



Supporting the Work of Family Groups

A Toolkit for Strengthening Local Family-Based Advocacy



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THE WORLD BANK



INCLUSIVE EDUCATION INITIATIVE

Transforming Education for Children with Disabilities

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Introduction

For people with intellectual disabilities, their families are typically their first advocates and continue to be strong advocates throughout the course of their lives. During childhood, individual families of children with intellectual disabilities fight for their family member(s) to be included in schools, to get access to support and services, and to be included in their communities. As their family member(s) grow, they fight for access to employment, to independent living options, for their right to make their own decisions, and for them to be valued equally as a member of their community.

Despite this crucial role that families play in advocacy for people with intellectual disabilities at the local level throughout the lifespan, family members of people with intellectual disabilities are less likely to be consulted by decision makers or engaged by stakeholders than other groups within the disability movement.

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 at the local level to help combat this exclusion.

By coming together in groups, families create a strong united voice pushing for inclusion in their communities, and are able to advocate for change that has a real impact on the way that people with intellectual disabilities are included at the local level. Community level family groups around the world have a record of wins that would not have been possible without family mobilisation – from opening up spaces for children with disabilities in mainstream schools, to improving the availability of healthcare and support services, to influencing local municipal policies and plans.

Family groups are essential for spreading a vision of inclusion for children with disabilities in communities, and for making real change at the local level for children and adults with disabilities.

Groups of families come together organically, but also require support and partnerships with other stakeholders to maximise their impact.

Recognizing the need for strong local-level family groups to help build inclusive communities, this toolkit aims to provide a set of resources that partners can use to support the grassroots family groups that they work with, fund, or collaborate with.

The tools, guides, resources, and other content included in this toolkit were developed in response to the needs of local family groups at the community level. National federations of grassroots family groups in Latin America and sub-Saharan Africa from the Inclusion International network conducted interviews and focus groups with family members of people with intellectual disabilities at the local level to help build this toolkit. This toolkit on supporting family groups was also created under the direction of a group of family leaders from sub-Saharan Africa and Latin America, who shared their own experiences and the experiences of the family networks in their countries and regions to create a set of practical and contextually relevant tools aimed to strengthen family groups.

Each section of this toolkit covers content that organisations need to know about the structure, strategies, and successes of family groups. Equipped with this information and the practical tools and resources embedded within it, this toolkit enables organisations to be better partners for local family groups and to ensure that they are contributing to supporting and strengthening families as essential advocates for inclusive communities.

The content of this toolkit was created with funding from the World Bank Inclusive Education Initiative.

Support for Family Groups

This toolkit covers essential information and tools for partners of grassroots family groups, whether those partners are international non-governmental organisations (INGOs), national federations of family groups, cross-disability organisations, other civil society groups, funders, and more.

The five sections of this toolkit follow the trajectory of how local family groups typically evolve over time:

Supporting family groups to:

- 1 ...come together
- 2 ...build a shared vision
- 3 ...have their voices heard
- 4 ...work with stakeholders in their communities
- 5 ...be sustainable

Each section includes contextual information for organisations to understand the way family groups operate, tools and resources that organisations can share with and use to support the local family groups they work in partnership with, as well as action points for organisations to take as they begin the process of integrating support for families into their work.

These tools were created with the feedback of local family groups in Kenya, Zanzibar, Benin, Peru, and Nicaragua, who explained what resources they needed from partners to strengthen their work.

By using these tools to support family groups, organisations are helping to strengthen strong advocacy networks of families who lead the fight for inclusion at the grassroots level.



Family Mobilisation

At the local level, families come together in their communities in a variety of ways, and opportunities to engage, collaborate, and support family groups will vary depending on how the group came together and how it has changed over time.

The ways that family networks form are unique to different communities, but one factor that is consistent among groups of families is that family networks are formed and built organically. Regardless of where the leaders of a family group made their initial connection or the mechanism they used for outreach, family groups come together through word-of-mouth and peer-to-peer connections. Many family groups initially come together through a “snowball” model of connection, whereby one family member hears about another child with an intellectual disability in their community and connects them directly to another family. Through word of mouth, that small group continues to hear about, connect with, and bring new families into the fold.

These family networks and family groups come together because families of people with intellectual disabilities often feel isolated and excluded from their communities – participating in a family group provides family members with a platform

to share their concerns and experiences and with access to advice and support from others in their situation. Family groups are particularly valuable as a mechanism to access to information from families who may be further ahead in their journey – for new families, it can be particularly overwhelming to see the barriers to inclusion in the community and think they need to start from scratch, but through family groups they can learn about the experiences of the families that came before them and realise that they are part of a bigger movement. Through these conversations within family networks, a sense of solidarity and peer support are created.

While an initial family leader will be the catalyst for building a new group or network of families, other actors in the community also have a role to play in facilitating the connection between family members. Community-based rehabilitation (CBR) workers or community health workers are particularly important for this process, as their knowledge of individual members of the community

“We have topic of interests that families want to talk about, and all we need are meetings to come together and discuss. It’s like a catharsis – we can give a space where each parent says the challenge that they are facing with their experience in that moment. We see if they need advice, this is a way to for the families to get close.”

A family member and family group leader in Nicaragua



helps with identification and referral before family groups exist in a community. Particularly in sub-Saharan Africa and other contexts where stigma or misconceptions result in children and adults with disabilities being isolated in their homes, CBR workers are often one of the only actors in a community who know which families have a child with a disability. The work of CBR workers in identifying where children with disabilities live,

making sure parents and siblings know that they are not the only family in a community with a child with a disability, and then introducing those families to each other often becomes the first step in a family group's story. With an initial connection to one or two or other families facilitated by a CBR or community health worker, a leader within those families can take the reins and begin to mobilise and grow a family group.

Top Tips for Supporting Families

For organisations that fund, support, or employ community-based rehabilitation (CBR) or community health teams, make sure that these teams understand their role in supporting families of children with disabilities. Initial training and objectives for these teams should include:

- ✓ An understanding of the essential role peer support plays for families who have children with disabilities
- ✓ A mandate to link new families of children with disabilities to other families in the community when they are identified
- ✓ Strategies for connecting new families of children with disabilities to one another through existing local or national organisations of persons with disabilities
- ✓ A recognition of the need to build strong partnerships with existing family groups

CBR and community health workers who recognize that linking families of children with disabilities to one another is an essential part of their role are helping to build a strong family movement within their communities!

Similarly, many family groups come together after being connected while accessing services through local government or service providers. Families of children with disabilities meet in the waiting rooms of medical clinics, while dropping their children off for childcare services, or in hallways between therapy sessions.

In these cases, service providers naturally provide the spaces for families to connect, and as families build relationships with one another through these connections, family networks form naturally over time. Service providers in many cases also provide these spaces for family connection more directly – for example, by also providing services and support for the families of people with disabilities

themselves, or by creating social opportunities for the families of service users.

Historically, services for children with disabilities at the community level have often been provided as segregated spaces. With the recognition that service provision is best delivered in an inclusive environment and as service providers phase out segregated centres for children with disabilities, strategies for how family members of children with disabilities will connect through new inclusive service spaces will evolve. The vision that families have for their children will evolve with it, as inclusion now becomes a frame of reference for where families have connected.

► TOOL: Frequently Asked Questions about Family Groups

Review these FAQs before working with family groups, and share them with your teams, partners, and funders when you bring a family group on board as a partner

Top Tips for Supporting Families

For organisations that fund, support, or run services for children or adults in communities, including health services, therapeutic services, and other support services, provide spaces for families of children and adults with disabilities to connect with one another. Examples of how service providers could create these spaces where families can link with one another include:

- ✓ Creating a user council for the parents of children with disabilities using the services to come together and share their feedback on the service
- ✓ Providing peer-led support spaces for family members of service users to come together and talk about their experiences

A family movement can only be built by families, but when service providers who have access to groups of family members of children with disabilities can facilitate bringing family members together, these connections can be the building blocks of a strong family advocacy group.

In some cases, family groups may also form through the initiative of one individual family member seeking support in their local community. Particularly in countries or regions where a national or sub-national federation of family organisations exists, individual family members often contact the federation for advice and guidance in establishing a family group in their community. OPD federations representing people with intellectual disabilities and their families at the national, regional, and even global level can support an individual family

member to build a group in their community through sharing their experiences, connecting them to other resources, and providing mentorship as they grow the family group.

This resource created by families on supporting a new family leader with their first steps in building a group is a good starting point for organisations supporting an individual who is working to create a new family group.

Top Tips for Supporting Families

For organisations in touch with an individual family member who wants to start a family group, look for links within the existing family movement to support them.

- ✓ Identify any national, regional, or global OPDs representing families that could help share advice, resources, or connections
- ✓ Connect individual family members to these existing OPDs

Family groups are most successful when they have access to advice, support, and solidarity from a broader family movement.

Top Tips for Supporting Families

For organisations of persons with disabilities (OPDs) representing people with intellectual disabilities and their families at the national or regional level, support and guidance for an individual family leader looking to form a family group can take many forms:

- ✓ Supporting family leaders to identify what other families may want from the group
- ✓ Sharing good examples of successes by family groups at the local level
- ✓ Supporting family leaders with training and mentorship

► TOOL: Family Support Action Plan

Use this tool to help new or emerging family groups you are working with to formalize their work and plan their next steps

Once a family group is formed, to stay active, groups come together regularly through both physical and virtual means. Family groups in Latin America are more likely to collaborate virtually - family groups in Colombia reported using WhatsApp and Zoom to meet regularly, and family groups in Bolivia report using WhatsApp to collect data from

families about their children. Family groups in sub-Saharan Africa are more likely to come together in physical meetings. In many cases, families tried to connect virtually using WhatsApp, Facebook, or Telegram, but found that meetings requiring a data connection are a barrier to lower-income families.

“Families have tried to connect through Facebook, but it didn’t work well since most of them do not have smart phones and data is expensive. Families opted to stick to physical meetings, mostly with specific agendas on solving an issue in the community.”

Family organisation leader in Namibia



The way that family groups practically come together and the ways that they connect and work are particularly important for organisations working in partnership with family groups to consider. Access to affordable telecommunications, schedules for harvest, and other factors for families will impact the type of mobilisation of families that the group can do and the timelines for engaging in activities. Family groups and other grassroots groups often face challenges when working with partners and funders who expect them to operate like an organisation as opposed to a movement - it is important for partners of family groups to be conscious of the way that family groups work and the barriers they may face.

“During the harvesting time and rainy seasons it might be difficult to have regular meetings ... Regular meetings [can only] happen while the families [are] available at their villages.”

Family organisation leader in Tanzania

Top Tips for Supporting Families

For organisations that fund, support, or partner with family groups at the grassroots level:

- ✓ Discuss with family leaders to understand the way that their family group works – do a deep dive into how the family network connects with one another, where they mobilise in person, and what constraints impact the ability of family members to come together.

Family groups receiving funding for their work often face challenges from funders who do not understand the way they work and the resources needed to bring people together in their communities – good partners for family groups work to understand family group models and support the group in a way that works for them.

For new family groups, their first step as they evolve from a group of families that provides peer support, connection, and solidarity to family members into a group seeking to have an impact on their community is building a plan.

The **Family Support Action Plan** is a resource that organisations can use with the family groups they support in order to help the family leaders have a conversation about what comes next for their group and make a plan for how to build out their group and its impact.

Building a Shared Vision

Initially, family advocacy groups tend to come together with peer support or mutual aid as their primary objective. Many of these family networks initially come together to share knowledge and to support each other with peer support groups, micro-credit, income generation, and table banking. When families have come together for peer support or to access these other forms of support within the group, they often arrive not knowing what to expect for the future of their family members.

Over time, these family groups evolve from primarily peer support to have broader advocacy objectives after identifying common issues they face. As family groups transition from mutual aid groups into advocacy groups, they begin to address a variety of issues that impact people with intellectual disabilities and their families – from inclusive education to gender based violence to supporting self-advocacy. The key issues that the group addresses will vary based on the needs and experiences at the time. For example, for groups that come together because they all have family members with intellectual disabilities of a similar age, the advocacy focus of the group will also evolve to address what is relevant to the phase of life of their family member at the time - such as evolving from advocating for access to education into advocating for access to employment.

However, for families to be successful as an advocacy group, family groups must undertake a collective activity to build a shared vision for the group as they move from working within the group to working beyond it with other stakeholders in the community. For some groups, this vision can evolve naturally over time. As family members share their perspective with others through a peer support lens, families realise that they are facing the same challenges – often around the denial of access to education for their children or denial of access to services in the community – and through conversation and peer support, families naturally identify the initial common issues that they would like to advocate to change.

For families who may have arrived to the family group or family movement without a specific vision for their family member's future, or for families who have been told that segregation is the only possibility for their child, within the group there may be conflicting ideas of what the big issues are to advocate for.

One starting point for family groups in building their vision for inclusion, particularly for families who are new to the movement, is looking at the language they use. The language that families use influences the way the group understands the potential of people with intellectual disabilities and what a good 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 will mirror and use, and as family groups 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.

Top Tips for Supporting Families

For organisations that fund, support, or do direct work with families, think about the language used and how it can influence perceptions of people with intellectual disabilities

- ✓ How do we talk about disability? Do we focus on diagnosis, or on a person’s support needs?
- ✓ Do we frame discussions in terms of what a person “cannot do,” or do we talk about the barriers that exist?
- ✓ Does the way we describe individuals focus on the person, or their disability?
- ✓ Do we notice a change in perspective when we start using person and rights-based language within our teams and with our partners?

► **TOOL:** Supporting Families to Use Inclusive Language

Share this tool with new family groups to help them align their language with the disability movement

Once families are aligned on language, the family group has set the stage for a broader conversation about what the big goals of their group should be. Family groups work together to develop a vision for inclusion, which is a set of big ideas about what the future will look like for people with intellectual disabilities, with inclusion at the core.

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 within a new family group 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.

Individual family members of people with intellectual disabilities recognize the barriers that their child, sibling, or other relative with an intellectual disability will face in being included

in their community, and without a vision of inclusion, might be hesitant to embrace inclusive environments. Family groups use a variety of

strategies to help families see beyond the barriers and recognize the possibilities that inclusion can create for their family members.

Family organisations report that building a vision for inclusion within a new group requires three main stages:

1

Building an understanding of rights

The first stage in building a vision for inclusion is a political exercise, supporting families to understand that their family member with an intellectual disability has the same rights as every other person with or without a disability.

2

Building an understanding of what inclusion should look like in practice

Even when family members are aware of the rights their child or sibling has, it can be difficult to imagine what accessing that right might actually look like when they have never experienced inclusion before. This stage helps families think through what inclusion would mean for their family members in their own life.

3

Bringing voices together

This stage moves family members from thinking about accessing rights for their family member as an individual into building a collective voice as a group to push for inclusion in the community more broadly.

“At this stage, the voices of the parents come together around the beliefs. It isn’t enough to have one or two people, you need a collective understanding of what inclusion is for everyone, not just because of one individual child. We have to bring voices together into one feeling and vision.”

A mother and family group leader in Colombia

Each family group supports families to build this vision in a different way, but peer support and family leadership is always at the centre of every strategy. Hearing from other family members of children and adults with disabilities that inclusive education,

employment, and independent living are possible or hearing directly from people with intellectual disabilities themselves about possibilities is most impactful and families can build a vision based on the real life examples and successes of their peers.

Example**Building a vision 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. Between the principal's discouragement and her own fears about the return to school, she chose not to send her son back to school.

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 to school.

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 attending 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 recognized 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 SPSD in Peru



► **TOOL:** Building a Vision for Inclusion

Family groups can use this tool to map out their group's vision for an inclusive future

For many families, even with the support of a family group building a vision of inclusion and possibilities, and even after bringing their language in line with their vision, the influence of the medical system and other service provision systems can have a significant impact on the attitudes and vision of family members. Other community actors that operate with a medical perspective are less likely to recognize the potential of children with disabilities, and report back to families about all of the things that their children “cannot” or “will not” be able to do in the future, even when these claims are inaccurate or do not account for what a person can do with support. For families who have dreams for the future of their family member that includes inclusive education, having a job, or living in the community independently, being told that their family member cannot achieve the future they had hoped sets families back on their journey towards an inclusive vision.

Medical, educational, and other services in the community in some cases advocate to families directly for segregation, convincing families that their child cannot be included meaningfully and that segregated solutions such as special schools

“It is so difficult because the rehabilitation process comes up, and everything [a family’s vision of inclusion] is destroyed. They will tell us our children can’t go to school, that our children aren’t capable of being with other children – this is what the doctors are telling us. For the family organisations, some mothers believe us, but the doctor’s opinions have a lot of weight in our context.”

A mother and family group leader in Colombia

or institutional living are their only option. These attitudes and assumptions counteract the progress made by family groups advocating for inclusion, and result in individual families not believing that inclusion is possible.

Top Tips for Supporting Families

For organisations that fund, support, or deliver services in communities, consider how your team that comes in direct contact with families could be impacting the vision that families have for their family members. Some reflection questions may include:

- ✓ Do the doctors, therapists, community health workers, and others providing direct service recognize the value of inclusion?
- ✓ Do the doctors, therapists, community health workers, and others providing direct service present health information to families in a way that creates low expectations or sets families on a specific trajectory?
- ✓ Do the doctors, therapists, community health workers, put families in touch with local family organisations so families can access a non-medical perspective?
- ✓ What action are your direct service teams taking to help ensure that families value and see the potential of their children with disabilities?

Training staff teams within service providers about the need to ensure that families are getting health information without promoting segregation or low expectations is an important step towards creating more support for families within communities.

Advocacy Strategies

Once family groups start working through collective advocacy, they use different platforms in their communities to make a difference.

Families working together in communities may work through meetings with leaders, campaigning, delivering training to key stakeholders, through media, and through town halls and other public platforms. In communities with better access to telecommunications, families are also gathering and

organising their advocacy online – Twitter has been one mechanism for advocacy that has been very successful for family groups in Latin America.

The advocacy style will vary from family group to family group and will vary based on the community.

“In one of the districts where the children were refused admission, there was a family advocacy group which through advocacy got permission for the admission. The families were campaigning to the school and to the district office for the education rights of their children, and they succeeded to admit or enrol the students back to school.”

Family organisation leader from Ghana

For example, families can strategically use the unique cultural practices of their community to access leaders and gain an audience for their key issues.

“In the local areas, families call together at the chief baraza [council]. They will talk about education, for example, what is happening at schools. Each community has big halls where people meet for different issues like election and other community local issues, there are also school halls for meetings related to education. Through their family support groups they are also going together to the teachers and other leaders, to create platforms where they can be able to speak up about their issues.”

Parent and family leader from Kenya



Example**Using cultural ceremonies as an advocacy tool**

In Ethiopia, family groups use coffee ceremonies in their communities as a strategy to connect with decision-makers and advocate for their goals. Coffee ceremonies in Ethiopia are an important communal tradition which supports community-building and starting conversations.

Family groups in Ethiopia will hold coffee ceremonies and invite elders from the community, religious leaders, cultural leaders, and other key individuals in the community, using the ceremony as a platform for conversation about inclusion.

“The coffee ceremonies, though informal, serve as a very good platform to discuss issues on inclusive education in a more relaxed way, some of the discussions that have happened in the coffee ceremonies include discussions on the Convention on the Rights of Persons with Disabilities, intellectual disability and inclusive education.”

Sibling and family leader from Ethiopia

Family groups have also been successful in using the media to have their voices heard. Exposing issues through the media has been an important tool not only for family groups to make a change in their local community, but has also been an important dissemination tool that has allowed family groups in other communities or regions to learn from the successes of family groups and replicate their strategies in new communities.

Top Tips for Supporting Families

For organisations that fund, support, or work with families at the community level, ensure that your activity plan for the family group includes supporting the group to create an advocacy plan if they do not already have one.

- ✓ Support the family group to build their own advocacy plan – this might look like sharing examples of successful advocacy, encouraging the group to set annual advocacy goals, and funding workshops that will bring the family group together to set their agenda and build their strategy.

► TOOL: Advocacy Strategy for Families

Family groups can use this tool to see what works making change and get inspiration for their own advocacy work

While families at the local level have a significant impact in their community, often the advocacy successes, strategies, and stories from families are not fully captured at the local level. Family groups are busy doing the work of building inclusion at the community level and are working towards a big goal, so often don't stop to think about how to track the changes they are making and their impact on their community.

Monitoring success and impact is rarely a priority for low-resourced grassroots groups, but supporting

family groups with basic monitoring of their impact helps them to demonstrate their impact in the community, access funding opportunities, prove their legitimacy as an advocacy group to other community stakeholders, and also to share knowledge with other family groups.

For family groups, impact monitoring rooted in consensus building is an effective strategy for tracking change in a way that is accessible and participatory.

Top Tips for Supporting Families

For organisations that fund, support, or work with families at the community level, encourage family group leaders to document their successes:

- ✓ Support family groups to capture and report on their successes
- ✓ Do not restrict family groups to using ready-made monitoring tools designed for larger organisations – consensus-based participatory monitoring strategies are likely a better fit for family groups.

Top Tips for Supporting Families

For organisations that fund, support, or work with families at the community level, share their work! The important advocacy work being led by families at the local level is not always shared with national, regional, and global family networks – work with family group partners to share their successes with the broader family movement.

- ✓ Connect with national, regional, and global organisations of persons with disabilities (OPDs) representing families to showcase the work family groups are doing at the local level. Members of the Inclusion International network, the global network of people with intellectual disabilities and their families, are a good place to start!

Sharing the advocacy of family groups at the grassroots level is an important strategy for building the family movement and giving other family groups the opportunity to learn from the success of others!

► **TOOL:** Most Significant Change Impact Monitoring for Families resource

Family groups can use this method to document what their biggest impacts are - this can help them in their advocacy and in seeking funding and partners

Working in Partnership

To strengthen their voice when advocating for inclusion at the local level, family groups often collaborate with other stakeholders in their community. By building relationships and partnerships with other groups or organisations in the community, family groups can get access to new platforms, build allies for inclusion who will share the family group's messages and advocacy points, and have the opportunity to deliver joint advocacy.

For newer family groups in particular, it can be challenging to break into the advocacy space or be recognized by decision-makers as a pressure group in the early stages of the family network's advocacy journey.

“Family groups who have been able to achieve more have done this because they could relate with other organisations related to other disabilities, and other organisations or coalitions. Through these avenues, we now have schools calling us about inclusion because they have heard of us through the network and they are calling because they are interested in the issue.”

Family organisation leader in Colombia

At the early stages, groups of families of people with intellectual disabilities often naturally work in partnership with the families of children with other disabilities to have a stronger voice. Families of children with disabilities working together as a united group has been successful in many contexts, with many national federations of families being formed as a result. However, families of people with intellectual disabilities working in partnership with other families as part of the broader disability movement have reported facing challenges with being included. Children with intellectual disabilities are among the most marginalised among children with disabilities, particularly in terms of access to inclusive education, and some family groups report that their issues tend not to be prioritised when working with families of children with other disabilities. In Latin America, family groups reported that collaboration with other disability groups who focus on diagnosis and medical and therapeutic interventions instead of inclusion can be challenging, as the joint advocacy network then does not have a single vision and may give conflicting advice to the relevant education authorities that results in outcomes that align more with integration than inclusion.

Family groups face a similar challenge with the broader cross-disability movement, where families of people with intellectual disabilities are often denied a seat at the table. With the recognition by the CRPD Committee that organisations of families of persons with intellectual disabilities are OPDs and belong in the disability movement, family groups hope to see better inclusion in the cross-disability movement.



Top Tips for Supporting Families

For organisations that fund, support, or work in partnership with cross-disability organisations at the local level, support the organisation to reflect on whether or not families are included in their work.

- ✓ Are families of people with intellectual disabilities included in the organisation?
- ✓ Are the issues that face people with intellectual disabilities reflected among the organisation's priorities?

This reflection can also apply to other underrepresented groups within the disability community, such as people with psychosocial disabilities and people with deaf blindness.

As family groups seek allies outside of the disability movement, they begin to look to social justice groups (such as women's groups or indigenous advocacy groups), groups working on education issues (such as parent-teacher associations or district education councils), and other community groups, which may be voluntary groups, neighbourhood councils, religious groups, or other groups. Family groups have also found success working directly with government actors, including departments and local committees.

These partnerships that family groups engage in with other stakeholders vary significantly in scope – from smaller scale interactions such as a family group working in partnership with one other community group on a campaign, to large scale advocacy partnerships such as a local family group joining a broader regional or national network that advocates for a topic that families of people with intellectual disabilities care about.

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

Mother and family leader in Namibia

"Families have come together in the Article 24 Group, which brings together more than 130 organisations in [Argentina], who decide to join forces for inclusive education. With them they have managed to approach the government and be heard, to make resolutions that refer that they must access all boys and girls."

Mother and family leader in Argentina

Family groups go through a process to identify which groups in their community could be potential allies and partners, thinking through questions such as:

- Who makes up other groups in the community?
- Do the thematic areas these groups work on align with the priorities of families?
- What are the values of the other groups?
- If the group has never advocated for inclusion before, are they open to learning more?

“[Families work with] local government, which is the responsible body for every public service like education, health, etc. They will communicate with this local government body, including police stations to report the situation of their children’s education.”

Family leader in Tanzania

Top Tips for Supporting Families

For organisations that fund, support, or work with families at the community level, support the family group to conduct a mapping of potential stakeholders in their community that could be partners:

- ✓ Which organisations or groups share the same values as families of people with intellectual disabilities?
- ✓ Where can common ground be found between the messaging of families and the messaging of other organisations?
- ✓ Which organisations or groups are strategically important to connect with?

► **TOOL:** Mapping tool for finding community partners

Family groups can use this worksheet to find and map potential partners in their community

When family groups identify a potential partner in the community, there are different models they might use to engage with them.

In most cases, family groups engage with other stakeholders through a standard partnership model, where the family group as a unit engages with another group or another advocacy movement. The two groups or organisations work alongside one another on joint work, with the family group retaining

its identity as a group specifically advocating for the needs of people with intellectual disabilities and their families.

The movement of families of people with intellectual disabilities in some countries have tried different models for engaging stakeholders and building their vision for inclusion, including Nicaragua’s unique “radiating” model.

Example

Nicaragua's "radiating" family advocacy structure

In Nicaragua, the Nicaraguan Association for Community Integration (ASNIC) is the leading organisation of families. Unlike other organisations made up of families, instead of advocating for inclusion in communities through strengthening family groups at the local level, ASNIC uses a model that integrates the viewpoint of families into existing organisations.

ASNIC identifies organisations in the community that do not yet include the perspectives

of people with intellectual disabilities and their families, and supports individual family members to get involved in the leadership of those other stakeholder groups. Instead of stakeholders seeing the perspective of families as a potential threat, the organisation sees the new family perspective coming from within their organisation as a strategy for strengthening their own work and advocacy.

"We find a community, identify the organisations there that work with boys and girls and youth who might not necessarily work with disability, but work on education, for example. These are community organisations – our work is reaching into a community, identifying these actors, getting involved, and promoting the design of an inclusive plan at the community level. Due to the organisational culture [in Nicaragua], families are used to working in that way. The organisations don't have families [in their organisations], and this had led to organisations at the local level having a different view where families are seen as a threat. We don't want to reach into a community to fragment it more, the idea is to arrive and strengthen and empower. The goal isn't creating new organisations of families, it is radiating families through the structures to have families involved in all organisations."

ASNIC Family leader in Nicaragua

Sustainability

For families of people with intellectual disabilities, participating in family groups, leading a family organisation, and advocating for inclusion in the community is a labour of love.

Most family groups operate informally, and while some may have formal governance structures such as an election process for its leadership, many local family groups exist as unregistered, informal networks. Their work is powered by family members acting in a volunteer capacity, in many cases is funded by personal contributions from the family members themselves, and rarely do family groups have external financial support for the work that they do. In some cases, and particularly in sub-Saharan Africa, these family networks may register as a community-based organisation (CBO) in their community in order to access funding and other services that will help them to support families in

their community, but resources are typically scarce at the local level.

In many cases, family groups at the local level are entirely reliant on national level family-based OPD federations to access funds to deliver their advocacy and family support work, but the chronic underfunding of the national federations means that they do not have the capacity to support all of the work families want to deliver at the grassroots level. The lack of institutional support for family groups is one of the biggest sustainability challenges facing the family movement.

“[Local groups] look for funding at their own local level to support some of the activities that they do, but when this doesn’t happen then the groups are not sustainable anymore – some of them close shop, they stop meeting, they stop engaging in advocacy activities, it affects their sustainability.”

Fatma Wangare, Director of Inclusion Africa, the African regional OPD federation representing people with intellectual disabilities and their families

Top Tips for Supporting Families

For organisations that engage in partnerships at the local level, consider how family groups could be potential partners.

- ✓ Identify existing family groups in the areas where you work
- ✓ Consider engaging local family groups in funded programming and advocacy partnerships

Family groups have a wealth of grassroots advocacy knowledge and are well connected with other stakeholders in their local communities – consider how a partnership with a local family group could be mutually beneficial!

When organisations and stakeholders do work in partnership with family groups, typically it is mothers of children with disabilities who are the person that organisations, service providers, and community health teams connect with as their first contact. As family networks begin to form, the leadership of family groups is typically women, and in most cases led primarily by mothers, which is reflective of the responsibility of caregiving typically placed on women.

The reality of this caregiving burden on top of taking on leadership roles in the movement means that female family leaders are disproportionately prone to burnout, balancing supporting their family member, advocating on behalf of their individual family member's rights, taking on a leadership role in a family group, and advocating on behalf of the entire community. Similarly, many female family members of people with intellectual disabilities who become family group leaders pivot to full time work mobilising families and advocating on a voluntary basis, often leaving them financially reliant on

“There is greater leadership from mothers, they are the ones who meet and seek solutions to the problems faced by their sons and daughters.”

Family leader in Bolivia

parents and extended family. The expectation that mothers in particular will operate in this precarious position indefinitely proves to be another challenge for sustainability within groups.

Reflecting on the diversity of family groups and the family movement is also important for long-term sustainability of the movement. Strong family groups are diverse, and family carers and supporters come in all forms – fathers, siblings, grandparents, and other extended family can all benefit from access to peer support from other family members and benefit from the solidarity and advocacy power of a family group.

Top Tips for Supporting Families

For organisations that engage with family groups at the local level, in partnership with the family group, support them to reflect on the diversity of their family group:

- ✓ Who holds the leadership roles within the organisations?
- ✓ Are siblings visible within the organisation? Are fathers? Are other family members?
- ✓ If the organisation is providing peer-led support spaces for family members to come together, how can they consider spaces for family members who are underrepresented in family groups, such as fathers and siblings?

Giving family members like siblings, fathers, and other extended family access to spaces to connect with other families will help create a more diverse family group in the next stage of a family network's evolution, and in the long term, a more sustainable family group!

► TOOL: Engaging Siblings in Family Groups

Organisations can use this tool to reflect on their governance and plan ways to better engage siblings

When reflecting on which family members are involved in an organisation, the engagement of family members across multiple generations is also particularly important for the sustainability of the family movement.

For family groups to continue to support families and advocate in their community in the long term, ensuring that new generations of family members are being engaged and new leaders cultivated is important for family groups. As founders of family groups age, siblings of people with intellectual disabilities often become the primary supporters for their family members with an intellectual disability and are also natural successors for leadership in the family movement. Siblings are best prepared to take on leadership roles and support family groups to grow in the long term when they have

been engaged in the family movement, have a strong understanding of the rights of people with intellectual disabilities, and are aware of the resources available to them.

This resource created by siblings of people with intellectual disabilities on how to engage siblings in a family organisation is a good starting point for family organisations to consider their strategy for building a multi.-generational movement through engaging siblings.

Example

Engaging siblings in Bangladesh

Many family groups begin as local peer support groups, but typically these groups are made up primarily of parents of people with intellectual disabilities. Recognizing the need for spaces that engage siblings in the family movement and create leadership and growth opportunities for siblings, some family organisations have begun creating dedicated sibling spaces. Sibling support groups are spaces where siblings of people with intellectual disabilities can come together, share experiences, give and receive advice and support, and provide peer support to each other.

Down Syndrome Society Bangladesh (DSSB), a family-based organisation based in Dhaka, has built a strong group of siblings through their sibling support group. DSSB recognized

that siblings play a constant role in the lives of their sibling with Down Syndrome - siblings are the most consistent supporter for their family members with intellectual disabilities throughout their lives, and the relationship between people with intellectual disabilities and their siblings evolve as they age. DSSB's sibling group brings siblings across Dhaka together to share their experiences and share support strategies and challenges. They meet once per month either online or in-person, and also organise counselling and mentorship to siblings. The sibling group is growing every day, and their next step is organising a sibling group at the national level.

"It is definitely true that sibling involvement in the disability movement is critical to ensure sustainability [...] the involvement of siblings ensures sustainability in making the disability movement really inclusive, successful, and results driven, and our sibling group is growing every day."

Sibling group leader from Down Syndrome Society Bangladesh

Another key challenge that family groups face in their sustainability arises when groups are formed without a shared vision for inclusion.

In most cases, family groups form because family members came together organically to support each other and share their experiences, and these groups are well placed to work towards building a shared vision for inclusion. Family groups that come

together but tend not to be sustainable are groups that are brought together through project funding – typically income generation projects – because the groups are brought together and begin immediately delivering activities for their funder without having an opportunity to build rapport or shared goals as a group, which are essential for building a collective vision in the long term.

Top Tips for Supporting Families

For organisations that fund the work of families at the local level, start with the building blocks to ensure the family group is sustainable.

- ✓ Before expecting a new group of families to deliver funded work or activities, begin with funding a vision building phase.
- ✓ Use the Family Support Action Plan to help the new family group find their feet.
- ✓ Encourage the family group to use the discussion guide for building a vision of inclusion to set their collective goals as a precursor to any other substantive project work.

Groups that have had a chance to develop their shared vision and build relationships through peer support will be better placed for strong project partnerships.

Having this vision for inclusion also helps family groups to have a strong sense of what the mandate of their group should be and what roles they should not be expected to play. In the last 50 years, many family groups came together to fill gaps in service provision and to create new services to support people with intellectual disabilities. Presently, there is a general consensus among family members that it is the responsibility of the government, not the individual families, to take on the burden of service provision, and this enabled family groups to retain their core purpose of advocating for inclusion.



Taking Action to Support Family Groups

For organisations that work with families – whether they be funders, INGOs, service providers, cross-disability organisations, or other actors – family groups need support from the organisations they work with to reach their full potential.

This section consolidates all of the action points for organisations who work with family groups that are addressed in the sections above.

Section	Top tips
<p>Supporting family groups to come together</p>	<ul style="list-style-type: none"> ✓ Organisations that engage CBR workers or community health teams in their work should ensure that these workers understand their role in supporting families of children with disabilities, including linking families to each other in the community when they are identified. ✓ Organisations that deliver services for children or adults with disabilities in the community should consider how they can create spaces that will bring families together, such as creating user councils for service users or providing peer-led support spaces as an additional service. ✓ Organisations in touch with individual family members interested in mobilising a group should identify existing OPDs within the family movement that could help share advice and resources and connect the individual to the larger movement. ✓ Organisations funding the development of new family groups should aim to understand the constraints that the family group face and support the group connecting in ways that work for them.
<p>Supporting family groups to build a shared vision</p>	<ul style="list-style-type: none"> ✓ Organisations that engage with families, including health care providers, schools, and other service providers should reflect on the language they use to describe children and adults with disabilities and consider how that language may be influencing the perceptions and assumptions that family members have. ✓ Organisations that engage with families should train team members who work directly with families to ensure that information is being presented in a way that does not promote segregation and promotes families valuing their child with a disability.
<p>Supporting family groups to have their voices heard</p>	<ul style="list-style-type: none"> ✓ Organisations that work with family groups at the grassroots level should support and encourage family groups to build out their own advocacy plan. ✓ Organisations that work with family groups at the grassroots level should support family groups to capture and report on their successes, and should not restrict family groups to using ready-made monitoring tools designed for larger organisations.

Section	Top tips
<p>Supporting family groups to have their voices heard</p>	<ul style="list-style-type: none"> ✓ Organisations should encourage the family groups they work with to share their successes and strategies within the broader family movement, and should support the group to connect with national, regional, and global OPDs representing families.
<p>Supporting family groups to work with stakeholders in their communities</p>	<ul style="list-style-type: none"> ✓ Organisations that have partnerships with community organisations, including cross-disability organisations, should support their partners with an exercise to reflect on what voices may be excluded from their perspective – including reflecting on how the issues of people with intellectual disabilities and their families are included in their work. ✓ Organisations that support or work with family groups directly should encourage family groups to conduct a mapping of community organisations to identify potential partners. ✓ Organisations that do not currently work with family groups should consider how family groups could be a potential partner in your work.
<p>Supporting family groups to be sustainable</p>	<ul style="list-style-type: none"> ✓ Organisations should fund the work of family groups at the grassroots level. ✓ Organisations funding family groups should account for the need to give family groups space to connect and build a collective vision before beginning to deliver on project activities. ✓ Organisations that work with family groups should support the group to reflect on the diversity of their group, including encouraging building a multi-generational movement and cultivating new leaders.

With the support of the organisations they work in partnership with, grassroots family groups around the world can strengthen their movements and grow their impact in the fight for inclusion in their communities.

Toolkit

This section includes guides, tools, and actionable resources that organisations can use to support groups of families organising at the local level.

These tools were created with the feedback of local family groups in Kenya, Zanzibar, Benin, Peru, and Nicaragua, who explained what resources they needed from partners to strengthen their work.

By using these tools to support family groups, organisations are helping to strengthen strong advocacy networks of families who lead the fight for inclusion at the grassroots level.

Tool list

- ▶ Family Support Action Plan
- ▶ Helping Families to Build an Inclusive Vision
- ▶ Inclusive Language Guide for Families
- ▶ Community Partnership Mapping Tool
- ▶ Advocacy Strategies for Family Groups
- ▶ Monitoring the Impact of Family Groups
- ▶ Building a Multigenerational Family Movement
- ▶ Frequently Asked Questions about Family Networks








Family Support Action Plan: Strengthening Local Family Groups

Family groups can use this tool to think about ways they can support and connect families in the community.

What type of support do individual families want from family groups?	How can organisations support family groups to deliver on this support?
 <p>Peer Support</p> <p>For many families, the opportunity to connect with other families who share similar experiences and benefit from peer support and solidarity is the primary reason for coming to a family group.</p>	<p>Building and maintaining informal and semi-formal support networks in the community - for example, family peer support groups - is an important strategy for local groups to build a family movement. It is important for national federations to support local family groups to create these types of spaces because having support networks at the community level improves awareness for families and accountability for other local actors, as these peer support groups often evolve into advocacy groups over time.</p> <p>National organisations can support their local family groups to deliver on peer support by:</p> <ul style="list-style-type: none"> ✓ Training family leaders on how to facilitate peer support groups at the local level. ✓ Training family leaders on specific strategies to support families to cope with stigma and discrimination in their communities. ✓ Providing examples of effective peer support models used in other communities to help local groups share strategies.
 <p>Referrals</p> <p>Families often do not know what services they are entitled to, what support is available to them, or where to look to find these things. Family groups play a key role in guiding families to find the support that is available to them in their community.</p>	<p>Without becoming a standalone family outreach service, the ability to deliver referrals for individual family members is an important tool for family groups to support their members.</p> <p>National organisations can support their local leaders to deliver on referrals within their communities by:</p> <ul style="list-style-type: none"> ✓ Helping local family leaders to do a mapping of available services and allies in their community who could provide different types of support to families. This list might include institutions that deliver inclusive education, health, social services, economic empowerment programs, and more. ✓ Helping local family leaders identify existing commitments to disability inclusion in their community that can be used as a basis for accessing services, such as identifying the language on disability included in a community development plan. ✓ Sharing connections with social and child protection services, networks of community health volunteers, organisations delivering psychosocial support, and more with local leaders. ✓ Creating resources for families that provide clear examples of available support and services in communities, such as access to support people, speech assistive and text to speech devices, wheelchairs, dignity kits, respite care, etc.

What type of support do individual families want from family groups?	How can organisations support family groups to deliver on this support?
 <p>Access to information</p> <p>Many families come to family groups to learn - family groups are relied on to be a source of information, resources, and tools for family members who want a better life for their family member with an intellectual disability.</p>	<p>Organisations can play an important role equipping family groups with the information they need to support individual families.</p> <p>National organisations can help family leaders deliver on access to information by:</p> <ul style="list-style-type: none"> ✓ Developing and providing accessible informational resources focused on inclusion that local family leaders can share with members of their family groups ✓ Training family leaders at the local level about human rights, entitlements under local laws and international frameworks including the Convention on the Rights of Persons with Disabilities (CRPD), and other essential information for families so that they can go on to train others in their communities ✓ Providing family leaders with training modules on inclusion and inclusive practices to use with external stakeholders in their community - such as teacher training, training for public office holders, or other stakeholders.
 <p>Accompaniment</p> <p>When families understand the rights of persons with intellectual disabilities, it can be difficult to understand what the process is for challenging the denial of rights. Families come to family groups seeking accompaniment, or support with individual level advocacy from other families who have gone through similar experiences.</p>	<p>In order to be able to successfully accompany individual family members through their advocacy journeys and provide support and guidance, family groups need to be equipped with knowledge of advocacy strategies.</p> <p>National organisations can support local family groups to do this by:</p> <ul style="list-style-type: none"> ✓ Equipping family leaders at the local level with information about rights under the Convention on the Rights of Persons with Disabilities (CRPD) and under local laws to help them build a case for families ✓ Providing advocacy resources, including advocacy messages to equip local groups to contribute to the advocacy of the movement and examples of effective advocacy strategies ✓ Sharing success stories of local advocacy between family groups to show examples of what has worked in other communities ✓ Linking family leaders with cross-disability networks in their country that can provide support with understanding how the broader disability movement works and link the family leaders to other key stakeholders.
 <p>Building a vision for the future</p> <p>Families often come to family groups with the expectations for the future of their family members with an intellectual disability that medical professionals have given them - this is typically a vision that does not emphasise inclusion or the potential of people with intellectual disabilities. Families want to know what is possible, and family groups play a key role in helping families to dream bigger and build an inclusive vision for the future.</p>	<p>Once families have built a vision for inclusion, they are more likely to engage in advocacy and spread the message of inclusion to other stakeholders.</p> <p>National organisations can support local family groups to help their members build a vision by:</p> <ul style="list-style-type: none"> ✓ Training family leaders to be peer facilitators for vision building workshops. ✓ Sharing strategies for building a vision, such as using the practical experiences of families of older children or adults or using the testimonies of self-advocates to demonstrate possibilities. ✓ Creating resources on the national organisation's vision for inclusion and what this might look like for an individual family at the local level.

Your turn: Family Support Action Plan

Type of support	How can your organisation support family groups to deliver on this support?
 Peer Support	<p>.....</p> <p>.....</p> <p>.....</p>
 Referrals	<p>.....</p> <p>.....</p> <p>.....</p>
 Access to information	<p>.....</p> <p>.....</p> <p>.....</p>
 Accompaniment	<p>.....</p> <p>.....</p> <p>.....</p>
 Building a vision for the future	<p>.....</p> <p>.....</p> <p>.....</p>

Helping Families to Build an Inclusive Vision

This resource gives family groups the key ingredients to come together around a shared vision of inclusion.

An **inclusive vision for the future** is one where all people with an intellectual disability are fully included in their community at all stages of their life - from learning alongside students without disabilities in an inclusive school, to paid work in an inclusive workplace, to being included with neighbours and friends living in the community, and everything in between.

What big ideas can help form the basis of a family group's vision for the future?

Inclusion

Inclusion is the big idea that should guide all of the conversations about the future of people with intellectual disabilities. Inclusion should be the goal for families at different stages throughout the lives of their family members - 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.

Equality

A vision for inclusion is rooted in the idea of equality - including equal rights, equal access, and equity. In an inclusive world, all individuals must have the same possibilities as others in their community.

Diversity

Diversity is a key value that guides the vision and the advocacy of families - in an inclusive community, everyone's diversity is celebrated and society recognizes and appreciates the different contributions of every unique person. An inclusive world is one where everyone respects and appreciates all members of the community regardless of their particular characteristics, disability, race, religion, sexual orientation, gender, among others.

Belonging

An inclusive vision is rooted in the idea that everyone, including people with intellectual disabilities, belong in their family, in inclusive schools, in their community, in workplaces, and everywhere else without conditions. People with an intellectual disability have an equal right to be fully included in all spaces and feel a sense of belonging along with everyone else.

Breaking down barriers

Historically, support for people with disabilities has focused on improving the ability of the individual and addressing “limitations.” Rooted in a medical understanding of disability, often there may be a focus on “curing” an impairment through medical interventions or therapies instead of providing forms of support that will enable a person to be included in their community. An inclusive vision recognizes that individual people with disabilities do not need to be fixed - our systems and our communities do - and that with the right forms of support, everyone can be fully included.

The goal of breaking down barriers that prevent people with intellectual disabilities from being included and making our systems work for everyone and include everyone is a key principle of an inclusive vision. Some examples of these barriers might be:

- **Attitudinal barriers** - such as negative attitudes or stereotypes about disability that affects the way people with disabilities are treated
- **Cultural barriers** - such as cultural beliefs about disability that lead to stigma, like the belief that disability is caused by a curse
- **Environmental barriers** - such as buildings without ramps or other barriers in the physical environment that prevent people from fully participating
- **Political and legal barriers** - such as laws and rules that prevent people with disabilities from accessing their rights

Your turn: Helping Families to Build an Inclusive Vision

What other big ideas can help form the basis of a family group’s vision for the future?

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Some of the strategies that Inclusion International members use to build an inclusive vision include:

Using peer support to help build a vision

It can be difficult to imagine what inclusion looks like in practice, or for young families to imagine what an inclusive future might look like for their child or sibling. Families of older children or adults with intellectual disabilities can share their own experiences and examples of how they came to have a vision for inclusion and how they support and push for their family members to be fully included in their own lives. Hearing firsthand how other people with intellectual disabilities in their community are thriving and being included will help new families see the possibilities.

Hearing from self-advocates directly

Where family groups are connected with self-advocacy groups, hearing people with intellectual disabilities themselves speak about the future they want and about the impact of inclusion on their lives can be a powerful tool for helping families to build a vision of inclusion for their own family members.

Using the Convention on the Rights of Persons with Disabilities to think about how it applies in our own lives

The Convention on the Rights of Persons with Disabilities (CRPD) in countries where it has been ratified is a standard that governments must meet and affirms the right to inclusion for people with disabilities, but it can also be used as a practical tool for families. With a facilitator, families can look through some of the articles that apply most clearly to their own lives - for example, Article 24 on inclusive education or Article 12 on legal capacity - and think through what they are doing to help their family members have their rights fulfilled.

For example, a discussion around Article 12 on legal capacity gives families a chance to think about if and how they are supporting their family members to make independent decisions about their lives, and how they could be giving better decision-making support to help them find their voice and make choices.

Challenging stereotypes and encouraging reflection

Supporting families to do some self-reflection can help families understand their expectations and think about how that impacts the potential of their family member with a disability. Facilitators can help family members to think through:

- Does the language I use promote negative myths and stereotypes about people with intellectual disabilities? See our **inclusive language guide**.
- What can I do to dismantle these stereotypes?
- Does my family member have a leading role in their own life?
- How am I supporting my family member(s) to fully participate in our community?
- Do I support my family member(s) to use their voice and be listened to?

Families and family groups should also recognize that unlearning and eliminating myths and stereotypes that have been learned from generation to generation about people with disabilities will take time! Thinking through these questions can help families think through if their actions match the vision for inclusion they are building, and generate some personal commitments to working towards inclusion.

Pushing back on conflicting ideas of what family groups should do

Historically, groups of families have often created what we now see as segregated spaces in response to the complete lack of services and other support for people with intellectual disabilities in the community at the time. As service providers denied their family members access to support, families began to create segregated places where their family members would be welcomed and not discriminated against based on their disability.

The family movement has since moved away from this approach and pushes for full access to inclusive services, but many new families prior to building their vision for inclusion still come to family groups seeking segregated services and spaces for their family members with an intellectual disability, not being aware of other better options. Family groups can push back on these ideas and reinforce the idea that the best option is always inclusive spaces in the community, being present in all of the same places where their peers are.

Once family groups have thought through how the principles of inclusion apply in their own lives and they have a collective vision for inclusion of people with intellectual disabilities, families can begin to think through how to harness this vision for their advocacy work to spread the message of inclusion.

To achieve full inclusion, it is a constant process and a responsibility shared by all. Everyone must commit to achieve the vision of inclusion, to ending negative attitudes and prejudices, and to valuing diversity - families must lead the way towards this vision.

Your turn: Helping Families to Build an Inclusive Vision

What other strategies can you think of that would work in your organisation?

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Inclusive Language Guide for Families

The words that families use to speak about their family member with an intellectual disability also becomes the language that others in the community will mirror and use. Neighbours, teachers, and others in the community will follow the lead of families and adopt similar language to describe people with intellectual disabilities. This places a responsibility on families, who must be consistent in the way they refer to or identify their family members, using language that reflects their rights and an inclusive perspective, otherwise families may unknowingly promote negative stereotypes and exclusion.

The inclusive language that families aim to use is not limited to the family movement - organisations of persons with disabilities (OPDs) across all

impairment groups have been working to shift the language that is used to describe disability and people with disabilities. The responsibility to push back against stereotypes is shared with the cross-disability movement, which is united in the shift towards empowering and inclusive language.

For families who are new to the disability movement, leaders of family groups may need to model inclusive language and support families with beginning to use this language. Some of the key inclusive language lessons for organisations or family groups to share with individual family members include:

⊘ Don't use...

Language about sickness and suffering

"My daughter is sick with autism"

"My brother suffers from Down Syndrome"

Language that replaces someone's name or identity with their disability

"My Downs son likes to play soccer"

"My autistic child is 9 years old"

✓ Instead, say...

People with intellectual disabilities are not sick with their disability, nor do they suffer from a disability

"My daughter has autism" or "my daughter is autistic" - depending on if person-first or identity-first language is common in your country.

"My brother has Down Syndrome."

Use the person's name, or the same language that you would use for other family members or their peers

"My son Alejandro likes to play soccer"

"My child Mahra is 9 years old"

⊘ Don't use...

Language that implies people with intellectual disabilities are "special"

"My child has special needs"

"My son goes to a special school"

Everyone has needs - it is not "special" to need support sometimes. The "special" language also promotes the idea that people with intellectual disabilities are different and belong in "special" spaces (like "special schools") instead of being included - special schools should be called "segregated schools."

Language that suggests someone's "mental age" is lower than their physical age

"My son is 12, but mentally he's really 5."

People with intellectual disability do not have a different mental age - if someone is 12 years old, they are 12 years old - no matter what their interests are, what milestones they have reached, or what their reading level is.

Differentiating between mild, moderate, and profound intellectual disability.

"My child doesn't go to school because their disability is profound."

This language promotes the idea that not everyone with an intellectual disability has equal rights, and is often used to justify people who have higher support needs being excluded or only including people who need less support to be included.

✓ Instead, say...

If it is necessary to communicate that your family member has a disability, avoid "special" and just describe the disability

"My child has an intellectual disability."

"A doctor suggested that my daughter go to a segregated school, but we are enrolling her in our local inclusive school instead."

When sharing a family member with an intellectual disability's age, the only option is their physical age.

"My son is 12."

Communicate about your family member's needs by describing the type of support they need, not using a label that describes "functioning."

"My child has higher support needs so will need X, Y, and Z support from the teachers to be fully included at school."

⊘ Don't use...

Results of IQ tests

"My neighbour has an IQ of 70"

IQ tests are outdated, unreliable, and discriminate against people with intellectual disabilities. IQ levels should not be used to describe someone's disability.

Framing challenges in a way that implies the person with the disability is the source of the problem or the reason why they cannot do something

"The student in a wheelchair can't go to school."

If there is a barrier in place that is preventing inclusion, name the barrier, don't blame the person.

Stereotypes about what your family member with an intellectual disability cannot do based on myths or prejudice

"My nephew can't learn because he has an intellectual disability"

"My grandson can't make decisions"

Ideas about people with intellectual disabilities not being able to learn, not having autonomy, not being able to make decisions, and more, are rooted in stereotypes. People with intellectual disabilities can do all of these things.

✓ Instead, say...

If you wouldn't feel the need to talk about the IQ level of someone without a disability, it is not appropriate for someone with an intellectual disability either. If the goal is to communicate the level or type of support a person might need, just describe the support needed.

Framing access issues in terms of the barriers, not the individual with the disability

"The school does not have an accessible entrance, which means the student using a wheelchair is prevented from entering the classroom"

Once the barrier has been named, we can identify the support or accommodation needed and eliminate the barrier that prevents effective participation.

If the goal is to communicate a particular challenge that a person is having, frame the conversation in terms of the support that is needed or being given


"Getting support in these ways helps my nephew to learn on an equal basis with others"

"We use supported decision-making tools with my grandson to support him to make decisions independently"

Through families modelling using inclusive language, communities will become more inclusive in the way they talk to and about people with intellectual disabilities.

Your turn: Inclusive Language Guide for Families

What are some other examples of inclusive language?



Community Partnership Mapping Tool

To find allies, family groups should look for:

Other disability groups

Organisations of persons with disabilities (OPD) representing other disability groups

Groups of parents of children with other disabilities

Social justice groups

Women's groups

Indigenous advocacy groups

LGBTQ+ groups

Groups working on education

Groups of parents of school-aged children, including committees and groups affiliated with specific schools. For example, this may include parent-teacher associations (PTAs) or district education councils

Other community groups

Voluntary groups

Neighbourhood councils or associations

Religious groups, including social justice groups or SACCOs affiliated with churches, mosques, or other religious institutions

Citizen engagement groups formed by local governments

Your turn: Community Partnership Mapping Tool

To find allies, family groups should look for:

Other disability groups

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Social justice groups

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Groups working on education

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Other community groups

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To identify if the group could potentially be an ally for the family movement and could support with advocating for issues that affect people with intellectual disabilities and their families, family groups can use these scoping questions to understand if the organisation would be a potential partner.

Big questions for identifying allies

Who makes up this group?

- Is there a target population that this group works with? For example, this could be an identity group (such as women or members of a religious community) or a location-based group (such as people living in rural areas, people living in a particular neighbourhood).
- Have people with intellectual disabilities and their families been involved in this group's work before?
- If people with intellectual disabilities and their families have not yet been involved, is it likely that they could already be among their target group, even if they may not be visible? Does their target group overlap with ours?

What are the thematic areas that the group works on?

- Do the group's priority areas line up with ours?
- Does the group work on issues that are important to the family movement, like inclusive education or living in the community?
- If the group does not work on our priority issues yet, could our issues be a natural extension of the work they do? For example, if the group is already advocating for children's access to school but are not including children with intellectual disabilities yet, could working with us help to expand their advocacy into inclusive education?

What are the group's values?

- Do the group's values, beliefs, and assumptions line up with ours?
- Do we have a common understanding of the issues that are important to us?
- Does the group believe in inclusion?
- If the group has never advocated for inclusion before, would they be open to learning more?
- Is the group willing to get to know the experiences of families?

Who else does this group work and engage with?

- Does this group already build bridges with other groups?
- Are the other groups they work with ones that families would want to engage with? Do they share the values of families?

How does the group work?

- What is the group's understanding of community engagement? How do they work with the people they represent, support, or advocate for?
- What type of programming, activities, or advocacy do they do that aligns with the needs of families? Is it relevant, accessible to, inclusive of, and acceptable to families?

Your turn: Community Partnership Mapping Tool

Big questions for identifying allies

Who makes up this group?

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What are the thematic areas that the group works on?

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What are the group's values?

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Who else does this group work and engage with?

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How does the group work?

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If the group is identified as a good potential partner, family groups should begin to identify a plan for outreach and engagement with the external group.

This might include:

Establishing the roles of members of the family group for building partnerships and engaging with community groups based on their backgrounds, interests, and experience.

This often looks like engaging families who are a member of the other group's target population to help build bridges and demonstrate the relevance of the family experience to the group's work - for example, mothers of people with intellectual disabilities engaging with women's groups or family members with a specific religious background opening up communications with groups within their faith.

Thinking about cultural differences between family groups and other organisations, and identifying common ground, a common vision, and the first steps to bridge the gap.

Family groups will need to gain an understanding of the vision of the other groups, which may happen through research or through direct dialogue with the group. Families can identify areas where families and other groups share priorities to start building a case for collaboration - for example, engaging with women's groups on the care agenda as an issue that impacts women broadly and female family members of people with intellectual disabilities specifically. Some of the same strategies that family groups use to build a shared vision together can be used to build a shared vision between a family group and other stakeholders and partners.

Identifying a strategy for how the partner can get to know the experiences of people with intellectual disabilities and their families on their key thematic areas and tap into the strengths and knowledge of families to build their own work.

Consultation with families and conversation with family group leaders will help other groups to begin to build an understanding of the needs and priorities of families. This could entail building platforms for two way communication between partners and families (such as regular engagement meetings or identifying a family leader to serve as the link and spokesperson connecting the two groups). This could include using other strategies for cross-cultural communication in communities where needed. Through effective and open communication between family groups and other groups, trusting relationships that can reinforce each other's advocacy and priorities can be built.

A strategy for how the partner can begin to include families and people with intellectual disabilities in their monitoring and evaluation.

Other groups may not have good data on people with intellectual disabilities and their families within their target population, and family groups can help them to update their data collection strategies to capture the experiences of families.

Advocacy Strategies for Family Groups

What works when advocating for change in the community?

Examples of advocacy goals that a family group might have for their community

1

Make local cultural hubs accessible for and inclusive of children with disabilities

2

Get 3 local schools to adopt a zero rejection policy for enrolment of children with disabilities

3

Expand local social protection systems to include support for families

After building a shared vision of inclusion and identifying key messages to advocate for, family groups can use a variety of advocacy strategies to push for change.

These strategies have helped Inclusion International members be heard in their communities.



Building Allies and Partners

For family groups at the local level, connecting with other groups in the community is a good way to spread a message and amplify voices. These could be groups of parents at local schools, women's groups, religious groups, other groups of persons with disabilities and any other community groups that share similar values. Coming together to form coalitions, do joint advocacy work, and share key messages for change in the community helps to build more allies for inclusion of people with intellectual disabilities and their families, and increases the chances of family voices being heard. In some cases, there may already be community platforms that exist that family groups can join.

Monitoring for Accountability

Family groups can play an important role in holding communities accountable for the promises they make, or holding communities accountable for meeting the standards that are set by the national government. Governments and public bodies are sensitive to criticism, especially when these are based on strong evidence and analysis, come from a credible source, and are widely published and disseminated. This often looks like investigations, doing studies to collect data on the impact of policies and decisions, or creating and publishing monitoring reports. These same strategies can be used at the local level by family groups, who can use the stories and experiences of members of their group to paint a clear picture of the impact of policy decisions on people's lives and the need for change.

Joining Policy Conversations

Joining policy conversations is an effective way for family groups to have their voices heard and directly influence decision-makers. When family groups have clear messages and have set their goals for the change they would like to see, they can be prepared to get into policy conversations at the earliest stages. Being part of policy conversations as an advocacy strategy is a step further than going to public forums such as town hall meetings, it means having direct contact and conversations with decision-makers. At the community level, this might look like joining a committee or working group within a local council or other governance structure or family groups having meetings with local leaders to raise their issues and propose solutions.

Contributing to Global Reporting

Families can influence not only decision-makers in their own community, but decision-makers at the national and international level by contributing to global reporting to the CRPD Committee or other global mechanisms about the rights of persons with disabilities in practice in communities. Family groups at the local level can do this through their national federation, and their experiences at the community level can help influence national change.

Strengthening Self-Advocate Voices

Including people with intellectual disabilities themselves in advocacy is important so that families and self-advocates can speak up together. With advocacy work, hearing from people with intellectual disabilities directly about change that needs to happen is impactful for the person hearing their message. For family groups at the local level, this might mean introducing people with intellectual disabilities to self-advocacy for the first time and giving good support so that self-advocates can be in the lead of communications and advocacy activities.

Campaigns

Campaigning is one of the most common advocacy strategies used by family groups. Campaigns do not usually have fast results and require patience from campaigners, but are a great way to reach entire communities. Family groups can create successful campaigns by having clear messages that the community can relate to, an achievable goal, and a specific “call to action” that the community members are being asked to do. Teaming up with other groups in the community can also be helpful for building support for the campaign, and also helps groups find common goals. With campaigning, it is important to reach people on the platforms they use to connect - in some communities this could be radio and newspapers, in others it might be social media and WhatsApp, and in others it could look like in-person campaigning at community gathering spaces.

Using the Media

Family groups can tap into local television, radio, or print media to help spread their messages. Family groups often use the media as a way to get more attention for special events or advocacy-focused days such as the International Day of Persons with Disabilities or World Down Syndrome Day, and local television stations or community newspapers are often open to covering awareness events. Spokespersons from family groups doing on-air radio interviews is also a great way to spread your message and to help new families who may not be part of the group to find a community, and publishing an article that tells the story of the experiences of people with intellectual disabilities and their families and the change that is needed is a great way to make the broader community aware of your calls to action.

Creating Spaces for Families

While bringing families together to share experiences is the core of what family groups do, these activities can also be part of an advocacy strategy! By expanding these spaces from just places for connection and peer support into advocacy tools, family groups have an opportunity to consult other family members on key messages and advocacy actions, to collect information and experiences to help build an evidence base, to share knowledge about what is happening in the community and identify new opportunities, and to strategize together and set collective advocacy goals.

Your turn: Advocacy Strategies for Family Groups

What other strategies have helped your organisation be heard in your communities?

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Monitoring the Impact of Family Groups

Members of family groups often report that their participation in the family movement has led to their life changing for the better - whether that is making them feel less alone, providing peer support, allowing them to access referrals for services and supports, building them an inclusive vision, or helping them to build knowledge that led to their family member with an intellectual disability being more included in the community.

Family groups don't only make change for the family members who are part of their group, they have an impact in their community - from advocating for inclusive education and getting more children enrolled in schools to influencing community leaders and making policy change.

For family groups, this work to support transforming systems and improving the lives of people with intellectual disabilities and their families is at the core of what we do. Family groups are busy doing the work of building inclusion at the community level and are working towards a big goal, so often don't stop to

think about how to track the changes they are making and their impact on their community.

To capture the way that family groups have had a positive impact in their community, they can use simple monitoring and impact tools to understand their successes. The "Most Significant Change" strategy is one way to do that which family groups can use without having a background in monitoring or experience with data collections.

The Most Significant Change methodology designed by Rick Daves and Jess Dart was originally created to help identify the changes generated by the programs, projects and initiatives carried out by governments and civil organisations. For family groups, this strategy for collecting information about impact allows them to identify, through the voices of the people with intellectual disabilities and their families, what changes have occurred in their community and which changes are considered most significant, relevant, and important to family members.

Being able to track the impact and changes that are resulting from their actions can be a big asset to family groups - doing some monitoring of impact at the community level can help family groups to:

- ✓ **Build legitimacy with other stakeholders** - by monitoring how the group's actions have resulted in real change in people's lives, family groups can demonstrate their impact and experience and use that to take their place in advocacy spaces.
- ✓ **Access funding** - in places where family groups have access to funding to support their work, whether through grants from their local government or through their national federation, being able to demonstrate the impact the group has had helps build the case for funding community-level work.
- ✓ **Share knowledge with other family groups** - by showing how the group's actions have led to a positive change for people, this helps to build up the knowledge of what works to share with other local family groups trying to achieve the same successes.

Family groups can start using this exercise after three planning steps:

Choose what type of changes you want to learn more about

Family groups then need to define what kind of changes they want to identify. For example, the group might want to track personal changes, such as increased self-esteem, autonomy, ability to participate in family or community decisions, or attitude changes of either family members themselves or decision-makers. The group could also choose to track institutional changes, such as a change in quality of or access to public services for people with intellectual disabilities as a result of their advocacy.

Define the timeframe for the changes being tracked

Family groups must clearly state the period of time in which the changes they are identifying occurred, for example, limiting the discussion to changes that have occurred in the last year.

Choose participants

The Most Significant Change is identified through holding a workshop with a group of people who are directly involved in the program, project or initiative being monitored and asking them what changes have occurred in their lives as a result of the work. For family groups, this likely means inviting a small group of family members to come together and talk about how the work of the group has impacted their lives - this could be an existing peer support group, or a variety of family members involved in different areas of the family group's work. It could also mean bringing together other stakeholders like teachers or government officials who the family group's work has been trying to influence.

To apply the Most Significant Change methodology, family groups can:

- 1** Gather a group of up to 15 people who have participated in or benefited from a program, project, or initiative that the family group has led.
- 2** Frame the conversation - facilitators should create a safe space based on mutual respect where family members feel comfortable sharing their thoughts. Remind participants that there are no wrong answers, and everyone's opinion is valued.
- 3** Invite each participant to write on an index card what the most significant change in their life has been as a result of being involved in that work - it can be a change in attitude, vision, access, material circumstances, etc.
- 4** Encourage each participant to place their index card on a wall so that everyone can read the changes they have written.

5

Ask each participant to read their change out loud and explain it, while the others listen carefully.

6

Ask the participants to think about the changes they have identified together, and the group agrees to choose from among the index cards which change or result they consider to be the most significant or important. Together, the group will choose a change that everyone identifies with and feels reflected in.

The result is a clear consensus from the group about the most significant impact of the group's work, identified by the group themselves. The Most Significant Change method not only tells family groups what their biggest impacts are, but also helps to show the leaders of the family group and other stakeholders what the group values and sees as most important about their work.

Family groups can then share the stories of changes that the group shared and share what they learned about the group's values to help demonstrate not only how the family group has a positive impact, but also how its work is built on the values of family members themselves.

Your turn: Monitoring the Impact of Family Groups

What type of changes do you want to learn more about and track?

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What is the timeframe for changes to be tracked?

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Who will participate?

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Reflecting on outcomes

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Building a Multigenerational Family Movement

Why should family groups make an effort to better include siblings?

- ✓ Siblings have a unique perspective and relationship with their sibling with an intellectual disability that comes from being a peer, often having shared friendship groups, attending school together, and more.
- ✓ Siblings are the most consistent supporter for their family members with intellectual disabilities throughout their lives, and their relationship with their sibling evolves as they age.
- ✓ Siblings often become the primary supporters for their family members with an intellectual disability as parents age, and they are best prepared to do this when they have been engaged in the family movement, have a strong understanding of the rights of their family member, and are aware of the resources available to them.
- ✓ The family movement cannot be fully representative of the needs of families without understanding the role that siblings play!

For family movements to fully represent and advocate for the needs of family members and of people with intellectual disabilities, family organisations must engage siblings. Some examples of ways to engage siblings include:

Sibling peer support

Many family organisations have family support groups that exist at the local level - these are spaces where family members can come together, share experiences, give and receive advice and support, and provide psychosocial support to each other. Typically these groups are made up primarily of parents, but many Inclusion International members report a growing need for psychosocial support and mental health support among siblings as well.



Family groups can engage siblings better by:

- ✓ Proactively inviting siblings to participate in peer support spaces
- ✓ Creating dedicated sibling support groups
- ✓ Considering dedicated psychosocial support and mental health awareness for siblings

Developing sibling-inclusive resources

When family groups create resources for family members, these typically reflect the experiences of parents and are directed primarily towards parents.



To make the tools being created for families more useful for the whole movement, family groups should reflect the sibling lens on resources they are developing by:

- ✓ Creating a system to review new family resources being produced to ensure they do not only reflect the parent perspective - family groups can create a list of questions to reflect on to think about who the resource speaks to and if siblings will see themselves in the content.
- ✓ Create content and resources specifically for siblings, including on how to engage in advocacy

Co-facilitation in trainings and advocacy

The family movement needs to reflect on whose voices are being presented to new families joining the movement - parents are typically in the lead for support and referral with new families, but co-leadership of parents and siblings makes the movement more welcoming to siblings and invites more siblings into the space.



Family groups can:

- ✓ Use a joint facilitation model for trainings and awareness raising, where trainings are delivered together by one parent facilitator and one sibling facilitator
- ✓ Elevate the voices of siblings in advocacy alongside parents and ensure the advocacy reflects both perspectives

Encouraging sibling leadership in decision-making

A more representative family movement means leadership roles are held by a diverse group of families, including siblings.



Strategies for doing this vary based on the type of organisation, but some strategies for doing this include:

- ✓ Creating leadership training opportunities for siblings
- ✓ Actively consulting siblings on high-level decisions
- ✓ Reserving seats on Boards or other leadership groups for siblings

Engaging siblings in support and awareness trainings

Training delivered by family groups for families is common - they often cover topics such as the human rights of persons with intellectual disabilities, how to give good support, and the community support and services that are available for people with intellectual disabilities to access. These trainings are often targeted at parents, with siblings rarely getting access to the same training opportunities or information, which leaves them unprepared for delivering support at different stages of their life.



Family groups can:

- ✓ Reserve spaces in awareness and capacity building trainings for siblings
- ✓ Create sibling-specific trainings that equip siblings with the knowledge they need to give good support at different times in their lives, from youth through to taking on a permanent primary supporter role
- ✓ Create resources for siblings and parents to prepare for a transition in support and manage the change together

Through engaging siblings, family groups will find themselves with a stronger and more sustainable multi-generational movement, with access to new spaces and ideas that come from sibling involvement, and with a more representative voice for families.

Your turn: Building a Multigenerational Family Movement

How else can family groups better include siblings?

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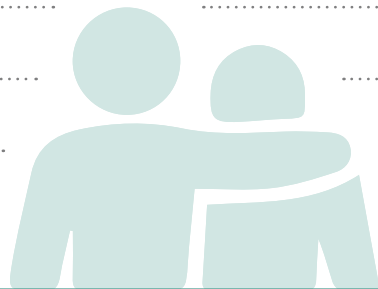
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Frequently Asked Questions about Family Networks

What is a family group?

A family group is a voluntary group made up of mothers, fathers, siblings, and other relatives of people with intellectual disabilities. The family members who are part of the network come together because they share the same goals, objectives or plans for the future. For example, most family networks come together because they believe in a society where people with intellectual disabilities are fully included in all areas of life, and they want to work together to achieve it. Family networks exist at different levels - there will be local family networks active in a community, regional and national family networks in a country, and international networks of families, all of whom maintain a dialogue and aim to work together to make change and build a more inclusive world.

Who can be part of a family network?

Family networks are typically limited to parents, siblings, grandparents, parents who themselves have an intellectual disability, and other extended family members. While blood relatives are always

going to be at the core of the family movement, many family groups recognize that other people who are important to people with intellectual disabilities, such as friends or neighbours also want to come together to learn about how to give good support and advocate for inclusion in their communities. Some groups define “family” as whoever a person with an intellectual disability identifies as their family, opening up these spaces to other community connections.

The most important requirement for being part of a family network is believing in the full inclusion of people with intellectual disabilities and their families in their communities.

Why do families choose to be part of a family network?

In many communities and countries, people with intellectual disabilities are excluded from their communities - they might be excluded from education, from access to employment, or from equal access to a life in their community. In many places, access to information about intellectual disabilities and human rights might also be limited,



and the lack of awareness in societies means that families have to face barriers to defend the rights of their family members with an intellectual disability. Being part of a network of families benefits families by:

- Creating a sense of solidarity - being part of a network of families allows families to belong to a group that shares common ideals and goals and develop a shared vision for the benefit of people with intellectual disabilities, their families, and society as a whole.
- Providing an opportunity to exchange experiences, learn new information, access tools and resources, receive guidance, and access peer support.
- Connecting new families to the families who have come before them - families of younger children with intellectual disabilities can benefit from the lessons learned and strategies tested by families of older people with intellectual disabilities who have experience navigating systems.
- Giving families a safe space for interaction, reflection, and non-judgemental support from others who have shared hopes, fears, and experiences.

How does it benefit family members to belong to a network of families?

Family networks fulfil three essential functions: to provide support and solidarity, to provide access to learning and sharing, and to create platforms for shared advocacy.

Many family members want to access a safe space in which they can feel heard and receive support from their peers when navigating challenging situations. For example, in a situation where a person's family member with an intellectual disability is experiencing a violation of their rights, belonging to a network of families provides the family with the support of other families who may have gone through something similar. For many families, the emotional support is also a clear benefit to being part of family networks at the local level.

In the same way, forming groups of family members allows for the creation of a space in which information can be shared based on the experience of each individual, it also helps build shared knowledge through the exchange of information and experiences. Family networks create spaces where family members can be heard, share, and learn, and through these exchanges families can come together with a shared agenda to push for their communities to be more inclusive of people with intellectual disabilities.

What are some of the ways that family members connect and build solidarity?

Families who decide to form or join networks and belong to family organisations do so to fight for better opportunities for their family members with intellectual disabilities. The shared spaces, shared learning, and peer support help to build trust and a sense of friendship within families, creating welcoming spaces with strong bonds between members of the family network.

Inclusion International members use a variety of strategies to build these connections among members of family groups. One of the most common strategies for building solidarity among families is creating platforms for families to connect from home - for example, many family groups use a WhatsApp or Facebook group where they can exchange anecdotes, experiences, photos, and more in conversation about their family member with an intellectual disability. These spaces can be moderated by the families themselves, and in other cases the organisation might generate specific discussions from time to time by asking a question for everyone to share and respond to.

In addition to their peer support and advocacy work, some family groups engage members in recreational activities that give families a space for rest and recreation. For example, this could include classes, crafts, picnics, or other activities that families can come together to enjoy.

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