



## **Families in Action:**

Case Studies of Family Mobilisation around the World

## Families in Action: Case Studies of Family Mobilisation around the World

Inclusion International's research and analysis of 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).



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# Introduction

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For the rights of people with intellectual disabilities to be fulfilled at the community level, family groups are essential for spreading a vision of inclusion. Groups of individual family members of people with intellectual disabilities – parents, siblings, grandparents, and others who have a person with an intellectual disability in their life whom they love – come together in groups to help combat exclusion and create real change in their communities. By coming together, these family members strengthen their voices and their impact.

Each family group has a unique story for how the group came together and transformed their individual goals of a better life for their family member with an intellectual disability into a shared vision and a broader movement in their community. This case study report documents the ways of working and tells the stories of family groups and networks around the world. These case studies capture the work of family groups that have come together in a variety of ways – from connecting through religious institutions or service providers, connecting through their national OPD federation, or connecting around a specific issue that inspires families to fight for change. Family groups and networks connect, work, advocate, and support each other in ways that are specific to their context and goals, which means there are no two family groups that use the exact same approach or model for how their group achieves its goals.

The case studies were collected through focus groups with local family groups held in local languages, and individual interviews with the members of local family groups. These case studies were collected by the national OPD federations representing people with intellectual disabilities and their families in their countries, which support local family groups to have a strong impact.

These case studies help paint a picture of how family groups come together and why they matter – each of the family groups documented has leveraged their unique approach and connections to make real change in their communities across a variety of real issues that matter to people with intellectual disabilities and their families – from inclusive education to economic empowerment to access to services and support. These examples can serve as a model for future family leaders to build out new family movements in their communities, or for organisations that support work in the community to better understand the models and evolution of family groups to better engage these essential players in building inclusive communities.

This report presents the stories of 9 family groups from Latin America and sub-Saharan Africa:

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# Cajamarca, Peru

## Unión Down Family Group

<b>Location</b>	Cajamarca, Peru
<b>Founded</b>	2012
<b>Membership</b>	300 families of children with intellectual disabilities, primarily parents
<b>Key Focus Areas</b>	Inclusive education, family support



The family movement tends to be dominated by female family members, primarily mothers and sisters, and the origin story of most family groups begins with a mother of a child with an intellectual disability starting to build a community. Unión Down in Cajamarca, Peru is unique in that it was started by a father, who grew the group for an initial connection with 4 families into a community of nearly a hundred.

The founder of the group initially established Unión Down after the birth of his son, who was diagnosed with Down Syndrome. He quickly realised that there were few facilities in the community that provided information about Down Syndrome. He began to meet with a small number of other families of children with disabilities to create a space to exchange experiences and provide each other with support and advice.

**“When [my son] Matteo was born, with my wife, we did not know much about what to do. So, when we met [another family member], we approached them and invited them to the house for a little lunch. We talked and shared. First there were four families and we organized Christmas, then more joined, and we celebrated the day of inclusion. More came together, and we have come to meet up to 300 people. We understand that together we are stronger.”**

Alberth Aguilar, father and founder of Unión Down

New family members have found and connected with the group in a variety of ways - some were invited by friends; others were encouraged to join by a nurse or speech therapist. In all cases, members found out about the group through word of mouth. Once in the group, members of Unión Down maintain contact through virtual means, and typically use their WhatsApp group and their members register with contact information which allows families to connect with each other. The group also comes together face-to-face for workshops and socially for group celebrations on important holidays and festivals in Peru.

In recent years, the group has also made use of social media, which has brought more families into the fold and has allowed the group to stay visible and connected during times when in-person connection wasn't possible, such as during the COVID-19 pandemic.

Over time, the family network has evolved from a group focused on peer support and knowledge building for parents into an organised group with a focus on making change in their community. The group has also developed a more formal structure over time – shifting from the initial founder-led model into a group with a President and other elected representatives who are elected in 3-year cycles.

**“In the first moments, the first meetings were like a catharsis, we met to cry or tell about our problems [...] but later it was like they had already cried, they had let off steam. Now we have to think about what we can do, how to improve and benefit our children.”**

Alberth Aguilar, father and founder of Unión Down

As the family network has grown, so have their goals – the group now aims not only to share information with families and to build a strong network of support between families, but they also have new objectives around fighting for inclusive education in their community and improving the awareness of Down Syndrome and disability rights in Cajamarca. The evolution of Unión Down is a common path for family groups, which often start with a goal of peer support and become advocacy and pressure groups over time.

### **What does family group support mean to parents in Cajamarca? Family members told us:**

**“This group gives us strength, reminds us that we are not alone, that we are several parents who share experiences, the same experiences and we love each other. I summarise it in the word gratitude.”**

**“There are parents whose children are older and have more experience that help us, we are a family where there is trust and friendship. I summarise it in the word family.”**

**“The network strengthens us to get our children forward. I summarise it in the word solidarity.”**

**“I have felt a lot of support from the moms. As much as I have the support of my husband, many times at home they don't understand it. It is better to take advice from someone who is going through it. I feel like I have someone to lean on. I summarize it in the word gratitude.”**

The family group works together by consensus to set their objectives, which works because family members in the group have the same vision – that their children will grow up to be independent and to have the same opportunities as others.

As part of this advocacy and vision, Unión Down also retains its core goal of helping parents access the information they need and supporting them to navigate demanding the rights of their children. Unión Down first realised the importance of a support network between families when the group was invited to participate in cases in which the rights, especially the educational rights, of people with Down Syndrome was being violated. Parents wanted to go and make reports and demands to the educational centres, and they wanted the support of the family group behind them. They realised that if the representative of an organisation went to the meeting, the actions taken by the school in response were more appropriate and ensured the well-being of children and adolescents with disabilities. Recognising this strength of their network helped them understand the true impact the group had, and their potential to create changes within the community.

### **Supporting Parents to Navigate Advocacy & Complaint Mechanisms**

An example of the success of Unión Down's peer support and accompaniment functions is their work to ensure that children are not excluded from school.

A parent who was a member of the group felt that something was wrong at the school her son was attending. She decided to make a surprise visit during the day to see how her son was doing. When she arrived at the school, she discovered that her son was not in the same classroom as the other students. Instead, he had been sent to an empty classroom because he was not progressing like the rest of the children in the class. The mother was concerned about this situation and contacted Unión Down for support.

Unión Down assisted the mother in making a complaint against the teacher. Unión Down provided the mother with the support, accompaniment, and professional help she needed to ensure her complaint was heard and addressed so that her son would not be excluded from the class again.

The family group uses a variety of strategies to achieve their goals in the community, ranging from direct lobbying to working in partnership with strategic allies. The group regularly meets with authorities such as their Congresswomen for Cajamarca, their regional government officials, and the national and regional education ministries. Families use the media to make the segregation that their daughters and sons experience at school visible in the community and push the schools to take action. The group has also established alliances with educational authorities in the community so that they can access school and monitor whether or not the educational institutions of their daughters and sons comply with the principles of inclusive education. Once the group has a link with an educational authority, they encourage schools to make sure they are following inclusive principles with a reminder that the group is in touch with the authorities who want to ensure that they carry out full inclusion.

The group adopts a very collaborative approach to its work. It has developed strategic alliances and works to build relationships with various stakeholders in the community to achieve its objectives. In this way it maximises its influence both in terms of providing its members with easier access to information and services and in terms of changing society for the better.

For example, Unión Down has also developed strategic alliances in the community with lawyers and doctors. Through these relationships, Unión Down's members gain access to important information and services. Furthermore, these alliances facilitate the bringing about of change in society. For example, one of Unión Down's strategic allies is a law firm which provides support in cases of discrimination or exclusion occurring in educational centres. Allies such as this law firm also carry out training to inform parents about the rights of their children, and give them the tools they need to ensure those rights are respected.

## **Unión Down's Family Advocacy Group Model: What works?**

### Building a Movement:

- ✓ Connecting through word of mouth
- ✓ Leveraging connections with nurses, speech therapists, and other service providers to spread the word
- ✓ Beginning with peer support, then building a shared vision of inclusion
- ✓ Formalising structures through registration and electoral processes

### Advocacy Strategies:

- ✓ Lobbying of government officials
- ✓ Using the media to document exclusion
- ✓ Directly monitoring inclusive education implementation
- ✓ Strategic partnership with a law firm to help address exclusion and discrimination

## Lima, Peru

### Family Inclusive Education Network

**Location** Lima, Peru, and neighbouring cities

**Founded** 2020

**Membership** 50 families of school-aged children with intellectual disabilities

**Key Focus Areas** Inclusive education



Since 1995, Sociedad Peruana de Síndrome de Down (SPSD) has been bringing together families across Peru for support, joint advocacy, and networking. In 2020, the SPSD decided to create a network of families specifically for inclusive education. The purpose of this network was to help families reflect on the meaning of quality inclusive education and its benefits for the educational community. The broad goal was that the network will aid families in breaking down the barriers imposed by society and helping to ingrain a vision for inclusive education.

The network was built based on data collected by SPSD about the needs of families. SPSD planned an activity that would map out how the network of families for inclusive education would work. At the start, the needs, expectations, and experiences of families were collected. The SPSD initially brought the Inclusive Education network together by inviting 20 families already involved in the SPSD to be part of the new family group. After that, from time to time the families would meet to establish specific objectives depending on the specific needs. The family network for inclusive education set three main objectives: providing and exchanging information about educational rights of children with disabilities, creating a peer support space for parents, and advocating for inclusive education in all educational spaces. There is no elected leader within the family network, but there are informal leaders who lead these processes - fathers and mothers who are active members and take initiative to propose changes or new activities that benefit family members.

Currently, the network is made up of 50 families from different parts of the country. Members now come from Lima, Tarapoto, Ica, Arequipa, and Puerto Maldonado, taking advantage of the virtual connections to work with families in other cities. The network of families, at this time, is primarily made up of fathers and mothers of children and adolescents with Down Syndrome of school age. Most of their children are enrolled in a mainstream school, and some are enrolled in a special school. The group is primarily made up of mothers and some fathers, but members of the family network share the information with their relatives, such as children, uncles, nephews.



Members have joined this new network in a variety of ways - some members found out about the organisation through social networks or through an invitation by a member of the family network. One member first contacted the SPSD after seeing an advertisement at a Children's Hospital. Another member joined on the advice of a nurse who encouraged her to make contact with the family group. SPSD also runs regular introductory events for new families, where they are pointed in the direction of the network among other SPSD support.

Benefiting from the institutional support of SPSD, the inclusive education network organises both face-to-face and virtual activities. Virtual activities are generally run using WhatsApp and Zoom, including workshops and training on themes in inclusive education. These events give families the opportunity to share the experiences they have faced with their school-age children. They operate as spaces for emotional support where families can share challenges and receive guidance and advice from others about how to respond to them. The network also utilises Instagram and Facebook to build on and share their work. Through these platforms, news is reported (in text and audio-visual format), awareness campaigns are shared, workshops aimed at people with intellectual disabilities are promoted and success stories related to inclusive education are shared.

The network's activities, delivered with the support of the SPSD staff team, are varied and are based on requests from the family members in the network themselves. In the early stages of the network, families wanted to participate in activities that were to raise awareness and reflect on broad concepts in inclusive education. With some experience being part of the network, families now propose more specific and contextual themes; for example, if curricular adaptations should be made or a universal design for learning should be used. Additionally, some workshops have been offered in which lawyers are invited to explain the importance of knowing and defending the rights of children.

Peer support among the members of the group remains a key activity of the family network, since one of its main objectives is to provide support or advice based on their own experiences. The family network is usually attentive to the problems that families share, first validating their emotions and second generating questions for reflection and questioning. They also often provide direct and specific guidance, based on their experience.

**"The network has helped me to be more oriented, and I know how to act in certain circumstances that could arise because I have the experiences of other parents [...], and when the time comes I also hope to share my experiences with the new parents of the network."**

Julia Alayo, mother and family group member

The interpersonal connections that this network for inclusive education has created have been invaluable for families, particularly following the COVID-19 pandemic which disrupted education for all children. With the return to face-to-face teaching in schools, many families in the network were afraid to physically send their children to school, feeling they would be safer and better accompanied learning at home.

This resulted in many parents opting to continue with virtual education for their child. Little by little, through the links established by the network, families that chose to send their child to face-to-face teaching persuaded other parents to return to physical education also. Innovative ideas were shared (e.g., the child attends some face-to-face classes, or the parent accompanies the child at school for a few hours) to increase the comfort level of parents and help the family work back towards accessing inclusive education. Every time a parent was encouraged to take their child to school, the other families congratulated and encouraged them, providing peer support in addition to guidance and advice on inclusive education.

**“It is a space in which parents share the achievements of their children, you feel listened to, you feel that what you have experienced is useful to others, there is trust and you want to receive from other parents and not only receive information from the heads but from all the members.”**

Myriam Carmen Percovich Hualpa, parent and family group member

The inclusive education family network is still in the early phase of its evolution as a family group. While the group remains focused on building the knowledge of parents about inclusive education and providing peer support, SPSPD expects that the group will begin to do direct advocacy as they build their knowledge and skills about the right to inclusive education and how to defend it.

### **SPSPD's Family Network Model: What works?**

#### Building a Movement:

- ✓ Leveraging the support of a national level family federation to build a new network
- ✓ Using institutions like hospitals and services to spread the word
- ✓ Engaging a small group of self-selected family leaders to drive progress
- ✓ Choosing one key topic (inclusive education) for the group to rally around

#### Advocacy Strategies:

- ✓ Focusing on knowledge and building a collective vision as a pre-cursor to beginning advocacy
- ✓ Linking the network with other family groups at the national, regional, or global levels

## Managua and Ocotal, Nicaragua

### Asociación Nicaragüense para la Integración Comunitaria (ASNIC)

<b>Location</b>	Managua, Nicaragua Ocotal, Nicaragua
<b>Founded</b>	1996
<b>Membership</b>	100 families across different communities
<b>Key Focus Areas</b>	Issues vary by community



The Asociación Nicaragüense para la Integración Comunitaria (ASNIC) is unique among examples of family groups, as the family members connected to ASNIC do not operate as a formal group at all. ASNIC operates as a loosely coordinated family network within Nicaragua. Its strategy is not to promote parallel groups of families to exist as their own pressure groups, but rather to strengthen family members' capacity for involvement with already existing organisations to work on the issue of inclusion from different perspectives that already exist in the community.

Members of ASNIC are primarily mothers and fathers of children with disabilities, which includes both children with intellectual disabilities and children with other disabilities. ASNIC's mobilisation and work in Nicaragua links families of children with intellectual disabilities to the families of children with other disabilities for a unified family movement. In particular, single mothers are the predominant group among the family network. Families find ASNIC in many ways – through their independent searches for information online, through other family members through teachers and counsellors in schools, through community organisations, and on the advice of health professionals. ASNIC's unique model of working through other community organisations means that awareness of their work is high and many organisations have enough information about ASNIC to make referrals for new families.

ASNIC's focus for the families that form part of their network is to build the capacity of individual family members to work towards the inclusion of people with disabilities through partnerships in their communities. ASNIC supports family members to learn about a broad range of issues - the law, healthcare, the rights of persons with disabilities, self-care, advocacy in the community, family involvement in community activities, and more. Equipped with this knowledge, families are well positioned to make links with organisations, schools, government officials, and other stakeholders in the community to make an impact. The members of the network all gain experience and strengthen their capacities so that they can develop as social actors, participating and influencing the existing organisational spaces in local communities and in government agencies linked to the issue of disability. ASNIC's approach for these family members is all about building social capital within communities to influence the fulfilment of human rights.

Due to ASNIC's loose network structure, there is no primary leader of the family network. While there are individuals who have been involved heavily in the work of ASNIC for many years, ASNIC's approach is supporting families to all be leaders in their own community with the power to influence schools, communities and local governments.

Despite the lack of a coordinated group or network, ASNIC provides space for these family leaders in Nicaragua to learn from the experiences of others, obtain emotional support, share their knowledge with others and raise awareness in society regarding disability issues through the loose family network. Peer support also happens informally through this network.

### **What does family group support mean to parents in Nicaragua? Family members told us:**

**"I expected knowledge, because I didn't know. But the most important thing I find in ASNIC is to see other people, it is not only me, that there are different disabilities and perhaps [others] with more needs than I have... sharing and listening to testimonies from other parents, that helps a parent who has a child with a special need a lot.'**

**"Now I am not intimidated, I have a very high self-esteem... I feel guided, accompanied, that they have understood me."**

Members of the family network place a strong emphasis on working with local authorities in different communities. Members of ASNIC lobby local government officials about a wide range of issues. Families in Ocotal have had particular success lobbying local government because of the strong links they have built with local organisations and public institutions, which has resulted in strong communication between members of the family network and government.

Members also campaign on local issues with marches, talks and informative posters highlighting the importance of the inclusion of people with disabilities and of compliance with the laws that protect them. Through their connections and relationships with other organisations in the community, family members can get support to do these activities.

Members of ASNIC have also developed links with teachers and other staff in the community who work with children with disabilities. Training has been provided for those working with children with disabilities to help them make adjustments that benefit them.

## ASNIC's Family Network Model: What works?

### Building a Movement:

- ✓ Operating as a loose network of members with shared goals instead of a formal group
- ✓ Acting as a space to share experiences and lessons of working in communities
- ✓ Empowering all families to be leaders instead of having one central leader

### Advocacy Strategies:

- ✓ Partnering with a variety of community organisations
- ✓ Helping organisations working on different topics understand the family perspective
- ✓ Advocating to government and the community in partnership with other organisations



## Abomey-Calavi, Benin

### IFE Family Group

<b>Location</b>	Abomey-Calavi, Benin
<b>Founded</b>	2020
<b>Membership</b>	18 family members of people with intellectual disabilities
<b>Key Focus Areas</b>	Inclusive education



The IFE Family group in the Kansounkpa neighbourhood of Abomey-Calavi in Benin's Atlantique region forms one of two family groups that make up La Chrysalide, the national advocacy voice for people with intellectual disabilities and their families in Benin.

Members join the family group for a variety of reasons. Most wish to better understand and help their family member with a disability. Some join specifically to get help enrolling their family member with a disability in a school. Word of mouth referrals play an important role in the addition of new members to the family group. Most members joined after being encouraged to do so by a friend or neighbour. Teachers and religious organisations also refer family members to the IFE group.

Members of the family group use WhatsApp and email to stay in touch with each other. In-person visits are also organised by representatives of the family group to the homes of members to help families stay connected. These in person visits are particularly important for new families who are looking for information about what they can access in the community – other parents with more experience help members of the to understand where services and consultations may be available and what action they can take at home to best support their family member with an intellectual disability.

**“The family group helped me meet the challenge of enrolling my child in a regular school and took charge of his health care through a program.”**

Chitou Adebayo Sanni, parent and IFE family group member

The IFE Family Group has a particular focus on inclusive education. The group advocates for inclusive education by explaining its benefits to parents and helping to enrol children with disabilities in mainstream schools. An important element of this work involves explaining the benefits of inclusive education to parents.

## What does family group support mean to parents in Benin? Family members told us:

**"I was constantly stressed and anxious about my son's situation. Being part of the family group has calmed me down and allows me to feel more mentally at peace. I have great hope for my son's future."**

**"Being part of the group gave me a lot of relief because I could talk to other parents who understand me."**

**"Being part of the group allows me to have people to talk to. I feel strengthened and relieved."**

**"The family group made me discover functional and speech therapy rehabilitation which improves the development of my child."**

The IFE family group leaders realised early on that many parents fear that if their children are registered in a mainstream school, they will experience discrimination. This has led to parents in Benin enrolling their children in segregated educational institutions. The IFE family group works to counteract this trend by raising awareness among parents about the importance of inclusive education and the positive impact it can have not only for their child, but for others in the school environment as well.

Some of the other strategies that the group uses to advocate for their issues and for inclusive education specifically include meeting with local elected officials such as the neighbourhood chief to raise disability issues, and organising door-to-door awareness campaigns to reach members of the community with its message of support and inclusion for people with disabilities.

The family group also works with a wide range of other stakeholders in the community to advance its vision, including the cross-disability movement in Benin. The family movement in Benin, including the IFE family group, was one of the founding members of Benin's cross-disability federation. The IFE family group uses these connections to deliver joint advocacy alongside other disability constituent groups.

One key success of the IFE family group's participating in joint advocacy was their partnership with organisations of people with physical and sensory disabilities to create government support for rehabilitation access. The IFE family group and the other organisations of persons with disabilities (OPDs) they worked with secured a meeting with the President of Benin to advocate on this issue, and their meeting led to the creation of the Support Fund for the Rehabilitation and Integration of Persons with Disabilities.

## The Ife Family Group Model: What works?

### Building a Movement:

- ✓ Using teachers, religious groups, and other community actors to spread the word to families
- ✓ Providing one-on-one connections at the homes of new members
- ✓ Using knowledge sharing to help parents build a vision of inclusive education

### Advocacy Strategies:

- ✓ Collaborating with the cross-disability movement
- ✓ Organising door-to-door community awareness campaigns
- ✓ Meeting with government officials





## Cotonou, Benin

### Djidjoho Family Group

<b>Location</b>	Cotonou, Benin
<b>Founded</b>	2019
<b>Membership</b>	27 family members of people with intellectual disabilities
<b>Key Focus Areas</b>	Access to services, inclusive education



The Djidjoho Family Group in the Houenoussou neighbourhood of Cotonou, Benin's largest city, forms one of two family groups that make up La Chrysalide, the national advocacy voice for people with intellectual disabilities and their families in Benin. The Djidjoho Family Group began with 5 or 6 family members working together, but quickly grew to over 25 members involved.

Most members are parents of children and adults with intellectual disabilities who joined the family group to deal with the isolation they found themselves in as a result of the stigma surrounding their child's disability. Although predominantly parents, siblings and other guardians of people with disabilities are also part of the group. Most members join through word-of-mouth referrals after hearing a positive story from another member of the group. In some cases, religious groups may also refer new families to the group.

The family group started off with primarily peer support and the sharing of experiences as their objective. To meet this objective, the family group runs both virtual and in-person activities. In-person meetings are held quarterly, and there is also a WhatsApp group which members can use to stay in touch. The group also organises group outings and trips for the families, which are an opportunity for parents and their children with intellectual disabilities to connect with one another.

The group does not operate with a formal structure or leader – there are no elections or other leadership processes, but families take on natural leadership roles in the group over time. This informal leadership process works because the group members share a broad vision and goal – all of the parents who form the group want to work towards full independence and autonomy for their family members with an intellectual disability. Priorities for what the group works on within this theme of independence and inclusion are set together by the group – employment has emerged as a priority due to the concerns that many parents in the group have about jobs that their child may be able to access in the future.

Gradually, the group's work has evolved towards advocacy, and the Djidjoho Family Group uses a variety of different advocacy strategies and partnerships to help achieve their goals.

The family group meets with the members of other disability organisations on relevant international organizing moments, such as the International Day of Persons with Disabilities on December 3rd and World Down Syndrome Day on March 21st. The family group seeks to build alliances with other disability organisations, so that they can work together to defend the rights of people with disabilities and promote inclusive education. The family group also collaborates with like-minded non-disability networks such as children’s rights networks and education for all networks. The group also works with the media to raise awareness about disability issues. Its members occasionally take part in radio and television broadcasts to talk about key issues facing people with intellectual disabilities and their families and propose solutions. The family group also reaches out to local leaders (such as chiefs), community organisations, and networks of organisations to promote disability rights.

The family group also works with schools to advocate for inclusive education. For example, when a school refuses to accept children with disabilities, the group meets with the director of the school to explain that according to the CRPD and national law, children with disabilities have a right to attend the same school as their brothers, sisters, friends, and neighbours who do not have a disability. In one instance where a young girl with an intellectual disability was expelled from school due to what the school described as “behavioural problems,” the parents mobilised, met with the principal, and helped the school understand that inclusive education is a right so that the girl could be re-enrolled.

### **What does family group support mean to parents in Benin? Family members told us:**

**“I understood that I was not alone, that there are other parents who have children like me and I feel listened to. It gives me great comfort and relief.”**

**“By being part of the family group, I benefited from several sessions of information, training and sharing of experiences which allowed me to better understand my child and to know how and towards what to direct him while taking account of his skills.”**

**“The family group helps us to establish links with other actors in our community.”**

**“It is thanks to my membership that my son benefits from health care, and he is gradually becoming independent.”**

The Djidjoho Family Group also runs community awareness campaigns in response to specific issues that they identify in the community. In one instance, there was a recurring problem of non-disabled children refusing to allow disabled children to play with them or even come near them. The family group learned that this behaviour was happening because children and their parents were afraid that they could become “infected” through contact with a child with an intellectual disability. The family group then organised an awareness campaign for families and children in the community to spread the message that intellectual disabilities are not contagious. The campaign was successful in helping community members understand that inclusion posed no risks to them, and following this campaign, the family group hosted a party for the community where disabled and non-disabled children played, sang and ate together to cement the community’s new approach to inclusion.

## The Cotonou Family Group Model: What works?

### Building a Movement:

- ✓ Using social spaces and events to help families connect and build relationships
- ✓ Allowing group leaders to naturally emerge through engaging members

### Advocacy Strategies:

- ✓ Community awareness campaigns
- ✓ Partnerships with the cross-disability movement
- ✓ Engaging with political leaders and decision-makers



# Machakos, Kenya

## Born Together Family Group

<b>Location</b>	Machakos County, Kenya
<b>Founded</b>	2020
<b>Membership</b>	80 families, mostly mothers, sisters, and grandmothers
<b>Key Focus Areas</b>	Social protection, inclusive education, employment and income generation, and peer support



In Machakos County, bordering Nairobi, Kenya, a new family group formed in the midst of the COVID-19 pandemic. The group came together through a series of connections in different parts of the community – some family members met at the local chief’s office while looking for relief food during the pandemic, other members met through attending the same church in the community, and others still joined in after connecting a meeting for families about access to justice that was organised by the Kenya Association of the Intellectually Handicapped (KAIH), the national federation representing people with intellectual disabilities and their families. The group is a mix of families of younger children and adults with intellectual disabilities, and the majority are mothers, sisters and grandmothers.

The family group began with just 15 members but has now expanded to 80 members. It is the only family group that brings together persons with intellectual disabilities and families in Machakos, which has contributed to the demand from families once they learned about the group. New families continue to hear about the group through schools, churches, local government offices, and health facilities. With the growth of the group, Born Together is making an effort to divide up the group into a few smaller groups, which they will support to register as community-based organisations (CBOs). The group meets physically once a month in one of our local churches, which has donated meeting space to the group. They also may meet more than once if the group is connected with a project that their national federation, KAIH, is working on.

The group set their trajectory by discussing common concerns in their lives and identifying some common issues that would be the focus of the group in its first years. Priorities that the group identified included advocating for their inclusion in relief services and social protection, which was particularly important for a group that came together during the COVID-19 pandemic, as well as advocating for quality education, providing peer support, doing income generating activities together, and supporting each other to look for employment opportunities for their adult family members. Economic empowerment and table banking form a large part of the group’s activities.

**“When I joined the group, I realized there were other people going through the same moments as me and I felt relieved. [I have] peace of mind and am free from stress since I get encouragement from other members. We share almost the same problems as other members, and so through teamwork we can go far.”**

Pauline Kalili Kiilu, parent and Born Together member

One of the family group’s first successes was around their first objective about access to relief services and social protection. After nearly a year and a half of advocacy to the Relief Committee that handles distribution of relief food and other basic commodities, Born Together was asked to nominate one of their members to the Relief Committee which sits at least once a month to identify community members who need access to these supports. Born Together now has a representative in the Committee who has been instrumental in helping them identify and assist the households of people with intellectual disabilities who require support.

As a new group, Born Together is still working on creating a shared vision among the members of the group. Members do believe in shared general ideologies about inclusion, but the expectations of the future of their family members differ greatly depending on the age and the nature of support needs of their family members. As an example, at a forum on education held in 2022, some of the group’s members advocated for inclusive education while others, having been made to believe that segregated schools employ personnel who are more sensitive to the needs of PWIDs, advocated for segregated education. This lack of a common vision amongst the members of the family group is a challenge Born Together is currently seeking to address.

Education has continued to be a priority part of the group’s work as they support newer members of the group to understand the benefits of inclusive education. Born Together works closely with schools in Machakos County to help ensure that children with intellectual disabilities are included in education on an equal basis with their non-disabled peers. The family group nominates representatives and sends them to schools which are not inclusive of students with disabilities to lobby for inclusive education. In one instance, Born Together sent ten family members to meet the principal of the school and the school management committee after the public school denied admission to a student. The more difficult the school, the larger the group of parents they sent to demand inclusion. Following three meetings, the child who had been refused admission and three other children with intellectual disabilities were admitted to the school.

Born Together also engages with local chiefs, religious leaders and representatives of state bodies to advocate for the rights of people with intellectual disabilities and their families. In 2021, Born Together addressed representatives from the Kenya National Commission on Human Rights regarding the violation of the rights of people with intellectual disabilities in the community – a huge success for a group that had only been operating for one year. The group also engages in walks to raise awareness, home visits where people with intellectual disabilities are identified and connected with relevant services, and participation in community meetings to advocate for their shared goals. Born Together also partners with other CBOs in Kenya working with orphans, people with psychosocial disabilities, women and youth.

## The Born Together Family Group Model: What works?

### Building a Movement:

- ✓ Using awareness activities like community marches to find new family members
- ✓ Keeping group sizes small so families retain more personalised support
- ✓ Linking with the national federation to connect and share with other family groups

### Advocacy Strategies:

- ✓ Seeking spaces on local groups or committees to represent families
- ✓ Connecting and working with other underrepresented groups, such as groups of women, youth, or people with psychosocial disabilities.
- ✓ Registering as a CBO to have better access to advocacy opportunities

## What does family group support mean to parents in Kenya? Family members told us:

**“Before I joined the group, I did not know that someone who has a child with a disability can be helped. But when I joined the group, I met my fellow mothers. We shared our experiences, everyone her own experience [...] I saw I was not alone. We helped each other with ideas to help our situations, so I accepted that I have a child with disability, and other families also have children with disabilities. So, I accepted myself.**

**“Some time back, I used to feel like I was alone. But the moment I joined the family group, I knew I am not alone, and I was motivated and had the courage to talk and walk with my child to various places.**

**“The [other] parents told me that [...] if I wanted to heal, I have to accept the situation the way it is, and that I should not live in denial. So we talked to each other and I realised that this thing - giving birth to a child with a disability - is not a curse.**

## Taita-Taveta, Kenya

### Baraka Self-Help Family Group

<b>Location</b>	Taita-Taveta County, Kenya
<b>Founded</b>	2018
<b>Membership</b>	40 members
<b>Key Focus Areas</b>	Education, health, social protection, economic empowerment, and self-advocacy



The Baraka Self-Help Group, a Kenyan family group based in Taita-Taveta County, has been operating since 2018. The group is now part of the Kenya Association of the Intellectually Handicapped (KAIH).

The group numbered approximately eighteen members at first but has since more than doubled in size. Word-of-mouth testimonials as well as referrals by the Department of Social Development, the National Council for Persons with Disabilities and local community leaders have led to the growth of the family group. New members are also attracted by the activities organised by the group. The group meets twice a month. Sometimes the group meets in a social hall, other times in a social compound, but the group always meets in physical community spaces.

The group decided its priorities by consulting with its members and identifying the concerns they shared for their family members with intellectual disabilities. While developing a common vision was challenging initially, ultimately it became clear that members of the family group had common objectives and challenges for their loved ones with disabilities.

Following this process, the Baraka Self-Help Group set broad goals of advocating for the rights of people with intellectual disabilities in the areas of education, health and social protection; lobbying for economic empowerment; working with local governments on disability issues; and building a self-advocacy movement.

**“[Peer support] is very important - many families live for the group meeting days where they can come to offload their concerns.”**

Elizabeth Wavua, parent and Baraka Self-Help Group member

The group began operating with informal structures, but after two years of working together the group formally registered as a community-based organisation in 2022, strengthening their advocacy as a result as it opened up new partnerships. Now, the family group sustains strong working relations with the Department of Social Development and the County Commissioner. This facilitates the organisation of meetings with local government leaders about disability issues. The Baraka Self-Help Group also partners with other CBOs (e.g., women's groups and youth groups), and the family group works with schools in the community to address inclusive education. For example, where a school refuses to admit people with intellectual disabilities, the family group organises a team of members to visit the school and make the case for inclusive education.

The Baraka Self-Help group also played an important role in data collection in the community – while family groups often engage in advocacy on different topics, public data is a less common issue for family groups to take up, despite the benefits that good data has for ensuring that people with intellectual disabilities and their families are counted and have access to support and services. In collaboration with the Department of Social Development, the National Council for Persons with Disabilities and certain faith-based organisations, the Baraka Self-Help Group gathered data from across Kenya about the situation of people with intellectual disabilities and their families. This data could then be used by the government to improve services and access for people with intellectual disabilities and their families around the country.

The family group requested a meeting with the Department of Education to discuss the exclusion of children with intellectual disabilities from schools and the need for financial support to be made available to families to support them in accessing education. As a result of this meeting, twelve children with intellectual disabilities were admitted to school.

Through its data work and advocacy on inclusive education, Baraka Self-Help Group has had a real impact on the number of children with disabilities accessing schools in their county, and have successfully increased the visibility of people with intellectual disabilities and their families in the community.

## **The Baraka Self-Help Family Group Model: What works?**

### Building a Movement:

- ✓ Having government offices and services refer family members to their group
- ✓ Registration as a CBO to open up access to new opportunities

### Advocacy Strategies:

- ✓ Using data collection to demonstrate the need for action
- ✓ Collaborating with government actors and decision-makers to have family voices heard



## Nairobi, Kenya

### Jonsaga Family Group

<b>Location</b>	Nairobi County, Kenya
<b>Founded</b>	2019
<b>Membership</b>	75 families of people with disabilities
<b>Key Focus Areas</b>	Economic empowerment for families, inclusive education, and inclusive health



In Nairobi, Kenya, the Jonsaga Parents Group is a great example of parents uniting across the disability movement to have an impact in the community. Many family groups active in their communities are made up exclusively of family members of children with intellectual disabilities – as an underrepresented group within the disability movement, family groups report being excluded and the issues of people with intellectual disabilities not being taken seriously when they try to operate in cross-disability spaces. The Jonsaga Parents Group bucks this trend, and from its inception aimed to represent the family members of children with a wide range of disabilities, not exclusively intellectual disabilities.

The Jonsaga Parents Group was established in 2019 when a single parent of a person with an intellectual disability took the initiative to arrange a meeting for the parents of other children with disabilities in their community, which then became a regular group. At first, the group comprised only six parents, but this quickly grew to twenty-five. Currently, there are more than seventy-five families in the group. The group includes family members of people with a variety of different disabilities and experiences, but there are more family members of people with intellectual disabilities than there are persons with any other type of disability. Despite having "Parents" in the group name, there are also some siblings who are part of the group.

New members commonly join the group through word-of-mouth testimonials as well as through referrals from local churches and schools. Another factor behind the group's growth has been the local chief's knowledge of the group, and the awareness walks organised by the group to raise awareness about disability issues in the community. The family group normally meets in person once a month at their centre. The group operates primarily physically together, but plans to start a WhatsApp group to help members stay in touch between meetings.

The Jonsaga Parents Group operates formally, having registered as a community-based organisation in Kenya. The leaders of the group are chosen through elections, and their process includes a series of consultation meetings organised by the group leading up to elections.

The Jonsaga Family Group developed its shared goals by consulting its members and focusing on the issues which members highlighted most frequently. The group decided that their primary aims would focus on support for families themselves, and among their key goals are helping members develop strategic partnerships and start small businesses, establishing a space where members can meet and access daycare, and operating a table banking group.

Peer support is also a priority for the group and the reason why many families are involved, and the group provides advice and support to families, particularly new families who may not know where to start.

Advocacy on inclusion in education, access to justice, access to quality healthcare and employment and entrepreneurship are important parts of their work. The group advocates on behalf of its members by speaking to local chiefs, ward representatives, religious institutions and like-minded organisations to raise the issues that people with intellectual disabilities and their families are facing in the community. This direct approach of connecting face-to-face with has led to an increased acceptance and appreciation of people with intellectual disabilities in the local community.

The Jonsaga Parents Group also uses the platforms provided by government projects such as the Nyumba Kumi Initiative, a strategy designed to bring neighbours and communities together to interact and share information to make their community more safe and secure.

In addition to the advocacy work they do in the community, economic empowerment for families has been the main issue that the group works on. Recognising that a key challenge facing many families was the lack of child-care that would enable them to work and support their families, the Jonsaga Parents Group set out to create access to daycare services that families could use. With a lack of other daycare services that include children with disabilities in the community, the group connected with Heidmare Primary School in Mathare which provided the family groups with one of its rooms to use as a daycare centre. This story is consistent with how many family groups begin their journey – recognising a lack of inclusive services, many families come together around the need to create a service in the community that can be relied on not to exclude their family members. The group also succeeded in obtaining a loan from the National Council for Persons with Disabilities to start a business as a group.

The Jonsaga Parents Group also accesses support from the national federation representing people with intellectual disabilities and their families, the Kenya Association of the Intellectually Handicapped (KAIH). This partnership means that members of the Jonsaga Parents Group can access training provided by KAIH on intellectual disability and the rights of persons with intellectual disabilities, which helps them strengthen their community-level advocacy.

**“Not all of our community think that people with intellectual disability [belong] in the marketplaces, or anywhere. But we explain to them that people with intellectual disability fit in the community, in our homes. They are part of our families and they have got their rights.”**

Parent and family group leader from Kenya

## What does family group support mean to parents in Kenya? Family members told us:

“I was just sitting, thinking about my child. I was moving out and meeting with other mothers while carrying my child, and one of the mothers said, “you have a child like mine!” and I realised I was not alone. At that time, I stopped the “too much” thoughts about my child with intellectual disability, and we discussed what we can do for our children. We saw that the most important thing was to take our children to school.

“Things always get well through encouraging each other. I see things get better with encouraging each other, and changes the perspectives that maybe this was a curse.

### The Jonsaga Family Group Model: What works?

#### Building a Movement:

- ✓ Connecting with the cross-disability movement to build a diverse group of family members
- ✓ Using local churches and schools to help refer new members
- ✓ Building connections between families through face-to-face meetings and time together

#### Advocacy Strategies:

- ✓ Hosting awareness walks through the community to profile key issues
- ✓ Registration as a community-based organisation to open up access to new spaces and opportunities
- ✓ Accessing support from their OPD federation representing people with intellectual disabilities and their families for advocacy training
- ✓ Using platforms provided by government programmes to connect with neighbours

## Bububu, Zanzibar

### DOLE Family Group

<b>Location</b>	Bububu, Zanzibar
<b>Founded</b>	2010
<b>Membership</b>	100+ family members of people with intellectual disabilities, primarily parents and siblings
<b>Key Focus Areas</b>	Inclusive education and self-advocacy



In Bububu town on the island of Unguja, Zanzibar, set just off the coast of mainland Tanzania, one family group called DOLE has evolved from a small group of families into a key driving force for self-advocacy. DOLE was founded in 2010 and is a member of Zanzibar Association of People with Developmental Disabilities (ZAPDD), the OPD federation representing families in Zanzibar.

While many family groups in sub-Saharan Africa initially come together and connect as a peer support group or as an economic support group engaged in table banking, Zanzibar's family group was formed with advocacy objectives already in mind. The founders of the DOLE family group met while attending a seminar about inclusive education which was hosted jointly by ZAPDD and the Zanzibari Ministry of Education. After discovering that they all shared common interests as the family members of school-aged children with intellectual disabilities, the founders decided to unite and form a group.

Coming together at a seminar that was already supporting families to have a vision for inclusion in the education system for people with intellectual disabilities effectively allowed this group to skip the vision building step in the typical evolution of a family group. From the beginning, the family intended to develop a space not only where their experiences could be shared, but also to give them an opportunity to speak with a common voice about disability issues that were important to them to others in the community and further afield.

While many family groups exist informally without registration or formal structures, the DOLE group is also unique in that it implemented formal structures for the group very early on. The family group developed its objectives by sitting down together, agreeing on the purpose of the organisation, and writing a constitution that guided their goals and how they would work together. The creation of a constitution for the group at this early stage also created more formal leadership structures – the family group continues to hold elections to select the leadership of the group.

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The creation of a constitution for the group at this early stage also created more formal leadership structures – the family group continues to hold elections to select the leadership of the group. With a constitution and a plan in hand, the initial group of families expanded primarily through word of mouth – families in the group reached out to other families of children with intellectual disabilities that they knew to bring them into the fold and encourage them to get involved. As the group grew and as neighbours and others in the community started hearing about the group, families began hearing about the group and approaching them directly to join. The group has grown from the initial founders to 100 family members who are active members of the group.

The group connects regularly through in-person meetings once per quarter and stay in touch between meetings using WhatsApp and phone calls. As new families are drawn into the group, the collective vision set out in the group’s constitution helps families believe in an inclusive future for their family members with an intellectual disability.

**“Individual visions among members vary, though they have a commonality as most of them, their goals are tied around improved access to certain rights, especially education and employment for their children. In brief, there is a group vision and individual member’s vision. The group vision aims at feeding and empowering members to fulfil their individual vision.”**

Baraka Saidi Mataka, DOLE Family Group leader

Unlike some other family groups, this group expanded their reach beyond just families. While the core of their group remains primarily parents and siblings of people with intellectual disabilities, others in the community who support the inclusion of people with disabilities – such as community leaders – are also welcomed into the group. The way that this family group values external stakeholders has strengthened their work in Zanzibar and given them access to opportunities and an advocacy voice that they would not have otherwise had independently.

The family group makes a conscious effort to work with leading organisations of persons with disabilities, including cross-disability groups like the Zanzibar Organisation of People with Disabilities (UWZ) and other impairment specific representative groups like the Zanzibar Association of the Blind (ZANAB) and the Zanzibar Association of People with Albinism (JMZ). They work with these other groups and with their representative group ZAPDD on joint advocacy initiatives and collaborative training sessions about disability.

DOLE accesses changemakers through direct one-on-one meetings with local leaders, Ministerial Officials, and their Member of Parliament, and through letter writing. They also speak at community events where decision-makers will be present. 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.

The family group provides direct support to families of people with intellectual disabilities in making sure that their rights are being upheld in the community. DOLE takes direct action on inclusive education in particular by engaging with school administrators on behalf of individual children. They generally work in an advisory capacity on education, but also may intervene through engaging school administrations for addressing the education issues for their members.

A big part of this work is also ensuring that family members have the information they need to advocate for the rights of their family members themselves. DOLE supports family members to learn about rights and how to address violations.

Over time, the group has evolved from their original connection over inclusion education to covering a wide range of topics that impact the lives of people with intellectual disabilities and their families in Zanzibar. Economic empowerment and access to health are two big focus areas, and the family group now focuses on self-advocacy as a major priority.

The family groups emphasise encouraging their family members and other youth with intellectual disabilities to speak up for themselves and advocate for their rights in the community – a main goal is supporting self-advocates in the community to have meaningful representation within decision-making bodies in local government and other community groups.

### **What does family group support mean to parents in Zanzibar? Family members told us:**

**“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 headteacher in school to facilitate the enrolment and access to other opportunities in school.”**

**“The family group helped me through awareness creation on the rights of my son, including right to education. Through this I was encouraged to enrol my son in school. Having had access to knowledge on my son’s rights I am now able to visit various institutions to advocate for my son’s rights when I feel violated.”**

## The DOLE Family Group Model: What works?

### Building a Movement:

- ✓ Connecting with the cross-disability movement to build a diverse group of family members
- ✓ Using local churches and schools to help refer new members
- ✓ Building connections between members through physical meetings and time together

### Advocacy Strategies:

- ✓ Hosting awareness walks through the community to profile key issues
- ✓ Registration as a community-based organisation to open up access to new spaces and opportunities
- ✓ Accessing support from their OPD federation representing people with intellectual disabilities and their families for advocacy training
- ✓ Using platforms provided by government programmes to connect with neighbours

**“I experienced the aha moment when I realized I had a lot of misconceptions about my own child that, in essence, did not hold water. They were beyond the truth. One of them is that I thought my child could not learn skills, but after joining the group, I was inspired to send him to school and was assured that he could learn something. Being part of the family group has enabled me to discover the potentials in my son that I didn’t see before. It is this discovery that influenced me to believe that with support from the community and educational institutions I can work to develop skills of my son. Joining this group was the best decision I have ever made for my son.”**

Faiza Hamad Mbwana, parent and member of DOLE Family Group



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