



Toolkit for Parents' Groups Supporting Deaf Children

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Volume I: KNOWING EACH OTHER

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Volume I: KNOWING EACH OTHER



INTRODUCTION



Tools placed together in a box form a toolkit. This toolkit provides information which may be helpful for parents and other caregivers of deaf children to come together and grow as a group. It covers aspects like group formation, functioning and future planning and is outlined in four volumes and a supplementary document. In that sense, these are tools that can be used to evolve a vibrant parents' group.



Why this toolkit?

Parents of deaf children can learn more about their children's development and do more for them if they come together as a group. The parents' group can work collectively to ensure that children can access their rights and other opportunities. Parents of deaf children can also share their struggles and joys and learn from each other in a group. This Toolkit provides guidelines on how such a Parents' Group can be formed and function. Some information regarding working for a brighter future for deaf young people is also included.

How was the toolkit prepared?

The Toolkit was developed from the experiences and suggestions of parents' groups and deaf young people across multiple locations in West Bengal, Odisha and Karnataka in India. Representatives from communities, local self government bodies, government functionaries across multiple departments and likeminded individuals working with/for deaf children were also involved. Non-government organisations, partnering with Deaf Child Worldwide in these states, played a key role in facilitating the interactions and providing their own inputs. The content of the Toolkit was consolidated through these interactions and a subsequent round of feedback.

The Toolkit was prepared in two language versions – Bengali and English.

What does it contain?

The Toolkit is in four volumes.

Volume I: Knowing Each Other

Volume II: Coming Together

Volume III: Growing Together

Volume IV: Looking Back, Looking Ahead

Together, the four volumes provide suggestions on how a parents' group can be

formed, how it can function, which stakeholders it can connect with, the range of activities it can undertake, how it can track its progress and also shape its vision for the future. A supplementary document provides suggestions for capacity building of parents' groups and some additional resources.

Who can use it?

Parents who are already part of a group or those wanting to form groups are the main audience of the Toolkit. Staff in organisations working with parents of deaf children may also find this useful. Other practitioners working with parents' groups may refer to it as well.

This Toolkit can serve as a reference or guide. It is meant to trigger ideas and reflection and encourage parents' groups to grow. It is, by no means, final. It can be improved upon with our evolving experiences.

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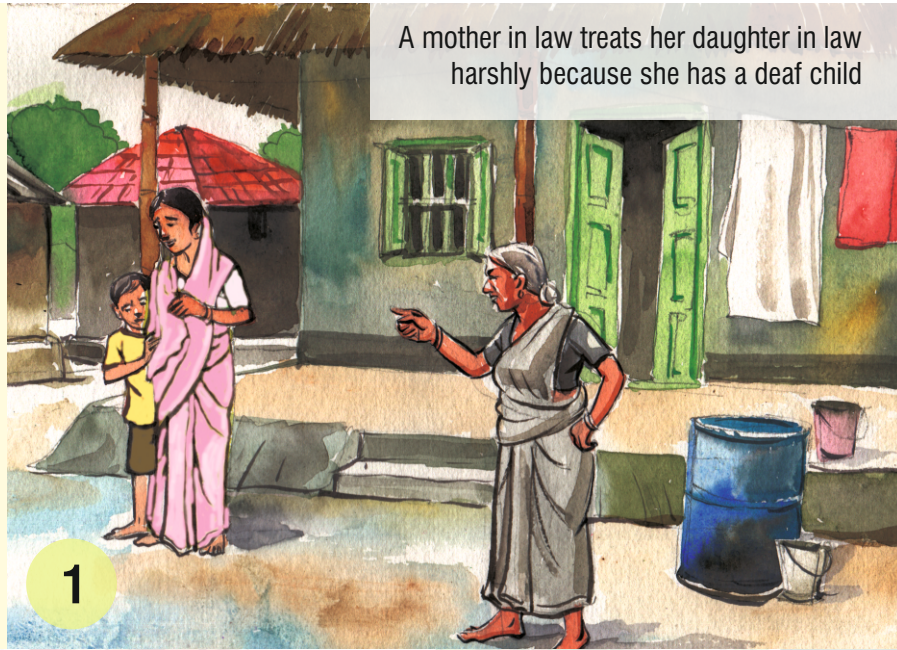
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Parents' Groups of deaf children can play a key role in transforming the lives of their families



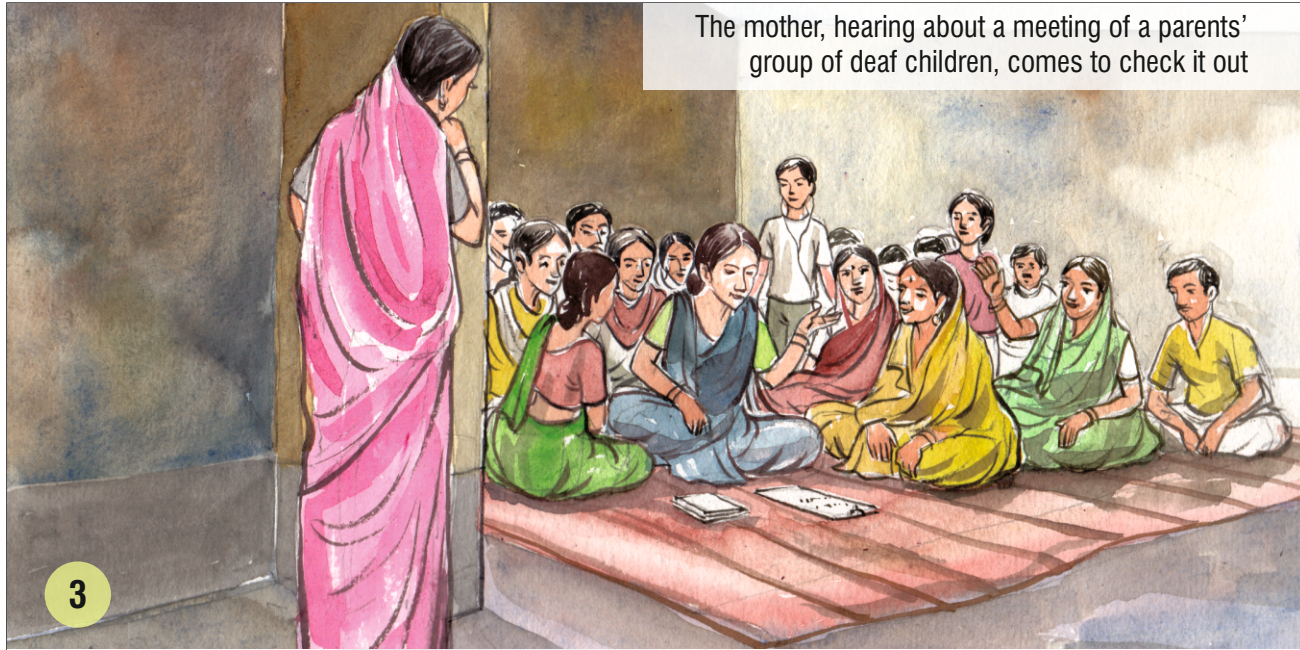
A mother in law treats her daughter in law harshly because she has a deaf child

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The father of the deaf child feels uncomfortable and does not like walking together with his family



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The mother, hearing about a meeting of a parents' group of deaf children, comes to check it out

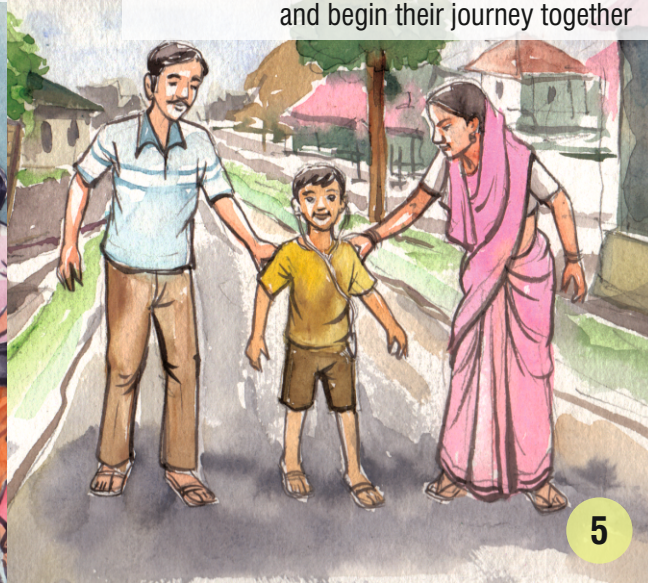
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The mother joins the group and begins to share with others; she also brings her husband to the meetings



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Both parents learn about the importance of contributing to their child's welfare and begin their journey together



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WHY FORM A GROUP?

What are the advantages and benefits of being in a parents' group supporting deaf children?

- We can share our thoughts frankly without being judged since we are all facing similar circumstances; we can draw strength from each other
- We can learn from each other's experience and other inputs and become better equipped in contributing to our deaf children's development
- We can find and share information about our deaf children's rights and opportunities and help each other in accessing them
- We can identify and build linkages with government departments, service providers and others who can support us for our children's development and improving their lives
- We can conduct various activities that highlight the potential of our children and also draw attention to the issues affecting them
- We can highlight the issues of deaf children at a larger scale and also work together with people and organisations at various levels
- We will be able to draw hope from our collective efforts and enhance opportunities for wellbeing of deaf children and their families

SOME KEY CONSIDERATIONS

We have to believe in our deaf child's potential.

We have to believe that our deaf children have strengths and capacities just like other children. We have to believe that they have rights including those for health, education and protection. We have to motivate them to move forward in their lives. We have to ensure that they access mandated services and other opportunities so that they can participate meaningfully in society.

We have to recognise each other's situations and struggles.

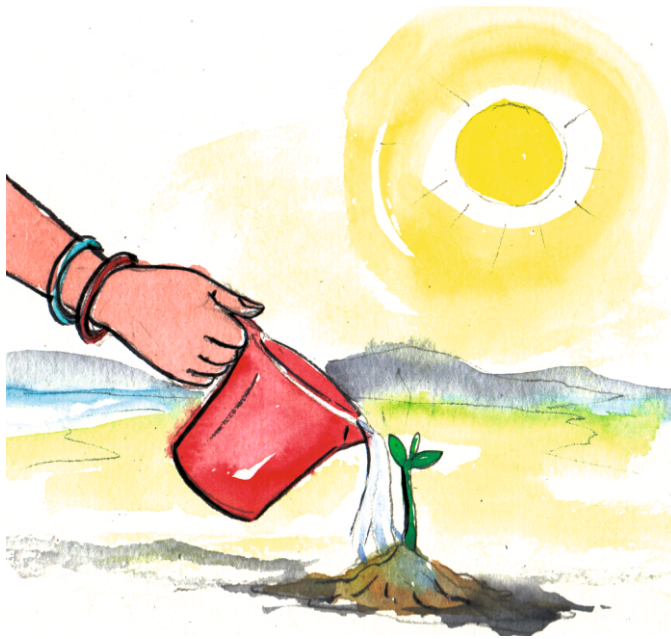
We may be blamed for giving birth to a deaf child and told that this is a result of past sins. Our families may not support us. We may be struggling with poverty, uneven sources of work and income and other problems. Women, especially, have to face many problems and restrictions. They may have limited scope for mobility. They may often be unable to share their concerns and issues with others.

Those of us living in villages, particularly in more remote locations, may not have adequate means of transport. Travelling to government offices or other locations may be more problematic for us. Those living in urban slums may face uncertainty

about their present and future, particularly if the settlements do not have proper legal status.



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We have to remember that friendship and trust should form the foundation of our group.

We should first give time to knowing each other and developing bonds of friendship and trust. Just like a plant needs to be nurtured, a group also needs to be tended well so that it can grow and yield fruits.

Points to Remember

In a group, all members:

- Agree to work collectively towards a common objective
- Participate and share their opinions and issues
- Recognise and address concerns and conflicts within the group (differences in opinion among members is natural! How we resolve the differences is important.)
- Develop and follow rules for effective functioning
- Plan and implement activities with shared responsibilities
- Reflect on what has been achieved and the challenges faced and use these in planning for the future





GETTING STARTED

So, who can be members of the group?

Parents of deaf children are the obvious and ideal starting point. It could also be grandparents or any other family member who takes care of the child and is deeply concerned about him/her. In many places, we have seen older brothers or sisters also becoming group members.

We can directly contact families with deaf children in our community / neighbourhood that we know and invite them to be a part of the group. Information about such families can be obtained from others as well such as Anganwadi workers, ASHAs and honorary health workers, school teachers etc. As the group grows, other parents of deaf children may come forward themselves.

Points to Remember

A parents' group supporting deaf children may be formed in two ways.

- (1) A parent of a deaf child may himself/herself take the initiative to bring other parents together and start a group.
- (2) A local non government organisation may start an initiative which includes working with deaf children, their families and communities. As part of this, it may support formation of a parents' group. The project may provide opportunities for group trainings and activities.

No matter how a group is formed, it is important to remember that it will grow and sustain only when members begin to take ownership and decide their course of action for themselves!

What should we tell potential members when we meet them first?

We must be patient when establishing contact with family members of deaf children. When we approach them for the first time, we can share:

- Who we are and the commonality of our experiences – that we are also parents/other family members who are caring for a deaf child
- The purpose of the parents' group – that we can all come together as a group so that we can share, learn and support each other for creating a better future for our children and also to collectively decide how our group will function
- Share invitations for the first meeting – state that an initial meeting is being planned with other members; ask which locations, dates and time slots suit them and that this will be decided based on mutual convenience

It is good if we...

- Try to find out about all the family members who live together
- Ensure that we talk to both the parents; this may call for repeat visits
- Talk to the grandparents and other elderly members who may be key decision makers
- Try to identify who are most interested in learning more for the benefit of the child; ideally, it helps if it is one of the parents
- Encourage this interested family member to come for the first meeting and consider joining the group





THE FIRST MEETING

Why is the first formal meeting so important?

The first meeting will set the tone of what follows. It is important to provide a friendly atmosphere where people can share. If they enjoy the first meeting, then there is a greater chance of them choosing to come again and also joining the group.

Where should the meeting be held?

It has to be a location which everyone is familiar with and is easily accessible. It can be in somebody's house. It can be a room in a club, school or in the panchayat office (for these permission may be needed). The time for the meeting also needs to be fixed and communicated to all.



What should we keep in mind when preparing for the first meeting?

Encourage people to share about themselves and their children and get to know each other. Try to understand if they know each other from before.



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We have to focus more on introduction in the first meeting. It may seem that some are talking too much or going off the point. But we should be considerate and give them time to speak. We can also use some games to make it a more enjoyable experience for everyone.

Emphasise that everybody here wants the same thing – to support our deaf children so that they can have a better present and future and can fend for themselves when we are not around.





Introduce the idea of a parents' group and the benefits. Give them space to share their thoughts. Encourage them to respond. This discussion can be continued in the second meeting.

What can happen by the end of the first meeting?

It would be good if we track the following aspects and arrive at a preliminary understanding.

- How many people came to the meeting?
- What are their circumstances/situations?
- What is their level of knowledge regarding deafness?
- What are their needs?
- What do they think about the idea of a parents' group supporting deaf children?
- What was the level of participation in the meeting?
- Next meeting – was date and venue fixed? What needs to be discussed? Who will call whom?

Usually the, main points of a meeting and the decisions taken are noted. All the participants have to sign this as well. However, it is ok if we don't do this in the first meeting. People would have come for the first time and may not feel comfortable about signing. Once all agree to being in a group and we begin to hold more meetings, this practice of signing can be initiated. (This aspect is covered further in a supplementary document in the Toolkit titled *Enhancing Capacities: Suggestions and Resources.*)

Here are some positive stories from existing parents' groups in West Bengal, India.

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I. Over the years, a parents' group in Pandua, Hooghly, has helped many members in obtaining disability certificates and cards for their deaf children. They also raise their voice against any form of abuse of deaf children and children with other disabilities. This has taken them to police stations, panchayat and administration offices in the block and district levels. They even got together and constructed a road to ensure improved connectivity for the local non government organisation that supports them. (Earlier, a narrow, muddy pathway led to the organisation's office which became even more difficult to use during the rainy season.)

II. A parents' group in Jalpaiguri discussed their concerns in a meeting. The issues which emerged repeatedly – i.e. ensuring their children sit on the first bench in

school and that all receive disability certificates – were noted. This charter of demands was presented to the Block Development Officer on with International Day of Persons with Disabilities (December 3, 2015). Simultaneously, the parents had been interacting with other stakeholders including school authorities and teachers. As the International Day of Persons with Disabilities approached the following year, the group could see clear improvements. Teachers in the government primary schools had begun to ensure that their children sat in the front bench. They were also beginning to take more interest in them and encouraged parents to follow up on their attendance and educational performance.

III. Members of a parents' group in Kolkata have helped each other in obtaining disability certificates, cards and hearing aids for their children. Parents had also contacted the office of the Disability Commissioner for getting hearing aids free of cost and securing educational sponsorships for children. Moreover, members have also helped each other in obtaining ration cards and Aadhar cards.



Acknowledgement

Deaf Child Worldwide would like to thank the following for their role in developing the *Toolkit for Parents' Groups Supporting Deaf Children*.

West Bengal, India

- *Pather Disha and Muktir Alo (parents' groups of deaf children in Hooghly)
- *Milan, Asha and Nayan (parents' groups of deaf children in Jalpaiguri and Alipurduar)
- * Guardian Forum (Parents' group of children with multiple disabilities in Jalpaiguri)
- *Udita and Anwasha (parents' groups of deaf children in Kolkata)
- *Pratidhwani (West Bengal state level parents' group of deaf children)
- *Representatives of deaf youth from the above mentioned districts who are deaf role models
- *Graham Bell Centre for the Deaf (GBCD, Hooghly)
- *Khagenhat Welfare Organisation (KWO, Jalpaiguri)
- *Child in Need Institute (CINI, Kolkata)
- *Various government functionaries including service providers, community members and other like-minded individuals who contributed

Odisha, India

- *Mayurbhanj Pratidhwani (parents' group in Mayurbhanj)
- *Mahalaxmi Parents' Group (parents' group in Brahmapur)
- *Parents' Federation Digapandi Block (parents' group in Ganjam)
- *Pratidhwani Puri Sadar, (parents' group in Puri)

- *Representatives of deaf youth from the above mentioned districts who are deaf role models
- *Citizen's Association for Rural Development (CARD, Brahmapur)
- *Lower Income People's Involvement for Community Action (LIPICA, Ganjam)
- *Society for Action in Disability and Health Awareness (Sadhana, Mayurbhanj)
- *Sri Nrusingha Dev Anchalika Yuba Parishad (SNDAYP, Puri)
- *Various government functionaries including service providers, community members and other like-minded individuals who contributed

Karnataka, India

- *Yashwani Parents' Alliance (parents' group in Bijapura)
- *Chetana (parents' group in Dewangere)
- *Hongirana, Hombelakn, Jeevanemmdi, Hosavelaku (parents' groups in Koppal)
- *Representatives of deaf youth from the above mentioned districts who are deaf role models
- *Association of People with Disability (APD, Karnataka)
- *Samuha (Karnataka)
- * Various government functionaries including service providers, community members and other like-minded individuals who contributed

Deaf Child Worldwide is the leading UK charity committed to supporting deaf children and young people in some of the world's poorest communities. We provide vital support for deaf children and young people in South Asia, East Africa and Latin America focusing on communities where the need is greatest. We work with partner organisations to ensure that deaf children and young people are fully included in family, education and community life.

Deaf Child Worldwide is the international development arm of the National Deaf Children's Society (charity number 1016532).

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