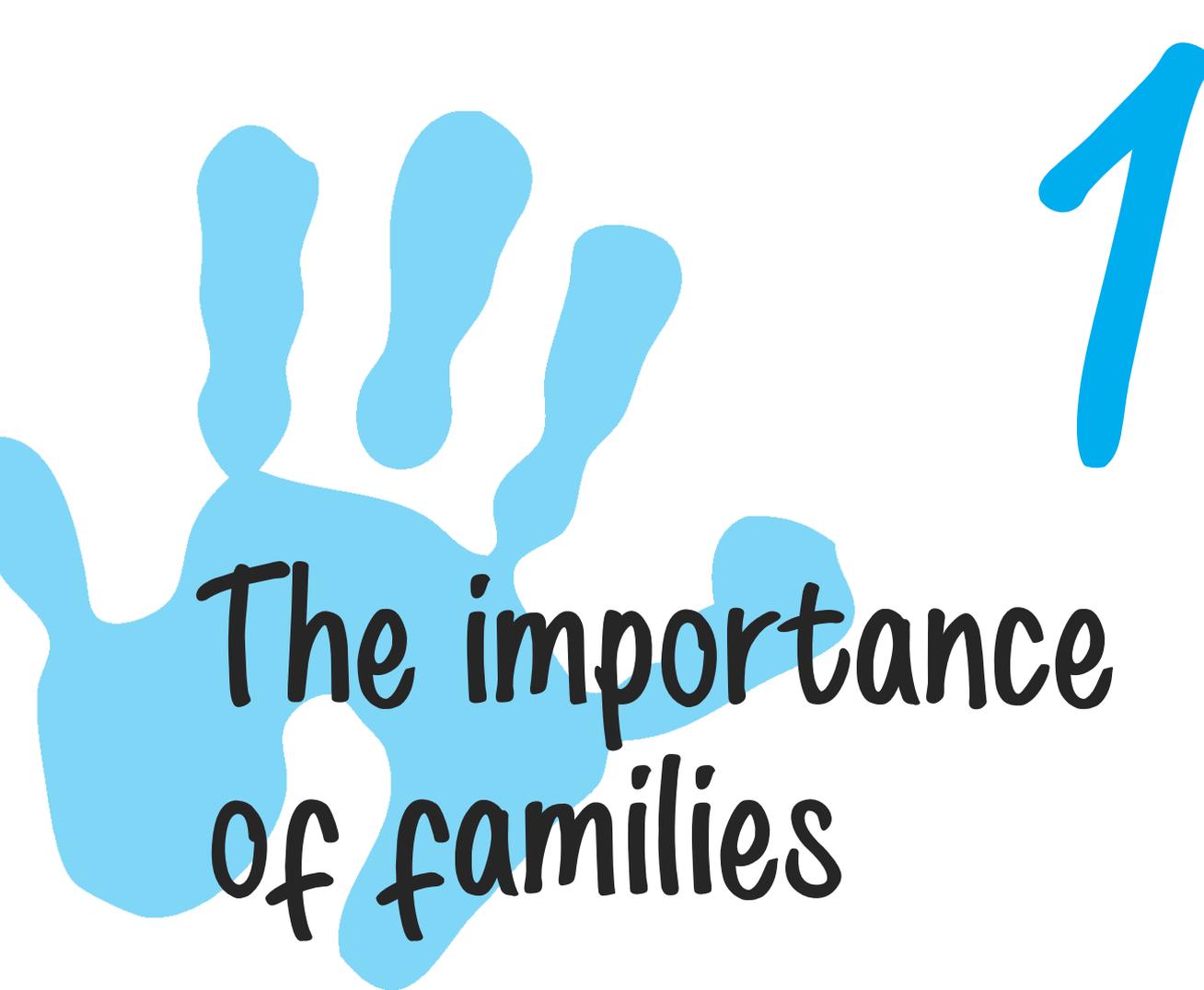
Deaf Child Worldwide refers to “parents” as the person or people who take responsibility for caring for a deaf child. Where possible, Deaf Child Worldwide refers to deaf children and their “families” to show that there are a wide variety of people who are involved in the deaf child’s life, for example grandparents, siblings, step-parents, aunts and uncles.

# Contents

	<b>About this book</b>	<b>2</b>
	<b>Using this book</b>	<b>2</b>
<b>1</b>	<b>The importance of families</b>	<b>7</b>
	Why focus on families?	8
	Families and language learning	9
	Families and access to services	10
	What is “parent empowerment”?	13
	What are deaf children’s rights?	14
	Deafness is a community issue	15
	Family friendly services for deaf children	17
	Learning from this chapter	19
<b>2</b>	<b>Providing Positive Information</b>	<b>21</b>
	Why is information so important?	22
	What kind of information is useful to families?	24
	Making information useful	27
	Positive information in practice	29
	Learning from this chapter	39
<b>3</b>	<b>Family groups and associations</b>	<b>41</b>
	Why come together?	42
	Supporting parents to come together	43
	Inviting parents to a group	43
	A reason to meet	46
	Becoming more sustainable	51
	Moving from professional-led to parent-led groups	54
	Parent-initiated groups	57
	Resources for parents’ groups and associations	59
	Learning from this chapter	61
<b>4</b>	<b>Working together with deaf adults</b>	<b>63</b>
	Deaf role models	64
	Deaf people are all different!	68
	Deaf people as sign language trainers	70
	Deaf people as advocates	73
	Becoming a deaf friendly team	75
	Learning from this chapter	79

# Contents

<b>5</b>	<b>Community based support</b>	<b>81</b>
	What is community based support?	82
	Why families with deaf children need community based support	82
	Balancing competing priorities	83
	What kinds of support can community based programmes deliver?	84
	Supporting families at home	86
	Keeping children safe	88
	What sort of training do community workers receive?	89
	Involving parents in the delivery of community based services	90
	Partnership working: parents and community workers	93
	Community based services and education	96
	Rebuilding relationships between deaf young people and their families	97
	Learning from this chapter	99
<b>6</b>	<b>Education</b>	<b>101</b>
	Introduction	102
	Teachers supporting parents: family communication	102
	Parents supporting teachers: quality of education	107
	Employing parents in education programmes	110
	Parental involvement in the running and management of schools	111
	Teachers and families learning together	114
	Learning from this chapter	116
<b>7</b>	<b>Families taking action</b>	<b>117</b>
	What kinds of action can families take?	118
	Supporting each other and sharing information	119
	Practical support	120
	Developing or improving services for their deaf children	124
	Lobby and campaigning for change	129
	Changing priorities	132
	Learning from this chapter	133
	A final note	135
	<b>Appendix 1 Keeping Children Safe</b>	<b>138</b>
	<b>Appendix 2 Useful Resources</b>	<b>143</b>
	Index of contributors	149



# The importance of families

## Chapter aims:

- To highlight research showing the impact of family involvement
- To introduce the concept of deaf children's rights
- To consider the roles played by families, communities, and governments
- To introduce the concepts "parent empowerment" and "family friendly services"

## Why focus on families?

Families play a major role in the development of their children, but for deaf children they are even more important. This book shows the impact that families can make on their own children's lives. It also highlights the way in which families can change the situation for other deaf children in their community. They can do this by working together with service providers, or through self-help initiatives. There is no question that parent power has a huge role to play in improving deaf children's lives!

There are some huge challenges – made even greater by poverty – which can discourage parents from engaging with their children. Sometimes, practitioners comment that families feel as though they have nothing to contribute to their children's development or that it can take a long time for some families to see the benefits of getting involved actively in their child's life.

Many families are not always sure how they can support their deaf children. However family members have knowledge about their children and their family – knowledge which service providing organisations do not have. In most cases, family or community members also spend more time with deaf children. The impact of their support can be greater than anything done by an external service provider.

Families often don't know how they can make a difference to their children. Sometimes they need emotional support to help them take more responsibility for their children. Service providers, deaf adults and communities can help families to be more aware of this. This chapter highlights research which shows the impact of family involvement. It also introduces some of the issues discussed later in the book.



Think

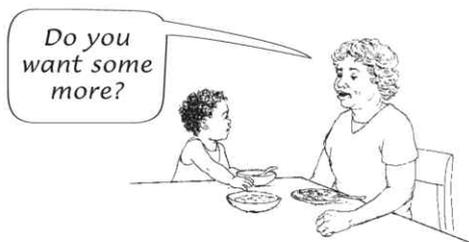
### Things to think about: Who has the knowledge?

- What do families know about their children that people outside of the family would not know?
- If you are working to support a deaf child, how could that knowledge be important to you?
- How can you show families that you respect their knowledge?

## Families and language learning

The early years of children's lives are the most important for learning communication skills and language. Research carried out in the USA showed that by the age of three, children who hear well, understood around 700 words and many grammatical rules, but undiagnosed, and unsupported deaf children of the same age only knew around 25 words.

- ① Babies begin to express their thoughts, needs, and feelings by making sounds or using facial expressions and pointing.



- ② They hear and understand other people's words.



- ③ They begin to use words. They know and use names of the people closest to them.



- ④ Later they start to talk and express themselves more completely.



- ⑤ Words help them think and learn new things.



Young children spend more time with their families than with anyone else. Families are best placed to provide children with language relating to their home environment, culture and community. Offering families support can greatly improve the quality of their communication with their young children. This can have a profound effect on a child's early development and their sense of inclusion within the family.

The key role that families can play in supporting children's language development is supported by practitioners' experience and academic research. Much of the academic research focuses on Northern contexts. However some research has been carried out in the South. It shows that similar ideas about communication can be applied in a variety of contexts.



### Communicating with babies – research in Zimbabwe

Maria Chiswanda (1999) carried out research in resource-poor families living in urban areas of Zimbabwe as part of her PhD studies. She worked with six mothers (not deaf) and their deaf children.

The study showed that offering simple support to these mothers helped to improve family communication and improved the mothers' ability to support their children's learning and intellectual development. The support was offered over a period of 12 weeks and aimed to raise awareness of effective communication strategies. It included three individualised training sessions and three group discussions where mothers were encouraged to learn from each other. Opportunities to meet and interact with deaf adults who modelled language and communication were part of these sessions. Visual modes of communication, shared visual attention and responding to children's communication attempts were all stressed as being very important.

**1.1 Maria Chiswanda, 1999, University of California San Marcos**

## Families and access to services

Estimates show that the percentages of deaf children in developing countries who have access to specialist services are relatively low. In addition, not all children who come into contact with these services benefit from them as much as they could. Often it is family members who enable children to access and benefit from services. The information and advice which families get from other families, organisations and professionals helps them in their search for appropriate support. Parents' attitudes will determine whether children gain access to health and education services or not. Also, parents' social and economic resources have a major influence.



### Searching for a school: a father's journey, Uganda

It was Abel's aunt who noticed that he was deaf, so we took him to the hospital. After a thorough examination, the doctors came to the conclusion that Abel was deaf. I was broken down. I had never experienced such in my entire life. I really saw that the world was coming to an end. My family is very poor. I sell second hand clothes in the market, earning very little income for sustaining the family - buying them food, medication and shelter and second hand clothes.

I started looking for a school where Abel could study. I moved from school to school that was teaching children with disabilities - but I was disappointed because of the very expensive school fees. After some time, I met an old friend and told him what I was going through. He advised me to go to the internet - yet I did not know anything about computers. I went to an internet café where I explained my problem to one of the attendants. He searched for organisations that could help me with Abel. We found many organizations within Uganda and others from abroad, and started writing to them. I was encouraged by their responses because they gave advice on what to do. If they were not the right persons to contact, they could link me to those who could help.

One day I got an email message from Ingrid Lewis at EENET. She asked for my postal address, but I did not know about PO Boxes and I did not have one. I looked for some money to open up a postal address. I was very much surprised by the books EENET sent us. I continued exchanging the letters with EENET.

One day I met a friend and had a chat about Abel. He said he knew of a school in Masaka that could help us. I took Abel to the Masaka School for the Deaf and he was admitted. I was told to pay half the school fees. That is where Abel is now - and he is doing well in class.

#### 1.2 Henry Sempala, Uganda

This story highlights the way in which Henry was determined to find an affordable school that met his son's needs. The advice and support he received from everyone - his relatives, his friends, the internet café and EENET kept him motivated. If information about affordable support for deaf children was easily available, then more families would be able to find sources of support for their children.

Parents' expectations of their children's abilities have a significant impact on children's educational achievement. Low expectations are likely when family communication is limited and there are high levels of stigma. Families with these attitudes may seem "hard to reach" but all families have the potential to believe in their child. There are many examples of how outreach work that supports the development of effective family communication has changed parental expectation and attitudes.

Positive parent attitudes can make a huge difference to children's ability to make the most of the services they access. Lourdes Acosta, a teacher at the Instituto Rosendo Ollenta in Mexico City comments: "Parental involvement is vital. It's like a motor, like fuel for a child's education. Without the parents, it's much more difficult for a child to progress." This statement is backed up by some research done at the University of Birmingham in the UK.



### Learning from success: high-achieving deaf pupils in the UK

Steve Powers (2006) researched the experiences of 27 severely or profoundly deaf secondary school pupils who were nominated by their schools as high-achievers. This research found that:

- a main factor behind their high achievement is deaf pupils' own determination and positive outlook;
- another important factor is the commitment and sacrifice made by their parents;
- most of the parents of the high achieving deaf pupils had empowered themselves rather than followed decisions made by professionals;
- teachers of deaf children and teaching assistants made a significant contribution to the success of the deaf pupils.

One of the most important recommendations made by the report was that:

- it is crucial that teachers of deaf children help parents understand the central role they have in developing language and communication in the early years;
- teachers of deaf children should aim to fully involve and empower parents at all levels in their children's education.

Continued

The report also stated that stories of successful deaf pupils should be publicised to raise expectations and provide inspiration and role models for younger deaf children.

### 1.3 Steve Powers, 2006, University of Birmingham, UK

Some families find the confidence and strength to work with or lobby service providers (both mainstream and specialist) to ensure that their children have access to the same opportunities as other children. Ultimately the work that these parents do benefits all children.

Snigdha Sarkar, a mother from Kolkata in India personally made sure that her daughter, Sneha could study in a supportive environment at a mainstream school. She says: "Those of us who do not want to accept defeat have to work very hard to help our children succeed...The few successes that we can see around us are because of the endless sacrifice of families fighting against all odds at every step."



### Things to think about: What are your priorities?

It is hard work to get families involved in our work, sometimes it seems impossible. But we must keep thinking of new ways to motivate families to get involved and new ways to adapt our work so that it is accessible to families. Without families' participation it is very difficult for deaf children to achieve their full potential.

- Is it hard to get families involved in your work?
- What are the challenges?
- Do you prioritise family involvement in your work with deaf children?

## What is "parent empowerment"?

Many organisations talk about aiming to "empower" their stakeholders. Some practitioners talk about empowered parents and what they can do for their deaf child.

Not everyone likes the word "empowerment", some prefer to talk about "enablement". Some practitioners talk about "acceptance" and feel that the need for families to become aware of children's basic needs is the first priority. Negative social attitudes, poverty and a lack of understanding of deafness mean that many practitioners focus on enabling parents to take on their basic

responsibilities before considering issues of empowerment. Nevertheless, even a discussion about basic responsibilities can be held in an empowering way. Family members become involved in their deaf children's lives from different starting points and with different attitudes. The way in which they become involved will affect the roles and responsibilities they take.

Staff from the Association of People with Disability, a partner organisation of Deaf Child Worldwide in India, described an empowered parent as one who:

- is comfortable with their child's deafness
- is patient and supportive
- is able to support their child, and ultimately other parents
- knows about deafness and tells others
- takes responsibility for their child's development and gives their child access to opportunities
- feels independent from service providers
- is able to make choices about their child's development

Does this definition of empowerment match your own understanding?

## What are deaf children's rights?

Deaf children have the same rights as all children. This means that giving deaf children equal opportunities with all children is not an act of pity or charity, it is an act of obligation and responsibility. It is required by law.

There are different frameworks and laws which guarantee the rights of children. These are enshrined in international conventions such as the UN Convention on the Rights of People with Disabilities and the UN Convention on the Rights of the Child. Many countries have also passed local laws which provide for those rights, for example, a Person with Disabilities Act or Children's Act.

### The UN Convention on the Rights of People with Disabilities

- **Article 19** states that governments must recognise the equal right of **all** people with disabilities to live in the community, with choices equal to others. In order to make sure this happens, governments must ensure that community services for the general population are available and responsive to disabled people.

- **Article 23** states that children with disabilities have equal rights with respect to family life. Governments have the responsibility to provide early and comprehensive information, services and support to children with disabilities and their families so that families do not conceal, abandon or neglect their children.
- **Article 24** gives children with disabilities the right to access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live. Governments have the responsibility to provide education and also to facilitate the learning of sign language.

Families and communities have a right to know about their rights and the rights of their children. It is an important part of understanding their responsibilities, alongside the responsibilities of communities and governments.

Families in most countries of the world feel that there is a long way to go until rights become reality. However, it is vital to create services which provide a model of what can be achieved. Many of the case studies are models that can be used to encourage others to develop similar services. They can also be used to lobby governments to take up their responsibilities.

## Deafness is a community issue

Positive community attitudes are critical in providing an enabling environment for deaf children. Deaf children can only be included in communities which have a positive understanding of disabled children's rights. Creating a more inclusive society will ultimately weaken the links between poverty and disability.

Governments have primary responsibility to ensure that all their citizens have access to community services. In addition, other actors such as international and local NGOs working on community development issues also have a responsibility to make sure they include deaf children and their families.

Many families across the world live in areas where support from established service providers is limited. In these circumstances families and communities themselves can provide a supportive environment to their deaf children.

*“When your child is involved in the community, it helps your child. When your community is involved with your child, it helps your community.”*

**Helping Children Who are Deaf**

Sometimes families with deaf children come together themselves to support each other. Community-based and community-led support programmes also have a long history of involving families in service provision. In some instances this has also led to the formation of parents' associations. Specific examples of groups and associations are explored in more detail in Chapter 3.

Whether a service originates with a parents' group or a disabled people's organisations or is done in partnership with government or non-government organisations, the work can still be "empowering" to parents. This means considering how parents contribute to decision-making about how the service is delivered. The way that associations or services are organised will determine the extent to which they are empowering to parents.

The following distinction between "top-down" and "bottom-up" approaches is helpful when considering the way services are organised.



### An excerpt from *Disabled Village Children*

In top-down programs, people are asked to participate only in ways that have already been decided from above. For example, a decision might be made that certain persons in each community be selected as "local supervisors". The local supervisors are taught several pre-decided "packages" of cookbook-like information. Each supervisor then instructs a given number of "local trainers" how they "must train" each particular disabled person. Thus "community participation", from the viewpoint of the experts, means "getting people to do what we decide is good for them"...

In a bottom-up approach there is a greater sense of equality, and of arriving at decisions together. People do not just follow instructions. They consider suggestions. They want to know why. This greatly increases the chances that exercises, aids, and activities will really fit the individual needs of the child . . . Planning is a continuous learning process that responds to the changing needs, difficulties, and possibilities within the community.

Above all, a bottom-up program organised by those it serves, decentralizes and redistributes power: people who have been powerless begin to find strength through unity. **You can never be sure where things may lead, how far people may go in terms of taking charge of their own lives or in demanding their rights.**

1.4 David Werner, *Disabled Village Children*, (1987)

The difference between “top down” and “bottom up” approaches is not just about who manages a service or starts a programme. There are examples here of many different models and approaches:

- Parents who come together and initiate services for their own children;
- Service providers that have worked to support families on the path to empowerment;
- Parents and service providers who are working in partnership.

Some practitioners who work in a “top down” environment have taken action to empower parents and children. The attitudes of service providers are perhaps one of the most important factors in promoting parental empowerment – no matter who that service provider is. Deaf Child Worldwide calls services which promote parent empowerment “family friendly services”.



Think

### Things to think about: Empowering attitudes

If you spend time visiting a family with a deaf child and talking about their child’s future,

- How long do you spend listening and learning about a family’s context?
- How long do you spend passing on technical knowledge, sharing skills and experience?
- How long do you spend working together to find solutions that meet the families’ needs?
- How do you make decisions? How is power shared in decision-making?

## Family friendly services for deaf children

All services for deaf children, including health services, audiology, playgroups, schools, community based support programmes and other services, could promote family involvement. Adopting a family friendly approach is an important way of achieving this. Chapters on information, education and community based services provide some practical examples of this.



## Basic principles in family friendly services

- Service providers should acknowledge that deaf children and their families have the same basic needs as other families. For many families, their immediate needs are clean water, sanitation and basic health services. These should be considered alongside those needs relating to deafness.
- Families should be continuously and sensitively consulted about what they want from services and whether those services are meeting their needs. Consultation should lead to action.
- Families have a right to clear and balanced information in a language they can understand.
- Families have a right to make their own decisions about how best to support their child.
- Families should be given the opportunity to come together with other families who have deaf children.
- Service providers should listen to families, and their attitude should be characterised by listening.
- Families should have the opportunity to actively influence the services which affect their child.
- Service providers should actively encourage partnerships between parents, professionals and deaf people. Partnership calls for mutual respect and understanding and involves making decisions together.

Family involvement in service provision will only be possible where the culture of the organisation providing the services is welcoming to families and sees family members as equal partners. Parents and services providers should also respect each others' rights and responsibilities.



### Learning from this chapter

- Family members are crucial partners in service provision for deaf children. Without family involvement, deaf children will not achieve the most positive outcomes.
- “Parent empowerment” has lots of different definitions. The ability to take responsibility for children’s development and to take action for change are key to parent empowerment.
- Deaf children have rights. Families, service providers and governments should be aware of these rights.
- The process of parent empowerment can be initiated by anyone with the right attitude – services can be run in an empowering way.
- Parents’ associations can be run solely by parents. These associations often focus on providing information, peer support and undertaking advocacy or campaigning.
- Services for deaf children can be organised in a way that is empowering to families. This means involving families in partnership with service providers.





# Providing positive information

## Chapter aims:

- To describe the kind of information that families find useful
- To understand parents' perspectives on deafness
- To give examples of information that parents can access and understand

## Why is information so important?

Most parents know nothing about deafness when their deaf children are born. Over 90% of deaf children are born into families with no experience of deafness. Parents may feel ashamed, since negative attitudes about deafness and disability are common all over the world.

- worry about what to do



*I don't know anything about deafness. How could I possibly help my child?*

- fears of what it means to be deaf and fears about the future

*How will my child get married or earn a living?*



- denial



*My child will hear well if I just find the right treatment.*

- anger at what has happened

*It's not fair that this happened to my family.*



- loneliness



*No one else knows what this is like. No one can help.*

- guilt about what you might have done to cause the deafness

*If I had eaten better during my pregnancy, this would never have happened.*



- shame because your child is deaf



*What will our neighbors think?*

- sadness, helplessness, or no feelings at all (depression)

*I feel so hopeless...*



- accepting it as fate or punishment

*We can't do anything to change a curse. It is just our fate.*



Often parents have no way of finding out about language and communication, education, social and emotional issues, or the deaf community. This lack of accurate information often prevents families from seeking advice. Concerns about a child's hearing may be dismissed by other family members, community members or even professionals.

When families find out for certain that their child is deaf – what do they do next? Felicia Foinbaum, a mother of three deaf children from Cameroon remembers those early years and how important it is to receive useful information when children are first diagnosed.



### **“No one believed me that something was wrong”, Cameroon.**

I had started suspecting there was something wrong with my son, Gerald, when he was about two. But family members reassured me that everything would be OK. My mother-in-law told me my husband uttered his first words at the age of four so there was nothing to worry about. Others told me that first born boys always took longer than usual to talk. Some suggested that we take him to a regular school so that he would learn to talk by interacting with other children.

I started to look for a place to take him for a hearing assessment. I finally found a hearing assessment centre in Yaoundé, the capital city of Cameroon, about 250km from Douala where we lived. When I informed my immediate family, I was accused of being anxious, impatient and over-reacting. However, I was sure it was the right thing to do, so I slipped out of the house with Gerald and his five month old brother, Samuel. We travelled to Yaoundé and did the test. The results were that he was profoundly deaf – 110decibels. This was a shock to me as I did not understand what it meant and I did not even know what decibels were.

#### **2.1 Felicia Foinbaum, Cameroon**

This is a common experience for parents of deaf children all over the world. Sometimes doctors don't take parents' concerns seriously and this delays the diagnosis.



### Diagnosis but no support, Mexico

I am the mother of Ernesto Carlos. When he was two months old, I realised something was wrong. I kept telling doctors that when we made a loud noise he didn't really react. I already had other children and, as a mother, I noticed this kind of thing. But the doctors said I was wrong. So my husband and I decided to come to Mexico City to do some tests. The doctor broke the news very abruptly: "Well, your child's deaf". Just like that! It was awful. My husband and I left her office crying. She didn't tell us what support we could get, where we could go, what the problem was really, nothing. Just: "Your child's going to be deaf!"

2.2 Asminda Carillo Acasio, Mexico

Many families will not be in a position to seek help from a doctor or support service and those parents are in greater need of information!

## What kind of information is useful to families?

Without information, parents and families might not be aware of the following:

- **How** to find out if their child is deaf.
- Deafness is **not the result of a curse, or a sin**. Parents should not be blamed or excluded because their child is deaf.
- Deafness is **no reason to exclude** a child from family and community activities. Deaf children have a right to be included.
- There are **different levels and types of deafness** – different children benefit from different support.
- The **impact of deafness** on language and communication.
- That there are many **simple actions** that families and other organisations can take to support deaf children **to develop communication and language skills** from a very early age.
- That given support, **their deaf child will have a lot to communicate to them**.
- That there may be **community based, audiology, education or other service providers** in their country or area.

- That all deaf children have **a right to an education**.
- That there may be **groups or associations of deaf adults** in their area.
- That deaf people do grow up to be **successful people**, married with children, property, jobs or businesses.
- Some children who are deaf have additional disabilities. They need the informed support of their parents and others working to support them even more.



Think

### Things to think about: community attitudes

- What are the beliefs that prevent families from seeking advice about deafness?
- Have you ever asked families why they think their child is deaf?
- Are families with deaf children involved in the production of information about deafness?

Felicia's reaction to the diagnosis was shock, and confusion. This is a common reaction in many different circumstances. Snigdha Sarkar from India shares her experience:



Read

### Confusing terminology, India

It was August 1992 and we were preparing to celebrate our daughter's first birthday when we received the news. The doctor told us she had a problem and prescribed a hearing assessment for her. Yet four months earlier he had found Sneha perfectly healthy. We were both puzzled and stunned; we did not even think of asking him anything at the time.

We took Sneha to the audiologist the next day - at that time I did not know what an audiologist was. He performed some tests and said she had a "congenital sensory-neural binaural profound loss of hearing" - words that carried no meaning for us. I went back to the doctor the next day with the test results. He gave us the names of two special institutions in Kolkata on a piece of paper and that was all the help he provided.

**2.3 Snigdha Sarkar, India**



### Things to think about – language

- How can you find out what families need to know?
- What kind of words do you use when talking to families?
- Are you sure the words you use are easy to understand?
- How often do you rephrase or check that families have understood what you are explaining to them?

Many families in rural areas are not able to get a diagnosis from an audiologist or even a hospital hearing test. The testing centre may be too far away. Many are afraid to go against the recommendations of family members, as Felicia did. They are likely to feel confused when their child is not learning to communicate.

It can be hard for service providers to understand what it is like for parents as they struggle to come to terms with their child's deafness - especially when they have no personal experience of childhood deafness.

Families can play a role in their deaf child's development. It is therefore very important that any information given to parents is clear from the beginning. Many parents look to professionals or service delivery organisations for solutions. Information about deafness should be positive and empowering. It should not create dependence on an "expert".



### Helping parents understand deafness, Bangalore, India

One of our greatest challenges is making parents independent of us. Information can help them to be more independent. Our own attitude can also help to promote independence. Most parents look to "experts" for everything. They feel they can't know what we know. They would rather we took responsibility for everything. The more that parents can understand how to read an audiogram, how to make teaching materials, and teach language, the more involved they feel, the more responsibility they will take.

**2.4 Usha Rani, CBR Manager,  
Association of People with Disability, India**

## Making information useful

The first challenge is to make information available to families and communities. The next challenge is to make information **accessible** to parents. It is important to think about what you say (content) and how you say it (format).

- The **content** of the information may not reflect the context of families. It might have been developed for an urban audience or an audience in another country.
- The **format** of the information may not be accessible
  - written material might not always be accessible – how literate are parents, how often do people read, what about vision problems?
  - the language used may not be familiar to the families – technical words, jargon or fancy writing / speaking styles might not be accessible.



## Basic principles

### 1. **Respect** parents' own knowledge about their child and their own needs.

Parents have a lot of knowledge about their child's language, and behaviour. If you are not aware of their knowledge, then the support you offer might not be helpful. It might not be easy for parents to share this information with you – so make sure you give time and space for them to do this in a friendly, non-threatening, way.

### 2. Be **positive and practical**

Acknowledge that families find having a deaf child tough. There is no point in pretending everything is fantastic and without challenge. Be sympathetic about parents' feelings and worries. However, you don't need to add to their fears. Try to use positive language.

Instead of saying: "I am so sorry it seems your child is deaf..." or "Your child has failed the hearing test", say: "Your child is deaf. I know that this will be a shock, but there are people who can help."

Talk about positive examples, opportunities and practical steps. Most people won't automatically know what to do.

Some examples:

- Keep talking and communicating with your child.
- Use gestures to give everyone in your family a name and teach your child these names.
- Use gestures to refer to household objects.
- Use facial expressions to convey emotions – for example, happiness, fear of danger.

### 3. Be **realistic**

It is important to raise expectations as most families have low expectations of what they and their children can achieve. However, every child and every family is different and it is important to take this into account.

### 4. Be **empowering**

Information should be designed to give parents knowledge, confidence and a feeling that they can do it!

### 5. Be **creative**: there are many ways to find out about things, for example:

- Visual information - posters, pictures, cartoons.
- Meeting other people, listening or having a conversation (deaf or parent role models, meetings, radio programmes etc.)
- Public events, for example dance or theatre performances, community forums etc. These can motivate people to learn.

### 6. **Keep it simple and memorable**

- Use accessible language – check through for technical terms, long sentences and difficult words.
- Simple messages are the easiest to understand and the most memorable.
- Use stories and examples to help families understand a point – so rather than saying “Deaf children can go to school and learn to read and write” Tell a story of a deaf adult that you know – better still give families the opportunity to meet a deaf person and talk about their experience of education.

## Positive information in practice

The following case studies aim to demonstrate a few of the many varied and creative ways that information about deafness can be shared with families and communities.



### Making information visual, South Africa

Parents of deaf children in the rural areas of South Africa are unlikely to have access to information about deafness that reflects their homes and communities. In addition many have limited education and find written information hard to access. With Deaf Child Worldwide funding, Sign Language Education and Development (SLED) has been working to produce a toolkit, to help community workers and schools deliver this information. Designed by a Deaf and hearing team, a flipchart and video conveys information in a visual and easy to understand format.

As many parents in rural areas have limited literacy, there is an emphasis on visual information. Key themes are communicating using South African Sign Language, getting help, starting to learn, keeping your deaf child safe and praising your child.



#### Contents of the toolkit:

- A mini-dictionary in a booklet and on video/DVD covering family focused vocabulary, using English and illustrations.
- A video and DVD - Understanding your young deaf child. This is aimed at all families and gives examples of successful communication between deaf parents and their deaf children.
- Flip charts containing similar information to the video for use where there is no video player. The flip chart has pictures which support the work of a social worker. There is text on the reverse of the flip chart to help the social worker remember the most important points to cover with families.
- A wordless picture book and video/DVD showing a signed story which is an excellent tool to help teachers and parents read to their deaf children in sign language.

Continued

Some learning from the toolkit

- A needs assessment can help to find out what information is important before developing materials.
- Visual accessibility helps where families speak different languages and where many families are not literate.
- Involve parents who are deaf as well as those who are not in selecting and producing information.
- Information provided on a flip chart does not need any technology!
- Disseminating the materials and making sure they are used is just as important as producing them.
- It takes time to produce high quality materials – but it is worth it!

### 2.5 Sign Language Education and Development (SLED), South Africa

## Making information part of an event

Many people find it easier to learn through conversation or listening. So families may learn more when they have the opportunity to meet others. Such hands-on events give families the opportunity to actively discuss their experiences and address their concerns with other parents and with professionals in a supportive environment. These meetings can also become the starting point for a group or association – see Chapter 3.

The following example from India points to the importance of information-sharing meetings for families:



#### Information days for families in Karnataka, India

A series of information days were conducted in Karnataka by VOICES. This is an Indian NGO that uses new ways of sharing information to empower communities and create social change. The information days had the aim of enabling and empowering parents and other stakeholders to make the right choices for their deaf child.

It is important for families to be able to make “informed choices”, where a choice of services exists. Ideally parents and other

Continued

stakeholders should be able to understand all the available options so that they can make a decision about what is best for their child. They should not have to follow “solutions” that have been prescribed for them by professionals, without understanding the alternatives and the impact of that decision.

Families shape children’s lives. However many organisations working in India think that parents do not actively participate in the lives of their deaf children. The main factor is the lack of communication between parent and child. Other problems include parents’ lack of education; parents not having enough time because they are wage earners; and simply a lack of awareness. IDCS-India and VOICES felt the need to reach out to the parents in a way that made them feel comfortable and without making too many demands on their time and resources.

When VOICES held their first information day, they invited deaf adults and parents. Many deaf adults attended, but no parents of deaf children. The deaf adults were very vocal about their problems and issues. The information day was conducted in an informal way and deaf participants were asked to discuss the challenges they faced. Some deaf people complained about isolation and conflict in the family.

It was clear that parental involvement was necessary to address many of the issues faced by the deaf adults. The communication problems originated in the family when the deaf family members were very young. Ten parents participated in the second information day. The parents attended because they were curious. A panel of professionals was present at the information day to answer queries raised by parents. Parents’ queries included questions about: the audiological aspects of hearing impairment; the medium of instruction in schools; higher education opportunities for their children; the methods of accessing government schemes; and requests for financial assistance.

At the close of the second information day, the parents came up with solutions for some of their problems. The information day provided them with a common platform where they could meet, discuss issues, compare notes and encourage each other. These meetings also served as an excellent platform to promote advocacy. They promised to bring other parents along to future information days. An information day will now be organised exclusively for parents.

**2.6 Ekta Mittal, VOICES, Janani Raghupathy,  
Sandhya Srinivasan, IDCS-India**

## Other ideas for verbal information sharing

Home visits through community based support programmes are a very successful way of delivering information. Information delivered by a deaf person or a parent of a deaf child can be particularly effective. See Chapter 5 about community based support for more information about this.

Community radio has often been used to raise awareness in communities about deafness. In Pakistan, community radio was used, as it was difficult to reach families in rural areas. A series of radio interviews were broadcast where parents of disabled children discussed their concerns with an advisor. The aim was to ease anxiety and indicate action that could be taken.

The National Institute of Hearing Handicapped (NIHH) in India runs a telephone helpline for families. This can work well where families have access to a telephone and where the helpline can be well advertised.

An SMS (telephone messaging) service would also be accessible to deaf people and would be cheaper. It might be useful for conveying simple information to families, for example, the address of the nearest school, unit or hearing test centre.

## Arts and drama

Making information enjoyable to access often has the most profound impact of all. Art, dance and drama have often been used as tools to raise awareness of deafness. Kweku Addison describes how he and his dance group take their deaf awareness message to communities in Ghana:



### African Footprint - a deaf and hearing dance group, Ghana

I knew that I needed something to attract people so that they would come and hear my message. African dance became the tool. Performing around Cape Coast attracted interest in the group and helped the deaf and non-deaf dancers realise their unique talents. In turn, this broke down communication barriers. The message of the group makes the social model of disability easy for people to understand. After watching the dancers perform, the audience are asked: *Come up here and dance with us. Then we will ask you who is disabled?!*

**2.7 Kweku Addison, African Footprint, Ghana**

Being involved in drama does not only have a profound impact on the general public, it can also be used to enable parents and families to see their children's skills and abilities in a different light.



### Raising awareness through drama, Morogoro, Tanzania

Many deaf children in Tanzania face social exclusion. Declarations and Conventions that are meant to benefit these children have no meaning in poor rural communities. Most people are not aware of the fact that a deaf child may be entitled to any rights.

The Kilakala Unit for the Deaf in Morogoro town, Tanzania, has made an attempt to overcome social barriers for deaf children. In May 2003 the Unit initiated an integrated early education programme in cooperation with the Dutch based Tanzatoto Foundation. A drama group, mainly consisting of young deaf people, plays an essential role in the programme. The main aim of the group is to promote community awareness about the needs and rights of deaf children by providing plays containing useful information which are then followed by discussions with the audience. Demonstrating young deaf people's acting abilities helps to challenge negative attitudes. The theatre group is coached by a professional drama teacher and the sign language teacher from the Unit.



Theatre helps young people express themselves and can involve the whole community

It took time to find teachers with enough signing skills, creativity and motivation to support the group. A deaf volunteer from Holland provided much needed expertise. She worked closely with a drama teacher from the capital, Dar-es-Salaam. Group members are between 9 and 20 years of age and all almost all deaf.

The group has had an encouraging effect on parents of young deaf children. They see how older deaf children are confident communicators and actors. This gives them some insight into how their own young deaf children might develop. We have organised two parents' workshops about "first aid". The drama group acted out some horrible accidents with a lot of humour. This caught the parents' attention, they laughed a lot, and some parents were able to understand some of the signs and take pride in that.

Continued

The drama group members help with sign language teaching. Giving young deaf people the opportunity to teach has a positive effect: the young people realise they have a valuable skill to share and the parents realise the young people know something they do not.

The drama group is contributing to the development of well-informed and welcoming communities in which deaf children can grow up. Theatre provides young people with an opportunity to express themselves and to discover more about themselves and one another.

Seminars on AIDS are organised on a regular basis by NGOs, but deaf young people still have little knowledge about pregnancy, sexually transmitted infections and AIDS. The drama group supports the young people through the process of growing up. Adolescence is a confusing period. There is little information about what happens in their growing bodies. Intimidation and harassment of girls is seen as normal. Deaf girls are especially vulnerable as they do not know how to protect themselves from forced sexual encounters. In the drama group girls learn how to overcome their shyness. It is a place where certain issues such as sex, drugs and AIDS can be acted out and discussed.

**2.8 Monique Bekker, Tanzatoto Foundation, Tanzania**



Think

### Things to think about: being creative

- How do you communicate messages about deafness with families and communities?
- What new methods would you consider having read these examples?

## Parent-to-parent information sharing

Parents of deaf children can themselves be very positive role models. By sharing their experiences and insights with others, parents of deaf children provide not only useful information, but also much needed inspiration for those in similar circumstances.

Some parents have found raising a deaf child a positive experience. Sometimes facing challenges enables people to develop new skills, confidence and strength. Parents of deaf children often have powerful stories to tell about the tremendous and sometimes life altering insights they've gained from their children.

Information that originates with families or deaf people can have more of an impact than information coming from professionals. The following stories written by parents of deaf children illustrate this.

Felicia Foinbaum is originally from Cameroon. She moved to Kenya in order to search for services that would meet her children's needs.



### Challenges and rewards in the search for education, Kenya

I have three children who have all been diagnosed with profound hearing loss: Gerald is 12; Samuel is 8; and Victory is 6. I moved to live in Kenya in order to seek education for our children. Earlier I lost my job because no employer was willing to give me time off to run around seeking help for my children. I still do not have a job since my permit to live in Kenya does not permit me to work. My husband has remained in Cameroon to work and support us.

The culture in which I live sees my children's problem as originating from the spirit world – they say that the gods or ancestors have cursed us for some wrongdoing. The feeling of shock, embarrassment, inadequacy, confusion and worry about how to cope with the enormous task were immediate. Learning more about deafness really helped me to cope and to come to terms with the problems that my children face. I try to stay strong so that my children are not affected emotionally.

I wanted my children to pursue the aural/oral approach. So six years ago they were fitted with hearing aids at the ages of six, three and two. The results have been encouraging, but I am still not totally happy with the education which is available here in Kenya. I wanted my children to learn in mainstream schools alongside children who are not deaf. The schools that accept deaf children are extremely expensive. The hearing aids and school fees take up a lot of our resources.

I have learned a lot from professionals, other parents and from the internet. It has been an education for me! Learning has also helped me to be able to cope better. In particular, I found it useful to:

Continued

- register with the John Tracy Clinic correspondence course in the USA;
- read books, magazines and websites about hearing impairment;
- talk to professionals in the field;
- talk to other parents to learn from their experiences.

I have done things that I never thought I would be able to do. I have completed my studies and am now a diploma holder in management of non-governmental organisations. I have worked with other parents of deaf children to set up HIVO-Kenya - Hearing Impaired Voices of Kenya, an organisation which supports other parents to access information and support.

### 2.9 Felicia Foinbaum, Hearing Impaired Voices of Kenya

Snigdha Sarkar from India tells us about the challenges and the rewards of raising her deaf daughter and how it changed her and her family for the better.



#### Broadening horizons, India

When I look back to those early days, I realize that we did not give in to self-pity. My husband and I never asked why this happened to our daughter, Sneha. Instead, we discussed the things that needed doing. We did not listen to lay people's advice, including our relatives. Now I know that we were right. Within a month of realizing our daughter was deaf, we found PKK – Pratibandhi Kalyan Kendra in Bandel, Hooghly. I am one of those few lucky parents who had to waste very little time before reaching the right place.

PKK took a holistic and comprehensive approach that aimed to support parents and families. It helped them access information, learn new skills and develop positive attitudes. The pre-school programmes for young deaf children placed emphasis on a natural aural approach. The teacher worked with the deaf child along with the mother to enable her to learn the skills. Regular workshops were held to enhance the knowledge and understanding of parents.

Continued

They also had a very good individual and group counselling service for the parents, and extended families. It was a concept of “all under one roof” that PKK promoted especially because they worked with people from very diverse backgrounds. Many of the people who went there would not have been able to access any other services. We met other children and parents at PKK and that itself was a great learning experience. We also saw parents coming from difficult situations due to poverty, distance or a non-cooperative family. When we saw older children who could speak, we became hopeful that our daughter would also learn to speak.

We were also lucky that we lived in a city and had the education and resources to access the facilities for our daughter. Most people (70%) live in rural areas and have almost no access to the services in urban and semi urban areas.

Sneha is now 15. She is a balanced, well-adjusted child in class 9. She learns an Indian form of classical dance, Odissi. She trekked to Sandakphu at the height of 4000 metres in the mountains of Darjeeling, in the Himalayas, when she was in class 6. She knows she has a hearing difficulty but she also knows that she has to cope with it like any other problem. She has friends at school and is confident and happy.

These successes have tremendous toil and struggle behind them. People often refer to the experience of realising your child is deaf as a tragedy, a catastrophe. But the arrival of Sneha in our lives has given us so much, has broadened the horizon of our lives to such an extent that we cannot think of our lives being different.

We have learnt with her, grown with her and are still growing. She has opened a new world for us that gave us opportunities to get to know really good people. We witnessed the suffering of other families and children, making our troubles seem insignificant and this has transformed our lives. Today I am planning to start practising law (which I had given up for my daughter) with a new perspective. What I had planned to do only for myself has turned out to be an inspiration for me to help others. I would have never learnt to think for others if I did not realise that some people somewhere had thought for her even before she was born.

**2.10 Snigdha Sarkar, India**



### Positive attitudes – a mother's story, India

I often ask myself: "Would I have it any other way?"

If we are talking about the thousands of conversations that Natasha is cut out of; the strain in her eyes from constantly following lip movements; the opportunities lost; the negative and hurtful attitudes and behaviour; or the way society is organized to suit those who can hear; then the answer is: "Yes. I would like these things changed".

But if you are asking me of the growing; the learning; the fun we have in each other's company; the challenges we have met and overcome successfully; and the hopefulness with which we have learnt to look at the future; then the answer is: "No – I would have it no other way". I wonder if the latter is possible without the former?

**2.11 Erica Taraporewalla, India**



### Things to think about: individual stories

- What have you learnt from these individual stories?
- What is the value of parents learning from each other?
- How would you facilitate this learning in your community?



### Learning from this chapter

- Most parents know very little about deafness when their child is diagnosed.
- Support from the early years is important.
- Information, support from other parents, or a professional organisation can make a big difference to families.
- Parents often do not understand the words that professionals use.
- Simple and accessible information is essential – it needs to be in a format which parents can understand.
- Balanced information about available services is important to families.
- A range of different support “under one roof” can be very helpful.
- Awareness raising is needed to counter negative perceptions of relatives and community members. There are lots of creative ways to raise awareness.
- Emotional support is just as important as technical support in developing a positive attitude.
- Meeting other families can be a source of motivation and inspiration.
- Parents find it helpful when professionals think carefully about the words they use to communicate about deafness.



# 3



## Family groups and associations

### Chapter aims:

- To highlight the purpose and benefits of parents' groups
- To acknowledge the challenges that families face in coming together
- To provide practical examples of groups which have overcome challenges
- To provide advice and guidance for professionals who facilitate parents' groups

More information on groups' activities can be found in Chapter 7 - Taking Action

## Why come together?

Families come together for a variety of reasons. Sometimes a facilitating organisation supports a group of parents to get together and sometimes parents themselves take the initiative to form a group.

Many parents feel lonely and isolated. They may be frightened, confused and unsure of what to do next. It is very hard for professionals to understand how parents are feeling and to offer the emotional support that parents need so badly.



### Building parents' confidence – the story of a parent group leader, India

The parents are very isolated and some felt quite helpless and frustrated. This is where the strength of working as a group lies. It is a place where a mother can pour her heart out. This is something that she cannot often do, even at home for various reasons. In a group the feeling of loneliness and helplessness gets removed. This is gradually replaced by self-confidence and motivation. For some mothers, the problems of their children occupy their time so much that life is all about problems, but in a group this burden is lifted slowly.

#### 3.1 Snigdha Sarkar, Anwasha parents' group, India



Many parents start with a low expectation of their own abilities. Some say they are “too poor” or the meeting is “too far to travel” or that the members have “too little education”. Often groups want professionals to guide them. Despite these challenges, parents’ groups can be supported to play an important part in their children’s lives and in the life of the local community. Often all it takes is some sensitive and encouraging facilitation.

Although parents’ groups start for different reasons, the activities involved can often be similar. Groups can act as:

- a source of emotional support
- a forum for information sharing that gives parents skills and confidence
- a place to get training on sign language or other communication techniques
- a focus for discussion and action

In this chapter we look at examples of groups which have been involved in these activities and examine some of the challenges which groups face.

## Supporting parents to come together

Outside agencies often take the first step in bringing parents together. They help raise awareness and motivate parents. Parents can benefit from the knowledge, advice and resources that professionals and others can offer. Parents are unlikely to take action without support or earlier experience. Supporting parents to come together helps parents to see for themselves how a group can be useful and can help parents to develop the skills that they need to sustain a group in future.

Consultation with families in planning group activities is essential. The best outcome is that parents themselves feel ownership of the group. This will only happen if professionals treat families with respect and do not patronise, or look down on them.

## Inviting parents to a group

One of the first challenges in starting a group is to identify parents who might be members. Groups may spring up around schools or centre-based services, but it is important to remember that in some countries, the majority of families are not in touch with such services and this very first step might require initiating outreach activities or linking with an existing community based support programme.



### Finding parents of deaf children in northern Namibia

The Association for Children with Language, Speech and Hearing Impairments of Namibia (CLaSH) received a one-year grant from Deaf Child Worldwide to reach out to parents in a rural area of northern Namibia. The majority of these parents faced numerous challenges in their daily lives, they lived far away from each other, they lacked even the most basic information about hearing loss and many were not immediately convinced of the need for a group.

One of the main costs to CLaSH in running this project was to recruit and hire a “Community Facilitator” who took on the role of identifying families and facilitating meetings. Identifying parents who would benefit from the project in such a sparsely populated rural area, without public transport and telecommunications systems was a challenge, even with a dedicated staff member:

A number of methods proved successful:

- Making use of the links between CLaSH and the mobile audiology unit, HARK. This is a SoundSeekers project, see the Resources section for more information.
- Linking with other individuals who are responsible for identifying deaf children such as the HARK nurses, medical rehabilitation workers, regional school counsellors and the VSO Namibia Disability Programme.
- Using the radio to announce the meetings. This included calling already identified parents by name and making general appeals for parents of deaf children to attend.
- Asking parents to refer other parents to the group (as the project went on the number of parents attending meetings increased).

Where possible the project staff linked with the mobile audiology unit to test the hearing of newly identified children. Each time a new family was identified, the project gathered background information about their deafness and whether they were at school. In a few cases, the community facilitator made visits at home to encourage families to attend parents’ meetings and to collect information, but the distances to travel unfortunately made such home visits unsustainably costly and difficult.

Linking with hearing test services helps promote a group to potential members



Continued

By the end of the project, staff had collected the names and contact details of around 200 parents whose profoundly deaf children age 5-17 were not accessing school.

When these parents attended group meetings, they were able to get involved in specific actions. The groups became a focus point for parents to take action - these actions included:

- learning about deafness and developing communication skills;
- carrying out local-level advocacy about the lack of educational opportunities;
- setting up a pre-school for deaf children in a previously unserved area

### 3.2 Heide Beinhauer, CLaSH, Namibia



Think

### Things to think about – starting a group

- How would you tell parents about a group in your area?
- What would the focus of a parents group be?
- How would you encourage parents to join the group?
- How would you sustain their interest?

## A reason to meet

Parents are unlikely to feel motivated to attend group meetings unless they benefit from the meetings. This could include emotional support as well as communication skills. In Namibia, the payment of transport costs, food and sign language learning resources motivated and helped parents to attend. In addition, the community facilitator and other invited speakers gave information about the causes of deafness, traditional beliefs, educational opportunities and the lives of deaf adults. All families expressed a need to learn to communicate with their child. So, each meeting contained some sign language training on relevant topics, such as: family members, greetings, domestic animals, emotional and religious words, household chores and colours. Booklets depicting basic Namibian Sign Language were distributed to all the parents.

As it often has immediate practical benefits, learning sign language or other skills which help deaf children to learn language and communicate is often the way in which parents groups and associations start.

However, the value of sign language may not immediately be understood, so more general awareness raising activities might be needed to convince families of the effectiveness of this. If there are doubts about whether sign language can be used to convey the same ideas as spoken language, it can be helpful to use the examples of the deaf MPs in Uganda and South Africa – both of whom use sign language for parliamentary business.

This example from a family sign language course in Somaliland shows how some parents can become committed to learning sign language when they realise how this can change their relationship with their deaf children.



### Communication beyond nodding – a mother's story, Somaliland

Deega is a single divorced mother who sells milk to provide for her family of six. Deega's son, Abdiaziz, is 12 years old and has been in school for 2 years. Deega has been learning sign language. She reports that:

"I decided to take part in the sign language course because I want to learn the language of my son. I hope that every message between me and my child will be clear and without problems. I am eager to learn enough sign language to communicate with him well. I am ready to attend further courses for sign language. I am requesting this course not to be the last but to be the first.

Continued

Actually, in the first days I had a problem with how to move my fingers, so I was a little bit afraid that the other parents would laugh at me, but later on I relaxed and learned how to use my fingers.”

One challenge Deega faces is that she does not have time to sell milk when she attends the course. But she feels it is worth doing. She says:

“My son is playing a more important role in the family now. Since the course started I can send him to go shopping around the corner. We understand each other better than before. The self pity he had has disappeared. Now he talks more to me. I facilitate communication between my neighbours and our son. So I became a little bit of an interpreter.

Before the course it was difficult for me to understand any messages he brought from the teacher. So I often had to come to the school to ask for help. I understand some signs and try to teach what I’ve learned to the other family members. For example now there is a little girl from our family living with us. She is the same age as my son and has learnt most of the signs. So mostly they play together, but she cannot yet understand everything he says.”



Abdiaziz says he is happy that his mother is doing the sign language course because now he has a partner to communicate with: “Before my mother joined the course, it was difficult to understand her. Mainly we used head nods to communicate and in general I mostly used to say “yes” to whatever she said. Now this has changed and we can communicate better.”

### 3.3 Ulrike Last, Handicap International, Somaliland

It is not easy for parents to realise the value of learning sign language. Sometimes professional organisations need to encourage parents to come along. The Kenya Society for Deaf Children (KSDC) and Deaf Child Worldwide worked together on a sign language project which involved about 100 parents from five urban areas in Nairobi. One of these parent groups was from Korogocho, which is home to 150,000 people. It is considered one of the most densely populated and unstable slums of Nairobi. KSDC faced many challenges in reaching parents in this area. Initially parents were unwilling to get involved in the classes. After some time families came to appreciate the group and around 20 parents regularly attended meetings over a three-month period.

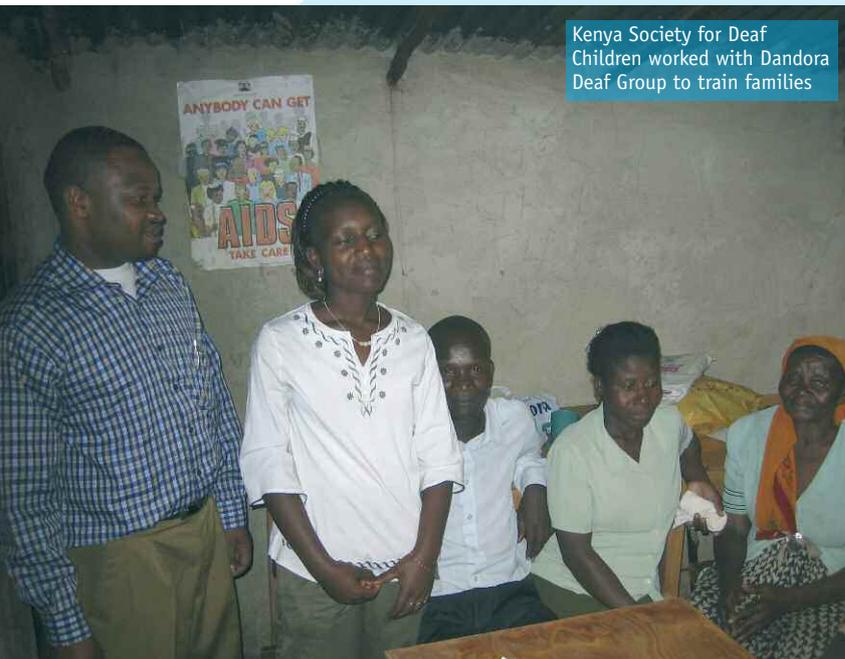


### Encouraging parents to meet, Kenya

The existence of a community-based rehabilitation (CBR) programme run by the Catholic Church in Korogocho slum meant that the Kenya Society for Deaf Children (KSDC) was able to work with the existing CBR workers to identify and communicate with the parents of deaf children in the community. However the initial invitations to parents for sign language classes did not meet with success. The parents were very reluctant to attend and attendance at the first few meetings was poor.

Parents were happy for their children to attend the informal school run by the CBR programme and did not understand what they could gain from participating in meetings. However, most acknowledged that their ability to communicate with their own children was limited.

#### Introductory meeting



Kenya Society for Deaf Children worked with Dandora Deaf Group to train families

The first meeting was organised in a hotel outside of the slum. Food was provided and parents were invited to attend. The purpose of this meeting was to use the pleasant environment as motivation for parents to attend. The space in the meeting gave parents an opportunity to think about how learning sign language could improve family communication and what else KSDC could offer in terms of referrals to schools, and government audiology services. Although this exercise had a financial cost, it attracted a relatively large number of parents and was a turning point in parents' attitudes.

Although parents attended for the "wrong" reasons, the meeting provided a space for parents to become aware of the "right" reasons. Presentations from active parents of deaf children from other areas of Nairobi were a key part of the workshop. It was made clear that the meeting would not be held in the hotel again. Future meetings would be held in Korogocho and would require commitment and motivation.

Continued

### Parents attend sign language classes

Parents were encouraged to attend informal classes as often as possible. The children of this group of parents went to the informal school funded by the CBR programme – but only if their parents attended the classes! Parents decided when the training sessions should be run, and this was kept flexible. This helped parents to attend more regularly.

KSDC organised a playgroup in the holidays alongside the classes so that the deaf children and their siblings could learn Kenya Sign Language (KSL). This enabled them to access learning and play opportunities outside school time. A young deaf woman from Korogocho was employed to run the play group on a part time basis.

The Dandora Deaf Group came from a neighbouring area to provide training in sign language for the parents. This also gave parents an opportunity to meet deaf role models as well as fluent users of sign language. Learning sign language became the main motivation for parents to attend group.

#### 3.4 George Gachanja, Kenya Society for Deaf Children and Kirsty Wilson, Deaf Child Worldwide

This group went on to get involved in other self-help activities that met the immediate needs of the families involved. See Chapter 7 for more information about this. Despite the fact that this group was reasonably successful, there were some important considerations which KSDC realised could be taken account of in the future:

- Greater efforts could be made from the beginning to involve parents in designing the timetable and the contents of the course.
- It would be useful to include information about other topics – such as education, causes of deafness as well as Kenyan Sign Language training.
- The trainers from the Dandora Deaf Group had studied at residential schools where they learnt English. Yet the families involved in the project mostly used Kiswahili and so would have benefited from an interpreter or from resources in Kiswahili.
- Enabling parent groups from different areas of Nairobi to meet each other and discuss their plans for the future would both motivate parents and become a source of ideas.



## Basic principles for family sign language training

- **Involve deaf people.** Deaf people are the experts in sign language. If it is not possible for deaf people to be the lead trainers in your sign language training programme, they should be involved as training assistants with the aim of developing their ability to lead training in the long term.

### Planning

- Do not try to train more than 12-15 people at once.
- Plan to meet the communication needs of all families. Use local languages, visual training materials, and provide translation if needed.
- Develop handouts and teaching resources. Use visual resources in the class and give trainees resources that they can keep and refer to at home.

### Teaching

- Think about words and communication techniques that will be useful to the families in “real life”, when you plan your training topics. Use the trainees to suggest words and phrases that they need to learn.
- Don't just teach words - think about how to teach communication – sharing information, asking questions, giving direction, telling stories etc.
- Make sure there are opportunities for trainees to actively participate and practice what they have learnt.
- Leave plenty of time for revision and repetition. Revise previous weeks' topics at the beginning of each session.
- Give positive feedback.

### Logistics

- Hold the training somewhere easy for parents to reach.
- Consider refunding transport costs or providing refreshments. Take regular breaks.
- Think about motivation to complete the course. Will you award the trainees with a certificate of attendance or achievement? Can the training course be accredited by a training institution?

### Follow-up

- **Create an opportunity to discuss experiences of using signs outside class.** This can help trainees to encourage each other, and could give you ideas for topics to cover in the future.
- **Give trainees an opportunity to provide feedback at the end of each training session, but think about how this can be done in private so trainees are not afraid of letting the tutor know how they really feel!**
- **Encourage trainees to set their own objectives and goals at the beginning of the training and ask them to evaluate whether they have achieved them at the end.**
- **Encourage the trainees to plan for continuing their sign language learning after the training session.**

## Becoming more sustainable

Ensuring that the group genuinely meets the needs of families is most easily achieved by giving families the opportunity to make decisions about it. In addition, groups where parents feel a high level of ownership are much more likely to be sustainable. However, giving parents the opportunity to take ownership does not just mean “leaving them to it”.

Professional organisations can encourage and support parents to take the lead in parent groups. They can also help in making such groups sustainable.

Teachers in units for deaf children in Bushenyi District, Uganda received funding to involve parents and families in sign language lessons at the school. (See Chapter 7, for more information). However the future of the project will depend on the parents.



### Becoming a group, Bushenyi, Uganda

Teachers in Bushenyi District organised sign language classes for the parents of the children in five integrated schools, where there was a unit for deaf children. The project has been a big success – parents enjoy learning sign language and there is better communication between students, parents and teachers. Plans for the future will depend on how each group makes the step from “coming to meetings and getting something” (lunch and some money for transport) to “being a group” and having to develop it. The teaching staff are confident that the groups will keep going –

Continued

but only time will tell. The continuation of the groups will depend on the initiative of one or two parents or the teacher. The plan is to make sure the groups keep going and to keep the connection between the parents and the school alive.

**3.5 Nathalie Arinda, Education Dept,  
Bushenyi District Government, Uganda**

In the example earlier in this chapter, The Association for Children with Language, Speech and Hearing Impairments of Namibia (CLaSH) described how they set up a parents support group in Northern Namibia. Learning from this project helped CLaSH develop some simple suggestions for helping to ensure parent ownership and sustainability of parent groups.

The group in Northern Namibia was facilitated by an employed community facilitator, but gradually a greater sense of ownership was developed by parents themselves.



### **Advice on parent ownership of parents' groups, CLaSH, Namibia**

Each meeting allowed time for the following activities:

- Discussion and peer support on sign language learning and family communication.
- Discussion and agreement on purpose of the group and action planning for the way forward.
- Appointment of office bearers and representatives to carry out specific tasks.
- Evaluation and feedback on the contents of the meeting.
- The date of the next meeting.

Decisions were made by the parents about reducing provision of drinks and snacks for meetings by the organisation. The need for members to make a small contribution to the cost of meeting was agreed as a group. Those who really struggled to pay were able to make reduced contributions. Parents themselves took the lead in making sure fair contributions were paid.

In May 2005: "A resolution was passed that we can meet by ourselves to discuss issues even if the community facilitator is not there".

**3.6 Heide Beinhauer, CLaSH, Namibia**



## Basic principles in facilitating parent groups

### Parents have a lot to offer

Facilitators should stress that parents have a lot to offer their children, each other, and other service providers.

### Time to talk

Time should be allowed for discussion and sharing of ideas and experiences. Parents should be encouraged to offer each other advice and support, rather than only seeking advice from professionals. When discussions are held with professionals, this should be led in an empowering way – ideally by a parent.

### Self-determination and control

Parents should have the opportunity to discuss when and where the meetings should be held. This will mean that parents are less likely to drop out of the group at a later stage.

### Organising meetings

The meetings should be as fun and relaxed as possible. Consider how you organise the chairs for meetings, and if possible make it easy for parents to make eye contact and discuss openly. Concentrate on building relaxed relationships of equality and trust. Try to avoid having a “high table” in the room. Consider how you can ensure equal participation of both men and women. Even if equal numbers attend, this does not necessarily mean equal participation!

### Financial sustainability

Parents should be encouraged to consider how they can contribute to the costs of the meeting. Even if parents cannot make a financial contribution, a contribution could be made “in kind” – food could be provided for meetings, for example. Project staff should be open about the budget (if funds have been raised from a donor) and what will happen when it finishes.

### Confidence

Potential leaders should be identified from the parents’ group. They will need confidence and a sense of responsibility for the task. The final decision about leadership of the group should be made by the parents themselves.

### Group activities

Parent groups are likely to have a wide range of interests and needs. Activities could include various types of training, such as:

- sign language;
- how to get support from professionals;

- encouraging communication with their children;
- developing vocational training opportunities.

It is also important to arrange social activities and celebrations, or fundraising events, to maintain the group identity, raise funds and reinforce friendships between the parents and their children.

## Moving from professional-led to parent-led groups

Many parent-led groups experience a transitional period as they move from being controlled more by professionals to being more parent-controlled. It can be difficult for professionals to find the right balance of providing support and encouragement without dominating a parents' group. If professionals try to control the parents' group, it will struggle to form its own identity and sense of purpose. Yet too little support could mean that parents' groups may lack knowledge, confidence and capacity for self-determination.

Sometimes administrative support is what parents need most. This prevents parent groups being side-tracked by time-consuming administration. A parents' association set up at the bilingual school in Mexico had very little administrative support. This made it hard for families to get together.



### The early days of a parents' group, Mexico

I really didn't have any experience in managing a parents' association. I was seriously disappointed. There were only 10 or 12 mothers supporting us - it was always the same people. We tried to meet when there was a special day, such as International Children's Day but many people didn't get involved - it was very frustrating. Maybe I didn't have enough experience to motivate people. Maybe we just didn't get on well together. I tried, but it just didn't happen.

At the end there were so many problems. Small details became big problems. I just didn't know what to do. I searched the internet to find another parents' association. I found one in Monterrey and downloaded all their statutes and other useful information.

It was the first parents' association in Mexico City. We didn't know what we were doing. We didn't have enough time because we all

Continued

worked. It was a good experience for all of us. I imagine the current association has learnt from our experiences, positive and negative.

### 3.7 Rita Hernandez Sarabia, Mexico City, Mexico

The Mexican group clearly needed more support in building up a core group of families. External help in managing finances and setting up administrative procedures could have helped other families understand more about the way that the group was being run.

Families at the NZEVE centre for deaf children in Zimbabwe have a good balance between external support and self-determination.



### Parents making their own decisions in Zimbabwe

A recent evaluation of the Nzeve deaf children's centre pointed out to us that the parents weren't really involved in decision making. It was the staff who made the decisions. The parents' group was just one part of the work with deaf children. The parents planned their programme each school term, but they were not involved in the strategic planning of the organisation. Originally we had a parent on the board, but when that parent left she wasn't replaced.

We held a parents' workshop in order to ask the parents if they would like to start their own parent support group. But before we got to that point, one of the fathers stood up and said: "We could have our own support group." The group represented the parents of the children in the pre-school as well as those in the resource units for primary school children. It was fantastic! It was exactly what we wanted them to do and they did it before we said anything. So they now have their own support group. As far as I know they are the only support group for parents of deaf children in Zimbabwe.

A staff member of Nzeve attends the parents' group, just to provide administrative help. She takes minutes, types them up and sends letters out to people, as required.

### 3.8 Libby Foster, Nzeve Deaf Children's Centre, Zimbabwe

The Hargeisa School for the Deaf in Somaliland, together with Handicap International and Deaf Child Worldwide, supported a group of parents to register their group and develop an action plan. The project team asked an NGO, the Capacity Building Network, to facilitate two meetings. This ensured that the families had access to appropriate support.



### Facilitating the development of a parents' group, Hargeisa, Somaliland

A committee of parents of deaf children was set up in 2002 at the Hargeisa School for the Deaf. In June 2006, the school organised a two-day workshop for parents in order to discuss how this group could go forward. Also - how the group could contribute to improving education for their deaf children. Forty six parents participated.

The workshop was facilitated by the Capacity Building Network. Its role was to guide parents in their discussions. They outlined some important questions for parents to think about when discussing the development of a formal organisation.

A second workshop was organised a few months later to establish an action plan for the parents' group. As most of the parents are illiterate, the meeting consisted mainly of discussions about the group's activities.

**A list of the questions discussed in the workshops and a sample Memorandum of Understanding is available from the Deaf Child Worldwide website, but some examples are:**

#### Needs analysis

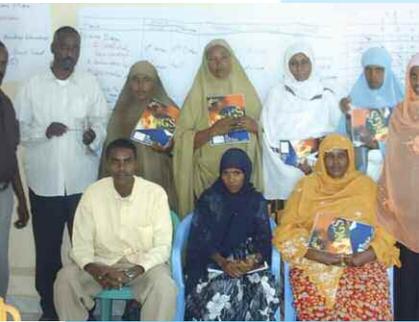
- How was your organisation created?
- Who are the members?
- What are the challenges that members face?
- What are some of the causes of the challenges?
- What are the most important priorities?

#### Creating a vision

- What do you think the situation should be like?
- What will this group look like in three years time?

#### Action planning

- How can you address the priority challenges?



Registering formally and having a clear action plan helped focus the group

Continued

- What specific action needs to be taken? Can this be broken down into smaller actions?
- What resources are required? How can we access these resources?
- Who should take responsibility for each action?
- When can we carry out each action?
- How shall we report back?

### 3.9 Ulrike Last, Handicap International, Somaliland

## Parent-initiated groups

In some contexts, parents establish their own groups or associations. In general this happens where parents have more time, and resources. These associations automatically have a greater emphasis on parental-decision making than those which are facilitated by professionals. However, the leadership of the group should still consider how they facilitate meetings and activities in a way which empowers the members and can be supported to achieve this.

Deaf Child Worldwide believes that all parents should be supported to implement decisions that they make for their children, as long as it is in the best interests of the child. It is important to recognise the role of these groups and to support them in their activities.



### Anwasha – the beginning of a group, Kolkata, India

In November 2004 a mother of a young deaf child met another mother whose child was in middle school. They talked for a long time about their children and shared their experiences. They felt comfortable in each other's company. The mother of the young child said that she often felt that there were many mothers who did not get proper guidance to help their hearing-impaired children. They decided to organise a meeting where parents could meet and talk about their children and themselves. This was the beginning of Anwasha.

There were five of us on the first day. We enjoyed talking to each other and we felt that we should meet every month. At present we have about 15 families in the group. All our children go to regular schools. They all use hearing aids and we use the oral method of

Continued

communication with them. We work in a small way, but we have realized the benefits of coming together as a group. Although we encourage both parents to be members, mothers play a more active role because they take the main responsibility for their children and they do not work.



Sharing experiences helps families to learn together

We believe that a lack of resources should not restrict our activities. We also believe in developing a clear plan so that we have the maximum possible impact. We have experience of bringing up a deaf child. But we also know that we need technical resources. Three of our members are training to gain technical expertise in teaching deaf children. We are planning to develop information resources. We ourselves would like to address the different needs of our children and their families.

We are not running an institution so we do not have many expenses. Our resources come from the group, as far as possible. One of our members has provided us with free office space. Another member uses her own computer so that we have free communication support. Our child-centred activities are held in members' houses and do not cost us anything. Members pay an annual subscription so that we can meet our small expenses. We are now looking for funding for our future activities.

**3.10 Snigdha Sarkar, Anwasha, India**



Think

### Things to think about – overcoming challenges

- What are some of the challenges for people working together with groups and associations?
- How are roles defined within the group?
- How should power be shared in decision making?
- How can you make best use of parents' and professionals' knowledge?

## Resources for parents' groups and associations

The Indian group may continue to run as a small-scale organisation, providing support to its members. It may be difficult to sustain such groups when the founder members' children grow up.

Some groups start with bigger ambitions. They want to bring about change for a larger group of parents. Funding is very important to support and sustain parents' groups, but it can be difficult to find. Parents may struggle to take time off work to travel to meetings. It may also be difficult for parents to afford membership fees. Despite financial hardships, parents often contribute a great deal of their time and even their limited financial resources to the support of parent groups.



Read

### The Kenya Association of Parents of the Deaf

At first I wasn't in touch with any other parents of deaf children. We had some opportunity to interact with other parents when we visited my son, Stephen, at his residential school. As people came to hear that I had a deaf son, other parents would approach me in Nairobi to ask me to help them gain admission to Kerugoya school for deaf children.

I realised that other parents were not visiting their children at school. These parents could not be blamed for their attitudes. Our society has a lot of stigma and many parents were not aware of what deaf children could achieve. I wanted to change their attitudes. Whenever I spoke to other parents I tried to give them encouragement. I think this helped some parents to believe in their children more. If they gave their deaf children the same attention that they gave the children who are not deaf, then their

Continued

children would be able to contribute something to the family in the future.

It was Dr Ndurumo, a Deaf lecturer, who gave us the motivation to set up the Kenya Association for the Parents of the Deaf. He had seen that a lot of different associations had been set up “by” and “for” deaf people, but they weren’t all working very well. We agreed that parents were vital in helping deaf young people to become successful. Parents can encourage their children in school, follow up with teachers, and expose their deaf children to out-of-school experiences.

He encouraged us to get help in writing our constitution, to form a committee and to register an association. We did this in early 2003 and called it the Kenya Association of Parents of the Deaf. I had taken a long time to find out what to do for my son, Stephen. We wanted it to be quicker and easier for other parents.

Our association reaches out to other parents. I have been to talk to parents at schools for the deaf and at workshops organised by various organisations. I have also used my own money to organise meetings and workshops for parents. So far we have been in touch with over 700 parents. There are so many parents who don’t know that their children are deaf or what they can do for their deaf children. There are parents who don’t know that their children have the right to education in the same way as any other. Sometimes head teachers don’t want to admit children and there are not enough opportunities for secondary and further education for deaf children.

Establishing a formal association helped us to reach out to others. It also means that there will be an institution which will remain in place for the future. Although we had a membership fee for the association, we realised that many parents could not pay this. As we want our association to be for everyone, we made this fee optional. We want to look for funding so that we can hold more meetings for parents.

**3.11 Geoffrey Mukonyoro Wathigo,  
Kenya Association of Parents of the Deaf**

Professional organisations often have a lot of experience in raising funds. Sharing this experience with parent groups and organisations can be very helpful for those groups. This could include:

- sharing information about useful contacts and sources of funding;
- providing help and advice in writing funding proposals;
- helping parents to organise fundraising plans and initiatives.



### Learning from this chapter

- Meeting other families can be a valuable source of support.
- Families have many priorities – often parents need to be encouraged to attend group meetings.
- Making the group meetings useful and enjoyable is the best way of convincing families to come.
- Family communication is a high priority for most parents – groups often use this as a starting point.
- Parent groups should be led by parents – but support in administration and fundraising is useful.
- Parents can achieve much more together than they can alone!

See Chapter 7 for more examples of the way parent groups pioneered new activities.

# 3

## Family groups and associations

# 4



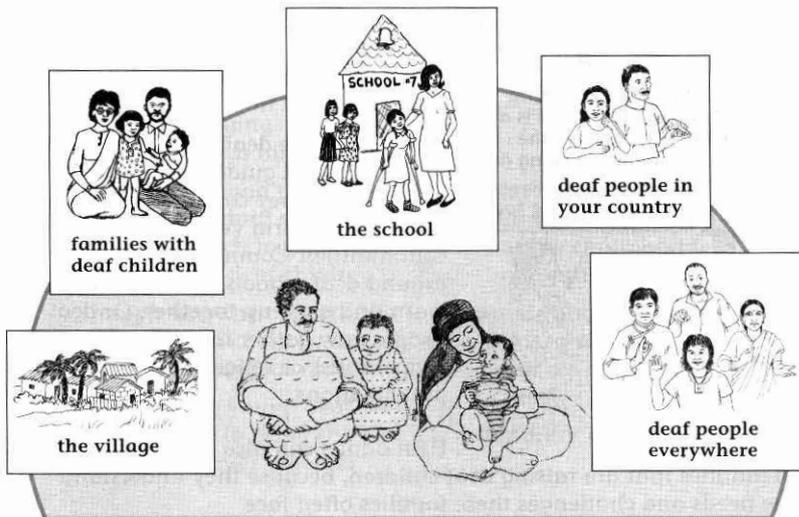
## Working together with deaf adults

### Chapter aims:

- To identify the important role that deaf people can play in supporting families with deaf children
- To highlight ways in which deaf people and families can work together to advocate for the rights of deaf children
- To acknowledge the challenges faced by people who are not deaf working together with deaf people
- To provide practical examples of how organisations have overcome these challenges

Deaf adults have a unique and vital role to play in supporting deaf children and their families. Every deaf child should have the opportunity to meet deaf adults and learn about the experiences of a range of different deaf people.

### Deaf people: a vital part of a deaf child's community



In this chapter we are focusing on the contribution that deaf people can make to families. The involvement of deaf people in education for deaf children, in deaf associations or in the documentation of sign language are equally vital, but there is no room to cover them here.

Many families report that meeting deaf people can have a profound impact on the way they see their child's deafness. Many professionals find working together with deaf colleagues very productive. However, despite this, there are not enough examples of partnership working between families, deaf adults and professionals.

Sometimes deaf adults have negative experiences of their own family life or of their relationships with professionals. In some countries, the Deaf community is only recently coming to realise its role and capacity to create change. Sometimes families and professionals find it challenging to communicate with deaf adults who use sign language. However, when these three groups work together deaf children benefit.

Throughout this book we have provided examples of deaf adults' involvement in responding to the needs of deaf children. Here we highlight how deaf adults can make a particular contribution as:

- role models
- sign language trainers
- advocates

This chapter also looks at some of the factors that need to be taken into consideration in partnerships between deaf people and those who are not deaf.

## Deaf role models

Deaf adults can be excellent role models. By drawing on their own experiences, they can show families that deafness does not need to be a barrier to achievement.



## Sharing childhood experiences, Samoa

In Samoa, the Loto Taumafai Early Intervention Programme (LTEIP), has two deaf fieldworkers, Siaosi and Henry, who visit deaf children and their families in the Samoan islands. The deaf field workers have an excellent rapport with the deaf children and are passionate about the empowerment of young deaf people. They are not only excellent teachers, but wonderful role models for young Samoan deaf children and their families.

The field workers describe their own childhood experiences and emphasise the importance of early intervention. They encourage deaf children by saying: “if you keep going to school and doing your homework, you could be the first deaf person in Samoa to go to university!”

When families first meet Siaosi and Henry they are surprised to see them employed in jobs and clearly able to teach and write notes. Then they realise that their children will be able to use a rich and wonderful language – Samoan Sign Language. They can begin to see possibilities for their deaf children - education, employment, independence and a family of their own.



Deaf fieldworkers are role models for families

It is wonderful to see the excitement on the children’s faces when the deaf field workers arrive at their “fale” (house). They genuinely look up to the field workers. Parents tell us that meeting the field workers in this capacity has given them an understanding and inspiration that their children can achieve the same goals as their peers who are not deaf. They can visualise their child’s future for the first time. Role modelling has definitely been a huge factor for the success of this programme.

### 4.1 Donna Lene, Loto Taumafai Early Intervention Programme

Many families with a deaf child have never had the opportunity to meet other deaf people. Sometimes families are overprotective of their deaf children which can add to the disabling impact of deafness. Meeting deaf adults reassures parents about the future and can help parents make decisions about issues such as communication or education for their deaf child.



### Selecting role models with a range of experiences, UK

In the UK, the National Deaf Children's Society has set up a Deaf Role Models project which will give families the opportunity to meet deaf role models. This programme will select and train deaf role models from the deaf community who have a broad range of hearing loss and experiences – deaf people using all the different methods of communication, deaf people with mild to moderate hearing loss, Deaf people who are active in the Deaf community, deaf people using hearing aids and cochlear implants, as well as deaf people with additional needs (disabilities). This will give parents the opportunity to speak to deaf people with different experiences and to select a role model whose experiences mirror the circumstances of their own child.

The deaf adults will be positive role models for the child and their family, and will share their experiences of growing up with a hearing loss; discussing education and career choices, work and life experiences, sharing their special talents and interests, and demonstrating the use of their assistive devices (if used). This will help the child and their family to develop positive attitudes to deafness. In some cases, we expect that it will be the first time that the deaf child and their family will have met a deaf adult, particularly for families living in rural areas.

#### 4.2 National Deaf Children's Society (NDCS), UK

Families can meet deaf people at a local deaf club or in their daily life in the community. Such meetings do not have to be organised formally. However it is advisable to:

- invest time and effort in selecting a suitable role model
- provide communication support
- advise and train the deaf person acting as a role model.

The following example from South Africa shows the impact of a meeting between a deaf adult and a deaf child and their family.



### Advice about education, Kwazulu, South Africa

In 2004 Nhloso was studying in Grade 1 at Pomeroy Primary School. He was 7 and Pomeroy was the only primary school in the community. Nhloso and his mother communicated using home signs.

Educators from the school support team noticed that Nhloso was having difficulties learning and communicating with his fellow classmates and teachers. Speech therapists and school educators felt that Nhloso would be happier and able to communicate more effectively if he went to a school where he could learn South African Sign Language (SASL). This school would be a residential school and Nhloso's father did not want Nhloso to leave.

The Special Education Services in Kwazulu province provided Pomeroy School with materials on SASL, information on deafness and a video to help Nhloso learn SASL. Unfortunately the school did not have a video player.

A meeting was set up for Nhloso's father and a respected young man of the community who was deaf, together with an SASL interpreter. The deaf man had studied at Vuleka Special School and at the University of Witwatersrand. This meeting helped Nhloso's parents, especially his father, to understand how learning South African Sign Language could help. It was clear to everyone that deaf people can carry a stronger message than departmental officials!

#### 4.3 Bev Garner, Special Education Services, KwaZulu Province

Raising the expectations of families and deaf people can really help young deaf people as role models can influence families and deaf children to be more committed to education, as the following story shows.



### Encouragement to aim high, Nairobi, Kenya

When my son, Stephen, graduated from secondary school, I was keen for him to go to university. However there were no interpreters, so Stephen could no longer study in Kenya.

From the beginning I encouraged Stephen to meet high performing deaf people who could act as role models and help him develop more confidence. Dr Michael Ndurumo was an influential

Continued

person in Stephen's life. He was a deaf man who worked at the Kenya Institute of Special Education and then as a Senior Lecturer at Moi University.

Dr Ndurumo told us about Gallaudet University for the Deaf in the USA. He also told us about the support that deaf students receive in other countries. Stephen applied to Gallaudet and got a place. However Stephen wanted to have the same education as anyone else. He chose not to study in a "deaf university". Instead we looked for a way for Stephen to be supported in a mainstream university. The British Council suggested Sheffield Hallam University in the UK.

Stephen went to study in Sheffield. We travelled with him the first time to support him during the induction. We also visited Stephen every year. This was a big commitment for us, but I wanted to do this for my first-born son. Attending his graduation ceremony was a very proud moment. We also know that he has called us "very supportive parents" to other people. This also gives me the feeling that the struggling has been worthwhile.

Stephen has now returned to Nairobi where he works as Assistant Web Developer for the Kenya Development Tea Agency. He works with people who are not deaf but also has deaf friends and is considered a role model for other young deaf people.

#### 4.4 Geoffrey Mukonyoro Wathigo, Kenya

## Deaf people are all different!

It is important to remember that deaf people have diverse skills and experiences, in the same way that all people do. They also have different levels of hearing loss and communicate in different ways.

Throughout the book, Deaf Child Worldwide uses the term deaf to refer to the medical condition of not being able to hear well. This includes all levels of permanent hearing loss, including mild, moderate and profound hearing loss. Using the Deaf Child Worldwide definition, people describing themselves as having a hearing loss, being hearing impaired, or being hard of hearing would all be included. Deaf Child Worldwide also uses the word deaf (lowercase "d") to describe deaf people who use spoken language and those who use their national sign language.

Deaf Child Worldwide only uses Deaf (upper case D) when specifically referring to the group of people who identify themselves as culturally and linguistically members of the Deaf community. This group of people use the national sign language as their first language and feel that being Deaf means being a minority group with its own language and identity.

The distinction between deaf and Deaf may or may not be very important to deaf people in your community. If it is possible to understand the different attitudes of different deaf people, then it may also be possible to explore how this knowledge and experience could help families make choices about their deaf child.



Think

### Things to think about: describing deafness

- Find out how families, professionals, and deaf people in your community describe deafness. In particular, how do deaf people describe themselves?
- Do the different words reflect the way that deaf people communicate or the level of hearing loss?
- Are the words positive or negative?
- What are the advantages and disadvantages of helping families to meet deaf people from different backgrounds?



### Basic principles for deaf role models

- **Every deaf child is different and so is their family - there is no single solution for all.**
- **Every deaf child should have the opportunity to meet other deaf people and learn about the Deaf community.**
- **Deaf children and their families can gain a lot from having access to deaf role models with similar experiences, ideally from their community**
- **Meeting deaf people can help children and their families to understand and develop positive attitudes to deafness.**

## Deaf people as sign language trainers

Ideally sign language trainers are Deaf people who use the national sign language as their first language. A local Deaf club or the national Association of the Deaf should be the first place to look for groups of deaf adults fluent in sign language. They can usually put families in contact with the nearest deaf adults. Young deaf people who have studied at a school for deaf children will also have good sign language skills.

Deaf people should be encouraged to assist in sign language training sessions at first. Eventually they will have the confidence to lead these sessions.



### Kazakh Deaf Association (KDA), Kazakhstan

In Kazakhstan most deaf children attend residential schools. It is therefore difficult for parents to develop and maintain communication with their children. The Kazakh Deaf Association (KDA) provides sign language training free of charge for parents of deaf children. Parents gain basic sign language skills so that they can communicate with their children.

A project funded by Deaf Child Worldwide in Kazakhstan involved bringing parents together in groups. At first parents did not see the need to get together. We organised a training programme about communication issues. We also discussed “attachment” issues and why it is important for parents to keep in contact with their children when they are in an institution. Some of the parents were deaf themselves. They were really important members of the group because they were able to share their personal experiences of deafness. The deaf parents also helped us with interpretation.

Parents’ groups have been working with the KDA in lobbying for better rights and services for families – at local and national level. The KDA recognises the need for parents to be involved in the association.

#### 4.5 Amanda Naylor, VSO Volunteer, Kazakhstan

In Brazil researchers have documented the positive impact on families from interacting with Deaf adults using LIBRAS (Brazilian Sign Language). In 1996 the University of Sao Paulo started a Sign Bilingualism research project on as part of an exchange programme with the University of London and City University in the UK. One of these projects involved 23 deaf children and their families in a one-year Sign Bilingual Intervention Programme. A research paper looked at the impact of involving three Deaf staff in the project.

Deaf staff members were employed alongside staff who were not deaf. They were involved in delivering education, and in leading training sessions and discussion groups with children and parents. Parents were also able to watch the Deaf staff communicating with their children freely and fluently in LIBRAS.



### Learning from deaf adults in a sign-bilingual programme, Sao Paulo, Brazil

There was a striking change in the parents over the course of the programme in a number of areas, including attitudes to deafness, to sign language and in communication in general with their deaf children. The contact between parents and the Deaf staff member allowed an exchange of experiences... and confirmation that a Deaf person can have an independent life. In this regard a different and more positive perspective on their child's future was offered, in comparison to that which could have been presented by hearing professionals alone.



Families in Alagoas learn LIBRAS through a project run by AAPPE

Another relevant aspect of the programme which developed through the relationship between the parents and the Deaf staff member was the recognition of LIBRAS (Brazilian Sign Language) as an effective way of communication. Parents' reports collected during the focus group interviews showed that the LIBRAS lessons and interaction with the Deaf staff member had a positive impact. Parents explained:

- The help here is very good; without signs there is no way to understand him (child)
- I learned lots of things with him (Deaf staff member)
- Everything that I learned here (signs), I took home
- I liked very much that part (...) with that guy (Deaf)
- The thing I liked the most was that lady teaching signs.

4.6 I. Lichtig et al (2004)

Deaf people's ability to train parents in sign language often means that parents' groups will form alongside Associations of Deaf people.

In Uganda, parents' meetings were originally organised by schools teaching deaf children, (this is covered in more detail in Chapter 6). In this rural setting, learning more about the National Association of the Deaf changed the way some parents saw their meetings.



### Learning about associations from deaf adults in Uganda

Deaf children attended "integrated schools" for the first time in Bushenyi District in 2002. Initially school, family and community attitudes were negative. However when the teachers realised how well the deaf children were learning, the parents and family members became more positive. We decided to introduce them to Deaf adults and to the Uganda National Association of the Deaf (UNAD). The Deaf Child Worldwide Small Grants Programme paid for a one-week residential training with Deaf instructors. The training was carried out at each integrated school. In many cases these were the first Deaf adults the parents had ever seen. The parents started to think beyond sign language for the first time. At two of the schools, the parents decided to start an official group themselves and elections for the chairperson were held. One day they intend to join UNAD.

**4.7 Nathalie Arinda,  
Bushenyi District Local Government Education Dept, Uganda**

In South Africa a similar process occurred, only in this case it was the Deaf Community of Cape Town that brought parents together rather than a school. Stephen Lombard summarises the way that this happened:



### Deaf people and families supporting each other, South Africa

The Deaf Community of Cape Town (DCCT) was established in 1987 - mostly by Deaf people. Its aim is to improve the quality of life for deaf people. In 2005 a successful project was launched to support families with Deaf children, funded by Deaf Child Worldwide.

Parents with children in three schools for the Deaf - Mary Kihn, Dominican Wittebome and Noluthando, were offered the opportunity to attend sign language classes. It began with a simple service of teaching parents the natural language of their

Continued

Deaf children. Now it has developed into a phenomenal support group. The dynamics between families crossed every kind of social barrier – especially cultural. We saw that deafness has its own culture, which makes everything else equal. Families were bonded into a close unit because they shared a common purpose - to educate their Deaf children.

#### 4.8 Stephen Lombard, DCCT, South Africa



Think

#### Things to think about – the deaf community

- Are you in contact with deaf adults living or working in your area?
- How could they be involved in the lives of families with deaf children?
- How can you use deaf people's skills and interests for the benefit of families?

## Deaf people as advocates

There are many laws that protect the rights of deaf children and adults. Many countries have laws relating to equal opportunities, and access for disabled and deaf people. The new UN Convention on the Rights of People with Disabilities also provides for the rights of deaf children.

National governments are responsible for implementing these laws. It is their job to make sure that deaf children receive an education that meets their needs. Also, that they have equal opportunities to access social and recreational activities and employment in later life.

Where deaf people and parents work together to campaign for their children's rights – the impact can be powerful. Sometimes parents and Deaf people may have different priorities. However where there is a shared vision, working together can make the voices of campaigners louder and more likely to be heard.



Read

#### Campaigning together in Cape Town, South Africa

In Cape Town, DCCT organised a joint meeting where parents and Deaf community members came together with a representative of the Ministry of Education (Western Cape). In this meeting, presentations were made by a 14 year old deaf boy, one parent

Continued

from each of the schools involved in the programme and one Deaf community member. Everyone who spoke stressed the need for resources to be invested into training for teachers and parents in South African Sign Language (SASL).

“There are three schools involved in this programme. We are all struggling with our children. What is the problem? We have no teachers who can communicate with the learners – they do not know sign language at all...I am scared my child is 16 and can't read in Grade 8 – What will he do? What about his future...Without help from Deaf adults what has happened in the past will continue. With deaf and hearing helping them, we can change things!”

**Mr Saal, parent of a child at the Dominican School for the Deaf**

“I am a deaf adult, 33 years old and still blocked. I can't communicate when I go to the Department of Education, I am just asked to wait and wait. I sign and become angry. The Department of Education ignore sign language. English, Afrikaans, Xhosa, but where is the 4th language, sign language? My language. Every year, new schools, new teachers, but they do not know sign language.”

**David Pedro, Deaf community member**

Deaf people and families share many issues and joining together to fight for our rights made sense.

**4.9 Stephen Lombard, DCCT, South Africa**



## Basic principles for joint advocacy

- Ideally parents and deaf people should work together.
- Both parents and deaf people should also have their own voice and be able to express their own views and ideas.
- A relationship of shared trust, discussion and listening is necessary for a partnership in advocacy.
- Parents' groups should establish shared vision with deaf people's groups and coordinate their efforts together.
- Where different groups have different priorities, then groups can also be involved in advocacy work on their own.

- The combined voices, energy and ideas of many people are better than those of a few.
- Joint advocacy can ensure that deaf children access their rights.

## Becoming a deaf friendly team

Deaf adults have much to offer families in terms of knowledge, inspiration, advice and support. However, where deaf people are employed to do a specific job, it is important that they have access to the training and support they need to do that job successfully.

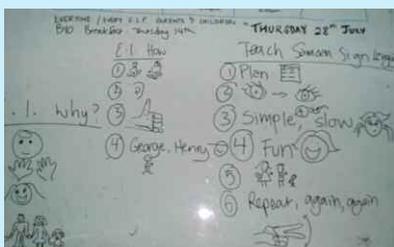
It is important to acknowledge that in some countries, education for deaf children is of a poor quality and as a consequence you may need to adapt some of your training or reporting procedures to make sure they are fully accessible. In Samoa, the Loto Taumafai Society were particularly keen to make sure their training and monitoring formats were accessible to deaf early intervention workers, who had low levels of literacy.



### Involving deaf fieldworkers in all aspects of CBR work, Samoa

The employment of deaf adults and parents as field workers is very important in a community based programme. Deaf field workers may not have accessed a full education and may face challenges in coping with the demands of the job. However they have demonstrated high levels of commitment and determination to overcome all challenges. They provide a positive model of empowerment every day in their communities, and for the children and families they visit.

Deaf fieldworkers with excellent Sign Language skills can make a big impact on families



Making sure training and monitoring tools are visual helps deaf staff

The tools used for collecting information in the field have been modified to enable people with low levels of literacy to use them. This is an example of good practice in the workplace and a strategy that could be shared. It has enabled the deaf fieldworkers to be involved at every stage of the programme.

#### 4.10 Donna Lene, Loto Taumafai Society, Samoa

Deaf people working together with colleagues who are not deaf can present challenges in the workplace. It is really important that all colleagues understand what it means to be part of a deaf friendly team.

The research undertaken in Brazil highlighted the following challenges faced by deaf and non-deaf people working together for the first time:

- People speaking too quickly and more than one person speaking at once in meetings - this made it impossible for the interpreters to keep up and made it difficult for deaf staff to lipread.
- Home visits with families which were scheduled at the same time so the interpreter could not attend all the meetings.
- Most of the staff who were not deaf did not know LIBRAS so could not communicate easily with the deaf staff outside of interpreted meetings.
- The interpreter was also a staff member and it was problematic when she could not contribute to meetings because she was interpreting.
- Deaf people were not provided with detailed information about the programme's schedule and contents.
- Some staff found deaf people's interaction style in meetings too direct which sometimes caused conflict.



### Including deaf people in the workplace, Sao Paulo, Brazil

We faced difficulties during the course of the sign bilingual research project. However these were gradually overcome. Staff who are not deaf became more aware of the importance of establishing effective communication; allocating more time; and making themselves more available to their Deaf colleagues when required.

The Deaf members of staff became more confident. They persisted in asking for necessary information. They became more aware of the importance of their own opinions and more forceful in asserting them. Understanding of cultural differences provided the basis for increased mutual respect and enabled a more effective work partnership over time.

**4.11 I. Lichtig et al (2004)**



Deaf and hearing staff work together at a project in Alagoas

In Samoa, the Loto Taumafai Society also realised the importance of training all their staff in deaf awareness, so that the deaf members of the team could work effectively with families and with colleagues.



### The Loto Taumafai Early Intervention Programme (LTEIP), Samoa

The Deaf field workers have improved their teaching skills, ability to carry out assessments and as a result, their confidence and self-esteem has noticeably increased. They are active members of the team and contribute to all discussions and meetings. Their input and opinions are valued by the entire team.

It was important that training in relation to deafness was provided to the entire Early Intervention team. This means that there is a large group of skilled field workers who understand issues related to deafness. They can all communicate effectively in sign language and use relevant teaching techniques.

Ten colleagues at the Early Intervention Team have all learnt sign language and can now communicate clearly with the two Deaf field workers. This means that a number of staff can now interpret for the Deaf staff.

#### 4.12 Donna Lene, Loto Taumafai Society, Samoa



Training courses for deaf awareness have been developed by many organisations around the world. Having more knowledge and opportunities to practice basic techniques helps people to understand deaf people's perspectives and communicate with them effectively. Cultural norms of communication vary from country to country but some basic elements of deaf awareness training might include some of the following:

- Simulation exercises (lip reading game, guess the facial expression game, using ear plugs, communicating non-verbally).
- An opportunity to hear deaf people talking about their own experiences.
- An opportunity to discuss the different communication methods used by deaf people and how successful communication is a joint responsibility.

Continued

- Communication tips and opportunities to practice these:
  - **Be open** – encourage the deaf person to talk about their communication preferences and get ideas about how the work environment could be more inclusive.
  - **Get a deaf person’s attention**, for example by touching their arm, waving or calling their name. It is good to discuss what would be inappropriate for example, touching someone on the back of the head or suddenly approaching from behind
  - **Don’t leave deaf people out.** It is important to make the effort to explain if you respond to sound when communicating with a deaf person or if they have not understood a conversation, a joke or an instruction whether it is work-related or social. Make sure deaf people have equal access to after work social occasions as well as the work environment.
  - **Create opportunities for deaf people to join in conversations** – it is harder for deaf people to break into a conversation as they can not judge from intonation when a part of the conversation is about to end. Be proactive – use eye contact as a signal to join the conversation, or ask a question.
  - **Make the topic of conversation clear.** Understanding the context helps everyone communicate more easily.
  - **Make sure only one person speaks at once.** In meetings, ask colleagues to raise their hand before speaking or have a “talking stick”, a pen or other item which a person must hold before being allowed to speak.
  - **Speak slowly and clearly but don’t exaggerate your mouth shapes or shout.** Don’t cover your mouth or eat whilst speaking.
  - **Make your communication as visual as possible** - Use eye contact, facial expressions, body language and gestures
  - **Write things down** – remember to establish the topic first, write legibly, use drawings and diagrams, eye contact and facial expressions.

Continued

- **Use open questions rather than yes/no questions.** This helps you to check that you are being understood.
- **Learn the finger-spelling alphabet and/or some basic signs used in your region.** This can really enhance your communication with deaf people who use sign language.
- **Use a sign language interpreter** – ideally make sure the interpreter uses the same dialect sign language as the deaf person. If possible recruit an independent interpreter for team meetings, rather than relying on other participants in the meeting for interpretation. Always talk to the deaf person, not the interpreter.
- **Produce written documents in simple plain language.** This will help deaf people whose first language is their national sign language or who have not accessed quality education to understand. Adding visual elements such as drawings, diagrams and pictures can also help.



Think

### Things to think about – a deaf friendly work place

- Would your colleagues benefit from deaf awareness training?
- Who could deliver the training? How can deaf people be involved?
- Do deaf workers have an opportunity to regularly review their environment and make suggestions for improvements?



### Learning from this chapter

- Every family with a deaf child should have the opportunity to meet a range of deaf adults.
- Deaf people should be involved as sign language trainers.
- Deaf people and families can learn a lot from each other.
- Parents can work together with deaf people to advocate for deaf children's rights.
- Patience helps people who are deaf and those who are not deaf work together.
- Organisations and their staff must be deaf friendly in order to make sure deaf people can contribute equally to the work.
- Deaf awareness training for everyone in an organisation helps it to become a more inclusive place to work.

# 5



## Community based support

### Chapter aims:

- To show the importance of community based services for families
- To highlight how community based programmes can support families to:
  - communicate with their deaf children
  - help their children to learn language and other skills
  - keep their children safe from abuse
- To show how deaf adults and families can be involved in the delivery of community based services
- To illustrate how community based services interact with and complement education services

## What is community based support?

The early years are the most important time for deaf children to learn language and develop communication skills. However, it is challenging for children at this age to travel a long way to specialist services and often their families will not be aware of simple things that they can do to develop deaf children's language and communication skills. Many families cannot access centre-based services close to home, so community based support takes the services to the family in their community or home.

Such support may be delivered as part a Community Based Rehabilitation (CBR) programme. These programmes should target the whole community and aim to ensure that all disabled people and children are included in community activities. This is why a new name used to describe them is Community Based Inclusive Development (CBID). Sometimes CBR organisations will employ paid staff or will work with volunteers in the community. Whilst CBR programmes aim to make the whole community more inclusive, they may also have specialist staff to support groups of people with particular impairments.

Deaf children have the right to be included in their community and to be supported to develop communication and language skills. However, CBR workers do not always address deaf children's needs. The term "rehabilitation" is seen as offensive to some groups of disabled people and is not very appropriate to deaf children. Nevertheless, CBR programmes often have a presence in areas where other organisations do not and they are likely to come across deaf children in their work. It is therefore important that CBR programmes have the skills to provide specific support to deaf children.

## Why families with deaf children need community based support

Deaf children often do not have equal access to community services. It is the responsibility of governments to ensure that community services for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Discrimination can mean that deaf children and young deaf people are often cut off from traditional support structures within communities. Sometimes families are excluded because of their deaf child. This means that deafness is a barrier to accessing the basic needs of nutrition, health care, clean water, sanitation, and a means to generate income. Community based services help to raise awareness of deaf children's rights and challenge discriminatory attitudes. This means that families and deaf children are more likely to be included within a community and deaf children are less likely to be neglected or denied opportunities available to other children.

In addition, community based services can offer specific emotional and practical support to families. Many parents need help to feel positive about their deaf child's abilities. Developing communication is an essential part of this process. If parents cannot communicate with their children it is difficult for them to become actively involved in their lives. Information about where and how to get training and support is not enough. Families need support to find the time and resources to travel to areas where services are available. Even better, that support could be delivered to them in the home.

Community based support has an impact on the home and community environment and helps societies to become more inclusive.

## Balancing competing priorities

Training and support is not always easily available. This is a particular problem for parents living in isolated rural areas. It can be very difficult to find time and resources to travel to areas where training is available. Community based programmes can make it easier for parents to attend training or support groups. Community based organisations are familiar with the daily challenges that families face and are aware of the demands of subsistence farming or casual labouring. Parents sometimes struggle to meet their families' daily needs for food.

Deaf children's needs are basic needs. Support to help families access health services, clean water, or opportunities to generate income are just as important as help with family communication and education for the deaf child.



### Life can be very tough, Mutare, Zimbabwe

Parents of the children at our pre-school are finding life extremely difficult these days. Simple things like buying a bag of sugar can take a long time. It is no longer possible to walk into a shop and buy a bag of sugar. People have to search for it on the black, or illegal, market. This is very expensive. It is possible to buy cheaper sugar by finding out when it is coming into a shop. Then people have to be there in time to queue for it. Even maize meal, the basic food, can only be bought by queuing. This takes a great deal of time away from parent support groups. If basic foods were easily available, mothers would have more time. Learning to communicate with their deaf children is not as important as trying to get enough food for the family.

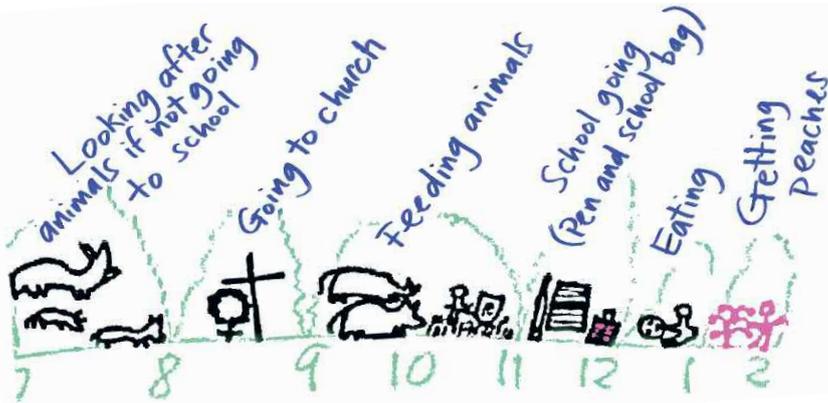
**5.1 Libby Foster, NZEVE Deaf Children's Centre**



Think

### Things to think about – meeting priority needs

- How can community workers work sensitively with families who are struggling to meet basic needs?
- What else can a community programme do to support families in meeting their basic needs?
- How can mapping daily activities, the geography of the area and location of services help make sure community based support is accessible to families?
- How can community workers take families' daily activities into account when planning meetings and classes?



Using drawings to map out daily activities helps plan the best time for CBR work

Source: S. Stubbs (1995) *The Lesotho National Integrated Education Programme: a case study of implementation*, Masters Thesis, University of Cambridge

## What kinds of support can community based programmes deliver?

Community based support services are able to find deaf children. Without these services families may remain isolated, receive little support and understand very little about what they can do to support their deaf child.



Read

### Improving communication between young deaf children and their families in Vietnam

Trang and Binh are two Deaf community workers employed by the government's Inclusive Education Programme, supported by CBM through a USAID / Pearl S. Buck International grant. They both graduated from the secondary school for the Deaf in Ho Chi Minh City. The job of the Deaf community worker is to facilitate communication and understanding within the "Deaf family".

Continued

Thuan is a bright and energetic eight year old deaf boy. He was envious of his sisters when they brought books home from school everyday. Thuan tore their papers out of frustration and anger. The family used crude signs to order Thuan to help with the housework.

Trang and Binh found Thuan sitting under a mango tree playing alone with his colourful marbles. They gave copies of the picture-sign language dictionary to Thuan and his sisters. There was a picture and sign for “marbles” and all the colours. Thuan quickly signed “green” and “marble”. He then pointed forcefully at the pictures and looked accusingly at his sister – she returned the green marble she had hidden!

Thuan was invited to a Saturday Social Day for the Deaf at a nearby primary school where his hearing would be screened. After that Thuan might be able to go a school in a nearby community. The parents were amazed: “How could Thuan catch-up with the other children his age?” The community workers offered to tutor Thuan twice a week using the sign language book and a workbook to prepare older children for school.

Thuan and his family were introduced to the other deaf children from the area – about 40 altogether. They realised they were not alone in the world. The other families had also faced communication and behaviour problems. The other parents said this improved once the children started school and the family learned to sign. Thuan’s mother reported she had contracted Rubella when she was pregnant. Thuan’s audiogram confirmed that he is profoundly deaf and, therefore, a good candidate to learn to sign. Deaf adults tutored the Deaf children individually and in groups on basic pre-primary and primary school skills. Family members were shown ways to encourage speech, sign language and writing.

The Deaf community workers returned to Thuan’s home to begin tutoring him. Two months later, Thuan entered the first grade with another Deaf boy and girl. Each one was placed next to a bright student who was not deaf but was shown how to coach the deaf students. The teachers used some signs and many drawings. The student coaches seemed to know even more sign language than the teacher! Thuan progressed well in school and proudly carried his exercise books home each day.

## 5.2 Ron Brouillette, Christoffel Blinden Mission

Community based programmes can deliver the following range of support:

- Promote positive attitudes towards deafness and raise awareness of deaf children's rights within the community.
- Information about other support available – eg hearing aids, health services, groups and associations, schools, self help activities.
- Training and ideas on developing communication and language skills in the early years.
- Training in managing behaviour and teaching children basic skills for independence.
- Support in decision-making about education and plans for the future.
- Support in finding employment or getting involved in other self-help activities.
- Opportunities to meet parents and deaf people who have a range of different experiences.
- Information about children's rights and how to keep children safe from neglect, and abuse.

## Supporting families at home

The Loto Tamufai society in Samoa is an example of a holistic approach in which training and support are provided to address the many different and interconnected social issues affecting parents and their deaf children.



### Language begins at home, Samoa

Loto Taumafai has an Early Intervention Programme (LTEIP). Deaf fieldworkers visit deaf children and their families across the Samoan islands. They encourage sign language development and communication methods with the whole family. They also educate the family about the value of deaf children attending school. Many Samoan deaf children do not attend school because their parents do not see the value of it. LTEIP is challenging this belief at a family and village level.

The field workers support 40 deaf children and their families and communities through community based consultations in five districts in Samoa (one urban and four rural). Support consists of

Continued

two weeks intensive support to families followed by visits every two weeks and district meetings every month. The aim of the visits is to provide information about deafness, improve communication skills, increase family and community awareness of the deaf child's needs and support inclusion and appropriate support in school.

Fieldworkers encourage parents to think about their long term goals for their children by asking questions such as: "What are your dreams for your daughter?" and "Where do you see your son in 20 years' time?"

"I hope that my son will be able to go to university and teach other deaf children".

### Father involved in the project

Information and education is provided in relation to: deafness; school options; child rights; the value of children; the importance of positive relationships with children; communication and literacy development; counselling; health care, including mental health; budgeting; employment; and child safety. Advocacy services are also provided for the child, in relation to school, employment and safety from abuse or neglect; and for the family, when needed.

### 5.3 Donna Lene, Loto Taumafai Society

The support offered by the Loto Taumafai Society has a big impact on families. Developing effective communication skills helps families reduce communication barriers and the impact of positive deaf role models raises parents' expectations and their attitudes to their children.



Think

### Things to think about – the whole community

- What community-based services and activities exist that could benefit families with deaf children?
- How can children be encouraged to include deaf children in their play or daily activities?
- How can community workers support deaf children and their families to access other activities and services in their community?

## Keeping children safe

The Nzeve centre for deaf children in Mutare, Zimbabwe, is not only concerned about providing deaf children with an appropriate education. It also provides parents and families with strategies to make sure their deaf children are safe from abuse.



### Preventing abuse, Mutare, Zimbabwe

Nzeve staff go out to schools in the surrounding area to educate teachers, parents and pupils about sexual and reproductive health and sexual abuse. The fathers and mothers are split up for the sex education workshops to avoid embarrassment. Using signs which may appear rude is a real challenge. In African culture sex tends not to be discussed. Parents often tell their children that they have eaten a lot when actually they are pregnant.

A six year old deaf girl was raped in the community. When the police questioned her, she was unable to identify the abuser. Staff at Nzeve realised that parents need to teach their deaf children the name signs for every one in the community. This story was included in the book, *Helping Children who are Deaf*.

**5.4 Libby Foster, NZEVE Deaf Children's Centre**



### Learning from these examples

- Learning sign language helps to reduce communication barriers between children and their families.
- Learning to communicate has a positive impact on children's behaviour.
- Parents need much more than information – they need practical demonstrations, advice and teaching.
- Resources for teaching communication and language are essential tools for community workers.
- Community workers should take into account the literacy levels of parents when designing teaching resources – they should be as visual as possible.

Continued

- Families are more likely to understand the value of educating their deaf child when they are able to communicate well with their children.
- Raising family expectations means that children are more likely to access education and succeed at school.
- Deaf adults are the best sign language teachers and can become a key part of a CBR team.
- Training for community workers should also be accessible to deaf people.
- Organisations should ensure that they are deaf friendly places to work.

## What sort of training do community workers receive?

Community workers need training so that they can provide families with useful and flexible support to suit their needs. The Loto Taumafai Early Intervention Programme (LTEIP) in Samoa has developed a comprehensive training programme for CBR workers. This involves specialised training, but community workers need not be professionals.



### Training for CBR workers in Samoa

**Community based workers** are trained to provide information on Deafness; improving communication skills; increasing family and community awareness of deaf children's needs; and supporting school attendance.

**Volunteer advisors** from Australia and USA have provided specialist training in relation to: sign language linguistics; visual teaching techniques; literacy and numeracy strategies; child development; basic speech therapy; interpreter ethics; and the importance of story telling. The advisors also provided training on broad concepts including: family support, abuse, neglect, types of disability, mental illness, and stress management. (See Appendix 1 for more information on these issues).

**Deaf field workers** support the entire team with sign language vocabulary development.

Continued

**Samoa Family Health** provided an intensive six day sexuality training course for LTEIP field workers.

**The Samoan Red Cross** has provided training for all staff in first aid.

**An NGO** which focuses on family violence, Mapusaga O Aiga, has delivered training on human rights. The NGO has also provided support in relation to a deaf child who is the victim of family violence.

All LTEIP staff have received training in relation to the Deaf project. There is now a large base of people who are confident in using sign language.

The team has learnt:

- to be resourceful and creative with limited resources;
- to be flexible when working with children with different communication levels;
- different activities and methods of teaching sign language according to age;
- teaching skills and gained confidence when teaching sign language to the adult classes;
- to use community contacts in an attempt to locate deaf children in the villages.

**5.5 Donna Lene, Loto Taumafai Society, Samoa**

## Involving parents in the delivery of community based services

Ideally, community workers have strong links to the community, are deaf or are parents of deaf children themselves. A personal understanding of local contexts can be very useful. Personal experience of raising deaf children can also be an advantage in making connections with parents. Organisations delivering community based services do not have to be specialised CBR organisations. Any organisation with good links to a community can deliver community based support.

Nyadire Primary School is a mainstream school with a unit for deaf children in rural Zimbabwe. This school recruited two parents of deaf children and trained them to offer support to other families in the community.



### Training parents as community workers in Mutoko, Zimbabwe

The Nyadire Centre for the Deaf is a Deaf Child Worldwide funded project established in the Nyadire Primary School in Mutoko as part of the United Methodist Church Mission. Mutoko is a remote rural area in the north east of Zimbabwe. The school and centre provides services for people in the surrounding area irrespective of their culture, religion, or background. Nyadire is a boarding school and has 21 deaf children, aged 9 –17.

Teachers and project staff identified two parents of deaf children who had personally overcome challenges in improving the lives of their deaf children. These parents visited the Nzeve Deaf Centre in Mutare where they learned more about deafness and communicating with deaf children and received training in supporting other



Parents of successful deaf children are an inspiration for others

parents in communicating with their deaf children. Parents learned about: deaf issues; myths and truths; how to help parents of deaf children; developing materials which parents and guardians can use to communicate with their deaf children.

After receiving training in the Nzeve Centre, the parents went to work with the head teacher of the deaf at Nyadire to develop the programme of sharing experiences with other parents. They worked in regional villages and communities, gathering information and identifying deaf children, adults and their parents. This included attending community based meetings and announcing details of the programme. The parent trainers were given bicycles so that they could reach remote areas.

Continued

### **Parent trainers' feelings about their work**

Parent trainers who are parents of deaf children have unique skills in communicating with deaf children. They speak and teach from their personal experience when they raise awareness and advocate for deaf children and their families. The support from Deaf Child Worldwide helped give them wings to fly.

### **Lessons learnt**

- Parent trainers should be parents of deaf children.
- Training of young children and their parents will make a big difference to children's communication and development.
- The involvement of deaf adults in the programme is very important.
- Parent trainers can make home visits.
- Teaching from experience, using real examples, can help others understand.
- Parents can learn a lot from sharing experience in groups.
- Training in small local groups helps avoid the need to travel long distances.
- Parents trainers can work with regular schools to give deaf children in those schools access to sign language.
- Parents, teachers, head teachers, and local authorities work should work together as a team.
- Parent trainers need to be prepared to challenge negative attitudes, such as "deaf children are bewitched" and therefore "unable to communicate", or that "cutting underneath the tongue enables children to talk".
- Trainers should develop a plan of activities and good teaching materials.

### **5.6 Pastor Amos Muyambo, Nyadire Primary School, Zimbabwe**



### A parent trainer's view

I was discouraged at first when I met resistance. Most parents viewed my work with suspicion; others were discouraged because they did not know how to deal with their children. As a person who has gone through the same experience with my deaf daughter, I was able to share my experience and make a difference to the parents of deaf children. My daughter is now waiting to go to a teacher's college.

I walked long distances to see parents. Some were still in denial about their deaf children. Parents now come to me for advice. I am even approached by parents of children with other disabilities. I feel strengthened by the words of encouragement from parents and friends. I often feel I could do more if resources were available because of the great need in our area.

**5.7 Mrs Mwoyosviyi, Mutoko, Zimbabwe**

## Partnership working: parents and community workers

Parents do not need to become community workers themselves to contribute to community based support to other parents. Both parents and community workers have much to gain from engaging in training together. Such experiences can help community workers gain insight into the lives of parents and their deaf children. It can also help families to understand the service and what it offers. Parents' experiences and insights can provide a valuable contribution to the training of CBR workers.



### Training together: CBR workers with families, Karnataka, India

Samuha-Samarthya is a development organization. It has been working in the dry, drought prone regions of the state of Karnataka in South India since 1989. "Samuha" is the Sanskrit word for "organised group". It works with people with disabilities through its CBR programme, Samarthya. Its activities are spread across three districts of Karnataka: Raichur, Koppal and Uttara Kannada. Samuha-Samarthya operates in 269 villages with over 2703 families.

Continued

Samarthya identified the need for CBR staff to improve their skills in supporting deaf children. IDCS-India conducted a training needs analysis. The 4-day training programme which followed was attended by 20 members of staff. Children also attended with their parents, 6 fathers and 2 mothers. The training included plenty of fun and games.



Parents and children were invited to provide some practical experience during the training of CBR workers. This meant that CBR workers:

- received hands-on experience in working with parents and children
- gained an understanding of how parents felt and what their priorities were
- learned to have empathy when they talked to parents
- improved their skills and confidence
- have moved from teaching speech sounds to teaching the language.
- realized that it is possible to teach a child without a hearing aid
- realised the need for visual learning aids and learned to make them

Continued

- have increased their home visits from once a month to once a week.
- are able to transfer their skills and understanding to the families on home visits.

The families also benefited from the experience. They:

- feel motivated by the CBR workers' interest in their children and started to take a more serious interest in communicating with their children;
- are more likely to attend parents' meetings and access other services such as the ear mould and hearing aid maintenance centre;
- feel encouraged that they can communicate with their children even when hearing aids are not being used;
- have stopped preventing their children from using gestures and signs;
- feel more comfortable with CBR and understand it better.

Training parents and professionals together required a different approach. In one session parents made noun cards with matching flash cards. This gave parents a better idea of why CBR workers produced these materials and also the level of effort that went into the work. The families enjoyed engaging in creative activities with their children – something that could be done at home. Such teaching and learning aids have become an essential part of the CBR workers' training kit.

### **Fathers' involvement**

The training session took place away from the village, making it difficult for mothers to participate. This is not the usual location for training sessions. However it was a welcome experience to work with male relatives for a change. The fathers went home feeling very enthused and empowered and are more likely to be present at the regular sessions as a result.

#### **5.8 B Hampanna, Samuha and Sreela Bose, IDCS-India**



Think

### Things to think about – equal partnerships

- How can parents' expertise be used by community based services in your area?
- Would you consider employing families as part of your community-based team?
- How can you work towards an equal partnership with families?

## Community based services and education

A good community based support programme can change community attitudes. This can lead to the development of other services, especially in the area of education. In 1998 in rural North West Cameroon a home-based sign language training programme was started for two families. This led to the establishment of a school and the enrolment of over 100 deaf children.



Read

### Teaching sign language in the community, Mbingo, Cameroon

In 1998, the community based rehabilitation (CBR) programme Mbingo–Bamenda started working with deaf children in communities in the North West province of Cameroon. We realised that communication between deaf children and their families was very difficult. Some deaf children developed strange behaviour that was sometimes interpreted as mental problems. Even the deaf children who attended special schools found the sign language they learnt in school of little use in their communities - it was only a school language.

Families get together at a similar project in Buea



The CBR programme began a community sign language project with the objective of teaching sign language to the families of children attending special schools for deaf children. The only school at the time was over 300km away from the programme area. The CBR field workers and volunteers went from household to household teaching sign language. The strategy was to build on the signing of regularly used words to the making of common sentences and phrases. Depending on the literacy rate of the family, the alphabet and written documentation were used and provided to the family.

Continued

The project started with two families. News soon spread to other areas and families requested the service and began looking for schools for their deaf children. Teaching sign language in the community led to the identification of many more deaf children.

In 2000 the Baptist church that runs the CBR programme, started a deaf school in the area with 13 children. Today the enrolment is over 160 children in the primary school with the programme also assisting 10 deaf children who are integrated into a nearby secondary school. Sign language is also taught to the classmates and friends of the secondary school deaf children and also to their teachers.

Most of the parents are very proud of their deaf children who are not only in school but doing equally well outside of school. They say they can now communicate easily with their children. They are able to use this “secret” language with a lot of admiration from strangers. Sign language can be a real unifying force in the families of deaf people. The challenge is now to find more resources to enable this programme to develop and grow in a sustainable way.

#### 5.9 Peter Mue, Christofel Blinden Mission, Cameroon



Think

#### Things to think about – schools and communities

- How can community-based programmes increase the number of deaf children who can access education?
- How can community-based programmes help schools to make links with families and communities?

## Rebuilding relationships between deaf young people and their families

Where families have had very little involvement in their deaf children’s lives, young people can be especially vulnerable. In Kazakhstan, most deaf children are educated in residential institutions and young people are alienated from their families.



### Vulnerable young adults, Kazakhstan

When young people leave their residential school and go back to live at home there can be a lot of problems. Sometimes families break down. Parents do not always want their children to come back. There is a high incidence of deaf young people, especially girls, working as prostitutes in the sex industry. Many young men become homeless and work in low paid jobs, such as selling magazines on trains. They tend to lead unstable and insecure lives, associated with drug use.

In the rural areas, there aren't any special schools so children tend to stay at home and work on the farms rather than be sent away to institutions. If they do go to institutions far away they are unlikely to see their parents very often.

At Centre SATR, the project we worked on was called "Rights for All" We looked at the right to be in a family and also to be able to communicate with a family. We set up parents groups to get parents back involved in their children's lives.

We also worked with young people. A group of young deaf people consulted with 45 young hearing impaired and deaf people aged 8-18 and put together a lobbying resolution. The group travelled to Astana to present the resolution at the government Round Table meeting. This was attended by over 25 people including senior members of the Ministry of Labour and Social Protection and the Ministry of Health. The group were able to present the lobbying resolution to parliament. The group of young deaf people are very motivated to continue this work and plan to establish their own association so that they can continue to support deaf children and young deaf people in the future.



#### 5.10 Mandy Naylor, VSO Volunteer, Kazakhstan



### Learning from this chapter

- Be aware of competing family priorities and the need for community-based support to be accessible.
- Partnerships between families and community workers need to be based on trust, respect and listening.
- Consultation with families and children and their involvement in decision-making is essential.
- Families can be supported to communicate with their child and to help their child acquire language.
- Families, deaf people and professionals can work together on an equal basis.
- Community workers can help the wider community include a deaf child.
- Community workers have a key role to play in supporting families to access educational opportunities.
- Community-based programmes can raise awareness of child protection issues. See Appendix 1 for more information about this.





6

### Chapter aims:

- To emphasise children's rights to education and the need for families to understand them
- To highlight the important role that families play in ensuring that their deaf children access and benefit from education
- To give practical examples of how families and schools can work together to improve the quality of education

## Introduction

Most parents cannot choose where their child goes to school. The local school is often the only option – but local schools do not always welcome deaf children. A minority of deaf children attend special schools, although this varies a great deal from country to country. In some countries there are units attached to mainstream schools. This can enable deaf learners to attend school nearer to their family home, but they may still need to stay in boarding houses.

There are many different ways in which families, schools and deaf adults can work together to improve deaf children's access to education. The examples in this chapter show that parents and family members are a tremendous human resource. As carers, they are the first educators of their children, and have a vital role to play. As citizens, they can claim their children's right to education – and so make them more visible in the community.

In 2000, the UN declared the Millennium Development Goals as a policy approach to development. The second goal is to ensure that all children complete primary education. This goal will not be achieved if deaf children do not have access to education, either in special schools, special units or in their local schools. Deaf children are unlikely to complete primary education if their communication needs are not addressed. Children are more likely to experience educational success if families are fully involved.

## Teachers supporting parents: family communication

Teachers can do a great deal to support parents and families in their role as carers to their children. The main challenge is to support families to develop good communication with their children. In the following box, a parent in China explains some of the benefits of becoming involved in her son's bilingual education programme.



### Parents are the first teachers, Hefei, China

When my son Ding Xin was nine months old we discovered that he did not hear well. We saw the yearning for knowledge in his eyes and felt sad that there was nothing we could do. Our hearts, like his, were bleeding.

In September 2004 we sent him to a bilingual education class at Hefei Special Education Centre. This class taught sign language at the same time as spoken and written Chinese. There were lots of positive changes for Ding Xin.

Continued

I had doubts about bilingual education. I thought teaching children with hearing impairment to open their mouth and speak was the only way for them to communicate with others and assimilate into mainstream society. Students in the bilingual class received very little homework. Like many other Chinese parents, I thought the more homework the better for the children. My doubts disappeared upon seeing the changes in Ding Xin.

Before starting at the Special Education Centre, he could not say “Dad” or “Mom” clearly. After less than half a year at the Centre, he could pronounce several simple words and phrases. Though he did not yet speak very clearly, he had improved a lot. After one year studying at the Centre, he could not only read aloud children’s poems and sign stories, but had also learnt six to seven hundred new words. In terms of daily life, he could not only do all sorts of things by himself but would also help us with housework. Before this we had done almost everything for him.

While good schools can provide a positive learning environment, it is the parents who are the first teachers of their children. The teachers provide sign language training for parents and show parents various ways to assist their children to learn. This enables children and parents to communicate more effectively and to enjoy a closer relationship. Both parents and children become more self-confident. I hope other parents of children with hearing impairment can confirm their beliefs and make efforts to improve themselves. This sets a good example for their children and also promotes a good living environment for their children.

### 6.1 Ms Yao Chang Zheng, China

In some environments it may not be so easy for parents to get involved in school activities. It may be necessary for teachers to reach out to parents in order to explain why such activities are beneficial. Good organisation helps families see the benefits of such activities. Sometimes refunding transport costs or providing a meal for parents can help provide the initial motivation that gets parents started in their interactions with school.

In the following case study Nathalie Arinda demonstrates the added value that a parents’ group can bring to the challenge of educating deaf children in a poorly resourced rural area in Uganda.



### Teachers and parents working together, Bushenyi, Uganda

In the late 1990s rural communities in Uganda were informed that education was a human right for all children – including disabled children. All over Uganda schools faced a huge increase in the number of children with disabilities attending primary school as a result of the new policy. Specially trained teachers did not exist and the drop out rate for disabled children was close to 100%.

From 2000-2005 the local government of Bushenyi District opened five “integrated” schools in each of the five counties. Each integrated school has a unit catering for profoundly deaf children. The teachers in these units were ordinary primary school teachers who had an interest in teaching deaf children. They started teaching using gestures and by trial and error.

The majority of the parents in the rural district of Bushenyi have not had any formal education. Parents were aware of the high drop-out rates of disabled children. Some people asked the teachers why they were bothering to teach disabled children. It is difficult to convince parents in these circumstances that they should invest in the education of their deaf child – especially when it is assumed that “these children cannot learn”.

As teachers grew in confidence in their own ability to use sign language, and as they began to experience success in their teaching of deaf children, teachers and parents began to see that educating deaf children is possible.

In the school holidays, however, the children were socially isolated because their parents did not know any sign language. This also meant that their progress in school was slower.

The unit teachers suggested the idea of setting up parents’ groups in order to help families learn to communicate with their children. There were two major challenges:

- communication difficulties between parents and the schools;
- parents’ mistrust of schools and sign language.

Bushenyi District Education Department received a small grant from Deaf Child Worldwide to provide a small transport refund, and lunch for parents. The classroom teachers facilitated the parents’ meetings and in the beginning decided to focus on sign language lessons. We chose topics close to the daily life of parents and

Continued

children: kitchen, house, school, shop, market, hospital, family, etc. Initially the “free meal” and the “transport refund” was a bigger motivation than the sign language lessons!

After about five meetings, the parents have made a real breakthrough. They were sceptical at first, but now they are enthusiastic about sign language and their children. They still have all the normal frustration of all parents in Bushenyi: the cost of school fees, difficulty in accessing services, etc. But now they can see that their children can perform educationally. They want to know where their children will go after primary school! This is such a big change from “my child can’t learn” to the expectation that the children can pass the primary school leaving exams – especially since 60% of all children in village schools fail these exams.

### 6.2 Nathalie Arinda, Special Education Advisor, Uganda

In Russia in the early 1990s, the mother of a deaf child, Larisa Grishanova decided to establish a mixed school where deaf children could learn together with those who are not deaf in an environment close to their home. Nordis was set up as a private, not-for-profit school for deaf and hearing children in Nizhny Novgorod, the capital city in Nizhegorodsky region. This was the first mixed day school which offered specialist support for deaf children. Traditionally the education provided for deaf children in Russia was institutional and so alienated children from their parents and community.

Campaigns led by Nordis school and others have led to over 50% of deaf children being educated in their local mainstream school in the Nizhegorodsky region of Russia. A small grant from Deaf Child Worldwide in 2005-6 enabled Nordis to develop a model of support for deaf children in mainstream schools. This helped promote greater parental involvement and reach children in rural areas.



#### Bringing families together

The first step taken was to consult with over 100 parents and find out more about their educational priorities for their deaf children. This led to the development of a project with three main aspects:

- 1) Providing specialist support to deaf children in the form of individual and group sessions with a speech and language therapist, audiologist and psychologist (teacher of the deaf)
- 2) A programme of activities for deaf children to come together during the school holiday

Continued

## 3) A support group for parents of deaf children.

“This was an excellent opportunity for my son. The teaching staff are excellent and he has made a lot of progress. I wish this could carry on. He has learned new skills and made new friends. All deaf children should have this opportunity.”

*Father of a deaf young man*



Parents were given the opportunity to discuss issues of concern and ask for advice from trained professionals. They were able to meet other parents of deaf children, including some who lived in the same town but who they had never met before. They made new friends and kept in contact, even with those who lived far away in different parts of the region: “Sometimes the distance was a problem and it did mean travelling a long way just for a few hours but it was worth it”.

Nordis school has developed a very positive relationship with the families who took part in the project, and there is a strong commitment to meeting the needs of as many deaf children and their families as possible. Although this was a short project, led by teachers rather than parents, it has created the opportunity for parents to support one another, share experiences and work with professionals. The parents were very positive about the benefits they had gained from participating in the project. The formal meetings with professionals may not continue, but the majority of parents intend to keep in contact with one another. A number of parents also talked about forming a group in the area where they live and inviting other families to take part.

“My child did not want to communicate, she was shy and withdrawn and we were concerned about her. She also found it hard to make friends. She never wanted to stand-up and talk in class or give an answer. She also had to write about her happiest time and she wrote about her time at Nordis. Through this programme she has grown in confidence.”

*Mother of a deaf child*

### 6.3 Anne-Marie Hall (NDCS) with Larisa Grishanova, Nordis School



### Learning from these examples

- Teachers can support families to communicate with their children.
- If parents can communicate with their child, they can teach their children a lot about their home environment. This helps teachers in their job.
- Bringing parents together enables them to support each other which ultimately provide a better environment for the child.
- Understanding what goes on at school can make parents more supportive towards teachers of deaf children in their community.

## Parents supporting teachers: quality of education

Although there is much that teachers can do to reach out to parents to motivate them and improve the levels of communication at home, some parents are also keen to get involved in their children's education in a more practical way. This has benefits for parents and teachers, as well as the deaf children themselves.



### Encouraging the teachers in a residential school – a father's story, Kenya

My first-born son, Stephen, is deaf. We waited for him to say his first words, but that time came and went. When he was two years old we took him to the hospital and found out that he was deaf. Naturally, it was a shock but we had to swallow our pride. I was determined that my son would excel like any other boy. In our culture and tradition first-born sons are very important. Stephen is the future for my family and I wanted to do everything I could for him.

In 1982, when he was six years old, we found out about Kerugoya School for the Deaf. It is a residential school, 160km away from Nairobi. The living standards were not very good, but we had to leave Stephen there - we felt we had no other choice. A good education would be Stephen's future. But it was important that we continued to support and encourage him. We visited him regularly and made sure that we gave him exposure to lots of different experiences.

Continued

The teachers preferred children to study manual subjects like woodwork, rather than academic subjects which are harder. However I was sure that Stephen could pass exams so I convinced the teachers to teach him these subjects. I realised that the teachers also wanted parents to be more involved. When teachers see that a parent really cares for his child and is motivated to help, then they become more encouraged in their teaching role.

#### 6.4 Geoffrey Mukonyoro Wathigo, Kenya

When families have a good relationship with their children's school, it can make a real difference to their child's experience of school. In some cases, where parents disagree with what the teacher is doing, dialogue can mean that the outcome for the child will be more positive.



Think

#### Things to think about – teachers and families

- What do schools and families in your area have to offer each other?
- How can schools and teachers provide an environment which enables families to make a contribution? For example:
  - When are meetings called?
  - Where they are held?
  - What are the expectations of teachers and families about each other?
  - What are the attitudes of teachers and school management towards family involvement?

Some families can be very determined in making positive changes for their children and this ultimately makes education for all children better. Sometimes the changes that are needed can be quite simple and easy to manage for the school. Mrs Snigdha Sarkar writes about her experiences looking for a suitable school for her deaf daughter, Sneha.



### Real inclusion requires a supportive family, India

When Sneha was six years old, we put her in a girls' school in Bandel, in the pre-primary level. She was the first disabled child to attend this school and there was resistance at the beginning. Yet Sneha had a right to study in this school. The Persons with Disability Act in 1995 ensured that children with disabilities could be educated in regular schools.

Sneha was fortunate in having a highly sensitive, caring and supportive teacher throughout her primary years. In the first year she failed one subject (environmental science) in the annual exam. Out of a sense of protection, the teacher wanted to keep her in the class for another year. We had a difficult time persuading her to accept that this would do more harm than good. Once she was convinced that Sneha should be promoted to the second year, she became a "guardian" and ensured she did well in her studies.

After she reached class 5, we moved back to Kolkata. I felt that Sneha no longer needed intensive support so she went to a government girls' school near our house. At first, the headmistress was reluctant to take her because she did not do well in the admissions test. After much persuasion she was admitted. There were about 75 students in her section and she did not enjoy this school. She kept asking me to take her back to her old school. Sneha moved to another school which she liked from the very first day.

When I look back on those days I realise that I experienced ignorance not unwillingness. Most people do not know about disability and so fear it. Once this barrier is overcome, the school and the parents can develop a rational expectation of one another. It is very important to prepare both the child and the school for inclusion – the school must be ready to accept a child and the child must be ready to receive an education in the inclusive system. The skills and confidence gained during her early years really helped Sneha to make the most of her school in Kolkata.

Some schools integrate children because the Act says they should – knowing fully well that the child will not succeed and that in many cases the school, the state and the family doesn't really care. Real inclusion requires a positive environment at school and a supportive family. We need to work hard to give more children this opportunity.

Continued

Sneha's school does not have any special support structure, but they have given her a positive and friendly environment.

- They allow her to sit in the front row all the time.
- They make eye contact with her so she can follow what is being said.
- They have asked other students to help her.
- The teachers encourage her to ask questions.
- They do not discriminate against her – either positively or negatively
- They have helped her develop a sense of belonging in the school.

6.5 Snigdha Sarkar, India

## Employing parents in education programmes

In some circumstances, it might also be appropriate for parents to be employed as members of staff in education programmes for deaf children. This can help to ensure that the education programmes genuinely meet the needs of the children studying there. The following example from Afghanistan highlights how parents' attitudes can change when they become more involved in a programme. They can even become advocates for deaf children's rights.



### Supporting inclusive education in Afghanistan – a father's story

I am the father of six children, four of whom are deaf. One has some hearing and was accepted by the local school. She sits at the front and has a bit of extra input from the teacher. My three other deaf children were selected for the International Rescue Committee's new inclusive education programme for deaf and blind children in Herat. I was chosen to be a programme officer for the hearing impairment section.

I wasn't sure if this inclusive education method would work. Would the other children tease my children? How would the teachers communicate with my children? I had been to see two schools for deaf children in other cities of Afghanistan and I thought maybe that was the only way. But after receiving some training on

Continued

inclusive education and its benefits for all children, I decided to give it a go. We passed on the training we received to the teachers in the school, and we received more sign language training alongside the teachers. Some expert deaf adults came to train us both in inclusive education and in sign language. I was very encouraged to meet strong, confident deaf adults. I can now see a positive future for my children. One day when I have more time, I would like to start an association for the deaf in our city.

We now have 16 deaf children in the programme receiving education in regular schools. My colleague and I visit each classroom at least once a week. We give the teachers encouragement and more ideas and help them to solve any problems they face. Our programme is new and we need to do more work to improve the quality of education.

I am really enjoying my work and I enjoy being involved in my children's education. It is not so easy to encourage other parents to be involved. They have seen the positive changes in their children like I have, and they see the school system supporting them - but we have to put a lot of effort into convincing them to receive training in sign language themselves. I have contact with other parents of deaf children who are not involved in the programme. All of them want their children to go to school - if only we had enough resources.

**6.6 Abdul Ghani, Herat, Afghanistan**

## Parental involvement in the running and management of schools

Parents have a right to be involved in the governance of schools. Many schools have a parent-teacher association or a board of governors. It is essential that parents on those boards have a voice and an opportunity to:

- stay informed about the running of their school;
- put forward a parent perspective about the school's activities.

Sometimes parents need to learn more about their child's deafness and their rights before they feel confident in taking part in the management of schools. In Kazakhstan, Centre SATR started to deliver some of those skills to parents. The project team involved Mandy Naylor, a VSO volunteer, a SATR social worker and two workers from residential schools in Kazakhstan. They began by doing home

visits to try to engage families with their deaf children. The idea was to raise awareness of the problems associated with institutionalisation. The approach was based on child rights, and one of the main issues was abuse. Many families were not interested in their children – they had got used to the fact that their children no longer lived at home. Many parents became angry when they realised that their children need not have been taken away from them.

SATR developed a programme of education and awareness focusing on communication issues and attachment – the importance of maintaining close contact with their children. Some of the members of the group were deaf themselves. They were able to share their own personal experiences and help with interpreting.



### Children's rights and parents' groups in Kazakhstan

The SATR project was called "Rights for All". It looked at young people's rights to be in a family and to be able to communicate with family members. We set up parents' groups to encourage parents to become involved in their children's lives and act on behalf of their children in their residential schools – these are known as Internats in Kazakhstan. We looked at the whole range of children's rights, using the UN Convention on the Rights of the Child. Each week we focused on a different right.

Kazakhstan has the highest number of disabled young people institutionalised in Central Asia - approximately 17,000 young people, 6,000 of whom are deaf. There is a lot of stigma around disability and deafness and so it is seen as perfectly acceptable to put a child in an institution. Yet it is the only way many deaf young people get any education. Children in these institutions are often mistreated - physical smacking and sometimes more serious physical and sexual abuse. Most of the teachers in the Internats do not know how to sign - sign language is used almost exclusively by the deaf community. The children tend to be left alone, they sign in their own secret language and sometimes bully each other. Adults find it difficult to intervene because they don't understand what's going on.

The children find it difficult to tell their parents about it and so it tends to be very hidden. If parents do complain, they fear that their children may be thrown out of the schools or that they would no longer have contact with their children. Psychologists sometimes advise the school that the parents are "upsetting their child's education" and prevent parents from having contact with their children without even going to court. The professionals are

Continued

very powerful and parents tend to do what they are told. The project therefore engaged with school staff as well as parents.

We worked with parents' groups in two Internats. Young people are separated according to their level of hearing – one school was for hearing impaired young people and one for deaf young people. We chose a class of 12 young people in each Internat. First we worked with children aged 5-8 and then with a group of 9-14 year old children. We then worked with the parents of these two groups of children. We also worked with the teachers who were teaching these classes.

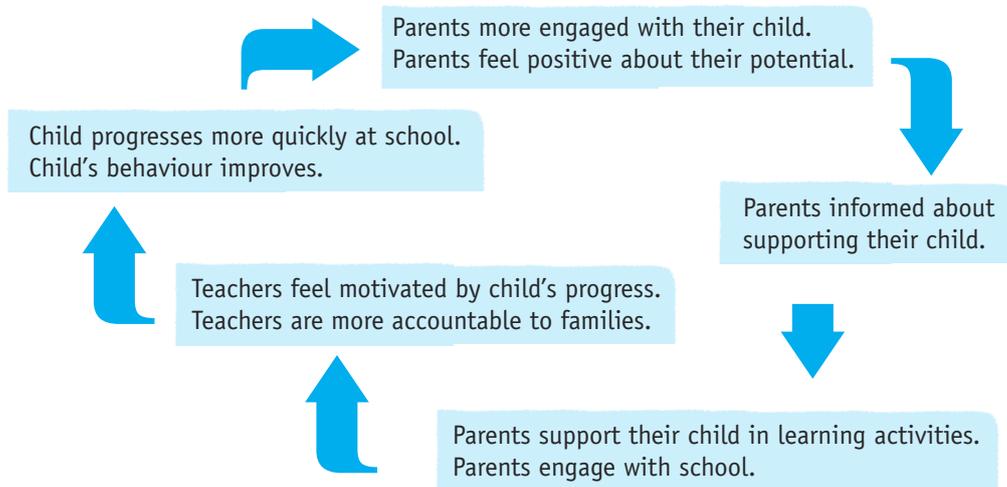
Some parents found it difficult to attend because of family commitments and little money. Some parents lived one or two hours away from the school. The extreme temperatures (-30c in winter and +40c in summer) also make it difficult to organise meetings for families.

The parents' groups are still going and are attached to the schools. Two parent representatives attend quarterly meetings with the school directors. A resource room has been set up in one of the Internats so that parents can access information when they visit the school. A parent volunteer works in the information resource room.

We wanted the parents' group to lobby local government. This is working in the rural region, but in Almaty City the government has refused to engage directly with parents. Instead they engage with the Kazakhstan Deaf Association (KDA) which in turn work with the parents' group. Now children are becoming more involved in the KDA which didn't happen previously. Parents have been much more vocal lately about the need for sign language and that's ongoing and one school is reviewing its policy around sign language. It is a huge change of attitude that schools have even started to look at sign language.

**6.7 Mandy Naylor, VSO Volunteer, Kazakhstan**

### Positive effects of parental involvement in schools



## Teachers and families learning together

The National Children in Need Network (NCNN) in Kenya realised that there was a need for young deaf people to learn more about puberty and the changes that take place in their bodies during adolescence. Most children access this information from their parents, siblings or peers. Poor family communication, however, means that many young deaf people understand little about their own sexuality and their rights. However their project showed that the greatest impact comes from working with both the young people and their parents.

This becomes particularly important during adolescence. In some schools in East Africa students aged 22 years old are studying alongside much younger primary school-aged children. This is because students often start school late or they fail the end of year exams and have to repeat a year. In such situations older students, who are often adults, have sexually abused younger children. Parents can play a major role in keeping children safe (see appendix 1 for more information).

With funding from Deaf Child Worldwide, 80 young deaf people were able to attend a life skills course. Children were selected from schools in Mombasa and Nairobi. The training was delivered in Kenyan Sign Language, backed up with visual materials and lots of participation and active learning activities. NCNN had not originally planned to involve families in the project, but in response to requests from families and teachers, NCNN arranged for 68 parents to receive the training during PTA meetings.



### Learning from life skills training in Kenya

The section of the life skills training covering sexuality and protection against abuse had a particular impact as some children had experienced abuse. It required very careful and sympathetic facilitation.

As most of the young deaf people had a very limited understanding of rights, a lot of time was spent explaining the Children's Act and the rights of children to be protected against abuse.

Parents in Nairobi reported that following the training their children:

- are more likely to request permission before leaving the house and to tell parents where they are going;
- show that they understand the risks of pregnancy and sexually transmitted diseases;
- are more likely to say that they do not want to have sex until they have completed school.

Although the project was initially only planned to involve young people, the importance of building up family knowledge about child rights was also realised. One grandparent, who was a primary carer, attended a training session as a member of the Parent Teacher Association. She was keen to take the idea of life skills training to the other PTA members and to other schools.

#### 6.8 Pauline Kamau and Nduta Mbarathi, NCNN, Kenya



### Things to think about – keeping children safe

- How much do you know about children's rights? Find out more about the UN Convention on the Rights of Persons with Disabilities, the UN Convention on the Rights of the Child or legislation relating to children's rights in your country. In some countries, organisations have made this information available in an accessible format.
- To what extent are families and children aware of their rights?
- What can you do to make more people aware of children's rights?



Continued

- What happens if you encounter child abuse – do you know what to do?
- What action can you take to make sure that children are safe?
- What is the government doing in your country to monitor conditions in residential schools?



### Learning from this chapter

- Families are the first teachers of their deaf children.
- Support from schools can help families to fulfil this role.
- Family involvement in schools can motivate teachers and children.
- Good quality education motivates more families to get involved.
- Family involvement can help raise community awareness of the need to educate deaf children.
- Some parents need to be supported to gain confidence to work with schools.
- Parents can be pioneers in education for deaf children.
- Schools have a responsibility to make sure children's rights are protected.



# Families taking action

# 7

## Chapter aims:

- To provide examples of simple practical action that families can take to support their children and each other
- To show how families can become involved in service delivery, either as teachers, fundraisers or the initiators of the service
- To give examples of families who have influenced policy by advocacy or campaigning at local and national levels
- To illustrate the role of national associations of families and how these change over time



## What kinds of action can families take?

Most forms of parent action directly address the needs of parents and their deaf children. The action may be large or small, local or national.

Parents often take action in order to:

- support each other and share information;
- help their deaf children to learn;
- develop, improve or manage services for their children;
- lobby and campaign for change for themselves and their children;
- initiate projects to meet other family needs, such as income generation.

## Supporting each other and sharing information

Some parents may choose to take action as individuals. They may be unaware of other parents with similar concerns. Or they may be unable to access parent meetings. The mutual support, learning and encouragement offered by parents' groups can make a big difference to parents' emotional and social well being and can offer very practical help. Groups are often dynamic forums for sharing ideas and offer their members support and strength in numbers. There are more examples of the way in which parents' groups come together and start to take action in Chapter 3.



### Walking the same path, Mexico

Meeting other parents was incredibly useful. It helped me realise that I wasn't alone and that there were other parents going through the same things. We were "walking the same path", each concerned for their children. We were a very close group of parents. We phoned each other to chat. We don't see each other as often as we used to because of work and time limitations. But we do phone each other to find out how things are going. I have to say thank you to one of the mothers, in particular, because she phones me regularly.

**7.1 Rita Hernandez Sarabia, Mexico**

In Chapter 3, Snigdha Sarkar wrote about how the parent support group, Anwasha was formed. Here she explains why the group is such an important source of support.



### Anwasha – finding strength together, India

There were two main objectives at the time of starting the group. Each of us had some confusion and unanswered questions about our own children. We felt that we would be able to solve our own problems better by forming a group and sharing information and knowledge among ourselves. At the same time, we did not want to restrict this only to ourselves. We felt that we should be able to help others through this group, with our collective information, knowledge and understanding, since each of us had a personal experience of bringing up a hearing impaired child.



Snigdha, one of the founders of Anwasha

Continued

In a group where we have children from different age groups we have different levels of experience to solve the problems we face. We become stronger as individuals by interacting with other parents, families and children. Our collective information, knowledge, skill and experience enriches the group. We are also beginning to realise that we must also work on issues such as rights of our children, their inclusion, which cannot be achieved individually.

**7.2 Snigdha Sarkar, Kolkata, India**

## Practical support

As well as just “being there”, many parents are prepared to work together in proactive ways to make sure their deaf children get the opportunities that they need to learn. Parents’ needs often relate to their concern for the welfare (material and social) of their families. Parents may find it difficult to balance the need to earn a living to support their families with the specific needs of their deaf children. As parents’ time is precious, they may not have much time to meet with other parents or address the social and educational needs of their deaf children. Parent groups can be helpful in addressing this difficult balance as shown in the following example of a shared child care scheme in Vietnam:



### Sharing the parenting: making the most of time off work, Vietnam

It is difficult for parents of deaf children to arrange to meet each other in Vietnam. Most cannot afford to take time off work. However parents worry about how their children will learn to communicate, play with other children and become part of the local community. Although hearing aids have been provided through a voluntary agency, they are of little value. Children have few opportunities to learn to use their hearing aids and listen carefully to spoken language.

The mothers decided to try an experiment. Usually when they all went to work the children were left to fend for themselves. The mothers agreed that if they all took turns to be at home for a day the four deaf children could be together. This would provide an opportunity to play together and to learn together. The mothers agreed some basic activities that could be tried with the children, focusing specifically on everyday situations within the home.

Continued

Having agreed this, another problem needed to be solved. For any individual failing to work there would be little opportunity to buy food, there would be no money and the practicalities of taking four deaf children to the market were initially too great to meet. The mothers took a very pragmatic approach. Those who worked split their food with the mother who had stayed at home with the children.

By forming an active co-operative, parents organised their own support network. The teacher of deaf children visited the four deaf children as a group and provided ideas and guidance to the mother who was "on duty". This advice and training could then be passed on to the other mothers.

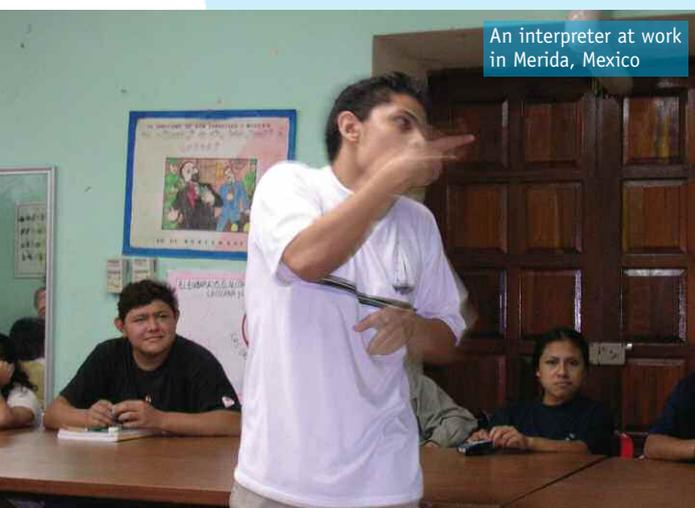
### 7.3 Wendy McCracken, University of Manchester, UK

Parents who listen to their children's ideas, suggestions and concerns also find strength to act and create change that is beneficial for others. This story from Mexico shows how one mother opened up opportunities for inclusive secondary education for a group of children.



### Sharing interpreter costs in Mexico

I have two deaf children. When they were small we went to the National Institute for Human Communication (Instituto Nacional para la Comunicacion Humana). Since we didn't have any hearing aids, and not enough money to buy them, they told us we could not have any therapy for our children. So we stayed at home.



My sister was doing her social service and heard of an organisation called Oira, which works with deaf children using an oral/aural approach. We went there for some time but the children were not learning. One of the therapists, who worked in the bilingual school, told me the children were losing precious years. So I took my children to the bilingual school and we all got on very well.

Continued

When my daughter, Karen, left primary school she was 16 and my son, Victor, was 15. They were too old for secondary school. We decided to go for distance learning. It was just the two of them and they stayed at home for a whole year. They didn't have many friends and didn't meet any other deaf young people. We are Jehovah's Witnesses. We socialise with other deaf people when we study the Bible. But my children say, "Not these deaf people! We want others".

I heard of a school that was happy to open a deaf unit. They agreed our children could attend if we paid for the interpreter. But we needed to find other children because of the costs. So I went out and found five kids and they started the school. We still do the long distance learning but they are in regular classes with others.

**7.4 Eloisa Perez Hernandez, Mexico**

Parents' needs tend to revolve around communication issues. However they are likely to have other, more pressing needs, such as income generation, which do not directly relate to deafness and communication. Parent groups can provide support for each other in addressing all their needs, whatever they may be.

In Chapter 3, the story of how a group of parents in Korogocho, Kenya, came together through a sign language training programme was introduced. The Kenya Society for Deaf Children (KSDC) was very keen to ensure that the parent group continued. The parents themselves were very keen to continue to meet and to support each other in other ways.



### **Parents saving money together, Korogocho, Kenya**

Towards the end of the initial three months sign language training in Korogocho, the parents attending meetings had formed relationships with each other. As the self-help movement is relatively widespread most families knew about the activities of other self help groups in their area and felt that this was something they would also like to do. Poverty is the most pressing concern for people living in Korogocho. The families involved in the group felt that a savings scheme would be the best way of staying together as a group. Such a scheme could, in the future, provide opportunities for families to access a small loan in an emergency or to establish an income-generating project. In order

Continued

to make sure this ran smoothly, the group registered itself, opened a bank account and laid down procedures for how the money should be saved and under what circumstances members could make withdrawals.



A parent discusses plans with government official in Kitui, Kenya

The members agreed to contribute around 100 Kenyan shillings per month towards a small savings scheme. They agreed not to draw on these funds until significant amounts had been saved. KSDC were able to provide a top-up amount of 20,000 shillings, which gave the group encouragement and motivation to continue.

At the same time, KSDC told the group that it would become their formal point of contact for Korogocho. Through the group, KSDC and other organisations are able to deliver other services such as subsidised hearing aids, school referrals, and the development of sponsorship links. KSDC also plans to link the groups with other sources of support such as funding from the Ministry of Youth for Community Groups and microfinance programmes targeted at women's groups.

### 7.5 George Gachanja, Kenya Society for Deaf Children



#### Things to think about – meeting member needs

- What are families' immediate concerns beyond the needs of their deaf children? For example, feeding the family, employment, leisure, social activities, emotional support.
- How can working together help families to meet these needs?
- What is the role of an external facilitator in helping families to take action?
- How can groups be facilitated in a supportive rather than controlling way?

## Developing or improving services for their deaf children

In Chapters 5 and 6 there are examples of parents who became involved in schools and community based support programmes. Many parents of deaf children already have skills which they can use for the benefit of deaf children if practical opportunities are presented to them. Un Sileap is a father of a deaf child in Cambodia. Here he talks about his experiences of becoming a teacher of deaf children:



### Becoming a teacher of deaf children – a father's story, Pursat, Cambodia

I was born in Sya village in Kandieng District, Pursat Province in Cambodia. After school, I began teaching in Kdei Oudom primary school. In 1997 I married Chum Kimyun. Nearly a year later a daughter was born, who we named Un Kimleng.

When Un Kimleng was one year old we realized that she didn't turn her head at all when we called her. My wife and I began having a crisis in our mind. We called her and observed her until she was two, when we realized that she couldn't hear and couldn't speak. I was seriously distressed and lost hope in my life. The weight of all this sorrow lived frequently in the hearts of her parents and grandparents. As for my wife, she became sick and was treated by the mental health services until she started to improve.

Four years later my wife had a second baby, another girl, called Un Sengly. When she was 10 months old she started to speak a few simple words such as "mummy" and "daddy". I was overjoyed to have such a child. When she was three years old I thought that I wanted another child who could talk with her and so I would have two children to look after their elder deaf sister. But it was a misfortune that this third child, born in 2004, could not speak and could not hear when we called her. This was another crisis that I couldn't deal with. I gave up all hope in my life. I was shy, thinking that some of the neighbours would laugh and other children would imitate the sound of my deaf children.

I heard someone say that a doctor was coming to Pursat to check people's ears<sup>1</sup>, so I took my daughters there. There I heard that a class for deaf children had been opened in Pursat Primary School

Continued

by a teacher and an NGO called Disability Development Services Pursat (DDSP)<sup>2</sup>.

Afterwards I went to meet the teacher of the deaf children, Prang Sina. He warmly welcomed me and agreed to accept my children to study in his class. But I was busy teaching in my school and the deaf class was far away. Sina then told me that if I could identify at least six deaf children in my district (Kandieng) I could open a deaf class there. I confirmed this with DDSP and from then on I began my contact with DDSP. I studied sign language with Sina from March 2006 for one month, supported by DDSP. Afterwards DDSP asked me to open a class for deaf children in Sya primary school, after getting permission from the local education authorities. But the parents didn't send their children to the class and it closed in May.

Sina and I discussed how to resolve this and thought that DDSP could help, for example by paying the deaf children's transport to school. I resolved to continue the class if there were enough deaf children. So DDSP and myself, together with the representative from the NGO Krousar Thmey checked at each deaf child's house to find out how many deaf children could attend the class and how many could not. Afterwards, the representative from Krousar Thmey approved the opening of the deaf class. I asked my school director for permission to study sign language at Krousar Thmey's school for the deaf in Phnom Penh from August to September 2006.

I have now become a teacher of deaf children. I now have a second occupation, of sign language training and farming at the same time. During school vacations I have to give up my family to get training in sign language. However I know that this is a great opportunity for me to help deaf people. There has never been a sign language class before in my district. At the end of term, I went to each deaf child's house to inform their parents to send their children to school in the next school year, in September 2006. The School Director is happy with the deaf class.

The deaf class has seven students, including three girls. They come to school every day with transport supported by DDSP. After studying for a month I have noticed that they are very happy and friendly with their classmates and schoolmates because they can communicate with each other by sign language. My own children have changed a lot. They know some sign language and can write

Continued

some letters, words and numbers. I explain to the other parents that they should send their children to school regularly. I have also assessed the income generation needs of the poor families with deaf children and informed DDSP so that we can help them.

Notes:

<sup>1</sup> The Phnom Penh-based NGO All Ears Cambodia started audiology clinics and basic ear treatment in Pursat in 2004.

<sup>2</sup> The class had been established by Krousar Thmey, who trained and supported the teacher. DDSP was supporting the children attending the class.

### 7.6 Un Sileap, Cambodia, translated by Pheng Samnang and Steve Harknett

Some parents establish their own organisation and employ staff. Often such parents feel committed to a particular educational approach and are determined that other families should have access to the same level of support that benefited their own children. Services which have been initiated by parents generally pay particular attention to the role of the family. In Durgapur, West Bengal in India, Shambhu Nath Jajodia, the father of a deaf child started the Speech and Hearing Action Society (SAHAS).



#### Parents initiate services, West Bengal, India

The Speech and Hearing Action Society (SAHAS) is a community-based organisation of parents of young deaf children. As the founder of SAHAS, I strongly believe that parents should be in the driving seat of their deaf child's support programme. SAHAS advocates for the oral and aural approach. For the method to be successful, it is essential that we create awareness for the need of early identification (i.e. in the first five years), providing appropriate hearing aids and giving educational support.

Besides creating general awareness, SAHAS instils in parents a sense of responsibility, reminding them that they are first and foremost responsible for their child's development. It is parents who must develop an understanding of the various aspects of the deaf child, first as a child, next as a deaf child and then, as a deaf child in society.

Continued

Parents are encouraged to understand that language learning for all young children, deaf or not, is a 24-hour activity in early childhood. For a deaf child it is even more essential to surround the child with accessible language. Since a child in the pre-school years essentially stays with parents, especially the mother, SAHAS makes every attempt to build the capacity of parents.

The training programme for the parents consists of modules related to the medical and technical aspects of deafness, hearing aids, building up of hearing skills, receptive and expressive language skills, behaviour management and social skills, etc. These are explained to the parents in non-technical and non-threatening language so that parents feel motivated to undertake the task of rehabilitation. Parents are encouraged to conduct the programme in the activity-based method of play and to enjoy the activities.

An essential component of the SAHAS programme is to conduct a monthly parents' meeting. During these meetings parents bring up their current problems, and experienced parents suggest possible solutions. This process of hand-holding helps to build confidence in new parents and also goes a long way in building up morale.

### **7.7 Shambhu Nath Jajodia, SAHAS**

Raising money is an essential activity for parents' groups who wish to develop services. Fundraising does not have to be on a huge-scale and groups of parents can be supported to establish services at all different levels, depending on the local context. Where there are no services at all, the motivation for parents to act is even greater. In Chapter 3, the story of a parents' group in rural Namibia was introduced. This group was initiated by a community facilitator employed by CLaSH.

The lack of education provision for the children of the group members was the most pressing concern, and the parents agreed that they wanted to initiate a pre-school in Eenhana which would cater to young deaf children and prepare them for entry into either mainstream or special school.



### Starting a pre-school for deaf children, Eenhana, Namibia

The group requested a plot from the Town Council of Eenhana and were provided with a suitable area of land where they could construct a pre-school.

The community facilitator helped to identify a deaf teacher and as CLaSH had run the first pre school unit in Namibia since 1984, they were able to offer some training to the teacher.

Among themselves the group collected around £200 towards the construction of a preschool classroom and requested CLaSH to assist them with additional funding, teaching materials and further training to sustain their work.

In 2006, the Eenhana parents group constructed a one-room zinc house (a simple structure made from corrugated iron sheets) and Tresia, the deaf teacher has started to teach some 14 deaf children with the assistance of two mothers, who took on the role of "hostel matrons".

Not all the out of school children identified through the project attend the pre-school and the group continues to develop their own skills to support their children and to continue their advocacy efforts. Towards the end of the Deaf Child Worldwide project, representatives of the parents group presented a list of around 200 deaf children who were not receiving specialist support in school to the regional educational authorities as part of their request for access to suitable educational opportunities.

Brighten, a dedicated teacher from Eluwa School for the Deaf (120 km away from Eenhana), has continued to support the group as a volunteer project coordinator and his commitment has helped teachers and parents to stay motivated and interested. The parents' struggle for their children's right to education continues.

#### 7.8 Heide Beinhauer, CLaSH, Namibia

## Lobbying and campaigning for change

Parents can take action through campaigns and lobbying. Such forms of action can lead to changes in policy and practice at both local and national levels.

Sometimes, the lobbying activity can be organised and coordinated, perhaps as part of a campaign with other organisations. The example of the Nordis school in Chapter 6 is a good example of this. Together with professionals from education and social care backgrounds in Russia, the mother of a deaf child played a role in gaining recognition for the rights of deaf children to be educated in inclusive settings.

Campaigning can also be done on a small scale such as the example described in Chapter 3, where a meeting was organised between the Deaf Community of Cape Town Parents' Support Group and the Western Cape Ministry of Education.

Parents' groups can also express their support for other campaigns and can give organisations already involved in those activities greater legitimacy or weight. For example, a mother belonging to the group in Korogocho made this statement at a meeting with Deaf Child Worldwide:

*"As parents living in Korogocho slums we have started a self help group...the schools for deaf children are far, some are 400kms from Nairobi and boarding and transport is expensive. We want to support KSDC in initiatives that promote the need for deaf units or a school for deaf children in Nairobi."*

**Mother of a deaf child from Korogocho**

Parents with particular connections can act on behalf of a wider group of people, taking small actions which ultimately have greater implications.



### The reading of the Disability Act in the Kenyan Parliament

One of the aims of the Kenya Association of Parents of the Deaf (KAPD) is to unite parents to a common voice. Just as soon as we had registered KAPD, the Secretary and I were invited by the Minister of Gender, Sports, Culture and Social Services to attend the reading of the Disability Act in the Kenyan parliament. This was because I had been so active in the past. As I sat waiting for the reading, I realised that many of the MPs were leaving the house. This meant that there would not be enough people for a

Continued

quorum to pass the bill. Individually I went to talk to as many MPs as possible about what the bill meant to me as the father of a deaf child and how important this was. I persuaded some of them to stay and finally the bill was passed.

Another thing KAPD want to do is campaign for sign language to be recognised. I want to improve my own sign language and it is important for more parents to learn sign language. So this is an area of focus for the future.

Throughout everything we do, we try to raise awareness. The media know about us and we have received positive coverage. We want other parents of deaf children to understand what is possible for their children. We want deaf people to feel confident in themselves and what they can do.

We also want government to know about what it still needs to do. It is important that society accepts deafness as a part of normal life and thinks that deaf people can do the same as anyone else. Seeing two people signing in the street should be no different to seeing two people talking in the street.

We want to take things to greater and greater heights. We will keep struggling and continuing our work to improve the education and situation for our children. There are many more children being born and many parents who need to know that things can be better than they think at first.

**7.9 Geoffrey Mukonyoro Wathigo,  
Kenya Association of Parents of the Deaf**

Sometimes it is parents' associations that spearhead campaigns and organise activities for the benefit of deaf children. Working together with governments is essential for activities and campaigns to be sustained.



### **Parents leading the way – parents' action in Moshi, Tanzania**

UWAVIKA is the Tanzanian Association of Parents of Deaf Children (Northern Zone), founded in 1994. It grew out of the existing group of parents whose children were at a large residential school in Mwanga-Kilimanjaro.

Continued

The members of the new organisation were very aware of the many deaf children in the surrounding regions who were not in school. The school had a waiting list of over one hundred pupils - like other schools for deaf children in Tanzania.

The association expressed its concern through the municipalities, cities and localities, to the national government. The intense efforts of the voluntary chairman and other board-members have resulted in the building of many more units attached to mainstream schools.

Mr Yusufuu Rajaba, the father of five deaf children, had waited a long time for a school place: "I was very glad to get a place in the Mwanga school for the deaf in 1991 for my son Yusufu, who was already 13 years of age and had been waiting for 6 years for a school place. He now works as a cook at the school."

UWAVIKA is concerned about the lack of access to secondary and vocational education. It is now in the process of building Tanzania's first vocational training centre for deaf young people in Moshi Rural District. A working relationship was developed with local, regional and national government, since the involvement of government at all levels is essential if a project of this nature is to succeed. Not only must the project receive statutory approvals but the senior management and teaching staff will be appointed and paid by central government.

#### 7.10 John Mwashu, UWAVIKA, Tanzania

#### Things to think about – advocacy and campaigning



Think

- Are there models of good services that you can learn from? Could they be replicated?
- What laws exist? How can you use these in your campaign?
- Who should be involved in the advocacy process? How can you show that your campaign represents all stakeholders?
- Have partnership opportunities been explored – especially the possibilities for campaigning together with Deaf people's associations?
- Has research been done to show what is needed? Who has been consulted?

Continued

For a useful guide to research for advocacy – see START: VSO’s advocacy research toolkit in the Useful Resources section.

## Changing priorities

Sometimes, parents’ activities change over time and in response to the needs of the growing membership and changing priorities of their associations.

The advantages of parents working together through an organisation means that there is a greater capacity to reach out to a target group beyond the original membership of a support group. It is also easier for an organisation to gain recognition from the national or local government and to have more weight when influencing services.



### Changing needs – changing priorities, Lithuania

The Lithuanian Association of Families with Deaf and Hearing Impaired Children (PAGAVA) was set up in 1994. It is a non-governmental, non-profit organization by a group of parents, largely mothers, who were not satisfied with the social and information support which was then available to parents of deaf children and with the situation of deaf education in Lithuania. Initially PAGAVA’s main aim was to lobby for the inclusion of deaf children in mainstream schools.

As the Lithuanian education system has changed and the membership of the group has broadened, so has PAGAVA. Currently PAGAVA aims to unite all deaf children regardless of method of education. This means that, as well as providing information and practical support to young deaf people and the parents deaf children, PAGAVA has also been involved in the following:

- A combined disability lobby which fought for a law relating to the social integration of disabled people.
- Work with the Ministry of Education to develop a sign language programme
- Work with the Vilnius School for the Deaf to improve opportunities for deaf children in secondary education. In 2001 the first group of deaf young people in Lithuania had access to secondary education and entered high schools.

Continued

- The establishment of the first early education programme for deaf children, aged 0-3 in Lithuania.

7.11 Joana Vanagiene, Vice Chair, PAGAVA



Think

### Things to think about – national associations

- How can an association meet the needs of diverse groups of parents with different ideas about communication and education approaches?
- How can an association include those parents who cannot be directly involved in taking action?
- If professional staff are employed, can the organisation remain parent-led?
- Is there a balance between professional and parent priorities?
- How can fundraising and management skills be developed to sustain the organisation?



Learn

### Learning from this chapter

- Families can support each other in a practical day-to-day way. For example, providing childcare, organising savings schemes or shared transport.
- Families can contribute to services and are highly motivated to learn new skills for the benefit of deaf children
- Families have an important role to play in lobbying and campaigning for change.
- Associations have to accommodate diverse opinions.
- Individual parents have huge potential to create change. Parents' associations can achieve even more!

# 7

## Families taking action



# A final note

## Thinking about your work

Many of the case studies highlight the challenging nature of work with deaf children and their families. Some points to consider are listed below. If you would like to discuss your own challenges or develop a further understanding of any of the examples here in relation to your work, please contact Deaf Child Worldwide.



Think

### Things to think about

- How can you share learning from this book with others in your organisation?
- How could your organisation improve the way it works with families to achieve the best outcomes for deaf children?
- Is there a way of planning to include families in services for deaf children? How could they be included in the development of strategy or work plans?
- Will you change the way you deliver information to families? How can communication with families be empowering?
- Are there any ways in which families with deaf children can support each other in your area?
- Can your organisation support family groups?
- How can you involve deaf people or family members of deaf people in delivering services?

## Feedback to Deaf Child Worldwide

Please tell us your thoughts about this book. We want to hear your feedback. Perhaps you found a particular case study relevant or interesting – please tell us why. Maybe you used one of the activities or reflection points in a team meeting or a workshop – we would like to know more about how this worked.

In particular, if there is anything in the book which you found unhelpful or which is contradicted by your experience, please also write and tell us so we can add your thoughts and experiences to our website or to future editions of the book.

## Who else would find this book interesting?

If you found this book useful or interesting, please tell other people about it! Please email **info@deafchildworldwide.info** to request further copies for distribution or write to us at the address inside the front cover. Please tell us how you will use the additional copies when you request them and include your postal address.

We are happy for you to photocopy relevant sections and use them to discuss specific ideas with your colleagues or the families you work with. If you translate any section of the book, please contact us so that we can include translated versions of case studies on our website.



# Keeping children safe



Children in all countries and in all contexts need to grow up in safety. Everyone has a responsibility to keep children safe and protect them from abuse. Physical, emotional and sexual abuse of children occurs in all countries of the world. It takes place in the home, in educational institutions, in the community and in the workplace. The perpetrators of the abuse can also be anyone – male or female, family or stranger, from any country, culture or religion.

## What is abuse?

- **Physical abuse** means touching or threatening to touch a person in a way which they have not agreed to and which hurts them. It can include hitting, kicking, pushing, pulling hair and many other things.
- **Sexual abuse** means: Sexual acts which take place when the person either did not or could not consent. "Could not" means that either the person did not understand or was vulnerable to pressure in the situation. Sexual abuse can include exposure (showing someone your genitals or private parts), molestation (touching, making someone touch your genitals, "talking dirty", or making sexual suggestions), sexual intercourse, rape and anal intercourse. Making someone watch pornographic movies or making them watch other people having sex is also abusive.
- **Emotional abuse** means making someone feel bad. It is sometimes called mental cruelty. This may include blackmailing, continually putting a person down, humiliating them in front of other people, making threats or, in the case of deaf children, refusing to communicate with them in a way they can understand.
- **Neglect** means not looking after someone's physical and emotional needs and not protecting them from harm. The term "child protection" is used to describe the responsibilities and activities undertaken to prevent or stop children being abused or ill-treated.

There are stories in many of the chapters which illustrate the important role that parents and other family members can play in keeping children safe and in responding to the problems caused by different forms of abuse. In particular, examples from Tanzania in Chapter 2, Zimbabwe in Chapter 5, and Kazakhstan and Kenya in chapter 6 highlight the practical ways in which organisations have addressed this.

Service providers and families can work together to raise awareness of child protection issues, help children to protect themselves and lobby for institutional changes which protect children. Children, families and service providers need to become more aware of the dangers of physical, emotional and sexual abuse, as well as of neglect.

The following letter illustrates the need for legal action, counselling, staff training and support for families.

Head teacher,  
Residential school for deaf children,  
West Africa

July 2006

Dear Deaf Child Worldwide,

In May 2006 we discovered that thirty six girls, aged 10–18, were being sexually abused in our school. Seven male teachers were involved together with a care worker, and they were protected by two female teachers. This is now in police hands, but support is urgently needed in the following areas:

- Long-term counselling for the girls, who showed great courage in coming forward, especially as they were threatened and intimidated by the perpetrators of the abuse.
- Staff training in child protection and the implementation of a school policy for all teachers, care and domestic staff.
- Support for parents and guardians to ensure their active involvement in preventing further abuse.

Yours sincerely,

Headteacher.



## Families can keep children safe by:

- establishing good communication within the family;
- maintaining close contact with children being educated in residential settings;
- being informed about the rights of children and the nature of abuse;
- teaching “life skills” to young people;
- providing a supervised environment in which to discuss issues and concerns;
- teaching children name signs for everyone in the home and community;
- teaching the signs or words for body parts;
- developing an understanding in children of what kind of touching is OK;
- practicing saying “No” or calling for help.



## Organisations can keep children safe by:

- raising awareness of children’s rights;
- developing a child protection policy and make sure staff and volunteers understand this;
- following up on references for new staff and volunteers to make sure that they are suitable people to work with children;
- training staff and volunteers to understand abuse;
- making sure all staff and volunteers know what to do if they encounter or suspect abuse;
- training staff and volunteers on how to support children to be safe and how to refer children to trained counsellors;
- training families, communities and teachers to help them talk to children about abuse and make sure they know what to do if they need to report incidents of abuse.

### Useful resources to help you keep children safe

If you would like to become more knowledgeable about how to keep children safe, then the following resources may be helpful.

#### Specialist organisations

In most countries there are organisations with specialist knowledge on child protection issues. They may run training sessions or produce resources specific to your country. You could contact:

- The country offices of international NGOs such as EveryChild, Plan International or Save the Children.
- Local NGOs or networks working on vulnerable children.
- Child Rights Information Network (CRIN). This network shares information about all aspects of child rights and has a membership database containing the contact details of organisations from across the world. Contact CRIN at:

Child Rights Information Network (CRIN), c/o Save the Children,  
1 St John's Lane, London EC1M 4AR, United Kingdom  
Telephone: +44 20 7012 6866, Fax: +44 20 7012 6952,  
Email: [info@crin.org](mailto:info@crin.org) [www.crin.org](http://www.crin.org)

#### *Helping Children Who are Deaf, 2004*

This book was written by the Hesperian Foundation. It has a very useful chapter entitled *Preventing Child Sexual Abuse*. This chapter includes practical activities for preventing sexual abuse and for identifying and supporting abused children.

The book can be downloaded free of charge from [www.hesperian.org](http://www.hesperian.org) or is available from:

Hesperian, 1919 Addison Street, Suite 304, Berkeley, CA 94704 , USA  
tel: +1 510 845-1447, Fax: +1 510 845-9141, email: [hesperian@hesperian.org](mailto:hesperian@hesperian.org)

If you don't have internet access, Deaf Child Worldwide can send you a paper copy of this chapter in the post. Please write to us and request this if you would like a copy.

### Child protection policies

Many organisations now have child protection policies which are available to download from their websites. There are also resources which help local organisations to produce and implement their own child protection policies. Some examples include:

#### Keeping Children Safe

This was developed by a group of international agencies and contains information for all agencies, big and small, who work with children and includes:

**Tool 1** Standards for Child Protection

**Tool 2** How to implement the standards

**Tool 3** Training for child protection

**Tool 4** A DVD – to support and help with training

**Tool 5** A CD Rom – this contains all the training materials, trainer notes, exercises, activities, sample forms and templates

The written materials can be downloaded from [www.keepingchildrensafe.org.uk/](http://www.keepingchildrensafe.org.uk/) or can be ordered as a hard copy, with CD and DVD by emailing [publications@keepingchildrensafe.org.uk](mailto:publications@keepingchildrensafe.org.uk)

#### *Child Protection Policies and Procedures Toolkit*

This was produced by ChildHope UK and the Consortium for Street Children. The Child Protection toolkit is a practical learning tool and set of resources designed NGOs, particularly in developing countries, working with children. It aims to outline both the key principles relevant to child protection, and also the stages needed to develop, implement and evaluate Child Protection policies.

The toolkit has been designed to help organisations to develop their own Child Protection Policies and procedures, and to train organisation members on such.

This toolkit includes:

- information and guidelines on the recommended principles and steps involved in developing organisational child protection policies and procedures;
- a set of exercises which are designed to provide relevant practice to help users to understand and work through the steps described;

- guidance notes for facilitators to enable the material contained within the toolkit to be adapted into a training course, supplemented by PowerPoint presentations included in the CD Rom version.

The toolkit can be downloaded free of charge from [www.childhope.org.uk/toolkit.php](http://www.childhope.org.uk/toolkit.php) or can be ordered from:

ChildHope UK, Development House , 56/64 Leonard Street, London EC2A 4JX  
United Kingdom, Telephone: + 44 (0) 20 7065 0961, Email [Sandra@childhope.uk](mailto:Sandra@childhope.uk)

## Research

For more information about the scale and nature of violence against disabled children, please see the UN report:

### ***Violence against Disabled Children, United Nations, 2005***

This is the report of a study conducted as part of a larger study of violence against all children. The report highlights the ways in which deaf children are particularly vulnerable to abuse because of their difficulties with spoken communication.

#### **Violence against disabled children**

Children who live with a physical, sensory, intellectual or mental health disability are among the most stigmatised and marginalised of the world's children. While all children are at risk of being victims of violence, disabled children find themselves at significantly increased risk because of stigma, negative traditional beliefs and ignorance. Lack of social support, limited opportunities for education, employment or participation in the community further isolates disabled children and their families, leading to increased levels of stress and hardship. Disabled children are also often targeted by abusers who see them as easy victims.

**Extract from the UN Secretary General's Summary, 2005**

The full text of the report is available from: [www.violencestudy.org/](http://www.violencestudy.org/) (Search for "Violence against disabled children"). Information about the study is also available from CRIN, at [www.crin.org](http://www.crin.org)



# Useful resources

## Websites and organisations

### Deaf Child Worldwide

[www.deafchildworldwide.org](http://www.deafchildworldwide.org)

#### United Kingdom

15 Dufferin St, London EC1Y 8UR, UK

Email: [info@deafchildworldwide.org](mailto:info@deafchildworldwide.org)

Tel: +44 (0)20 7549 0454

Fax: +44 (0)20 7251 5020

#### India

9D Annapurna Apts, 68 Ballygunge

Circular Rd, Kolkata 700019

West Bengal, India

Email: [idcsindia@idcsindia.in](mailto:idcsindia@idcsindia.in)

Tel: +91 (0)33 2289 2706

Fax: +91 (0)33 2289 2705

Deaf Child Worldwide is the only UK based development agency dedicated to enabling deaf children to overcome poverty and isolation worldwide.

You can join the Deaf Child Worldwide information sharing network at [www.deafchildworldwide.info/network](http://www.deafchildworldwide.info/network).

You will receive regular information and can search for other organisations working with deaf children across the world. There is also range of freely available information, project descriptions and articles about childhood deafness at [www.deafchildworldwide.info](http://www.deafchildworldwide.info)

Deaf Child Worldwide is the international development agency of the National Deaf Children's Society (NDCS) in the UK. The NDCS website contains practical information produced for families and

professionals in the UK. NDCS provides clear, balanced information about the full range of communication and education options. You can find out more at [www.ndcs.org.uk](http://www.ndcs.org.uk)

### Enabling Education Network (EENET)

c/o Educational Support and Inclusion, School of Education, University of Manchester, Oxford Rd, Manchester M13 9PL, UK

Tel: +44 (0)161 275 3711

Mobile/SMS: +44 (0)7929 326 564

Fax: +44 (0)161 275 3548

Email: [info@eenet.org.uk](mailto:info@eenet.org.uk)

[www.eenet.org.uk](http://www.eenet.org.uk)

EENET is an information-sharing network on inclusive education. Membership of the network is open to everyone. The EENET website is full of articles and resources on inclusive education which can be downloaded or requested for free. There are also dedicated sections where articles on deafness and parents can be found.

### CBM International (Christian Blind Mission)

Nibelungenstraße 124,  
64625 Bensheim, Germany

Tel: +49 6251 131 392

Fax: +49 6251 131 338

[www.cbmi.org/](http://www.cbmi.org/)

CBM works in 112 countries in 4 continents to act upon the needs and rights of people with disabilities, including children and adults with hearing impairment and deafblind people. CBM has supported 60 schools, 14 vocational training programmes and

13 training centres for teachers of deaf children. CBM also works to prevent hearing loss and works closely with the World Health Organisation Prevention of Deafness Programme. CBM website contains information about all of its partnerships.

### **Deaf Africa Fund**

Chapel Cottage, 7 King Street,  
Much Wenlock, Shrops. TF13 6BL, UK  
Email: dewdaf@aol.com

Deaf Africa Fund promotes education opportunities for deaf children in developing countries.

### **Forest Bookshop**

Unit 2, New Building, Ellwood Road,  
Milkwall, Coleford, Glos. GL16 7LE, UK  
www.forestbooks.com  
Tel: +44 1594 833 585  
Fax: +44 1594 833 446

An online bookshop selling a comprehensive range of books, videos and CD ROMs on deafness and deaf issues.

### **Gallaudet University**

800 Florida Avenue,  
NE Washington, DC 20002-3695, USA  
Text and Tel: +1 (202) 651 5815  
Fax: (202) 448 6954  
Email: OIPS@gallaudet.edu  
www.gallaudet.edu

Gallaudet University is the only liberal arts university in the world designed exclusively for deaf and hard of hearing students. It is an excellent source for finding deaf books, journals and research.

### **Source**

Source International Information Support Centre, 2nd Floor, Institute of Child Health, 30 Guilford Street, London WC1N 1EH, UK

Tel: +44 (0)20 7829 8698  
Fax: +44 (0)20 7404 2062  
Email: source@ich.ucl.ac.uk  
www.asksource.info

Source is an international information support centre designed to strengthen the management, use and impact of information on health and disability. Source has details of where to find books, reports, websites, organisations, newsletters and more. Some resources are available free to download.

### **John Tracy Clinic**

806 West Adams Blvd, Los Angeles,  
California 90007, USA  
Tel: +1 (213) 748 5481  
Email: kambrosi@jtc.org  
www.jtc.org/

The John Tracy Clinic runs a free correspondence course for families with deaf children who are following the auditory-oral method of communication. The course is available by post or on the internet.

### **Sense International**

11-13 Clifton Terrace, Finsbury Park,  
London N4 3SR, UK  
Email: info@senseinternational.org.uk  
www.senseinternational.org.uk

Sense International is the only UK charity working exclusively to meet the needs of deafblind children and adults in developing countries.

Contact details for offices in India, East Africa, Latin America and Romania are available on the website.

### **SoundSeekers**

34 Buckingham Palace Road,  
London, SW1W 0RE, UK  
Tel: +44 (0)20 7233 5700  
Fax: +44 (0)20 7233 5800

Email: [sound.seekers@btinternet.com](mailto:sound.seekers@btinternet.com)  
[www.sound-seekers.org.uk](http://www.sound-seekers.org.uk)

Sound Seekers works in partnership with developing countries in the Commonwealth to increase awareness of, and assist in, the prevention and treatment of deafness among children. They have established HARK! mobile audiology services in India, Lesotho, Namibia, and Swaziland. They are also supporting an Ear Care project in Sierra Leone and in conjunction with Kyambogo University, Uganda, running a short course for audiology technicians covering topics such as calibrating and maintain equipment such as audiometers, making earmoulds, fitting and servicing hearing aids.

### **Viataal**

Theerestraat 42,  
5271 GD St. Michielsgestel,  
Netherlands  
Tel: +36 (0)73 558 8930  
Email: [viataal.international@viataal.nl](mailto:viataal.international@viataal.nl)  
[www.viataalkennis.nl/international/](http://www.viataalkennis.nl/international/)

Viataal runs a Centre of Expertise which provides training to staff and partner organisations. Viataal works with partner organisations across the world to develop high-quality education for deaf children and appropriate care and services.

### **The World Federation of the Deaf**

PO Box 65, 00401 Helsinki, Finland  
Fax: +358 9 580 3573  
Email: [info@wfdeaf.org](mailto:info@wfdeaf.org)  
[www.wfdeaf.org](http://www.wfdeaf.org)

The World Federation of the Deaf is the central organisation of associations of Deaf people. The website contains contact details for the National Association of Deaf people in most of the world's countries.

## Useful publications

### **Helping Children who are Deaf**

Sandy Niemann, Devorah Greenstein and Darlena David, Hesperian, 2004

This practical, accessible book is part of Hesperian's Early Assistance Series aimed at families, community workers and teachers. The book explains how deafness affects a child's ability to learn language and develop mentally and socially, and is packed with activities on how to foster language learning through both sign and oral approaches. The book was developed in partnership with families, deaf adults, educators, community workers and other experts in over 17 countries.

Available from [www.hesperian.org](http://www.hesperian.org)  
or by post: Hesperian,  
1919 Addison Street, Suite 304,  
Berkeley, CA 94704, USA  
Tel: +1 510 845 1447  
Fax: +1 510 845 9141  
Email: [hesperian@hesperian.org](mailto:hesperian@hesperian.org)

### **Let's communicate: a handbook for people working with children with communication difficulties** (1997)

This manual is intended for mid-level rehabilitation workers who work with children with communication difficulties and their families. The manual contains information on general aspects of communication, causes of communication impairment, sample assessments, and advice for parents and those involved in the training of health and education workers. Chapter 6 focuses exclusively on deafness.

Available to download from [www.who.int/disabilities/publications/care/en/index.html](http://www.who.int/disabilities/publications/care/en/index.html) or from Deaf Child Worldwide by post.

### **Family Action for Inclusion in Education** Susie Miles, EENET, 2002

This EENET book tells the stories of family-based advocacy organisations which have helped to transform education systems in southern Africa, South Asia, Europe and Australia. It has been written for family and community members who may feel isolated and want to form a support group, or advocacy organisation, to challenge exclusion. It will also be of interest to those interested in promoting more inclusive practices in education, such as teachers, teacher educators, policy makers and consumer organisations.

Available from [www.eenet.org.uk](http://www.eenet.org.uk) or from EENET by post.  
(See contact details above)

### **Embracing Diversity: Toolkit for Creating Inclusive, Learning-Friendly Environments**

This toolkit is produced by UNESCO for schools and education practitioners. Each of the six booklets contains tools and activities for self-study to start creating an inclusive, learning-friendly environment (ILFE). Booklet 2 covers working with families and communities. You can download this at [www2.unescobkk.org/elib/publications/032revised/index.htm](http://www2.unescobkk.org/elib/publications/032revised/index.htm)

### **Working Together – Guidelines for partnership between professionals and parents of children and young people with disabilities**

UNESCO, 1986

These guidelines cover the needs and strengths of families, the definition of a professional-parent partnerships and practical tips for working together with families throughout the life of a disabled child.

This is available in hard copy from Deaf Child Worldwide and to download from the Deaf Child Worldwide website, [www.deafchildworldwide.info](http://www.deafchildworldwide.info) and [www.unesco.org](http://www.unesco.org)

### **START: simple toolkit for advocacy research techniques**

Lucy Tweedie, VSO

VSO's advocacy research toolkit, is based on VSO's own experience of low-cost, non-academic professional research. START enables the user to set up and manage their own research for the purposes of advocacy. You can use START to research and advocate on any issue. START is available to download from [www.campaignforeducation.org](http://www.campaignforeducation.org) or by post from Deaf Child Worldwide.

### Publications from the National Deaf Children's Society, UK

Here are just some of the publications produced by the NDCS for parents and professionals in the UK. Not all the information in these publications may be relevant to your country or context. However they cover a wide range of topics and can be adapted and translated with permission from NDCS. Please contact Deaf Child Worldwide to request permission.

The following are all available from [www.ndcs.org.uk](http://www.ndcs.org.uk) and or by post from Deaf Child Worldwide:

#### **Understanding deafness**

Information on types and levels of deafness.

#### **Communicating with your deaf child**

Information on communication approaches plus good communication techniques.

#### **Parenting a deaf child – parenting tips**

A practical guide to parenting a deaf child. All the advice and tips in the booklet are provided by parents of deaf children. There is an accompanying CD Rom.

#### **Helping your deaf child to learn**

A booklet of information, activities and tips contributed by parents of deaf children.

#### **Deaf Friendly Teaching**

A practical resource for teachers and school governors to meet the needs of deaf children in mainstream schools. Accompanied by two other booklets Deaf Friendly Schools and Deaf Friendly Pre-schools and Nurseries.

#### **What are you feeling?**

A workbook to help deaf children understand and talk about emotions and feelings. For parents and teachers.

#### **Vision care for your deaf child – information for families**

A joint booklet published by NDCS and Sense, which explains the importance of getting your child's eyes tested, the types of tests available and common eye conditions.

#### **Guide for local deaf children's societies**

Available from the National Deaf Children's Society. These are simple guides outlining the role of a Chair, Treasurer, Secretary and members. Although they are tailored to UK laws governing voluntary organisations, office bearers in small voluntary organisations, such as parents' groups, in other countries have also found them useful.

### Articles

There are many articles and case studies available on the Deaf Child Worldwide website. However here are a selection of articles which you may find particularly useful.

#### **Establishing a National Parents of Deaf Children Association**

John Mwashu, UWAVIKA, Tanzania, 2003

#### **Turning a Parents' Support Group into a Parents' Organisation**

Heide Beinbauer, CLaSH, Namibia, 2005

#### **Teaching Sign Language to Parents of Deaf Children**

Judith Collins, Leeds, UK, 2006

#### **The Deaf Dilemma**

Susie Miles, 1995

This article was first published in CBR News in 1995. It discusses the pros and cons of residential schools for deaf children and the need for CBR workers to be more knowledgeable about supporting deaf children.

The above articles are available from [www.deafchildworldwide.info](http://www.deafchildworldwide.info) or by post.

### Learning from the experiences of others

The following resources relate to families with learning disabled children. Although the issues facing these families are different some of their experiences in creating family-led movements are relevant for families with deaf children.

#### **A bundle of sticks, family-based organisations in developing countries**

Roy McConkey, School of Health Sciences, University of Ulster. Extracted from E. Alant and L. Lloyd (eds.) *Augmentative and Alternative Communication and Severe Disabilities: Beyond Poverty* (2005) Available from [www.eenet.org.uk](http://www.eenet.org.uk) by post from EENET.

#### **Fostering Parental Involvement**

Pramila Balasundaram

#### **Fostering the Formation of Parents' Associations**

Pål Skogmo

#### **Mothers of Disabled Children as CBR Workers**

Barney McGlade and

Rita Aquino

All these articles are from

*Innovations In Developing Countries*

*For People With Disabilities*, Brian

O'Toole and Roy McConkey (eds),

1995, Lisieux Hall Publications

#### **Parents as trainers of families, professionals and communities**

#### **Lesotho Society of Mentally Handicapped Persons, 1997**

A manual to support parent trainers, covering training of trainers, training tips, bringing families together, learning from families, action planning and needs analysis. There are two video guides covering *Bringing Families Together* and *Learning from Families*.

These resources are available from [www.eenet.org.uk](http://www.eenet.org.uk) or by post from EENET.

Most of these contributions were written for publication on the Deaf Child Worldwide website or especially for this book. However, some have been published elsewhere. The full references of published works have been included below this table.

1.1	Maria Chiswanda, 1999, Zimbabwe	10
1.2	Henry Sempala, Uganda	11
1.3	Steve Powers, 2006, University of Birmingham	12
1.4	David Werner, 1987, Disabled Village Children	16
2.1	Felicia Foinbaum, Cameroon	23
2.2	Asminda Carillo Acasio, Mexico	24
2.3	Snigdha Sarkar, India	25
2.4	Usha Rani, CBR Manager, Association of People with Disability, India	26
2.5	Sign Language Education and Development (SLED), South Africa	29
2.6	Ekta Mittal, VOICES, Janani Raghupathy, Sandhya Srinivasan, IDCS-India	30
2.7	Kweku Addison, African Footprint, Ghana	32
2.8	Monique Bekker, Tanzatoto Foundation, Tanzania	33
2.9	Felicia Foinbaum, Hearing Impaired Voices of Kenya	35
2.10	Snigdha Sarkar, India	36
2.11	Erica Taraporewalla, India	38
3.1	Snigdha Sarkar, Anwasha parents' group, India	42
3.2	Heide Beinhauer, CLaSH, Namibia	44
3.3	Ulrike Last, Handicap International, Somaliland	46
3.4	George Gachanja, Kenya Society for Deaf Children and Kirsty Wilson, Deaf Child Worldwide	48
3.5	Nathalie Arinda, Education Dept, Bushenyi District Government, Uganda	51
3.6	Heide Beinhauer, CLaSH, Namibia	52
3.7	Rita Hernandez Sarabia, Mexico City, Mexico	54
3.8	Libby Foster, Nzeve Deaf Children's Centre, Zimbabwe	55
3.9	Ulrike Last, Handicap International, Somaliland	56
3.10	Snigdha Sarkar, Anwasha, India	57
3.11	Geoffrey Mukonyoro Wathigo, Kenya Association of Parents of the Deaf	59
4.1	Donna Lene, Loto Taumafai Early Intervention Programme	65
4.2	National Deaf Children's Society (NDCS), UK	66
4.3	Bev Garner, Special Education Services, KwaZulu Province	67
4.4	Geoffrey Mukonyoro Wathigo, Kenya	67
4.5	Amanda Naylor, VSO Volunteer, Kazakhstan	70
4.6	I. Lichtig, B. Woll, M. Silvia Carnio, R. Akiyama and M. Gomes, 2004, Brazil	71
4.7	Nathalie Arinda, Bushenyi District Local Government Education Dept, Uganda	72
4.8	Stephen Lombard, DCCT, South Africa	72
4.9	Stephen Lombard, DCCT, South Africa	73
4.10	Donna Lene, Loto Taumafai Society, Samoa	75
4.11	I. Lichtig, B. Woll, M. Silvia Carnio, R. Akiyama and M. Gomes, 2004, Brazil	76
4.12	Donna Lene, Loto Taumafai Society, Samoa	77
5.1	Libby Foster, NZEVE Deaf Children's Centre	83
5.2	Ron Brouillette, Christoffel Blinden Mission	84
5.3	Donna Lene, Loto Taumafai Society	86
5.4	Libby Foster, NZEVE Deaf Children's Centre	88

5.5	Donna Lene, Loto Taumafai Society, Samoa	89
5.6	Pastor Amos Muyambo, Nyadire Primary School, Zimbabwe	91
5.7	Mrs Mwoyosviyi, Mutoko, Zimbabwe	93
5.8	B Hampanna, Samuha and Sreela Bose, IDCS-India	93
5.9	Peter Mue, Christofel Blinden Mission, Cameroon	96
5.10	Mandy Naylor, VSO Volunteer, Kazakhstan	98
6.1	Ms Yao Chang Zheng, China	102
6.2	Nathalie Arinda, Special Education Advisor, Uganda	104
6.3	Anne-Marie Hall (NDCS) with Larisa Grishanova, Nordis School	105
6.4	Geoffrey Mukonyoro Wathigo, Kenya	107
6.5	Snigdha Sarkar, India	109
6.6	Abdul Ghani, Herat, Afghanistan	110
6.7	Mandy Naylor, VSO Volunteer, Kazakhstan	112
6.8	Pauline Kamau and Nduta Mbarathi, NCNN, Kenya	115
7.1	Rita Hernandez Sarabia, Mexico	119
7.2	Snigdha Sarkar, Kolkata, India	119
7.3	Wendy McCracken, University of Manchester, UK	120
7.4	Eloisa Perez Hernandez, Mexico	121
7.5	George Gachanja, Kenya Society for Deaf Children	122
7.6	Un Sileap, Cambodia, translated by Pheng Samnang and Steve Harknett	124
7.7	Shambhu Nath Jajodia, SAHAS	126
7.8	Heide Beinhauer, CLaSH, Namibia	128
7.9	Geoffrey Mukonyoro Wathigo, Kenya Association of Parents of the Deaf	129
7.10	John Mwashu, UWAVIKA, Tanzania	130
7.11	Joana Vanagiene, Vice Chair, PAGAVA	132

## Previously published work

- 1.1 Maria Chiswanda, Zimbabwe  
**Hearing Mothers and Their Deaf Children in Zimbabwe: Mediated Learning Experiences.** Full text published in *Infant-Toddler Intervention: The Transdisciplinary Journal*, v9 n4 p391-406 Dec 1999. Abstract available at: [www.csusm.edu/thousand/chiswanda.html](http://www.csusm.edu/thousand/chiswanda.html).
- 1.3 Steve Powers, University of Birmingham  
**Learning from Success: High Achieving Deaf Pupils**, Powers, S. (2006) University of Birmingham, funded by RNID.  
Available at: <http://www.education.bham.ac.uk/research/projects1/lfs/index.shtml>
- 1.4 David Werner, Disabled Village Children  
**Disabled Village Children, A guide for community health workers, rehabilitation workers, and families.** David Werner, Hesperian Foundation, 1987, updated 2006. Available from [www.hesperian.org.uk](http://www.hesperian.org.uk)
- 4.6 and 4.11 I. Lichtig, B. Woll, M. Silvia Cárnio, R. Akiyama and M. Gomes, Brazil  
**Deaf staff members' participation in a Brazilian intervention programme for deaf children and their families: impacts and consequences**  
Published in *Deaf Worlds* v. 20, n. 3, p. 281-297, 2004

This book aims to raise awareness of the important role that parents and families can play in the lives of their deaf children and in their communities. It provides practical examples showing how families, service providers and deaf people can work together to support deaf children. The book takes an action learning approach and is packed with inspirational case studies from around the world, suggestions to aid reflection, and simple guidance for improving practice.

**Deaf Child Worldwide is the only UK based international development agency dedicated to enabling deaf children to overcome poverty and isolation**



Published by Deaf Child Worldwide [www.deafchildworldwide.org](http://www.deafchildworldwide.org)

**United Kingdom**

15 Dufferin Street, London EC1Y 8UR UK

Email: [info@deafchildworldwide.org](mailto:info@deafchildworldwide.org) Tel: +44 (0)20 7549 0454 Fax: +44 (0)20 7251 5020

**India**

9D Annapurna Apts, 68 Ballygunge Circular Road, Kolkata 700019, West Bengal, India

Email: [idsindia@idsindia.in](mailto:idsindia@idsindia.in) Tel: +91 (0)33 2289 2706 Fax: +91 (0)33 2289 2705