

Parents, Family and Community Participation in Inclusive Education

Webinar 13 - Companion Technical Booklet



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Parents, Family and Community Participation in Inclusive Education

Webinar Booklet

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What this booklet can do for you

The purpose of this booklet and the accompanying webinar is to assist UNICEF staff and our partners to understand the importance of engaging with parents, families and communities in the process of implementing inclusive education, with an emphasis on children with disabilities, and how it fits within UNICEF's mission.

In this booklet you will be introduced to:

- *Why the participation of parents and community organizations is important in general for education and particularly significant in the case of children with disabilities and their families.*
- *Different approaches to engaging families and community in support of inclusion and approaches to making it effective and meaningful for all parties.*
- *How to identify family and community assets that can assist the process of implementing inclusive education on the ground.*
- *Examples of successful experiences in different regions of the world in which parents and social organizations have acted in support of inclusive education.*

For more detailed guidance on programming for inclusive education, please review the following booklets included in this series:

1. Conceptualizing Inclusive Education and Contextualizing it within the UNICEF Mission
2. Definition and Classification of Disability
3. Legislation and Policies for Inclusive Education
4. Collecting Data on Child Disability
5. Mapping Children with Disabilities Out of School
6. EMIS and Children with Disabilities
7. Partnerships, Advocacy and Communication for Social Change
8. Financing of Inclusive Education
9. Inclusive Pre-School Programmes
10. Access to School and the Learning Environment I – Physical, Information and Communication
11. Access to School and the Learning Environment II – Universal Design for Learning
12. Teachers, Inclusive, Child-Centred Teaching and Pedagogy
13. Parents, Family and Community Participation in Inclusive Education (*this booklet*)
14. Planning, Monitoring and Evaluation

How to use this booklet

Throughout this document you will find boxes summarizing key points from each section, offering case studies and recommending additional readings. Keywords are highlighted in bold throughout the text and are included in a glossary at the end of the document.

If, at any time, you would like to go back to the beginning of this booklet, simply click on the sentence **"Webinar 13 - Companion Technical Booklet"** at the top of each page, and you will be directed to the Table of Contents.

To access the companion webinar, just scan the QR code.



Acronyms and Abbreviations

ABC	Assistance for Blind Children
CBR	Community-Based Rehabilitatio
CFS	Child-Friendly Schools
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Persons' Organizations
IE	Inclusive Education
NGO	Non-Governmental Organizations
ORS	Oral Rehydration Salts
UN	United Nations
UNESCO	United Nations Education, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund

I. Introduction

Inclusive Education is cross-sectoral and involves many different ministries and stakeholders.¹

This booklet accompanies a webinar on 'Parent, Family and Community Participation in Inclusive Education' and complements a series of resources to support the capacity of UNICEF officers in the field.

The webinar focuses on the challenges and opportunities for social participation that arise from the **Convention on the Rights of People with Disabilities** (CRPD), the experiences of implementing inclusive education worldwide and the need to embrace the post-2015 Development Goals with the collaboration of all stakeholders.

Engaging parents and the community is not a new concept. In fact, most of the approaches suggested will be familiar to UNICEF's staff and partners. Some may even be recognized as part of current practices and programmes.

Consequently, the ideas or suggestions for action presented are not meant to be used as isolated strategies, but rather to leverage existing programmes in the field. The participation of families, social organizations of children with disabilities, Disabled Persons' Organizations (DPOs) and Non-Governmental Organizations (NGOs) concerned with the rights of children in general – or the rights of children with disabilities in particular – will be examined here as tools that can benefit the goals of development, equity and the rights of all children through inclusive education.

There are many examples of programmes, such as the UNICEF initiative **Child-Friendly Schools**, which have been for many years and still continue to be effective platforms for involving parents and communities. Such practices that are already institutionalized in many regions and countries can assist the development of new inclusive education initiatives. There are also examples of family and community involvement experiences within the initiatives that UNICEF and others have conducted for a number of years in the areas of *Maternal and Child Health, Child Protection and Early Childhood Development*. All these programmes can provide the basis for strengthening the relationship between children with disabilities and their schools, families and communities to create environments that are prepared to address diversity and stimulate the development and social inclusion of all children.



II. Creating a Culture of Collaboration

Key Points

- *Family involvement is important throughout the lifecycle of children with disabilities, especially in the early years (UNICEF, 2012).*
- *Involving parents and the community is an important principle of quality, inclusive education, both in and out of the classroom.*
- *A positive connection between parents and schools influences children's attitudes and achievements in education.*
- *Families and civil-society organizations can also play an important role in the process of advancing a legal and policy framework for inclusive education.*
- *Children with disabilities are not the only ones that benefit: there are also advantages for parents, classmates, educators and schools.*

Involving parents and the community is an important principle of quality, both in and out of the classroom. It is even more relevant in the case of inclusive education, which is much broader than formal education and should not only take place within the four walls of a classroom.

Parents' collaboration is not only of benefit for children: there are also possible gains for all parties, for instance:

- Parents increase interaction with their children, become more responsive and sensitive to their needs and more confident in their parenting skills.
- Educators acquire a better understanding of families' culture and diversity, feel more comfortable at work and improve their morale.
- Schools, by involving parents and the community, tend to establish better reputations in the community.

Creating a climate and sustaining a culture of collaboration is a challenge for schools. But it is one that pays large dividends through time.

However, the recognition that family engagement in education benefits children does not make clear how the involvement becomes a positive force.

The first step for families to become involved in a collaborative way with schools is to promote a social and educational atmosphere where parents and partners feel welcomed, respected, trusted, heard and needed.

Cultural factors and traditions strongly influence the relationship between schools and the community. In many places throughout the globe, schools are the centre of community life and are used to encourage and achieve social participation. Such cultural environments will ease the process: parents, schools and community leaders know how to work together and find creative solutions for improving learning, responding to economic crisis and disease outbreaks, or assisting populations affected by disasters caused by natural hazards.²

This is demonstrated in Brazil, a country with a long-standing tradition of social participation. There is a centre of social action and popular education at the Alexandre de Gusmao School in Rio de Janeiro, which serves as an instrument for stimulating and enabling a future that is inclusive of all children. Transforming society becomes a major goal and a way to develop awareness and promote action, with the potential to triumph over the social and economic determinants and living conditions of the community, which influence everyone.

In this way, we see aforementioned societal 'ingredients' intertwined in the production of an effective educational system. Schools such as this, in communities with a profound lack of social policies, can benefit remarkably from participative approaches. The school provides one example of how to operationalize a culture of community participation.³

There are no 'recipes' for creating a culture of collaboration and a school climate that is conducive to inclusive processes in schools and the community. Collaboration is a result of social, institutional and interpersonal dynamics that are characterized by complexity. Because there are no recipes to address such complexities, it is key to think creatively, understand the resources, opportunities and challenges that exist in each case, and be aware of what has worked in similar cases.

Collaboration is a complex process that does not warrant the same approach used to resolve complicated problems.

Making a five-course haute cuisine dinner is very complicated... but if you have the ingredients, the recipe book and the equipment, chances are you will end up with something decent for your guests. Let's take another example: sending a rocket into space. This is even more complicated! Very complicated indeed. However, if you have the materials, the engineers, the blueprints and the launch pad, at the end of the day you are likely to have a craft ready for blast off.

Now complex is something different. Complex means that there is no recipe book or blueprint. It means that we are required to think out from start to finish, and that the outcome is always uncertain and unique.⁴



Food for Thought...

Bear in mind that an 'only-as-much-as-needed' principle dictates good practices in providing any external support to students in the context of inclusive education. This approach avoids imposing help on those who do not necessarily need or want it.

For instance, students who require supplemental support might receive additional help with academic and social skills from a professional or volunteer outside the classroom. Although supplemental help may be available, teachers, parents and students should weigh the benefits and drawbacks of receiving such supplemental help outside of the regular classroom. If the child will miss other valuable instruction or social experiences, supplemental help and curriculum modifications should be carefully considered.

Sometimes community organizations have the capacity to collaborate in certain specific areas. This collaboration can be related to the logistics of **inclusion** (for instance, volunteers might be able to support teachers by assisting children who have mobility restrictions and may need help to get in or out of the classroom or to go to the bathroom).

Looking at Examples: The Cross-Sectoral Nature of Inclusive Education

Facing her class of 60 children, Shirina Akter moves on to the last exercise before school breaks up for a short holiday: comprehension. While rows of girls with neat plaits and boys in short-sleeved shirts scribble away in their exercise books, one child sitting at the front delivers a series of pin-pricks into a black, plastic tablet.

Salim, who has been blind since birth, is using a simple device to write in Braille. It is just one of the things that allows him to sit alongside his peers at the Hasnabad primary school, in a small, thriving country town of textile mills, soap factories and farms, about 50 km northeast of Dhaka, Bangladesh.

Other elements include teachers and classroom assistants trained to read Braille, learning aids and – more importantly – a concerted campaign to overcome ignorance and press for the inclusion of visually impaired children in mainstream education. Sightsavers Bangladesh⁵ and a multi-sectoral partnership collaborate with communities and schools to make all this available.

Exclusion of children with visual impairments from education is not just a problem in Bangladesh. Across much of the developing world – home to the vast majority of preventable blindness and visual impairment – those who have difficulty seeing are often deprived because their families are unaware of available treatments or the fact that a blind child can receive proper schooling. There is often prejudice and misinformation about alleged risks of infection. Schools themselves can be reluctant to enroll visually impaired children. This fuels a cycle of illiteracy and poverty, and it also serves to reinforce the exclusion of children with visual impairments from society as they become adults.

In places like Hasnabad, Sightsavers has been facilitating a collaborative process in which local partners, such as a non-profit organization called Assistance for Blind Children (ABC), secure the support needed by teachers and school boards for the inclusion of the visually impaired. They fund the training of the teachers and assistants in Braille and supply necessary materials. Random house-to-house surveys are conducted by one of Sightsavers' community partners.

Community advocates talk to children in schools to create awareness on the right to education for everyone and prepare children to support and welcome those who are included. ABC sends rehabilitation assistants to the children's homes to evaluate their appropriate placement in schools. Many of the blind and low-vision children's parents assume that their child's **disability** means he or she is unable to learn and would not be accepted by schools. The new arrivals received teasing from classmates at first, but that has given way to empathy and support. If teachers are properly trained, and awareness exists to create an inclusive environment, teachers found that it is not difficult to accommodate a blind student in their class.

Now, a teacher trained in Braille helps Salim to mark his work on the Braille tablet. He is now one of the best pupils. "His memory is very sharp," the teacher says. The appreciation is mutual. Salim, whose favourite subject is English, says that when he grows up he wants to be a teacher.

To learn more go to:

- *Learn more about Sightsavers' work involving parents and communities at <http://www.sightsavers.org/stories/arifs-story/>*
- *Learn more about the story of Alexandre de Gusmao School in Rio de Janeiro at <http://escolaalexandredegusmao.blogspot.com/>*
- *Access an excellent social participation toolbox at <http://ctb.ku.edu/en>*

Activity

Are you in contact with local disability organizations in your country? Make a short list of which ones they are and what type of work they do.

III. How Can I Help? Understanding Different Levels of Collaboration and Partnerships

Key Points

- *In order to truly address current needs and opportunities, the relationship between families, schools and the community should be seen as a participatory, multi-centric experience.*
- *Expert agencies and disability organizations encourage specific actions to engage families and promote community collaboration for inclusive education.*
- *Providing support and regular training to parents and creating a friendly institutional environment appear among the most frequent recommendations to engage parents and the community.*

The levels of family involvement in children’s education might vary in accordance with the participation opportunities that the education system makes available to them. In the case of children with disabilities, the willingness of a family to engage in collaboration might be influenced by the type of disability, as well as the family’s socio-economic status and the nature of the parent-child (or guardian-child) relationship.

A number of scales have been used to evaluate the different types and degrees of collaboration between schools, families and communities. It is useful to distinguish between the different types and purposes of collaboration. While variances in approaches, dynamics and subsequent effectiveness and sustainability have been studied by numerous researchers, the value of understanding such distinctions is not merely academic. On the contrary: they have made it possible to systematize and analyze the different ways or levels of involvement, which is useful to understanding the dynamics amongst participants and helps in making collaboration a meaningful and sustained experience that is valued and appreciated by all.

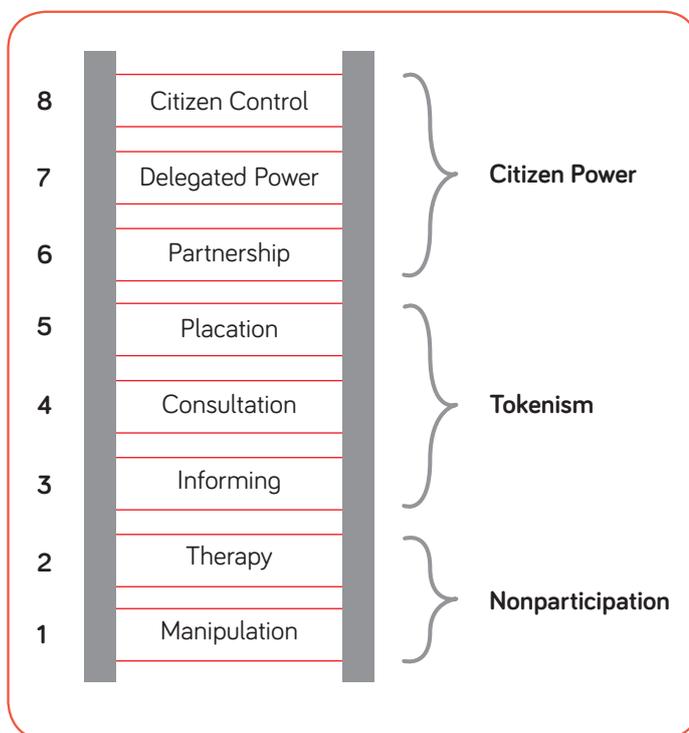


Figure 1: An example of a scale used to distinguish forms of participation

One of the most popular scales⁶ (Figure 1) was developed with the idea of encouraging an examination of *why* and *how* people participate throughout communities. The ladder helps us to distinguish among forms of participation that are oriented by the idea of empowering people, and others that remain at a symbolic level or are directly manipulative.

Another scale⁷ effectively demonstrates six types of involvement that go from schools assisting families with parenting and child-rearing skills to including families as decision-makers and coordinating community services with their expectations and needs.

Providing support and regular training to parents, facilitating regular access to information and consultation and creating a friendly institutional environment appear among the most frequent recommendations for implementing good policies to engage parents and the community with inclusive education.

In its well-known Open File on Inclusive Education, UNESCO⁸ introduces a detailed list of possible ‘parent engagement’ options aimed at making the experience a two-way-street type of relationship:

- **Families as activists:** Frequently, families – particularly those organized into networks or associations – play a lead role in moving education systems towards more inclusive approaches and policies. Some of the actions in which parent groups can have an impact are identifying schools that are willing to move forward, establishing links and partnerships with education authorities in support of inclusive education, organizing seminars and workshops to introduce new thinking and new practice, and supporting teacher development.
- **Families as contributors to inclusive education:** Under this option, the role of parents is emphasized in supporting inclusion in the family and children’s learning and development at home. The main idea is that families and communities should reinforce inclusive and learning experiences.
- **Schools, families and the community as partners:** There are many opportunities for partnerships and collaboration, from exchanging information to family members supporting learning at home.
- **Families supporting other families:** This is particularly advised in the case of parents of children with disabilities who live in poverty, isolated communities, or have culturally or linguistically diverse backgrounds. In this case the support of parents of children with disabilities who are in a better social or educational position can be extremely valuable.
- **Family and community involvement in school governance and management:** Includes the participation of families in decision making and in supporting aspects of daily management of activities.

Recent research shows that empowering families and enabling them to participate in decision making is an effective contribution to the process of change in the context of education.⁹ Instead of ‘involving’ families, or proposing specific tasks or set roles for parents, the idea of ‘engagement’ seeks the active participation of parents within the process of improving education for all.

Collaboration must be both constructive and efficient and this is more likely to happen when all parties feel comfortable in the process, the different roles are agreed and understood, and information is provided regularly in an open and democratic way.

Bear in mind also the need to provide regular opportunities for all participants to clarify their expectations, understand the complexities of the process (accomplishments as well as disappointments and drawbacks) and discuss how to improve the quality of the collaborative process.

Food for Thought...

Working with parents and community is good not only for schools. In a recent book, Professor Atul Gawandppe (2014) highlights an interesting story that comes from the field of community health and shows a very tangible result of involving parents in a programme. Not so long ago, in the 1970s, about five million children a year used to die from diarrheal disease in the world. Most of these children were from a few countries in Africa and Asia. The solution was a medical discovery that was at the time promoted with huge enthusiasm by international agencies, UNICEF and WHO amongst others: oral rehydration salts (ORS). The principle of ORS is simple: it involves drinking water mixed with sugar and salt, while continuing to eat.

At the time, there was a bit of a controversy because when it came to figuring out how to move the ORS around the world, the medical community said it was too complicated for mothers to learn how to give fluids by mouth to their children. WHO said the ORS ought to be administered by doctors. But that wasn't realistic either.

There were five million more dead the next year and another five million dead the following. In Bangladesh, teams of coaches were sent to the villages to work with the mothers, helping them figure out how to adapt to the essential new treatment. Many times a mother believed she knew what to do for her child who was sick with diarrhea. But without a source of medical advice there is too much room for error. For instance, the mothers would stop feeding their children because they were vomiting. They wouldn't give them fluids, which was dangerous. They had to be taught how to make the sugar and salt solution, and to give a complete treatment to the child regardless of the vomiting.

This outreach eventually cut the death rate by 250,000 children a year dying. It was a massive success, in great part because of the holistic view that you could provide skills to parents at both the village level and in cities in order for the mothers and fathers to appropriately protect their children's health. Now there are fewer than 2 million children per year dying from diarrheal illness.

This type of comprehensive approach to parent involvement provides a model for reaching out to the community. Can we apply this model to inclusive education? We think it is possible because it is the parents of children with disabilities who best know the learning needs and strategies of their children and can respond with the most effective teaching approaches.

Looking at Examples: Parents as Activists in Contemporary Russia

Based on an interview with Katya – Petrozavodsk, Karelia, Russia

To highlight an inspirational account of parent and community activism overcoming the barriers of exclusion, let us examine the story of Katya. She is one of the main organizers for a group of parents of children with disabilities that has become well known in parent networks around Russia for its success in utilizing civil legal cases to claim the rights of their children to inclusive education. She is the mother of an eight-year-old daughter with a degree of cerebral palsy that keeps her in a wheelchair, arrests her speech and limits her vocabulary to roughly 15 words.

Katya is an accountant by training and had worked two years before stopping to pursue her advocacy work. Her narrative revealed that organizing a parent group was rather difficult. "Our children had problems and

we didn't know where to turn. Then we met this young man, an organizer who worked with blind children. He said: 'It'll be easier for you if you work as a parents' organization and you can work out these issues together'."

Among the roughly 40 families represented in the group, "we have children, parents, grandmothers and grandfathers – not only moms and dads," and these people make up the heart of the organization. What they all have in common is a familial responsibility to children who simply require a different sort of care than others.

The first problem that the parents faced was the lack of adequate educational facilities for their children, who were offered only rehabilitative services. The parents began to discuss and question this 'not-quite-education'. Some parents of children with Down Syndrome convinced a local preschool to allow their children to attend along with the 'regular' children, Katya recalled. Hearing about these experiences, Katya and others realized that it might even be worth sending their own children to such a school.

After mulling over the idea, they eventually consulted a lawyer. "We lost the lawsuit at the first level. We ended up in high court. We lost the high court case. The argument was that there were no conditions and that our kids would be worse off in the circumstances available."

Perhaps the most important turning point in the struggle came when the group lost their lawsuit at the first level. Shortly before the appeal, the parents decided that they had nothing left to lose –and that higher visibility would help their cause. They gathered people to demonstrate that the administration was ignoring the educational rights of children with disabilities. Gathering families and children together at a local school, they gave a press conference.

By 2006, two primary/secondary schools in Karelia had been proposed as charter institutions to test inclusive education. Children with special needs, including Katya's daughter, began attending these schools – rather than one of the special schools for children with intellectual and physical disabilities – accompanied by para-professionals paid for by the designated funds.

Meanwhile, international disability organizations spread the groundbreaking news of a public school that had been integrated using legislative processes with civil rights as its banner. The news was announced via international mailing lists, reported on websites that were beginning to appear on the Russian internet to lobby for disability rights, and covered in the general press, where it served as evidence of democratic change.

To learn more go to:

- *As mentioned in Webinar 1, Child-Friendly Schools can be an entry point to advance inclusive education and promote partnerships with families and community. Find out more from <http://www.unicef.org/cfs/>*
- *Read more about the different levels, uses and meanings around the concept of social participation from the selected article 'Participation', by Majid Rahnema in the Dictionary of Development, available at https://books.google.com.uy/books?id=2bi_kf7QAq4C&pg=PA116&lpg=PA116&dq=dictionary+of+development,+participation&source=bl&ots=y_WOKDQCxq&sig=NbZyrE7sq2iglKU7eltoDzeU_Uw&hl=es&sa=X&ei=P6vPVKeaEOPHsQSD7YHABA&ved=0CCQQ6AEwAA#v=onepage&q=dictionary%20of%20development%2C%20participation&f=false*

IV. Starting from Scratch: Identifying Assets for Inclusion

Key Points

- *When development interventions begin with what communities have – their assets – as opposed to what they don't have – their needs – a community's ability to address those needs increases.*
- *Concepts such as social capital and community assets have emerged from literature on the cooperation between individuals and groups. It proposes that social capital has value¹⁰, often informs effective change and social progress¹¹, benefits equity¹² and assists the favourable development of individuals, families and communities.¹³*
- *An outcome of the invisibility of persons with disabilities to policy-makers and development agencies has been that they have developed social capital (in the form of resources and capacities as – often segregated – survival strategies).*
- *Disabled people's organizations, parents' organizations, peer-support groups, **community-based rehabilitation (CBR)** programmes and the independent-living movement have many of the resources needed for implementing inclusive strategies.*

Social capital exists at both the individual and community levels in the same way as other forms of 'capital' (e.g. economic, political or cultural) that are accessible to multiple layers of society. Despite the many definitions, there is a consensus that social capital refers to *a set of relationships and social ties, with organizations and to individuals, that can expand individual and collective choice-making opportunities, increase options and lead to a better quality of life.* At its core, it comprises a set of relationships and social structures that are based on trust and norms of reciprocity, which in turn are governed by values and/or rules of law.¹⁴

In the particular case of people with disabilities, looking at social capital implies a consideration (and appreciation) of their personal and collective power to achieve full inclusion within the community, to access social services, strengthen mutual support mechanisms and networks, and increase their quality of life.

Mutual collaboration is probably one of the most valuable assets and a longstanding tradition among people with disabilities. Because of the long fight for

For people with disabilities, collaboration and engagement has for long been a strategy to survive and sometimes overcome exclusion.

Often, the most knowledgeable person about a child is his or her parent. Parents understand the child's history in school, the learning style and personality. Inclusive schools enlist parents as partners in the learning process. Sometimes, this partnership takes the form of seeking consultation from parents as volunteers to facilitate inclusion or require their support on supplemental learning activities at home.

From Inclusive Education and Child-Friendly Schools, C. Johnstone, 2011

disability rights, community organizations have a long history of mobilizing the participation of families and individuals. While this has sometimes been applied to address specific needs and problems, such as fighting discrimination or tackling exclusion from education, it has often resulted in creative solutions and the production of alternatives as well as valuable knowledge in technical areas.

These traditions of mutual support and positive lessons learned by the families and organizations of people with disabilities are an incredible asset that can be used in support of inclusive education when properly identified and effectively bridged. Some examples of common collective assets existing among people with disabilities include:

- **Family organizations**, which often advise families using the reference of other families' experiences, especially in relation to raising a child with a disability, preventing future (secondary) disabilities and minimizing limitations.
- **Private, cooperative schools** and other educational institutions that involve families to provide day care and education, often created because mainstream schools have refused to include those children.
- **Vocational schools and workshops**, which provide safe, disability-friendly environments with opportunities for young people with disabilities from the local community to develop and improve their skills and to earn an income through their products to supplement their disability pensions.
- **Mutual aid and peer support groups**, which are increasingly used to provide peer advice and support on different matters.
- **Independent living centres**, which are usually run by people with disabilities. They often provide advice to those that have recently acquired a disability and may also provide opportunities for young people with disabilities from the local community to develop and improve their skills and to earn an income through their products. They may also assist persons with disabilities to manage their own disability supports, including the hiring of personal support workers.

Looking at Examples: Shaping a Deaf Identity

A remarkable example of grassroots collaboration evolving over time in order to achieve an empowered community with a strong identity is found in the deaf community of Uruguay. Its creation and growth has played out over time, with different individuals and organizations working together to break down the barriers that keep deaf Uruguayans from accessing services like education which are provided to the rest of society.

The movement took root with the founding of the Association of Deaf Uruguayans (ASUR), in the 1920s, to begin the fight for education and employment. A few years later, after gaining momentum and publicity, the movement was able to open a local institute of Uruguayan Sign Language (LSU). The institute promotes sign language courses taught by deaf persons, creating additional employment opportunities for the deaf community.

Another essential step in the successful evolution of the Uruguayan deaf community was the recognition that the services and support needed for deaf citizens to become entirely independent and fully integrated in society were not yet in place. For this to occur, a collective effort would have to be made, with initiatives involving not only deaf Uruguayans, but also their educators, parents, family members and friends. This

collective effort would need to be based on a shared vision of effective community involvement in activities and programmes to further the public's recognition of the deaf presence in Uruguay.

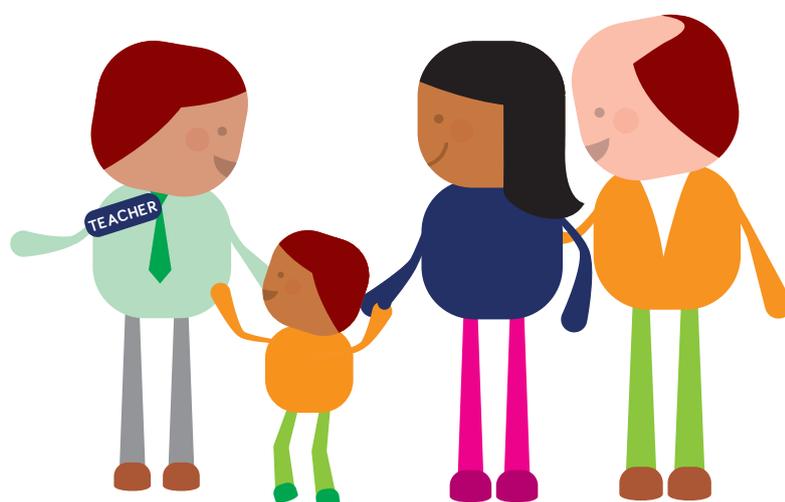
To this end, the Association for Parents and Friends of Deaf Uruguayans was created to unite parents with deaf children in a local school who expressed concern regarding the ability of deaf schools to prepare deaf children for independent participation in society.

A tangible example of the deaf network's efforts to improve access to social services is that of training seminars they have co-facilitated for the Montevideo police force, to provide officers with basic sign-language training. This is intended to be mutually beneficial: for the police to communicate effectively with deaf citizens in regards to their legal rights, and for deaf citizens to be educated by the police force about what constitutes a violation of the law, and how to report abuse, etc.

The Uruguayan deaf community makes no pretense that their work is complete – the legislation regarding provision of sign language interpreters in academic institutions is relatively recent and still nascent in its implementation. But the community serves as a model of real change created by the unification of separate bodies interested in a common purpose of accessibility and social inclusion.¹⁵



Figure 2: Community police attending a short training in sign language



Activity

A young deaf advocate, Maria Emilia Riotorto, is a teacher of Uruguayan Sign Language. Speaking with UNICEF at the International AIDS Conference, she emphasized the need for young people, families and institutions to collaborate and work together to promote and protect the health of deaf adolescents. Maria symbolizes an experience of self-advocacy from deaf people who have the shared belief that they have the same rights as others to make informed choices and decisions about their lives. Her captioned interview can be viewed at: <https://www.youtube.com/watch?v=WTullAlfIF0>

Some questions for discussion with your team:

- a) Why is the active involvement and support of family members and community organizations essential to deaf community livelihood?
- b) What are the essential elements of collaboration between hearing and deaf community leaders in order to make communication and project success possible?

To learn more go to:

- *Find out more about UNICEF work in Brazil to map youth assets and involve these capacities in social inclusion programmes at <http://rio.unicef-gis.org/>*
- *Learn more on social capital and mapping community assets from <https://socialcapital.wordpress.com/2007/07/30/community-mapping>*

Activity

In your experience, what are the main 'community assets' that contribute to protecting the rights of children?

Any of these?	Which others?
Good leadership	
Social integration	
Active community institutions	
Care for the most vulnerable	
Committed private sector	

Notes

V. From Paper to Practice: Policies, Partners and Challenges

Key Points

- *School-family partnerships are much more effective when (a) active policies are provided as a guide for families to become involved and (b) both educators and families understand and respect each other's roles.*
- *Policies to create structures and facilitate parental involvement and community participation are increasingly present in inclusive education.*
- *Principles to collaboration include fostering collaborative leadership and democratic decision making, proactive communication procedures, conflict-resolution, collective learning and shared ownership of achievements.¹⁶*

The CRPD contains a policy and legal framework that emphasizes the significance of involving families in support of inclusive dynamics both in schools and communities. It is Article 4(3) that emphasizes the need to “consult and actively involve people with disabilities, including children, through their representative organizations”. This provision clearly extends to education.

The UN **Convention on the Rights of Persons with Disabilities** (CRPD) recognizes the role of families in promoting the right of people with disabilities: “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the state, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

On the basis of the CRPD recommendations from international bodies, research has stressed the importance of families and community groups playing an active role in advocating the elimination of legislative or constitutional barriers to education for children and adults with disabilities¹⁷, as well as advancing changes in policy and legislation for inclusive education.¹⁸

The CRPD is in itself an example of how collaboration among the disability movement and networking among persons, families and organizations translated into empowerment and changed the political and legal determinants of disability. The process of promoting the CRPD created a strengthening of identity from a fragmented, marginalized and vulnerable community to a powerful voice with national and international impact.

The availability of policies, structures and specific opportunities for parents and communities to get involved also plays an important role. Sometimes, these elements are already in place and one can expect that a culture of collaboration has developed over the years, and that both educators and families are used to collaborating and feel comfortable in their different roles and tasks.

Sometimes, however, this is not the case and a culture of collaboration needs to be developed, together with policies and instruments to allow effective participation. Some typical examples of barriers to collaboration include:

- Policies exist but they are not actually enforced.
- People say that collaboration is good but they are not fully prepared to put it into practice.
- Policies exist but resources are not available to support their implementation.
- Educators feel reluctant to involve parents in making decisions on educational issues.
- Parents are only invited to come to school when there are problems in relation to their child. As a result, receiving an invitation to attend a school meeting has a negative connotation and makes parents reluctant to attend.

Another important challenge to bear in mind is that while parents of children with disabilities can be – and in many cases have been – in the vanguard of struggling for the inclusion of their children, some of them also share the negative attitudes to disabled people prevalent in their culture, or experience conflicted feelings and attitudes towards their children with disabilities. Families' views on inclusive education can be mixed, particularly when ordinary schools are not yet capable of responding to diversity and families see segregated provision as a preferable alternative.¹⁹

Some families and community members will participate more in their children's education than others. What matters in an inclusive system of education is that their role is recognized and their views and opinions are valued and respected.

UNICEF and other agencies and governments across the globe increasingly recognize the extent to which the negative attitudes of parents towards inclusion, often influenced by a lack of awareness of their children's rights, act as a barrier towards inclusive practices. Many additional barriers have traditionally hindered their involvement:

- Lack of awareness of the educational alternatives for their children.
- Fear of stigmatization and hostility from within their communities.
- Poverty motivating placement in residential special schools, thus transferring financial responsibility to the government.
- Lack of placement options near to home, particularly for families living in rural areas.

Very often, you will be able to observe these barriers in your context due to the persistent exclusion and stigma affecting children with disabilities and their families. Resistance to inclusive education still remains powerful among some parents and parents' organizations.²⁰ This is why it becomes very important to listen, understand and address the concerns of families. Parents need training, support and empowerment so that they understand the rights of children with disabilities and become allies of inclusive education strategies.²¹

In the meantime (and sometimes coexisting with resistance), there is growing awareness among parents about disability rights, which is gradually leading to parents becoming more conscious about the potential of inclusive education and, in general, more assertive about their children's education. With greater understanding of the social construction of disability, and of the benefits of inclusion for *all* students, parents – both with and without children with disabilities – can become more accepting of inclusion of children with disabilities into mainstream schools.

Looking at Examples: Parents and Family Organizations as Activists

In South Africa, parents associated with Inclusion International have been formally represented on national policy forums dealing with marginalized learners. Organizations such as the Parents' Association for Children with Special Educational Needs (PACSEN), the Disabled Children's Action Group (DICAG) and the Down Syndrome Association have campaigned vigorously on behalf of disabled learners. Working with disabled people's organizations, they have organized public meetings and workshops on inclusive education. Mobilizing support from UNESCO and other donor organizations, they brought international advisers to the country and used them extensively in teacher education and public awareness campaigns, with a positive impact on policy development.²²

Another example of the involvement of parents and family organizations in the development and implementation of policies is the creation of alliances for inclusive education. The Alliance for Inclusive Education was founded in the UK in 1989 to campaign for **integration** for disabled children in mainstream schools. It brought together adults and children with disabilities, the parents of children with disabilities and professionals such as teachers and psychologists. It has run many grassroots campaigns in support of families wanting to get children with disabilities into mainstream schools.

The thinking of people with disabilities has been the driving force of the Alliance, linked to the energy and will of parents wanting an inclusive life for their children. In the 1990s the Alliance coordinated a campaign to get rid of compulsory **segregation** of children with disabilities in special schools, which culminated in the passing of the Special Educational Needs and Disability Act 2001. The Act gave all parents a real choice of mainstream education. Later, in 2006, the Alliance lobbied the Department for Education and Skills, introducing evidence on the success of inclusive education and responding to uninformed and negative publicity opposing inclusive education in the UK.

Food for Thought...

Some schools are informally open to families and community. However, having policies and active strategies is more likely to make participation relevant, effective and sustained. What was the most common situation when you were in school? And what is the most common situation now?

VI. Moving Forward

Key Points

- *Support from families and community involvement can take multiple forms, from influencing policies to assisting with specific tasks at the school level.*
- *The key is for education stakeholders to consult parents in order to have a comprehensive understanding of individual students' learning styles. Stakeholders must be prepared to consider viewpoints and concerns and share in the decision-making.*
- *Identifying emerging opportunities for family and community engagement is key to successful collaboration. Schools and educators must be aware and prepared for such possibilities.*
- *Teacher willingness to welcome parental support in the classroom will help to manage classroom logistics and resolve issues that arise from individual needs.*
- *Regularly scheduled meetings outside the classroom between educators, administrators and parents can facilitate clearer communication and problem-solving.*

Where to Start

Strategies and opportunities for involving parents and communities in support of inclusive education should be identified locally and developed within existing programmes and taking advantage of existing capacities and assets.

However, being aware of the most effective entry points and successful experiences worldwide can help build a suitable foundation for effective partnerships with families, communities and social organizations and networks. These are examples of entry points based on existing experiences:

- **Policy-making:** As mentioned throughout this webinar, the *disability sector* (disabled people's organizations, international agencies and networks) have longstanding experience in engaging in partnerships and alliances in the pursuit of their rights. Inclusion International²³ explored the role that parents of children with disabilities have played in countries where education authorities have not yet addressed the issue of inclusive education and provided a number of recommendations for working with parent organizations to advance policies:
 - Identify schools that are willing to move forward and are interested in staff development.
 - Establish links and partnerships with ministries of education and local authorities.
 - Organize information seminars and training workshops to introduce new thinking and practices.
 - Facilitate school-based staff development, monitoring, support, evaluation and dissemination.
 - Engage with educational authorities on policy development in support of inclusive education.
- **The role of extended families:** In unplanned or *de facto* inclusive education, the lack of disability services in place and the lack of educational plans for students with disabilities require the guardians'

direct involvement in education. Students from families of low socio-economic status might lack knowledge of community resources that would make the student more successful in school. But who are the most frequent guardians of children with disabilities in rural, agricultural areas of less-developed countries? In such contexts, the extended family is often responsible for child-raising. Grandparents, for instance, are frequently better advocates for their grandchildren with disabilities than biological parents because they are likely to be responsible for raising the children at the rural homestead while the parents may be working in the cities in order to support the family. Through ongoing collaboration with the school, the extended family member will achieve a greater appreciation of their child's disability and future potential and of alternative interventions.

- **Advising curriculum adaptations and teaching methods:** Families of children with disabilities can often provide useful advice for curriculum adaptations and teaching methods, as they often know best what the functional limitations as well as strengths of their children are. This practice is not uncommon in early childhood education, when family involvement tends to be greater.

By giving parents a say in this and taking into account their priorities for instruction, it is more likely that skills learned at school are also applied in the home. When activities that are specifically designed for a child with special needs are based on the family's concerns and priorities, they are more likely to be appropriate within the cultural context of each family.

At the same time, some curriculum adaptations will be beneficial to children who, despite not having a disability, might have some special education needs. This is why it is always better for parent aides in the classrooms to be considered as available teacher support rather than assigned to individual students.

- **Working with NGOs to strengthen the demand for inclusive education:** Civil-society organizations can play a key role in creating greater demand and capacity for inclusive education. Families of children with disabilities need training, support and empowerment to overcome the 'special education paradigm' and play an active role in promoting their children's right to education. Civil-society organizations can play an important part in achieving this goal and developing a critical mass that creates awareness and advocates for inclusion. By organizing seminars, trainings and disseminating information, NGOs can support parents and children with:
 - Information on their legal rights – both the commitments governments have made under international law, as well as national legislation and regulations.
 - Information on what services are available and how to access them.
 - Information on where and how decisions affecting their education are made, and how to advocate, lobby and influence local and national political agendas.
 - Support to report and respond to violations of their rights using social media to challenge prejudice and discrimination.
 - Online resource centres making research and evidence available to support advocacy initiatives.
- **Using the web:** Spaces for family and community participation are changing. Increasingly, there are opportunities for families to be involved and informed about inclusive education through the internet. As families and schools become more connected, schools can:
 - Create a school website or a blog and provide regular information on activities and news. It is very important that school websites comply with accessibility standards.

See <http://www.w3.org/WAI/intro/accessibility.php> for a guide to digital accessibility.

- Collect suggestions by inviting families to send their comments and feedback.
- Create forums and discussion groups for parents to exchange ideas with others.
- Circulate a newsletter.
- **Supporting inclusion beyond the school:** Very often we see that despite the inclusion of children with disabilities in regular classes and the adaptations and efforts made by schools, teachers and children to facilitate inclusion, children with disabilities are still not included in leisure activities, are not invited to their non-disabled peers' birthday parties or do not participate in out-of-school play dates.

An interesting blog written by a parent integrating her experiences. Great read for parents and professionals alike.
www.storieswithsam.com

In the UK, the organization 'Parents for Inclusion' has been working to support inclusion beyond the school walls and has developed numerous resources and innovative approaches. Check out their website at <http://www.parentsforinclusion.org/>

In Pakistan, the Ministry of Social Welfare in collaboration with the Pakistan Disabled Foundation developed a glossary of terminologies (in English and Urdu) related to disabilities, inclusion, barriers to learning, development and participation to reduce the 'disabling' labelling of children and to support a consistent approach to these topics across the school and the community.²⁴

In Uruguay, we found through working with inclusive education schools that despite the inclusion of children with disabilities in regular classes, these children were not invited to their non-disabled peers' birthday parties or other out-of-school play dates. Workshops with families of children with and without disabilities were organized to facilitate information and understanding while addressing stigma and prejudice. Today, these types of invitations are used as indicators of family and community support for the inclusion process, and the schools work actively with families to address their concerns and facilitate understanding and information that can assist the inclusion process.

Disability Inclusion as a Building Block of Child-Friendly Schools

Existing programmes and practices that are institutionalized in many regions and countries can supplement or provide a foundation for inclusive initiatives and leverage with on-going partnerships with parents and community. Guyana has provided a concrete example of policy revisions made under the framework of Child-Friendly Schools that effectively implements inclusive education. Before 2008, children with disabilities in Guyana faced physical and educational barriers at school and, despite efforts to improve access, many Guyanese facilities were sub-standard. Children with physical disabilities, in particular, were unable to access school buildings and grounds.

Guyana's Child-Friendly Schools established policies about educating all children, regardless of race, ethnicity, language, gender, disability or religion. By creating policies that are aimed to serve 'all' children, Guyana established universal access (both physical and educational), and enrollment possibilities. At the same time, by not shying away from naming specific groups, they ensured that traditionally marginalized groups remained at the forefront of educational considerations.

Inclusiveness was also reflected in the curriculum. Children were taught about the history and culture of diverse cultures, races, genders and ability statuses within Guyana. Such an inclusive approach honours the

Glossary of Terms

Child-Friendly Schools (CFS) is UNICEF's approach to promote, support and implement child-centred, inclusive, protective and participatory schools. It was formerly referred to as Child Friendly Schools. For more information visit: http://www.unicef.org/cfs/index_19.htm.

Community-Based Rehabilitation (CBR) focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation. It is a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services.²⁵ It aims to enhance and use existing knowledge, skills and resources in the community. Its focus is the inclusion of people with disabilities, but ideally it is a community strategy that promotes inclusion for all.²⁶ For more information visit: <http://www.who.int/disabilities/cbr/en/>.

Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (A/RES/61/106) was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007. There were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and one ratification of the Convention. This is the highest number of signatories in history to a UN Convention on its opening day. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional integration organizations. The Convention entered into force on 3 May 2008.²⁷ For more information visit: <http://www.un.org/disabilities/>

Disability is the result of the interaction between long-term physical, mental, intellectual or sensory impairments and various barriers in the environment that may hinder an individual's full and effective participation in society on an equal basis with others.

Inclusion is where there is recognition of a need to transform the cultures, policies and practices in school to accommodate the differing needs of individual students, and an obligation to remove the barriers that impede that possibility.

Inclusive Education (IE) is "a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the state to educate all children."²⁸

Integration is where children with disabilities are placed in the mainstream system, often in special classes, or in a general classroom with no or inadequate adaptations and support.

Segregation is when groups of children are purposefully separated from the majority because of difference. For example, children with disabilities can be classified according to their impairment and allocated a school designed to respond to that particular impairment.

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