



## **Taking Action for Inclusive Education:**

Families as Catalysts for Inclusive Education in the Community

## **Taking Action for Inclusive Education: Families as Catalysts for Inclusive Education in the Community**

Inclusion International's research and analysis on the role of families of people with intellectual disabilities in supporting grassroots advocacy for inclusive education was funded by the World Bank's Inclusive Education Initiative (IEI).



The Inclusive Education Initiative (IEI) is a multi-donor trust fund overseen by the World Bank. Launched in 2019 with support from the Norwegian Agency for Development Cooperation (Norad) and the U.K. government's Department for International Development (DFID), the initiative invests in catalytic technical expertise and knowledge resources that support countries in making education progressively inclusive for children across the spectrum of disabilities.

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## Foreword

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Working with family leaders from around the world to create this report has been an exciting opportunity to document what the families and self-advocates that make up the Inclusion International network have always known – that it is the hard work and organising power of families that makes inclusive education real in our communities.

This report lays out the powerful efforts that have been undertaken by groups of families of people with intellectual disabilities around the world.

Families have not backed down from demanding system improvements. Rather, they have found ways to help construct a new reality. For all students. All in their spare time.

Often parents are the only thing standing in the way of an education system that would deliver services instead of real educational opportunity. Knowing that their children with disabilities deserve and are owed better, often parents are forced to be the unpaid compliance officers of government policies and international human rights agreements, pointing schools to their obligations of inclusion. This role means that systems sometimes don't like parents because we complain and argue. Or we are taught that we can only speak on behalf of our individual child, so they think we are powerless.

There is a challenge here for all parents of children with disabilities. We are challenged to work together. There is a challenge to collaborate with other marginalized communities. There is a challenge, too, for organizations of persons with disabilities that seek to ignore or discount the point of view of families. Despite these challenges, families continue to fight for real inclusion in schools around the world.

Organisations that believe in the work of families have a challenge as well - to make sure that we are doing everything in our power to support families that are making change in their communities. The family groups that you will read about in this report have told us what they need to strengthen their work at the local level and bring new families into the fold, and the Inclusion International network is responding by building toolkits and practical resources that will support the important work of families.

I hope that you will have a chance to read this important report and sit with the reality of it for a while. Let it sink in. Talk to someone else about it. Discuss it with your community. Try to understand that families of children with intellectual and related disabilities around the world must find the heart and courage somehow in their busy days to challenge their communities and their nations to provide the kind of education their children deserve. They do this important work on behalf of all children, and make schools a better place for everyone.

Please read this report and take it to heart - engage your own community in the effort to improve educational opportunity for all. We can all learn something. I know I did.

**Sue Swenson**  
**President of Inclusion International**

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## Introduction

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Calls to ensure that every child can access inclusive, quality, and equitable education echo around the world. From the 1960 UNESCO Convention against Discrimination in Education through to the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006 and its Article 24 affirming the right to inclusive education, the global consensus that all children deserve access to inclusive education continues to grow.

Despite the international policy environment favouring inclusive education, these legal frameworks at the global level do not always translate to real inclusion in schools for children with intellectual disabilities. In communities, it is not the legal and policy environment, but the families of people with intellectual disabilities that are the key drivers for making inclusive education a reality.

Families of people with intellectual disabilities play an essential role in local level advocacy for inclusive education, but get little recognition as agents of change in making inclusion in the community happen. In communities, when teachers, schools, and other actors break down barriers that exist for learners with intellectual disabilities and move towards delivering inclusive, quality, and equitable education for all children, it is the work of families behind the scenes that has produced that change. Families take the lead in breaking down barriers to inclusive education, creating allies for change in the community, and supporting the next generation of families to take up the mantle for inclusive education.

This report explores the essential role of families of people with intellectual disabilities, documenting their strategies and successes in promoting inclusive education. Through direct testimonials and case studies from families of people with intellectual disabilities working together in groups at the local level, the report expands the evidence base by documenting how family groups break down barriers to inclusive education, how they find allies in the community and spread the message of inclusion, and how they build on these successes to create a sustainable movement for inclusive education.



Members of a family advocacy group in Zanzibar.



Family members of people with intellectual disabilities in Zanzibar gather for a focus group.

The story of the role that families play in achieving inclusive education in this report is told through the experiences of family advocacy groups and networks in five countries - Benin, Kenya, Zanzibar, Nicaragua, and Peru - and is supplemented by the experiences of other family-led organisations of people with disabilities (OPDs) across sub-Saharan Africa and Latin America. The experiences, advocacy strategies, and success stories of family groups reflected in this report were collected through:

- Survey responses from 25 national-level OPDs representing people with intellectual disabilities and their families from 20 countries
- In-depth interviews with 15 national-level OPDs representing people with intellectual disabilities and their families from 13 countries
- Detailed case studies documenting the experiences of 9 family advocacy groups active in communities in Benin, Kenya, Tanzania, Nicaragua, and Peru
- Interviews with over 60 mothers, fathers, siblings, grandparents, and other family members of people with intellectual disabilities involved in advocacy in their communities

Reflecting on the barriers that exist to inclusive education for children with disabilities and on how families mobilise their grassroots reach to break down those barriers, the evidence of the impact of families and the essential role they play in the fight for inclusive education is clear. This report also reflects on how organisations can catalyse change through collaboration with family groups. Several recommendations are made through this report for governments, families, family groups, cross-disability organisations, non-Governmental Organisations (NGOs) and funders for how this essential role that families play can be supported and reinforced.

# Family Strategies for Breaking Down Barriers

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At the local level, families of people with intellectual disabilities seeking inclusive education for their children encounter countless barriers – barriers to accessing inclusive education, and barriers to progress and participation for children once they are in education.

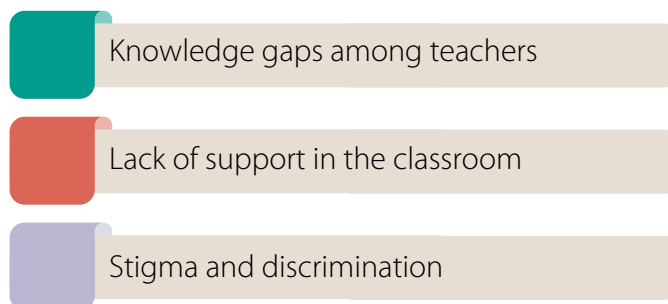
Many schools still do not allow access to children with intellectual disabilities, which means that if families do not have the support to navigate the systems and overcome the barriers that exist, they often have to either keep their children out of school or send them to schools that are outside of their communities. Barriers to inclusive education can result in parents being required to travel or move to a different city to access education, and the barriers that are in place also mean that families are forced to play the role of lobbyist to policy-makers, pushing them to ensure that their family member with an intellectual disability can access their basic right to inclusive education.

This section reflects on the different barriers that families encounter in their fight for inclusive education, and the action they take to dismantle those barriers and create inclusive education systems for all in their communities.

## Key Barriers to Access



## Key Barriers to Participation



## Barriers to Access

Barriers to access take many forms – from policy barriers to attitudinal barriers on the part of school administrators and teachers to financial barriers impacting the families of people with intellectual disabilities themselves. This section discusses each of these barriers and provides examples of strategies that families around the world have used to overcome these barriers in their communities.

### Legal and Policy Barriers

Even though the vast majority of countries have ratified the CRPD, which affirms the rights of all children with disabilities to access inclusive education, many national and local laws have not yet been updated to reflect this right to inclusive education. In most countries, legal systems still allow for parallel segregated education systems for children with disabilities, and education policies often do not fully capture the rights of children with disabilities to be included in and access support at school. Family groups play a key role in identifying laws and policies that violate rights and putting pressure on governments to enact change. Families do this work at the local, regional, and national levels.

## **Example: Family-led inclusive education policy reform in Zanzibar**

The ability of family groups to break down legal and policy barriers is well demonstrated by the work of the Zanzibar Association of People with Developmental Disabilities (ZAPDD), an organisation of persons with disabilities (OPD) network representing people with intellectual disabilities and their families in Zanzibar.

Prior to 2006, inclusive education was not part of the Zanzibari government's education policy at all, which meant that very few schools operated in a way that was inclusive of children with intellectual disabilities.

ZAPDD's expansive network of families took up education as a key area of their advocacy, pushing national and local governments to make sure that children with intellectual disabilities could also be included and supported in mainstream schools in Zanzibar.

A group of families connected to ZAPDD realised that an inclusive education pilot project would be the best way to demonstrate the value of and need for inclusive education in Zanzibar, and worked to coordinate resources to fund the implementation of an inclusive education project in Zanzibar.

After the success of this family-led initiative, the government of Zanzibar introduced inclusive education into its national education policy in 2006, and now over 200 schools in Zanzibar operate in a way that includes children with intellectual disabilities in line with this new inclusive policy.

Around the world, family groups have played a significant role in identifying laws and policies that do not align with the rights of their children with intellectual disabilities and taking action to break down the legal and policy barriers in place that prevent full inclusion.

### Attitudinal Barriers

The most common space where families of people with intellectual disabilities encounter attitudinal barriers in their fight for inclusive education is at the school administration level. This could be attitudes among school board officials, head teachers or principals, or other school administrators whose support can be essential for ensuring children with disabilities are included in schools.

One common way these negative attitudes of school administrators manifest and create barriers for families is with discriminatory enrolment policies. Inclusive education systems have zero rejection policies, where all children, regardless of their circumstances, can and should be welcomed to schools and included in the education systems. In reality, when school administrators do not believe that children with disabilities can learn or should be included in schools, enrolment policies are put in place that mean children with intellectual disabilities are turned away when their families try to enrol them in schools.



The refusal to enrol students with intellectual disabilities in schools may be formal school policy in some cases and undeclared or an informal practice in others.

**“Three years ago, my idea was to send my child to the (private) school here, but it looks like these kids with disabilities were not welcome, so they did not receive them.”**

Mother of a child with an intellectual disability in Ocotal, Nicaragua, and member of ASNIC family group

For families, informal rejection without a backing policy is particularly challenging to address, because it is often a strategy by school management seeking to avoid being accountable for excluding children with intellectual disabilities from the school.

When children with disabilities are excluded from schools, families band together and do collective advocacy, accessing decision-makers in the community, educating schools about the rights of their children, and pushing for discriminatory enrolment policies to be eliminated.

### **Example: Families in Kenya change discriminatory admissions policies**

The Baraka Self-Help family group in Taita-Taveta County, Kenya, addressed discriminatory enrolment policies in their community by going over the heads of the school administrators and taking the issue straight to decision makers.

The families requested a meeting with the Kenyan Department of Education to discuss the exclusion of persons with intellectual disabilities from schools - as a result of this meeting, twelve persons with intellectual disabilities were admitted to school. In the same meeting, the families also raised the need for financial support to be made available to the families of persons with intellectual disabilities to support their family members in accessing education.

The Born Together family advocacy group, based in Machakos County, Kenya, also used collective advocacy to pressure a school directly to change their admissions policy. When a public school denied admission to a child with an intellectual disability from the community, Born Together sent a group of ten family members to meet with the Principal of the school and the school's management committee.

Following three meetings where the group of parents made their case for the rights of children with disabilities and the benefits of inclusive education for all, the child who had initially been refused admission was admitted to the school, along with three other children with intellectual disabilities from the community who were previously out of school.

Families manage to break down barriers to admission by working on both the demand and the supply side of the issue – families work with schools to remove the discriminatory policies that would prevent children with intellectual disabilities from enrolling, but they also work with individual families to help them navigate what can be a potentially complex process of enrolling their children with disabilities in schools.

**"The motivation I received from my family group has helped me to work towards achieving my vision for my daughter's education... They have helped me in gaining access to school. They have engaged in direct talks with the headteacher in school to facilitate the enrolment and access to other opportunities in school."**

Mother of a child with an intellectual disability and family group member in Zanzibar

Families with knowledge of education systems and processes play a key role assisting parents in dealing with the challenges associated with enrollment in mainstream schools. The barriers to access can seem insurmountable to families who may be facing negative attitudes at their local schools or discriminatory enrolment policies, but through the accompaniment of experienced family members, individual families get the support they need to overcome barriers to access to education.



Parents in Benin gather to discuss barriers to education for their children with intellectual disabilities.

## Financial Barriers

Financial barriers are among the key system barriers that children with intellectual disabilities face accessing inclusive education, and financial barriers are particularly significant in countries and contexts where access to education is not fully funded by government budgets.

Families of children with intellectual disabilities are among the most likely to be living in poverty, and despite being more at risk, additional costs are often put in place for these families to access education. In many places, children without disabilities can access education for free, but children with disabilities need to pay for their spaces in schools. When families are asked to pay extra fees for the enrolment of their child with intellectual disabilities that they do not need to pay for their other children, these families often either face financial difficulties or are forced to make the decision for their child with an intellectual disability not to attend school at all.

For individual families in countries where the government does not fund their child's schooling, family groups themselves serve as a substitute for helping parents pay school fees for their children with intellectual disabilities. Particularly in sub-Saharan Africa, many groups of families of people with intellectual disabilities implement table banking as one of their group activities, whereby all members of the group contribute to a fund that other members can use as a loan when needed. In many cases, the support of family groups through table banking has been the way that many parents have been able to fund their child's continued access to school uniforms, school lunches, books, and enrolment fees in their schools. In some cases, family groups have played a leading role in lobbying their governments for additional funding for the families of children with disabilities, who have added costs in their day to day lives.

### **Example: Families push the government to create a fund for people with disabilities in Benin**

In Benin, members of the Ife family group participated in a meeting with the President of Benin along with other disability groups. This meeting led to the creation of the Support Fund for the Rehabilitation and Integration of Persons with Disabilities.

The families managed to achieve major financial support for persons with intellectual disabilities and their families across the country – this support can play a huge role in facilitating persons with intellectual disabilities to access educational opportunities in an inclusive setting in the community.

Family groups have also demonstrated an ability to tackle financial barriers to education by raising funds for their members in unique and innovative ways. Many good examples of supporting families come from the strong family groups in Kenya - the Baraka Self-Help parents group Taita-Taveta County, Kenya started a chicken rearing project using funds received for the economic empowerment of persons with intellectual disabilities. Similarly, the Jonsaga Parents Group in Nairobi, Kenya succeeded in obtaining a loan from the National Council for Persons with Disabilities to start a business as a group. There is a wide array of different ways in which family groups work to surmount the very real financial barriers that exist to the full and equal participation of persons with intellectual disabilities in education.

## Barriers to Participation

Once families succeed in enrolling children with intellectual disabilities in their communities in schools, families encounter new barriers inside the classroom that prevent their children from full participation. Families quickly learn that participation goes beyond merely being present. It involves engaging with others, making friends, and self-development. When persons with disabilities do enrol in a school, they often face barriers to a full and meaningful involvement in the educational programme of that school. Even when learners with disabilities access mainstream schools, learners with disabilities too often don't have the support they need to learn, participate, and advance.

These barriers to participation come in many forms – undertrained teachers, lack of funding for support in the classroom, and attitudinal barriers from fellow students, among others. In each instance, family groups have identified strategies to help remove these barriers and create environments where children with intellectual disabilities can fully participate in the classroom.

### Knowledge Gaps among Teachers

In many communities, and despite good intentions about including children with intellectual disabilities in the classroom, most teachers are not equipped with the knowledge and skills to teach using inclusive methods and fully include children with disabilities in their classrooms. The pervasiveness of segregated special education systems has meant that children with intellectual disabilities have been out of sight for mainstream teachers for decades, resulting in a significant gap in knowledge among teachers in mainstream schools about what meaningful inclusion looks like.

A lack of trained personnel can also be as a major barrier to the full participation of children with disabilities in the education system. If teachers do not understand the support needs of students with intellectual disabilities, they will not be able to meet their needs in a classroom setting. If teachers do not have the tools required to help students with intellectual disabilities learn, they will not succeed in supporting them on their path to real educational achievement.

The lack of personnel in mainstream schools who have been trained to support the educational path of persons with intellectual disabilities is also one of the main reasons parents of persons with intellectual disabilities sometimes opt to send their children to special education centres. Parents are repeatedly told that mainstream schools are not equipped to teach their children, and that their needs will be better met in segregated environments – in many cases, segregation is inaccurately presented to parents as the best and only option.

Recognising that mainstream teacher education programmes are not yet being designed to bridge this gap and train pre-service teachers on inclusive teaching methodologies, parents of children with intellectual disabilities have been bridging this gap themselves by supporting in-service teachers to understand good practice for including their own child in the classroom – one teacher at a time. Families have been leading the call for better teacher training around the world and across different contexts. When teachers as a whole are not aware of the rights of students with disabilities in a particular community or country, some parent groups go beyond the typical path of supporting teachers one-on-one and instead work with governments and other stakeholders to improve awareness of the need to implement inclusive education and how to do that at a systems level.

## Example: Families in Nicaragua spread the word about classroom inclusion

In Nicaragua, laws and policies are in place that provide for inclusive education in classrooms, but parents of children with disabilities found that teachers were not aware of these laws and policies, which meant that inclusion was not happening in practice in the classroom. A group of families connected to ASNIC, a family-based network in Nicaragua, knew about the existing government guidelines on teaching students with disabilities that was rooted in the framework of diversity, and saw how the use of those guidelines were limited in their children's schools.

The family group took news of this knowledge gap to the Ministry of Education and worked with the Ministry to develop a strategy for increasing the awareness of the guidelines among teachers, with the goal of full implementation of the inclusive education regulation in the country.

Following the creation of this government strategy developed in partnership with families and its roll out in schools in Nicaragua, families saw a real change in how inclusive education was being implemented in schools at the local level. Better awareness of the guidance has been instrumental in strengthening capacities in teachers, pedagogical advisors and educational authorities.

In Nicaragua, teachers across the country are now more aware of disability issues and the requirement to respect the rights of students with intellectual disabilities. Family groups play an important role in monitoring implementation of inclusive education in the classroom, ensuring that legal agreements such as the CRPD have a real effect on the everyday lives of students with intellectual disabilities and do not end up as empty words on the statute books.



Family members of people with disabilities in Nicaragua connect through ASNIC to build advocacy networks.

## Lack of support in the classroom

School admissions for students with intellectual disabilities can mean very little if it is not accompanied by individualised support measures which are needed to help children with intellectual disabilities succeed in the classroom. If learning methodologies have not been adapted to the needs of students with intellectual disabilities, they often struggle to participate on an equal basis with their non-disabled peers. The lack of adaptation, flexibility, and individualisation on the part of schools to facilitate and support students with intellectual disabilities represents a significant barrier to their participation in education.

In many classrooms, particularly classrooms in underfunded areas, a single teacher who often has not been given any training in working with students with disabilities is responsible for a large number of students without any additional classroom support. Even in schools that aim to be inclusive, if adequate support is not provided, instead of inclusive education being achieved, only integration is achieved – whereby the student with a disability may physically be in the classroom, but they are not getting the support they need to succeed.

In these schools that have neither adapted their teaching methodologies to fit every child's learning style and support needs nor provided for any kind of individualised support, families often find that children with intellectual disabilities are completely excluded. This lack of support results in teachers being hesitant to allow children with intellectual disabilities to stay in the classroom and learn at their own pace together with their peers with and without disabilities.

This results in parents of school-aged children with disabilities learning upon visits to their child's school that teachers have been removing their child from the classroom altogether to work alone separated from their peers, and in worst case scenarios, this lack of support in the classroom can also result in students with intellectual disabilities being expelled because the school believes that they are not capable of learning.

In these schools where support in the classroom is not in place, families - and especially mothers - are frequently asked to come into the classroom and play the role of a support teacher.

**"What I did as mother was to give up everything, all my time, to support (my son) in his life at school. (...) I always kept a close relation with the teachers, so my priority was to help him to advance. I also used to go to attend classes with him. Why? So then we could revise together the contents that were presented in the class."**

Mother of a child with an intellectual disability in Ocotal, Nicaragua

In an inclusive education system, parents should not be acting as support teachers, but this does not prevent schools and teachers from asking parents to play this role. The expectation that parents play this role also creates a new financial barrier for parents, who are being asked to take time away from their own work to act as an unpaid support teacher.

## **Example: Families monitoring levels of support in the classroom**

Unión Down, a group of families of people with Down Syndrome in Cajamarca, Peru, encourages family members to connect with schools and teachers so that they can monitor the support that students are getting in the classroom first-hand.

One mother who is a member of Unión Down made a monitoring visit to her son's school because she noticed that something her son was not progressing at the pace she expected. She decided to make a surprise visit to the school during the day to see how her son was doing, and when she arrived at the school, she discovered that her son was not in the same classroom as the other students. Instead, she learned that he had been sent away from his peers to an empty classroom because he was not progressing like the rest of the children in the class.

Union Down supported the parent to take action against the school, supporting her to make a complaint against the teacher and ensure that the complaint was heard and addressed so that her son would not be excluded from the class again.

Family groups such as Unión Down have been at the forefront of the fight for flexibility and individualisation in schools, assisting parents to fight for the inclusion of their children within schools. Family groups play a key role providing families with the support they need to lobby effectively for the appropriate changes required for the educational development of their school-aged child with an intellectual disability.

For education to be truly inclusive, learning methodologies in schools must be adapted to the needs of persons with intellectual disabilities through individualised support. Through the monitoring and lobbying of family groups, schools are moving in the direction of more support for students in classrooms that include children with disabilities, which results in better education for all.

### Stigma and Discrimination

Once schools have made the decision to include children with intellectual disabilities in the classroom, stigma and discrimination does not necessarily stop. In many cases, teachers and other school staff outside of the high-level decision makers in a school may still hold certain misconceptions about children with intellectual disabilities, as can the other students in the classroom, which can lead to discrimination.

Mistreatment in the form of harassment, teasing and rejection is an all too common feature of the lived experience of learners with intellectual disabilities in schools. Such experiences can have a deeply damaging impact on persons with intellectual disabilities - it can result in trauma and isolation from those around them, or even leaving school altogether. This is a common fear that families of children with disabilities experience prior to enrolling their children in school - families are on the front lines of the impact of stigma and discrimination in the community, and fear their children being mistreated and excluded if attending a mainstream school.

**“Parents fear that if their children are registered in regular schools, there will be discrimination against them.”**

Claudine Lawson Daïzo, La Chrysalide, a national family-based OPD in Benin

A common barrier that children with intellectual disabilities in classrooms face is the perceptions that their classmates have about intellectual disability. The opportunity to connect with peers, build friendships, and be treated as an equal by classmates is essential to the experience of an inclusive education, and students with disabilities in the classroom who are still being treated as an “other” are not benefiting from a fully inclusive education.

When there are misconceptions from other students in the classroom, the onus is often of parents of children with intellectual disabilities to correct these misconceptions. Some families handle breaking down these barriers with the support of classroom teachers, and others focus on spreading information across communities to break down misconceptions for school-aged children beyond their child’s classroom.

**Example: Families change perceptions among school-aged peers in Benin**

In Cotonou, Benin, a group of parents of children with intellectual disabilities recognized severe misconceptions about their children that were held by other children without disabilities in their neighbourhood of Houenoussou.

The lack of awareness among adults and children in Houenoussou about intellectual disability was demonstrated by the refusal of the community members to allow children with intellectual disabilities to play with or even get close to the non-disabled children in the community. This fear was held both by parents and adults in the community and the children themselves. The people in the community feared that intellectual disability was contagious, and that they could be infected.

The Djidjoho Family group, made up of parents of people with intellectual disabilities in Houenoussou, took action to remove these attitudinal barriers and began a campaign in the community to correct this misinformation and to inform children (and adults) in the community about what intellectual disability is and is not. The campaign aimed to spread the message that people with intellectual disabilities are not contagious, and that all children have the same rights.

The campaign was successful, and following the close of the campaign, the families hosted a neighbourhood party where disabled and non-disabled children played, sang and ate together, cementing the new approach to inclusion among children in the community. This step towards breaking down attitudinal barriers among the children who become the peers and classmates of children with intellectual disabilities at schools is essential for building more inclusive classrooms.



## How Families Build Allies for Inclusive Education

Families are the driving force behind progress on inclusive education at the community level, but families do not work alone in their fight for inclusive education.

Families recognise that working in isolation is not the best approach for making change at the community level – while family groups work themselves to remove barriers at the individual and school level, to achieve real system-level change in favour of inclusive education many family groups employ strategic community partnerships for inclusive education.

An important aspect of the work done by family groups involves developing relationships and building partnerships with a wide range of entities in the community. These alliances help family groups achieve their aims by strengthening their voices when advocating for the rights of persons with intellectual disabilities and their families, but also promoting the rights of all vulnerable groups in the community.

This section documents some of the key partners that family groups use to make inclusive education a reality in their countries and their communities.

### Key Allies for Family Groups:

- Local Schools
- Educational Authorities
- Teachers
- Local Leaders
- The disability movement
- Civil Society organisations
- Media
- Other community actors



A family group in Nicaragua discusses inclusion in schools.

**“What worked for us is to get to know our community, identify potential allies - organisations and institutions that work to help build a more inclusive society.”**

Indiana Fonseca, ASNIC Nicaragua

## Schools and Educational Authorities

Family groups commonly build alliances with schools and educational authorities to promote inclusive education - these linkages support their goal of changing the way that schools approach inclusion from a systems level. These partnerships look different in different contexts – it may look like building relationships with teachers, meeting regularly with staff from educational centres, joining management committees for schools or committees that advise local education departments, meeting regularly with staff in local and regional Ministries of Education, and more.

### **Example: Families training teachers in Nicaragua**

A family network based in Nicaragua recognized that if they approached teachers as partners and allies for education, they would be able to influence the way that teachers were working and have a direct way to help make teachers in Nicaragua work in a more inclusive way.

The group started by developing links with individual teachers in the community. The development of these relationships eventually led to the family groups delivering training to the teachers about inclusive education and good support in the classroom. This training helped teachers make adjustments to their teaching that would facilitate the educational development of persons with intellectual disabilities and improved the experience of all students in the school.

In many cases, these strategic relationships between family groups and government educational authorities have allowed family members to make real changes to education systems in their country. The Nicaraguan family group's work to develop a rollout strategy for building awareness among teachers about the new inclusive education guidance in partnership with their government is a good example, as is the success of Lima, Peru's family group in working with their Ministry of Education to develop an education policy that is inclusive of persons with intellectual disabilities.

Families do not only work to build relationships with schools and educational officials who are potential allies that can open doors to bigger change, relationships have also been built with schools which have refused to accept persons with intellectual disabilities to try to encourage them to change course and become inclusive in their admission policies.



The ASNIC network in Nicaragua is a leader in teacher training.

Family groups in sub-Saharan Africa, including in Kenya and Benin, use a one-on-one meeting strategy to build relationships with schools, sending a representative of their family group to meet with administrators at schools that do not enrol children with intellectual disabilities to build a relationship with the school and influence their admissions policies.

### Local Leaders

Family groups also typically develop relationships with leaders in the locality in which they are based. Families lobby local government officials about the inclusion of people with disabilities and speak to local leaders about compliance with the laws that protect them.

Many family groups have a strong relationship with their local county or district Commissioner, which provides them quick access to have issues addressed when people with intellectual disabilities are facing violations of their rights to inclusive education in the community.

### **Example: Networking with local leaders in Zanzibar**

The DOLE family group in Bububu, Zanzibar, has made relationships with local leaders a key part of their strategy for local advocacy success.

DOLE accesses changemakers through direct one-on-one meetings with local leaders, local Ministerial Officials, and their Member of Parliament. They also speak at community events where local leaders will be present to share their perspective and influence local government. DOLE also has managed to get a representative of the District Commissioner as a member of their group, which allows them to get grievances and concerns to the District Commissioner for resolution quickly.

### Disability Movement

Family groups commonly build alliances with other disability organisations. These alliances allow various disability groups to come together to advocate collectively for the rights of the communities they represent. This can make their advocacy more effective.

Many family groups use significant events within the disability movement – such as the International Day of Persons with Disabilities on December 3rd each year - to make inroads with other disability groups, organising joint events and opening up new opportunities for future partnerships. Establishing these partnerships then allows the movement to speak with one voice on disability issues that are inclusive of the needs of families. These partnerships also allow family groups to access various benefits for their members such as training.

**"[Families work with] faith-based organisations, other community groups for women and youth, local government and other community-based organisations of persons with disabilities, community health volunteers, they work with district education officers, district officers and gender officers."**

Family leader from Namibia

## Example: Family groups find their place in the disability movement in Zanzibar

The DOLE family group in Bububu, Zanzibar – a family group connected to the Zanzibar Association of People with Developmental Disabilities - partners with a range of other organisations in seeking to bring about change and inclusion in Zanzibar. The majority of these groups are other disability constituency groups. Some of the family network's main partners are groups like the Zanzibar Association of the Blind (ZANAB), the Zanzibar Association of People with Albinism (JMZ), and the cross-disability umbrella organisations Zanzibar Federation of the organisations of People with Disabilities (SHIJUWAZA) and the Zanzibar organisation of People with Disabilities (UWZ).

Areas of collaboration between the family group and other groups in the disability movement include joint advocacy initiatives and disability rights training sessions. The various groups also come together to share ideas and experiences on disability issues as well as strategies for dealing with the challenges they face. The family group also works with these organisations to advocate for inclusive policies and equitable access to political and socio-economic opportunities for people with disabilities. These partners have opened up new opportunities to access advocacy spaces, access training on disability issues, and to have a stronger voice for families through building the capacity of others in the disability movement.

It is important to note that within the disability rights movement itself, attitudinal barriers also may be in place that prevent the full and equal participation of persons with intellectual disabilities and their families in the community.

**"Many groups of persons with disabilities haven't really accepted us which is a huge challenge."**

Parent and family group leader in Taita-Taveta County, Kenya

**"Other groups of people with disabilities have strong feelings that as families we need to take back seats. Unfortunately, they are the most heard in government offices."**

Parent and family group leader in Machakos County, Kenya

Some family groups have been successful in having their voices heard and working in partnership in their local and national disability movement, while other family groups face a lack of acceptance by other disability groups which refused to recognise them as equally legitimate members of the disability rights movement, despite the CRPD Committee's recognition of families as part of the movement in its General Comment 7.

**The CRPD Committee in its General Comment 7 describes family organisations as being "pivotal in facilitating, promoting and securing the interests and supporting the autonomy and active participation of their relatives with intellectual disabilities [...] In such cases, these organisations should be included in consultation, decision-making and monitoring processes."**

Families play a unique role in the disability rights movement. Unlike other representative groups that rely solely on self-advocacy, the advocacy space for people with intellectual disabilities is composed jointly of people with intellectual disabilities themselves and their families. Family groups report that this unique space they occupy means that other representative groups are less likely to want to include families in the disability movement and fail to see them as a legitimate part of the movement, despite the commitment of many family groups to building and strengthening a self-advocacy movement. The CRPD Committee has recognised family organisations as a valid and important part of the disability community, but work remains to be done to persuade other groups to acknowledge this and collaborate with family groups on advocacy work related to inclusive education.

### Civil Society Organisations

In order for organisations of persons with intellectual disabilities and their families to strengthen their voice, there is the need for organisations to build partnerships with other disability groups as well as other civil society groups.

In the early stages of their journey into advocacy, family groups tend to expand their vision and begin to work within the human rights sector to find ways to collaborate with organisations representing other groups beyond the ones related to disability. At its core, inclusive education is about education for all – this includes children with intellectual disabilities, but also includes all other children who may need support being fully included for different reasons. This provides new opportunities for families, to ensure they partner with other constituencies and organisations and spread the word, which will encourage groups representing other marginalised groups to join the fight for inclusive education.

**"In the context of education for all, there are groups such as children, young people, youth and adults, those who are migrants, children of different ethnic groups, indigenous groups and other minorities who have had to emigrate to other countries or areas in their countries that today have found [support] in the tools we have developed from inclusive education designed for people with disabilities.**

**These are elements – such as flexibility in the curriculum and in the way that schools function - that favour the participation of all children. These are very favourable resources to ensure the education of other children. For example, children who speak other languages arriving in a new country might need a set of visual resources to learn a new language. This is a great opportunity for partners to recognise that educational systems have to transform and change to make them better for everyone."**

Monica Cortes, Parent and Executive Director of Asdown Colombia, family-led OPD in Colombia





Family groups in Benin strategically use partnerships with other organisations in their community in their advocacy.

Some family groups have focused their strategy entirely on external partnerships, creating allies in the community for inclusive education by embedding family members in the structures of existing organisations in the community.

### **Example: Families in Nicaragua partnering for inclusive education**

The ASNIC family network in Nicaragua focuses on gathering other organisations in the community and working with them to find common ground and on a common advocacy strategy. Unlike many family groups, ASNIC works differently, with the family members from ASNIC becoming members of different types of organisations instead of advocating as an independent pressure group of families.

ASNIC believes that if they are organised and linked to others, they are more visible and the impact of the work is greater. ASNIC works to identify organisations in the community that have the same goals – such as the implementation of inclusive education - and brings together diverse organisations working on human rights issues to look for what unites them. Once working with these other organisations, families can articulate their objective and develop a joint plan in the community that integrates the family perspective into the work that the other organisation was doing.

The embeddedness of families in the work of other organisations has been very successful in Nicaragua for generating empathy towards the key issues of families in other movements. Inclusive education is now a topic that many other organisations champion. Thanks to the work of families supporting civil society organisations to understand, communities now know more about the benefits of inclusive education and also know the relevant channels and paths to go through to ensure that the right to education of children in the community are not violated.

## Media

The media is another entity in the community with which family groups often work to advocate for the rights of persons with intellectual disabilities and their families. Family groups use the media to raise awareness about disability issues and highlight the situations of segregation that persons with intellectual disabilities experience at school.

### **Example: Families using media to expose rights violations in Namibia**

In Namibia, groups of families of children with disabilities are active in the fight for inclusive education at the local level. Particularly for rural family groups, most of their work happens in person through physical meetings, as the cost of data and poor connectivity have made virtual work difficult. With their focus on in-person work, this has meant that it has been challenging to share successes between family groups in Namibia.

One group of families in Keetmanshoop, in the ǀKaras Region of Namibia, broke this cycle by using the media, which not only allowed them to achieve local and national level successes on inclusive education, it also became a platform to share their success and provided other family groups the opportunity to replicate that work.

The families in Keetmanshoop created a media campaign about the need for zero rejection policies in schools in their region, and by using the media to spread the word about inclusion and what good inclusive school policies looked like, they succeeded in getting a number of children with disabilities from the community enrolled in mainstream schools. Through the media, the success of this initiative was escalated to Windhoek, the capital, where other schools heard word of the ǀKaras region's new zero rejection policies and were able to learn from this good practice and replicate it.

Using the media is effective not only for improving the profile of inclusive education issues, but because it also allows information and strategies to reach other families and family groups around the country who can learn from each other's successes.

## Other Community Actors

There are various other bodies and actors in the community with which family groups have built alliances to further their objectives.

Some examples of these other partners include medical professionals, lawyers, National Human Rights Institutes (NHRIs), national statistical agencies, and religious institutions. These are just some examples of the various other bodies and actors in the community with which family groups cooperate and build relationships to further their aims and promote the rights and interests of persons with intellectual disabilities and their families.

## Example: Families in Peru connect with lawyers to help protect rights

Unión Down, the Peruvian family group based in Cajamarca, has developed strategic alliances in the community with lawyers through a partnership with a particular law firm.

Through these relationships, Unión Down's members gain access to important information about rights enshrined in law and the responsibilities of support for different government agencies, as well as schools. The law firm carries out training to inform parents about the rights of their children and give them the tools they need to ensure those rights are respected.

The law firm also provides support in cases of discrimination or exclusion occurring in schools, giving parents the information they need to navigate making complaints or legal action when needed.

Some family groups also speak to and aim to build allies in the community as a whole through community-wide campaigns. Family groups in sub-Saharan Africa in particular use strategies such as door-to-door awareness campaigns and marches to reach members of the community with their messages of support and inclusion for people with disabilities.



Family members in Benin participate in interviews discussing their advocacy work.



# Building a Sustainable Movement for Inclusive Education

With every success of family group advocacy, communities take a step forward on their path toward the full implementation of inclusive education. Families of people with intellectual disabilities have been tirelessly pushing their communities forward on this path, one step at a time, for decades, and in most countries and contexts, still have decades of work advocating for inclusive education ahead of them. Family groups recognise this long path ahead and are actively investing in building the capacity of the next generation of families to learn from the families that came before them and continue the fight for inclusive education in their community.

Family groups around the world use creative strategies to maintain the momentum on inclusive education - helping families who are new to the disability movement build a vision of inclusion in the education system for their family members and supporting those families to become leaders in the fight for inclusive education.

## Building a Vision among new Families

The role of family groups in providing correct information to parents about the benefits of inclusive education is key to achieving inclusion in the communities. Ensuring that the parents of persons with intellectual disabilities understand the benefits of being educated in an inclusive system is fundamental to the promotion of inclusive education, as new parents and siblings of people with intellectual disabilities are the future of the movement.

Family knowledge of and demand for inclusive education varies from community to community and can be reflective of the type of education available for children in the area. For many families, the difference between segregated education, integrated education, and inclusive education is not always clear, and families may ask for what they know already exists in their communities. In many cases, if segregated education is all that a family knows is available, this may be what they advocate for, particularly in countries where segregated education systems are well entrenched, as is the case in many Latin American countries.

**"Families do not have one single way to demand education for their children. Many times, they are more inclined towards special education due to the great difficulties that the educational system faces for all children in general - in terms of professional training, number of students, educational resources, and the pandemic has worsened the situation"**

A family-based organisation of persons with disabilities (OPD) in Ecuador

This can result in divisions within the family groups, with some families pushing for access for segregated education while others want to organise around inclusive education. These divides are particularly clear between rural and urban families and younger and older families, and divides related to income also exist.

To sustain the family movement's progress on inclusive education in the long run, family groups must work to counteract the misinformation about the potential of people with intellectual disabilities and the misinformation about the suitability of inclusive education to help families that are new to the movement understand how an inclusive education will unlock the potential of their child and of people with intellectual disabilities as a whole.

A vision for inclusion is rooted in big ideas like equality, diversity, belonging, removing barriers, and full participation in the community for people with intellectual disabilities. For families and groups that have a vision for inclusion, they are advocating for a world where their family member with an intellectual disability is fully included in their community at all stages of their life - from learning alongside students without disabilities in an inclusive school, to working in an inclusive workplace, to being included with neighbours and friends living in the community and everything in between. A shared vision for inclusion is built through discussion, and family groups continue to do the work of supporting individuals to build their own vision for their family member's inclusive future with every new family member that joins the group.

There are many strategies that family groups use to help families build this vision for inclusive education. From connecting families across a country using WhatsApp, to harnessing technology to help families learn, to using media materials to demonstrate to families what inclusion looks like, family leaders within the movement use creative strategies to open the eyes of other families to how an inclusive education can create new possibilities for people with intellectual disabilities. Simultaneously, these actions also help to build new families into future leaders.

A first step for supporting future family leaders in building their vision for inclusion is looking at the language they use to describe disability. The language that families use influence the way they understand the potential of people with intellectual disabilities, and what their future might look like. The words that families use to speak about people with an intellectual disability also become the language that others in the community, including teachers and schools, will mirror and use. As new families begin to embark on a path towards external advocacy, the group must be consistent in the way they refer to or identify their family members, using language that reflects their rights and an inclusive perspective. This tends to entail moving away from language about sickness and suffering, moving away from language that describes people with intellectual disabilities as "special", framing conversations in terms of barriers instead of individual limitations, and using language of "support needs" instead of "functioning." These changes in language to promote inclusion go beyond just the movement of families and cut across the cross-disability movement – families aim to be consistent with other disability groups in their use of person-first language and other language that focuses on empowerment in the collective effort to shut down stereotypes about people with disabilities. This inclusive language will be essential for talking about inclusive education in a way that is led by rights, not by perceived limitations.

Peer support is another strategy that is very successful for helping new families build a vision for inclusion. A vision of inclusive education is built and promoted in group settings - such as community gatherings or inclusive education training for families, and are also reinforced through 1-on-1 discussions. Family members who have already gone through the inclusive education path have a role to play in guiding and supporting new families through their first steps in believing in inclusive education and then achieving it for their child.

Families often approach the family movement having been given low expectations for their child's future, and by encouraging the fathers and mothers of children with disabilities to engage with other parents who have already experienced the challenges associated with overcoming barriers to inclusion in the community, new families become more hopeful for the future.

### **Example: Building a vision for inclusion through peer support**

In Peru, following a break in education due to the pandemic, a mother of a child with Down Syndrome was told by the principal of her son's former school that he should not return when the school reopened as the lockdown eased. Combined with her own fears about her son's health post-COVID, she took the principal's advice and opted to keep her son at home.

She was part of a network of families affiliated with Sociedad Peruana de Síndrome de Down, a family-based organisation of persons with disabilities (OPD) working at the national level in Peru. SPSD activated their family network to support this mother, giving her access to the perspectives of other parents of young children with intellectual disabilities who were enthusiastic about sending their children back to school after lockdowns eased.

Although the family lived in a remote area, the mother was able to connect with SPSD's family network through WhatsApp, where she was able to speak to other parents about her fears related to her son returning to school. Members of the family network encouraged her to have her son return to school, and each shared photos of their own children happy to be going back to school on the first day of class that year. Through the encouragement of other parents in the network and the connection with a support network of people with shared experiences, the mother recognised the benefits of her son being back in the classroom.

**"The mom was very surprised with these photos and realised she also wanted her son to be reflected in that photo, doing the same activities and being with his peers. This gave her the courage to take him to school and she told the group about this process day by day, step by step. She shared her anxiety when she was taking her child to the school, when she was still at the door and so on. And so, little by little she realised that her son really was very happy to be with the others and in his school. This experience reflects how parents can also encourage those parents who have some insecurity or fear of their children returning to school."**

Family leader from Sociedad Peruana de Síndrome de Down in Peru

**"When families realise that the diagnosis is not a prognosis of their lives, that makes a change and this is when new and old families come together to influence and monitor the system. Together, they become more and more involved with other families and a whole social fabric is built up for long-lasting change towards inclusion."**

Astrid Eliana Cáceres, family leader from Asdown Colombia

## Example: Building an inclusive vision in Colombia through pop culture

Other accessible spaces such as pop culture can be a useful tool to help families buy-in to inclusive education. In a series of workshops for new families of persons with intellectual disabilities, Asdown Colombia found that the use of a telenovelas that talked about typical struggles that a family can encounter in their life to ensure their family member received inclusive education was a very important exercise.

The telenovela showed the impact of discrimination on the life of a family. The soap opera that was used for this exercise was a telenovela in which a mother had an adoptive daughter with Down Syndrome that they had separated from her twin brother without a disability. It told the story of the adoptive mother, a doctor, who had to fight for all the rights of her daughter. In particular, when her daughter got to school, the telenovela depicted her facing segregation and discrimination that can occur and is common to all. Watching the telenovela and conducting the exercise helped families to reflect on the barriers that they were seeing in the telenovela, and share about their specific barriers and real-life experiences. That soap opera helped families to understand what the fight for inclusive education was all about. This resulted in building a strong emotional link between families who were clear on their common work to ensure inclusive education for all learners.

**“Media languages can help us to understand what we are talking about when we talk about inclusive education and the struggle to achieve it.**

**We find that we see ourselves reflected, and the families were also reflected in the struggle of this woman for her girl to enter the school [in the telenovela].**

**Seeing the situation from the outside and through the soap opera helped our families realise that this is a common battle, and see the barriers more clearly.”**

Astrid Eliana Cáceres,  
Family leader from Asdown Colombia



# Recommendations for Building the Legacy of Families

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At the local level, families are a driving factor in making inclusive education a reality.

Families organise, work together to break down barriers, spread the word and build new allies for inclusion in the community, and bring new families on board to create a sustainable movement for inclusive education.

Families of people with disabilities do not need to be alone in the fight for inclusive education at the community level – governments, schools, organisations working at the local and national level, and other stakeholders in the community all have a role to play in ensuring that all children in the community can access inclusive education.

The following recommendations outline actions that actors in the community can take to support the work of families to achieve inclusive education at the local level.

Recommendations are provided for government actors, schools, organisations of persons with disabilities (OPDs), and other non-governmental organisations (NGOs) active in inclusive education work.

## Government Actors

- ✔ Consult organisations representing people with intellectual disabilities and their families on educational policy and strategies.
- ✔ Capture the family movement's vision of inclusive education in policies and strategies at the national and local levels - this includes funding only mainstream inclusive schools, removing barriers to access, and ensuring curricula are flexible.
- ✔ Budget for full participation and inclusion by ensuring schools have the resources to deliver on individualised support in the classrooms.
- ✔ Create dedicated spaces on education advisory councils or committees for representatives of families of people with intellectual disabilities - families are an important source of information about what good practice in inclusive education does and does not look like.
- ✔ Leverage the knowledge of families to better understand gaps in the system - there is often a disconnect between inclusive education policy and practice within the classroom, and families have first hand knowledge of what the real situation on the ground looks like.

## Schools

- ✓ Review enrolment policies to ensure they reflect that all children are welcome in the school, including children with intellectual disabilities.
- ✓ Encourage active engagement of parents of children with intellectual disabilities, including on school management committees - the depth of knowledge about inclusion held by parents can be a key asset for school management teams.
- ✓ Ensure that parent teacher associations also include and represent the perspectives of parents of children with intellectual disabilities in the school.
- ✓ Equip teachers to understand what is and is not the role of parents of children with intellectual disabilities - while parents can play an important role supporting teachers to understand how best to include their children, parents are not a substitute for classroom support staff!
- ✓ Invest in teacher training on inclusion and methodologies for teaching a wide variety of students with diverse learning styles, and consider how teacher training platforms can also be used to impart the knowledge and experiences of families.

## Organisations of persons with disabilities (OPDs)

- ✓ Recognise the place of families of people with intellectual disability in the cross-disability movement, as articulated in the CRPD and by the CRPD committee. Family voices strengthen the movement!
- ✓ Harness the decades of experience advocating for inclusive education held within the family movement to strengthen cross-disability advocacy and programming on education.

**"Strong partnerships and involvement are key. Inclusive education happens when everyone works together - not only within the education system, the administration, not only with the ministry of education, but also with the parents, the community members, and influential people, supporters, donors, and other stakeholders."**

Sibling leader from Ethiopia, representing Inclusion Africa

Other non-governmental organisations (NGOs)

- ✓ Consult families at the earliest stages on new projects that will impact education at the local level.
- ✓ Build the knowledge and experience of families into training and other capacity building work that aims to support teachers or local schools to understand inclusion.
- ✓ Consider groups of families of people with intellectual disabilities as project partners - families have a wealth of experience advocating for and supporting the implementation of inclusive education at the local level and can be strong partners for organisations.
- ✓ Invest in the work of family organisations - granting organisations looking to improve the implementation of inclusive education at the local level should fund the work of families to maximise their impact.



A family group in Zanzibar participates in a focus group to discuss the support they need from other community actors.

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