



Toolkit for Parents' Groups Supporting Deaf Children

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Volume III: GROWING TOGETHER


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Volume III: GROWING TOGETHER



INTRODUCTION



This is the third volume of the *Toolkit for Parents' Groups Supporting Deaf Children*. In the first and second volumes, we saw how parents and other caregivers can come together and form a group. In this volume, we provide suggestions regarding activities that they can undertake. The aspect of capacity building of group members is also highlighted. Further details are provided in the supplementary document in the Toolkit titled *Enhancing Capacities: Suggestions and Resources*. This volume ends with some key challenges that may emerge at this stage and their possible solutions.

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PLANNING ACTIVITIES

How can we begin working as a group?

It is natural for group members to start sharing their concerns with each other. They can share the solutions as well. So, for example, a parent who has obtained the disability certificate for his/her child can share the procedure for doing so. Another parent can talk about getting his/her deaf child admitted in a government primary school. All members possess some knowledge and can support each other. These initial steps are, in fact, the first actions of a group.

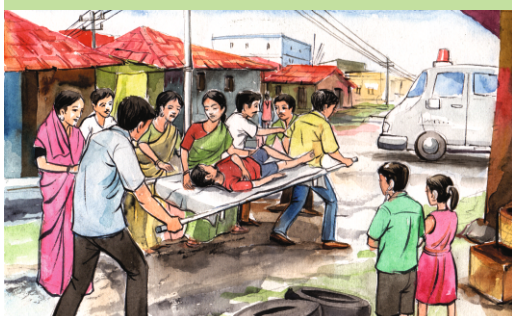
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Some experiences from parents' groups in West Bengal



1. A parents' group of deaf children in Hooghly discusses processes related to the medical test for assessing disability and subsequent steps for obtaining the disability cards and certificates for their children. They also go to these places with the concerned parent if needed.

2. A parents' group in Jalpaiguri checked if deaf children were accessing the benefits of a 50% discount in rail fare for long distance trains. This provision is available for those whose lack of hearing is validated by the disability card and certificate. Members were provided the necessary contact information for availing these benefits.



3. Besides discussing about provisions for deaf children, a parents' group in Kolkata has also been helping each other in other ways. When a group member's child fell seriously ill, she panicked. The other group members helped her. Some also accompanied her and the child to the hospital.

Such instances of mutual support help in strengthening the bond between group members. It also motivates us to work collectively.

Points to Remember

- All children and adults are rightfully entitled to certain provisions, services and opportunities.
- Children with disabilities, including deaf children, are entitled to certain additional provisions, services and opportunities.
- If our deaf children do not receive these, then we should take steps to address such issues. Being in a group can help us in these efforts.
- We need to be prepared with the necessary information for this! Knowing about *The Rights for Persons with Disabilities Act 2016*, in particular, would be very helpful.

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Who are the people and institutions that a group should be aware of?

Various institutions, key government functionaries and others can support / contribute in our children's wellbeing and development. We can start with a preliminary list. More names can be added to this list later.

Name	Address	Phone

Central level

- National Institute of Speech and Hearing Disability- Divyangan (earlier known as NIHH – National Institute for Hearing Handicapped)

State Level

- Parents' group at state level
- Office of Disability Commissioner
- Directorate of Social Welfare
- State Commission for Protection of Child Rights
- Government and non government organisation working with deafness



For Rural Locations

At Gram Panchayat Level

- Accredited Social Health Activist (ASHA)
- Anganwadi Worker
- Health workers associated with the sub centre
- Local clubs and non government organisations - NGOs (including those working on deafness)
- Head Teacher
- Gram Panchayat Pradhan and members
- Members of Village Level Child Protection Committee

For Urban Locations

At Ward Level

- Anganwadi Worker
- Honorary Health Worker
- First Tier Supervisor (health)
- Functionaries at Ward Medical Health Unit
- Head master/head teacher at nearby schools
- School Inspector (Circle level)
- Local clubs and NGOs (including those working on deafness)
- Special Educators at Resource Centre (run under Sarva Shiksha Mission)
- Ward Councillor
- Ward Level Child Protection Committee members

At Block Level

- Special Educators at the Resource Centres (run under Sarva Shiksha Mission)
- Block Welfare Officer
- Block Development Officer
- School Inspector (Circle level)
- Health functionaries at the Block Primary Health Centre including Adolescent Friendly Health Counsellors
- Block Level Child Protection Committee
- Child Welfare Police Officer at Police Station
- Member of Legislative Assembly (MLA)

District Level (For Rural and Urban)

- Additional Commissioner (District Administration – District Magistrate)
- District Social Welfare Officer
- District Programme Officer
- Inclusive Education for Disabled (IED) Coordinator (under Sarv Shiksha Mission)
- District Child Protection Officer
- CHILDLINE (1098- emergency service for children)
- Child Welfare Committee
- Functionaries at sub division and district hospitals (including counsellors for adolescents in urban areas)
- Member of Parliament (MP)
- Regional Transport Office
- Bank
- Station Master (Railways)
- Others (including Vocational Training Centres)

Emergency contact numbers (particularly for police, fire, ambulance services etc) should also be collated.

These lists are for reference. Each group can do this exercise for themselves.

What activities can we do as a group? How should we plan for them?

Each group should reflect on what it wants to do and available resources and then plan its activities. It is always good to start with something that can be easily managed.

Also, while some members may have experience in organising activities, others may be doing so for the first time. It is very important that we all have uniform clarity about what is to be done. Here are some points that can help in planning activities.

- We can discuss options for activities and then collectively decide what we want to do
- We have to check how much money is needed
- Do we want to share information about this activity (i.e. publicise it)? If yes, then - who will we inform and how, and, who will do this?
- If we face any problems, how will we solve them?

We can consider the following activities.

To start off...

Activity	Objective
<p>Organising events to commemorate key days like Republic Day (January 26), Independence Day (August 15), Children's Day (November 14) and others</p> <p>Participating in organising cultural and/or religious festivals</p>	<ul style="list-style-type: none">○ Enhance group bonds and confidence○ Introduce the group to others○ Enhance visibility○ Highlight the issue of childhood deafness
<p>Commemorating specific days such as World Hearing Day (March 3), International Day of the Deaf People (last Sunday in the month of September), International Week of the Deaf (last week of September) and International Day of Persons with Disabilities (December 3)</p>	<ul style="list-style-type: none">○ Introduce the group to others○ Enhance visibility○ Draw attention to the issue of childhood deafness in a more direct way○ Identify and build links with likeminded individuals and organisations

The group should decide on the nature and level of participation of deaf children in the activities.

As we gain some experience, then...

Drawing competition involving deaf children with other children in the local community / school	<ul style="list-style-type: none">○ Provide a platform for deaf children to display their skills and build confidence○ Promote interaction between deaf children and other children○ Help highlight need for more dialogue on issue of childhood deafness locally○ Enhance visibility
Sports competition involving deaf children or with other children in the local community / school	
Competitions on Indian Sign Language for children and adults (including the deaf and the hearing)	<ul style="list-style-type: none">○ Promote interaction between deaf children and other children○ Encourage ties between the deaf and the hearing



We can invite a key person as our chief guest. This way, we can connect with him/her. It will make our event more effective and successful as well.

It is always good to hold another group meeting after the activity is done to reflect on the experience. This can help in understanding whether the purpose of the activity was achieved, what went well and what didn't and how we can build on this experience in planning the next activity.





How We Started

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The first activity of a parents' group in Hooghly was to celebrate Gandhi Jayanti (October 2, 2016). Group members requested permission from the local school authorities to use their hall. Parents taught their children a small play on Mahatma Gandhi which they performed using mime. It was well received by the audience comprising of school authorities, teachers and some community members (besides the parents' group). Many were surprised by the children's talent and congratulated the parents' group.

In a subsequent meeting, group members discussed the reasons for not being able to draw a substantial audience for the event. These factors were identified – (i) it was a Sunday and people did not want to spend time at the event (ii) they were also caught up with the impending Durga Puja festivities. However, some other group members were more optimistic. They felt that the activity had helped them gain confidence as a group and that it was a good start.

As a group, what other activities can we undertake?

It is important for parents' groups to interact with a range of stakeholders. In fact, this can constitute an important activity for the group with multiple possible benefits.

Activity	Objective
Obtain and discuss information for the benefit of deaf children (existing programmes, key legislations with mandated services etc)	<ul style="list-style-type: none"> ○ Enhance understanding of the available provisions and remain updated ○ Work towards ensuring that mandated services and other provisions are being accessed
Visit and interact with key service delivery providers and other important agencies	<ul style="list-style-type: none"> ○ Learn about the services, specific roles and functions of key service providers ○ Facilitate an introduction so that one can approach them later if needed with more confidence
Periodic meetings with Panchayat Pradhan or Ward Councillor	<ul style="list-style-type: none"> ○ Make them aware about the parents' group and its activities ○ Highlight any concerns/issues as well as provide feedback on discussions and decisions taken on issues in prior meetings ○ Build relationship
Identify other deaf children in their communities (by door to door visits in survey mode or other means)	<ul style="list-style-type: none"> ○ Develop an improved understanding of the number of deaf children and their issues and concerns in their communities ○ Build linkages with newly identified families and explore their interest in joining the group

	<ul style="list-style-type: none"> ○ Enhance group's voice and representation of deaf children and contribute in larger processes of change
Undertake interactions with other parents' groups in the district	<ul style="list-style-type: none"> ○ Mutual sharing and learning from experiences ○ Building relationships and working together as needed
Attend Pratidhwani (state level parents' group) meetings and look at ways of being a part of processes at state or wider levels	<ul style="list-style-type: none"> ○ Learn from experiences of other groups ○ Learn about emerging developments, any new government initiatives etc at state and national level ○ Share our concerns and see how we can work together ○ Participate in broader process of empowering deaf children and working collectively on creating an enabling environment for them
Become involved in the workings and special events of Panchayat/urban local self government, health, education and other government offices (i.e. participate in panchayat related meetings, Village Health and Nutrition Day, immunisation camps etc)	<ul style="list-style-type: none"> ○ Enhance ties with other community members as well as the functionaries ○ Promote the spirit of participation ○ Utilise these platforms and opportunities for creating awareness about the issues of deaf children and also enhancing their access to services
Explore opportunities of growth for group members as well as deaf young people (vocational training, income generation and entrepreneurship)	<ul style="list-style-type: none"> ○ Retain interest of group members, particularly those whose children have passed out of school ○ Enhance sustainability of the group ○ Contribute to a better future for deaf young people

Parents' groups can also help organise specific activities such as summer camps for children with support from resource persons and NGOs. The camps can be a platform for providing further educational inputs for the deaf children. Their talents can also be promoted.

It is also important to ensure that:

- Members share responsibilities among themselves for the activities.
- The division of work can be discussed when the activity is being planned.
- Task based sub groups can be formed.
- Even otherwise, the group may decide to give specific responsibilities to certain people. For instance, some members may be asked to seek information from various service providers. They may be given the responsibility of keeping themselves updated and sharing news of any developments in the group.

We understand the need for approaching key functionaries and service providers and also attending Pratidhwani meetings. But we feel that we will not be able to handle such interactions. What should we do?

It is natural to feel nervous when we are doing something for the first time. But we can gradually gain confidence from our experiences. It also helps if we do our homework properly – we prepare what we want to say and how we want to say it.

We can discuss this within our group, maybe even practise beforehand through role plays.



Initially, I used to feel scared in attending Pratidhwani meetings in Kolkata. I would write what I wanted to say to prepare myself. After attending two to three meetings, I began to feel comfortable. I didn't feel so scared anymore. Now I can speak freely.

Working Collectively for Change

Parents' groups have to work together with other key local figures for ensuring significant changes in the lives of deaf children. We have to see them as partners in our journey.



Panchayat Pradhan: As a Panchayat Pradhan, I need to look at the issues and concerns of the deaf children in my area as well. It would help me if the parents' group shares such information. We can also tell them about available services and where they can go for assistance.

Anganwadi Worker: As an Anganwadi Worker, I have to check the health and nutritional status of all children below six years in my area. This includes deaf children as well. If we work together with the parents' group, we can try to increase early identification of deafness in children and ensure that they get the support that they need.



Club member: In my club, we do various cultural, social and sports related initiatives. We can organise activities for promoting issues of deaf children and their families together. We can promote more contact and

communication between deaf children and their families and our other community members.

Mahila dal leader: I help track savings, status on loans and



income generation in our women self help group. We also work on women's rights and social issues. We do share a common goal with the parents' groups. We too are interested in building a better future for our children. If parents' groups interact with us, we can learn more and highlight the concerns of deaf children. We can also use our ties with panchayat and other functionaries for this purpose.



School teacher: Interactions between the school and the parents' group can help us in collectively identifying challenges faced by deaf children and their families on the education front and how we can address them. We can explore how the children can draw maximum benefit from our teaching as well as the other opportunities for growth that a school can offer – i.e. engaging with teachers and other adults, mixing with peers etc. For ensuring significant change, we must emphasise the importance of education for our deaf children.





ENHANCING CAPACITIES

Can being in a group help me find answers to the concerns and questions faced in raising my child?

One of the biggest advantages of being in a group is that we can learn from each other's experience and find answers for ourselves. As a group, we can identify someone else who could provide the required information if we do not have the answers ourselves.

Do we need to know some particular topics and enhance our skills?

Yes. We essentially need to enhance our capacities in two areas - (i) knowledge and skills on topics which can help us in raising our deaf children and (ii) knowledge and skills on topics that can enhance functioning of our group. Some examples are given below.

Directly Related to Deaf Children

Basics of childhood deafness (structure of the ear, potential causes and types of deafness)

Early identification of deafness

How to communicate with our children (using sign language, reading lip movements and speech)

Children's rights including those of deaf children

Ensuring child protection

For Strengthening the Group and its Activities

Group formation (why form a group, points to keep in mind when choosing leaders and their roles, framing rules)

Communication (including public speaking)

Leadership skills

Maintaining records (documentation and finance)

A list of such topics and sources of information for the same is provided in the document entitled *Enhancing Capacities: Suggestions and Resources* in the Toolkit. Further information on how to maintain records like writing minutes and some financial aspects are also mentioned there. These aspects are very important for effective functioning of the group.

Should we focus only on structured trainings for the group?

We need both structured trainings as well as informal discussions where we share and learn from each other.



I feel scared in talking to my daughter's teacher. I don't know what to say or ask her.

There is nothing to be scared of. As a parent, you can always talk to the teacher about your child. You can check if the teacher makes your child sit on the front bench and all key points are written clearly on the board and whether she uses TLM (i.e. teaching learning materials).





You can discuss some common signs with her. The teacher may also have some queries that you can answer.

You can ask whether your child is able to understand what is being taught, how she is performing and what else needs to be done to support her. You can even ask the teacher if the child has the Mid-Day Meal and whether she goes to the toilet or not while in school.



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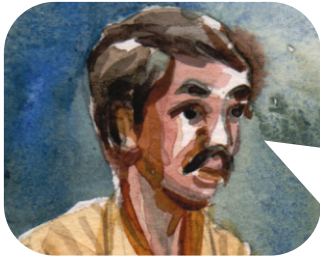


You can also ask the teacher how other children behave with your daughter. If you have any doubt, you can also ask the special educator who is available at Sarva Shiksha Mission's Resource Centre.

Points to Remember

Capacity building is a gradual and time taking process. A single training can be a beginning and is never enough. Also, we should not try to learn too many things at the same time.

SOME CHALLENGES, SOME SOLUTIONS



Our initial activities did not go as planned. Now, some group members are very demoralised. What can we do?

Initially, due to lack of experience or for any other reason, an activity may not go well or not yield the desired result. Naturally, this may cause disappointment. Some may start blaming others and this may further affect all the group members. Here, it is important for leaders to encourage a frank discussion on the activity in a supportive environment so that the group can learn from that experience. We have to identify the challenges faced and see how these could have been handled. It has to be pointed out that there will always be ups and downs in the journey of any group.



We often form sub groups when we do our activities. Sometimes, we have seen that this creates tension or ill feeling between members. How can we handle such dynamics?



It is important to ensure that group members are involved in discussions for planning any activity. We can see which members are suitable for the tasks involved. The kind of sub groups needed can be clarified as well. However, the leaders must make a conscious effort to involve every one. After all, each member can contribute in some way. If some members still feel that they are being left out, then the leaders may need to speak to them separately and also assure them of their importance in the group.

We have started identifying issues affecting our children and working on them. But everything takes so much time and we are not making much progress.



We have to be aware that some issues can be addressed quickly while some are more time consuming. Long lasting change, particularly for enhancing quality of services, takes time. We should persist and not lose hope.

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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