

Self-Advocacy for Inclusion: A Global Report



OCTOBER, 2016

Self-advocate Council Members

We have been working for the last two years to build a picture of what self-advocacy is like around the world. Self-Advocate Council Members represent five regions across the globe: Europe, Africa, the Americas, Middle East & North Africa and Asia Pacific.



Each of us has had the chance to meet with self-advocates and groups in different countries and regions and we have learned that there are a lot of different ways to think about self-advocacy – a lot of people still don't really know what real self-advocacy is. Everyone has a different experience about self-advocacy in their own communities. Some communities do it really well, in others, the lack of awareness and understanding of intellectual disability

remains a barrier that stops people from speaking up.

There are still some obstacles to true self-advocacy. Sometimes people are afraid to speak up. We need skills and self-confidence but we also need good support and encouragement to enable self-advocates – from our families, friends, volunteers and sometimes from paid support people.

For those of us who have had the opportunity and support to become strong self-advocates in our own lives and in our communities we want to share and support people who haven't had that opportunity. Together we can learn and empower each other. We hope that this report helps build an understanding of how we can all support self-advocacy.

We are people. We have rights. We want the same opportunities as everyone. We want to have the opportunity to share what we think. We want to live in a world where we are accepted for who we are and what we can do. We want to help others get the support they need to become strong self-advocates.

INCLUSION INTERNATIONAL COUNCIL SELF-ADVOCATE MEMBERS

David Corner, Asia-Pacific

Sara Pickard, Europe

Quincy Mwiya, Africa

Luis Gabriel Villarreal, Americas

Mia Farah, Middle East & North Africa

Mark Mapemba, Africa (incoming Council member)

Inclusion International

University of East London

Docklands Campus

KD.2.03

4-6 University Way

London E16 2RD

Tel: 44 208 223 7709

Fax: 44 208 223 6081

info@inclusion-international.org

www.inclusion-international.org

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In March of 2015 the self-advocate Council members of Inclusion International where asked by the Council to:

- conduct a scan of what our members and others are doing in “self-advocacy” in each region of the world ;
- represent Inclusion International at events and meetings to “inspire, support and learn”;
- develop principles and standards for self-advocacy leadership and support.

This mandate came out of a discussion which had started at the General Assembly in 2012 when member organizations asked Inclusion International to support and strengthen self-advocacy around the world.

As self-advocate Council members began talking to individuals and groups around the world it became clear that their task was more complicated than expected.

While there is increased talk about “self-advocacy” in many parts of the world, people mean quite different things by this.

Many organizations and groups claim to be training and supporting self-advocates, others tell us that self-advocates are leaders in their organizations. In many cases, self-advocacy groups were social groups that meet to go to the movies or to hold a dance once a month, in others the “self-advocacy” group was organized in an institution by the staff. Yet there were also very impressive stories about self-advocacy groups that worked together to make changes in their communities, raise issues with governments and provide support and advocacy for each other.

We also asked who is supporting self-advocates and what does that support look like? We heard about the support that individuals get from their families, paid supporters,

work colleagues and friends but we also heard about the support that organizations give to self-advocacy groups. Sometimes what was called “support” looked more like control or protection. In many parts of the world there is little understanding, experience or training in “good support” for self-advocacy.

Finally, we wanted to explore how organizations (our members and others) were involving self-advocates in their work and leadership. We heard about different ways that self-advocates were involved in organizations as members of a board; committee or working group and sometimes as staff members. While we heard about some good examples of organizations that support meaningful participation and leadership by self-advocates (including organization led and managed by self-advocates), there were far too many examples of “tokenism”.

This report will describe what we heard; provide some guidance from self-advocates on “good practice” and set out some recommendations for a global initiative to support self-advocacy.

About the Global Study

Over the course of the past two years we have consulted with Inclusion International member organizations; new self-advocacy organizations, groups, clubs and committees that are forming either formally or informally in over 70 countries around the world. These consultations included visits by self-advocate Council members; conferences; surveys and Skype interviews.

As a first step, the Inclusion International self-advocate Council members met to discuss and develop questions to guide a global discussion about what self-advocacy is, what good support is and how families and organizations can and should support self-advocacy. They discussed the difference between being called a self-advocate and the idea of self-advocacy as an action and the difference between personal support and support for self-advocacy. These reflections guided the development of surveys and interviews which were used to collect stories and information about self-advocacy.

Regional Consultations

Regional consultations took place at several conferences and meetings where self-advocate Council members conducted interviews and participated in discussions and workshops with self-advocates in those regions.

Africa



A number of workshops and conferences in Africa helped us to hear about the perspectives of self-advocates in the region. Inclusion Africa facilitated a full-day self-advocacy forum in Nairobi, Kenya (April, 2015). The purpose of the forum was to engage with self-advocates, their support persons, and representative organizations on the development of

About the Global Study

a strong and vibrant self-advocacy voice in Africa. The forum brought together more than 20 self-advocates from more than 12 African countries. The forum also had self-advocates from: Cambodia, Lebanon, the Netherlands, and Peru. Including support people and organizational representatives, more than 50 people from 20 countries participated in the forum. As follow-up to the forum in December 2015, over 70 people, including African self-advocate leaders came together in Kenya for a sub-regional event on self-advocacy. It brought together self-advocates from more than 10 countries and focused on sharing learnings from national level self-advocacy development efforts.

Americas



At various conferences and pre-conference events, we engaged with self-advocates to find out about what self-advocacy means to their group and what self-advocacy efforts they are involved in. We heard about what worked for their groups and what sort of supports they need to be successful.

In October 2015, in Sao Paulo, Brazil, we hosted the *Reunión Estratégica de Autogestores en la Región de las Américas* to connect with our members in the Americas about their successes and challenges in building self-advocacy. Self-advocates from Mexico, Colombia, Ecuador, Chile, Argentina, Uruguay, Paraguay and Brazil attending, representing ten organizations in the region.

Other events/consultations included:

- *Participate with No Barriers: Changing myths and prejudice around people with Down Syndrome* in Tigre, Argentina
- *Claiming Full Citizenship in Vancouver*, British Columbia, Canada
- *SOY MI VOZ*, Encuentro Internacional de buenas experiencias de personas con discapacidad intelectual, in Quito, Ecuador.
- *Sociedad Peruana de Síndrome de Down VI Taller Internacional de Formación para Docentes*, and *Encuentro Nacional de Familias 2016 Construyendo Ciudadanía* in Lima Peru

About the Global Study

Asia Pacific



Over 75 people with intellectual disabilities participated in a self-advocacy workshop hosted by Inclusion International in Cambodia. The workshop was an opportunity to hear about the self-advocacy efforts in Cambodia and the efforts of their regional network, Mekong Regional Network for Self-Advocacy.



From India, we received input from the Self-Advocates Forum of India organized by Parivaar.

Four self-advocates supported by Inclusion International participated in a human rights training event hosted by the International Disability Alliance and the International Disability the Development Consortium in Bangkok, Thailand. From this experience (and other similar training events in different regions) we learned about and developed strategies for including people with intellectual disabilities in complex discussions.

Europe



Inclusion Europe's, *Europe in Action (Rome, 2015 & Lisbon 2016)*, and the European Platform of Self-Advocates' (EPSA) *Hear Our Voices (Madrid 2015)*, were unique opportunities to hear from self-advocates about what self-advocacy means; what supports exist and how organizations can support and sustain self-advocacy. In Rome a session on self-advocacy and sustainability explored the ways that organizations can enable and strengthen self-advocacy.

At the *Hear Our Voices* Conference in Madrid Inclusion International self-advocate Council members conducted interviews and discussion groups with self-advocates from Europe to explore both the individual experiences of self-advocates and the ways in which EPSA has organized its work in the region. A video link connected Inclusion International self-advocate Council members, meeting in Madrid, with the Arc of the United States *Self-Advocacy Symposium* in Indianapolis, Indiana, USA.



MENA



Several workshops and conferences organized by regional and national members with Inclusion International

provided an opportunity to hear about self-advocacy.

A meeting of Inclusion MENA was held in Tunisia hosted by the Tunisian member organization of Inclusion International, UTAIM at the national conference, Together for a Better World. Self-advocates and families came together to begin to explore what self-advocacy means.

In Lebanon, two workshops on political participation organized by Inclusion International, explored the barriers and limitations to civic engagement people with intellectual disabilities face.

The Lebanese Association for Self-Advocacy-LASA delivered a programme of training in MENA (Middle East and North Africa) for self-advocates, families and support persons. Sessions in Egypt and Tunisia have contributed to our learning and consultations globally.



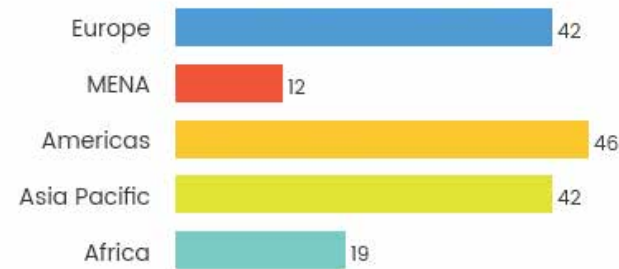
Self-advocacy means I am teaching you and you are teaching me.

Usually we don't see persons with intellectual disability, why?

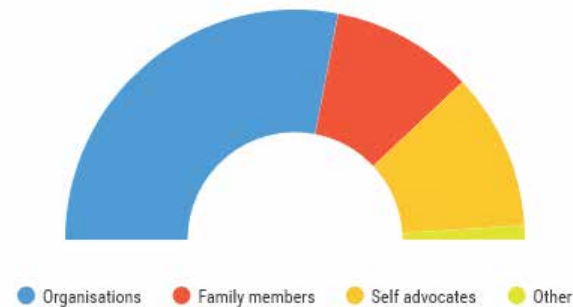
I am ready to help at home but I like to choose with whom I want to spend my time.

Survey

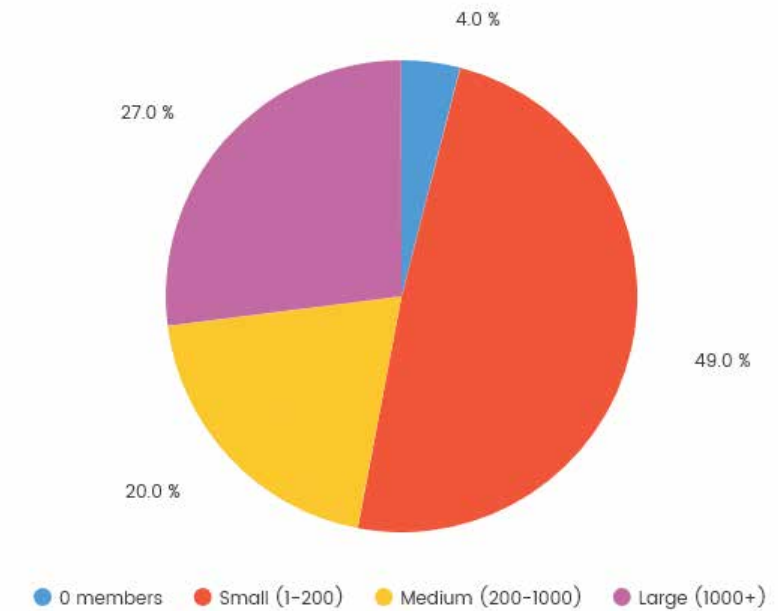
A *survey* was distributed across our network to explore in some detail the ways in which self-advocacy is being supported. We received 173 responses from 87 organizations representing 54 countries.



The survey respondents included individual self-advocates, family members and organizations of families, self-advocates and support providers.



49% of the organisations who took part in our survey, classed themselves as small organisations. 20% and 27% considered themselves to be medium and large respectively. Small organizations would include groups of self-advocates and families that come together informally. Larger organizations include community, state and national organizations.



This mix of responses across 5 regions provided a crosscutting view of the way that small self-advocacy groups have emerged and are growing as well as how larger organizations working for inclusion have considered both their role in supporting self-advocacy and how self-advocates are involved in the leadership and governance of their organizations.

Survey findings which are included throughout this report help us to illustrate and understand the ways in which self-advocacy is growing and changing.



Organizational Interviews

Building on the responses from survey participants, we wanted to explore in more detail what activities, resources and materials organizations and groups were using to develop and support self-advocacy. Interviews with organizations helped to identify both the challenges of real participation and support as well as some good examples and materials that can be useful to share.

Inclusion International approached organizations from all the regions of the world. We talked to organizations willing to share their experiences, including service providers, self-advocacy and family organizations and groups. Furthermore we wanted to have a balanced representation from all the regions.

We interviewed 29 people from 10 different organizations. We asked about how they are supporting self-advocacy and what strategies and activities they use to do it. We heard about their challenges (supporting people, funding; social attitudes; balancing the needs of families) and we learned about the tools they have developed. All of the organizations asked for the opportunities to exchange information and ideas with others to be able to strengthen self-advocacy.

“Inclusion International could organise self-advocacy experience share program for exchanges of self-advocates and experience. That is really useful to see self-advocate movements in another way” ETHIOPIA

“Strengthen international networking, offering exchange programs for self-advocates.” AUSTRIA

What is Self-Advocacy?

“Someone standing for himself, who has wishes, who speaks up, who makes a positive change also for the other citizens and the whole community” MAURITIUS

As we went out to talk to people and groups in different parts of the world we knew that in some countries and regions self-advocacy is well established and in others there has been little or no tradition of self-advocacy neither in the sense of support for a person to speak for themselves nor in supporting self-advocacy groups. Yet there is a strong and growing voice of people with intellectual disabilities who are finding ways to be heard and respected.

What is clear from consultations around the world is that self-advocacy is about actions. It is about learning and growing.

Self-advocacy is about having a voice (even when we cannot speak); being listened to and taking control of our own lives. Self-advocacy is about growing our confidence and belief in our abilities. Self-advocacy is about knowing our rights and that we must be included in all parts of community, just like people without disabilities. Self-advocacy is about working together to make change in our communities.

What is Self-Advocacy?

Personal Empowerment & Building Confidence

For people with intellectual disabilities, self-advocacy begins with building confidence and control in decisions about our lives. Learning about the right to decide is an important step in the lives of individuals. Article 12 of the Convention on the Rights of Persons with Disabilities says that all people have the right to make decisions about their own lives and they have the right to support in making and acting on those decisions. Many of the initiatives to support self-advocacy that we heard about in our global consultations were focused on individuals becoming empowered and building their confidence and control in their lives.

Peer Support and Self-Help

We heard about many examples of people with intellectual disabilities joining a group to listen to and support each other in day to day challenges. Sometimes these groups start as social groups that organize outings to the movies; the local shopping centre or hold a dance. In some cases the group provides a chance for people to explore issues and challenges in their lives (relationships, employment, housing etc.) As people get to know each other and learn from each other they help each other to build the skills to speak up. These groups can provide people with support to meet challenges in their own lives.

“Self Advocate meets with service users (at each facility every three months) where service users discuss issues and things that are going well and self advocates feed this information back to their service manager, who then completes action plans and effects change where possible.”

NEW ZEALAND

Advocacy for Action

When people come together and share their experiences and challenges they begin to identify common injustices and issues that are important priorities for the group. We heard many examples of self-advocacy efforts which were focused on key shared issues and strategies for action to make change. In these examples groups had developed ideas about specific issues and rights and they had organized actions to be heard and contribute to change. We heard about many different kinds of advocacy including: writing a letter to or having a meeting with politicians; campaigning using media; presentations to governments, conferences and the United Nations; running for elected leadership roles in organizations or governments.

From all of these different kinds of experiences we also learned about different ways in which self-advocates come together. In most cases self-advocacy groups have developed and emerged with support from family based organizations either to become independent organizations (as in the case of some People First organizations) or as a group that advises and contributes to the leadership of the organization (more on this in our section about how organizations can support self-advocacy).

“We are fighting the negative stereotype about capabilities of people with intellectual disabilities as well as legislation to support their rights” JORDAN

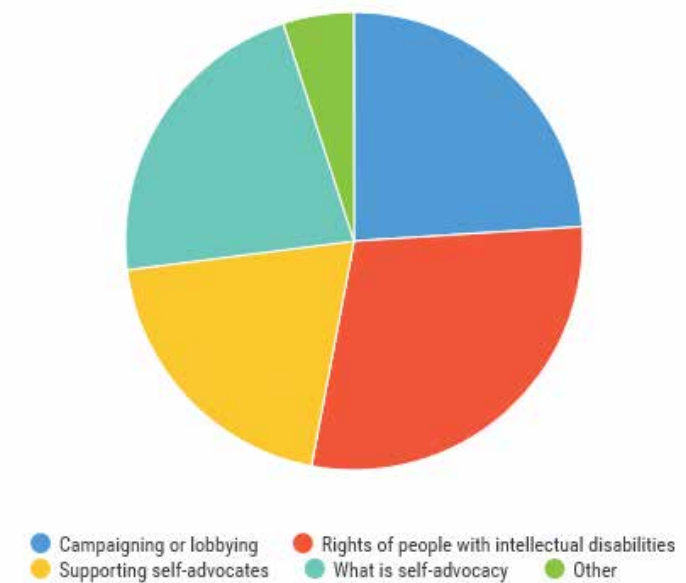
Increasingly we have seen a new kind of advocacy group which is made up of Youth with and without disabilities. As people with intellectual disabilities go to regular inclusive schools they have become part of groups that work together on social issues.

Some new approaches to self-advocacy...

Movimiento Estamos Tod@s en Acción (META), is a network created in 2012 by young activists with and without disabilities from Uruguay, Costa Rica; Peru; Colombia; Brazil; Argentina; Honduras; Dominican Republic; Mexico and Chile to work on the rights of people with disability as contributors to inclusive development in Latin-American from an equality and opportunities for all.

Re:Action4Inclusion, based in Ontario, Canada have created a space to support young people to deepen their understanding of what inclusion requires from all of us and what young people who have a disability are experiencing. Young people are working with their fellow students and alongside their education and community allies to create a cultural shift. They are committed to ensuring students who have an intellectual disability experience a sense of belonging. They believe everyone is and should be seen as a valued and contributing member in their schools and communities.

From our survey we heard about the different ways that self-advocacy groups are organized and what the focus of support to self-advocacy groups is. We learned that there are many groups working on human rights and campaigning actions but there is also still a need for people to build confidence and skills to become self-advocates.



What is Self-Advocacy?

Self-advocacy groups are working to identify and address a range of important issues:



While there appears to be a rapid growth in the number and types of self-advocacy initiatives globally, it is clear that not all initiatives are true efforts to enable and strengthen the voices of people with intellectual disabilities.

We heard many stories about large residential institutions that organize so called self-advocacy groups within the institution with the clear intention of manipulating and using the group to advance the interests of the institution.

“There is only one independent group of self-advocates In Romania. It is called Ceva de Spus. Ceva de Spus is trying to start a national movement. There are other self-advocacy groups in Romania set by service providers but the link between the groups is not very strong.” ROMANIA

What is Self-Advocacy?

What self-advocates say about self-advocacy...

- Self-advocacy is when people with an intellectual disability express for themselves about things that are important to us or for people like us.
 - Self-Advocates help to make changes happen. We speak to people who make decisions, and we help them to understand what life is like for people with intellectual disabilities.
 - We may be active members of our communities and it's important to make sure we are involved with the big decisions that happen.
 - Self-advocacy is all about what WE think and how we feel. It is not being told what to say and think by other people.
- But,
- Self-advocates must be willing to listen, learn, and share different ideas.
 - It is important for self-advocates to understand about rights and responsibilities and what laws say about our lives. These may be laws in our local areas, our countries or globally.
 - Self-advocates often need support from people who are not self-advocates. A good supporter will listen, help us to understand and support us to say what we think. They will not speak on our behalf.



People can “speak up” in many ways; not just by talking. It's about making yourself heard.



Self-advocacy encourages and supports people who may feel otherwise isolated to be connected to a movement.

Self-advocacy is about people with intellectual disabilities exchanging the power from people who have always made the big decisions for us. People like doctors, care providers, politicians and even family members.

Self-advocates should understand about Rights and Responsibilities. We want to make our areas, our countries and the world a fair and inclusive

place for ourselves and for all people with an intellectual disability.

Self-advocacy is about working with decision makers to make sure that self-advocates are totally involved and included in decisions that affect us. This could be small local things like bus timetables being accessible, national things like your Government consulting you on the laws that affect you, or big global things like campaigning on the Convention for the Rights of Persons with Disabilities (CRPD).

Self-advocacy is about raising awareness of disability in communities. Through our work self-advocates show communities that people with intellectual disabilities should be valued as equal and contributing members of society. This helps to change attitudes, stop discrimination and builds a more inclusive society.

Self-advocacy isn't

Self-advocacy isn't just about being in the room when decisions are made, it is important to be involved. Self-advocacy isn't being told what to think or what to say by someone else.

Self-advocacy isn't about treating people unfairly.

It is important for us to have the right support so we are involved in things.

Self-advocacy isn't just about making decisions



or saying what we want. This is a part of it. Self-advocates should be able to make decisions and say what we want, we all have the right to decide, but self-advocacy is more than this. It is about speaking up and making decisions about the things that matter or are important in our lives or to other people like us. It is about living and working together to make changes happen.

Self-advocacy isn't sitting around complaining. Self-advocacy is active and works to make change happen.

Self-advocacy is working with other people. Supporters and other people for instance, politicians, have to be a part of the work in order to make change happen. Working with people is a good way of influencing people!

Self-advocates want everyone to be included and involved in society. Self-advocates know we have to be role models to achieve this.

Self-advocacy is not a project that can stop and start. It is ongoing. The world can always be more inclusive!

What are self-advocacy groups?

For lots of people being involved in a group is the best way of being a part of self-advocacy.

People's voices are louder together! The more people that are saying the same thing, the easier it is to get other people to listen.

Self-advocacy groups are not a social group where you might go bowling or have a disco. Self-advocate groups may grow out of social groups or self-advocate groups may also do social things, but working together to change things and make people's lives better is what self-advocacy groups work on.

In a group there will be lots of different skills, experiences and knowledge that can be shared. We can help each other to develop the leadership skills and knowledge that we need to speak up. In a group people can ask questions and share experiences in an inclusive and friendly environment.

What does a person need to be a self-advocate?

Anyone with an intellectual disability can be a self-advocate! Here are some qualities that might help you become good at speaking up.

A self-advocate -

- Has good ideas
- Is a positive thinker
- Is persistent
- Is self-aware
- Is assertive
- Is informed



These are skills that you can learn if you don't think you have these qualities now. If you are a part of a group you can talk to people who you think have these qualities and share ideas about how to develop.

Being a self-advocate is an active job. You cannot just call yourself a self-advocate and not act like one! Here are things that self-advocates do.

A self-advocate:

A man with a beard and short hair, wearing a green and white striped polo shirt, is shown from the waist up. He is looking directly at the camera. Surrounding him are several light green speech bubbles containing text. The bubbles are arranged around him, with some pointing towards him and others pointing away. The background is plain white.

- Gets to know about other people
- Contributes at meetings
- Works with others
- Is organised and reliable
- Takes an active role
- Listens
- Wants to always find out more
- Wants to see change
- Uses the skills they have to do the best work they can do
- Interested in self-advocacy all around the world
- Speaks up
- Ask questions
- Challenges
- Make oneself heard
- Makes decisions
- Talks about who they are and what their group does

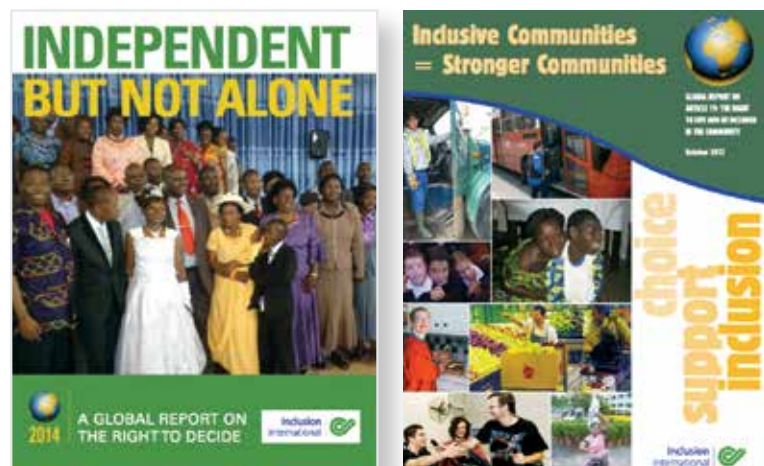
It is important as a self-advocate to feel comfortable speaking about your disability and how it feels to not be included.

Self-advocates must be open to meet and listen to other self-advocates who may have more experience or different skills than you do so. Learning from others is a good way to grow as a self-advocate.

What is Good Support?

We all make decisions and choices in our lives with advice, information and support from our friends, family, work colleagues, teachers, doctors, role models etc. People with intellectual disabilities are often denied the opportunity to make decisions and choices in this way because of preconceived ideas about their “capacity” and because the network of people in their lives has been limited to immediate family and service providers.

Inclusion International’s global campaigns on the right to live and be included in the community and the right to decide, clearly showed that the vast majority of people with intellectual disabilities live at home with their families.



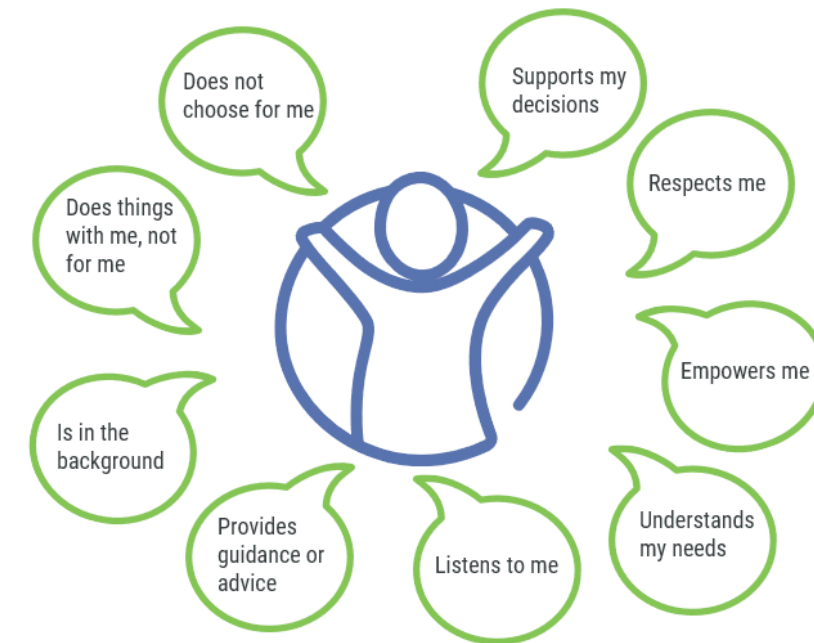
This means that families play multiple roles. They are often caregivers, advocates and supporters. We also know that families receive little or no support in these roles.

The second major source of support in some regions of the world is by paid staff. These people come from different professional backgrounds including teachers, medical practitioners, social workers and advocates. Whether the support people receive is informal, formal, paid or unpaid self-advocates have told about us they want and need in the different parts of their lives.

What is Good Support?

What we heard from consultations with self-advocates about the support they receive is the challenge of how those different sources of support enable or limit people to express themselves and have their views, opinions and decisions heard and understood.

From our survey self-advocates describe good support as:



Far too often in our consultations and visits in different parts of the world we witnessed many examples of people who claimed to be acting as supports who in reality saw their roles as controlling, protecting and in the worst cases manipulating people with intellectual disabilities. Anecdotally we have heard from “supporters” of people saying that the people they were supporting are not capable, or unable to understand, or that they cannot take part.

“Support person can be trusted and reliable. No attitude of pity but empower self-advocates. Understanding of needs and desires” SOUTH AFRICA

What is Good Support?

Beyond the support that individuals receive or need (*Personal Empowerment & Building Confidence*) the process of developing self-advocacy (*Peer Support and Advocacy for Action*) also require supports of a different kind. Enabling and supporting peer support groups to organize, meet and build relationships and facilitating and providing information for advocacy require different skills and resources than individual supports.



What self-advocates say about support...

Supporters include family members, paid support workers, teachers, co-workers and friends.

Good supporters give support that is empowering.

Good supporters understand that self-advocacy is not about them and what they think.

Good support is based on the understanding that society creates barriers for self-advocates. A self-advocate supporter understands that the support they give is a part of removing the barriers that exist for that person.

Self-advocate supporters must allow the people they support to make mistakes or take risks. They understand self-advocates are the ones that choose.

Self-advocate supporters recognise the influence they may have over people. They support people to understand ideas not tell people how or what to think.



What is Good Support?

“Anyone with enough patience and stubborn belief that persons with intellectual disabilities can do more than they had been told to”
CROATIA

What does a self-advocate supporter do?

Personal supports

A self-advocate supporter is there to give any support a person with an intellectual disability may need to help us speak up, make decisions and choices to the best of our ability.

Supports can help us understand complicated information.

Help us to make our own decisions about money, jobs, health, relationships and other things in our day to day lives.

Self-advocate supporters help people to develop and build skills to become confident and effective at speaking up. They help us recognise or seek out opportunities.

A self-advocate supporter is not a care giver.

A self-advocate supporter is not someone who the person does not want to support them.

A supporter is not just there to explain difficult words in a meeting, a supporter is there to ensure a self-advocate feels confident and is able to do their job of speaking up.



What is Good Support?

Supporting someone is not a long term fixed arrangement. It should be flexible and responsive to a person's needs. However it is important that a self-advocate knows that their support network is reliable and dependable.

Support for Advocacy and Action

Support for advocacy and action helps individuals and groups to understand their rights and responsibilities. They support self –advocates to understand the laws that influence their lives.

Self-advocate supporters help self-advocates with practical arrangements and organisation. This may be small things like planning a journey or bigger things like organising a group or finding funding.

Self-advocates may work in different important areas, locally, nationally or globally. This means self-advocacy support is varied. The right support may be needed to:

- Support a person to speak up and challenge a rule or laws.
- Help plan and coordinate a local group to campaign about an important issue.
- Help a group travel and speak at conferences.



What is Good Support?

Good support is

- ✓ Good communication
- ✓ Trust
- ✓ Developing my skills
- ✓ Being aware of my needs
- ✓ Have lots of fun but a professional relationship
- ✓ Respectful of individuals on both sides
- ✓ Being open, trustworthy, patient
- ✓ Translating ideas
- ✓ Having the choice to have support when we need it – not all the time; let me do things by myself

Bad support is

- ✗ Being overprotective
- ✗ Not having the money = no support
- ✗ Discouraging or insulting
- ✗ Saying things that make us not believe in ourselves
- ✗ Taking advantage of us
- ✗ Just giving the support THEY want – not what I want
- ✗ Influencing us
- ✗ Not explaining why we should do something or not.

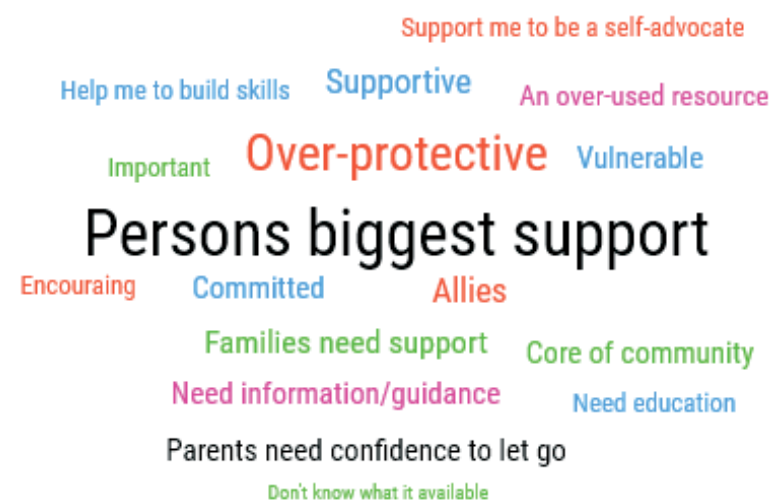


Families & Self-advocacy

Families play many different roles in the lives of people with intellectual disabilities. In addition to the care and love they provide, they are also advocates, supporters and community organizers. We know from our global studies and consultations with families all over the world they play these roles with little or no support. For most families they have to learn and manage these roles by themselves.

As we explored examples of self-advocacy in different cultures and communities a common thread through all of the experiences was the important role that families play. This role was especially critical for people who cannot speak or communicate in ways that are understood by others.

From self-advocates perspective families are both their biggest support and one of the challenges to their independence. Without strong support and encouragement from families, people with intellectual disabilities remain isolated and excluded from their communities and yet when communities have negative attitudes about people with intellectual disabilities, families act protectively.



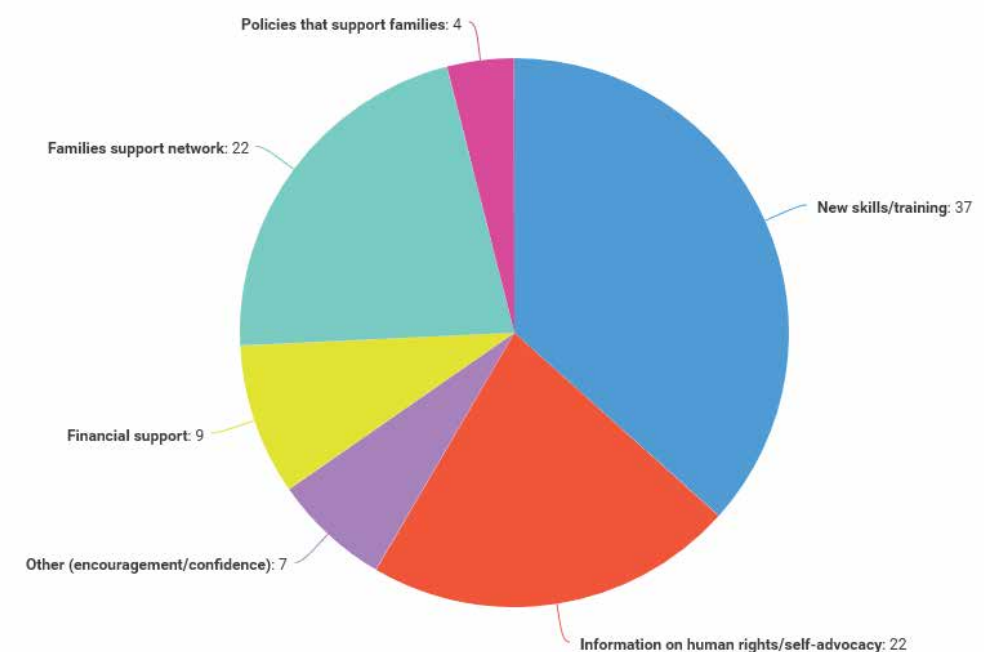
Families & Self-advocacy

Understanding the multiple roles and experiences of families who are fighting for the inclusion of their family member (in school, community, employment etc.) is important for how we think about self-advocacy both for the individual in their own life and for self-advocacy groups working for change in their communities.

Families who have been successful in supporting their family member to be included the community and in becoming strong self-advocates have usually done so by creating opportunities to build relationships and networks. Having a network of support and people is the foundation for inclusion and self-determination.

We heard often from families that their goals and dreams for their family member are inclusion, respect and acceptance by the community yet their strategies often remain focused on therapies and disability related services instead of building supports and networks.

For people to become self-advocates in their own lives and to further develop self-advocacy for social change, a significant focus and investment must be made in supporting families. We heard about some of the things that families need to play these roles effectively:



From our consultations with groups around the world, we see that self-advocacy groups are most often started by family based organizations. It is families that have recognized the need to support and strengthen the voices of people with intellectual disabilities. It is families and their organizations who have throughout the history of our movement lead the charge for self-advocacy.

As human rights organizations and other disabled persons organizations begin to join in these efforts, there has been some criticism and rejection of the role of families. While there may need to be a shift in the role that families play (from protection to empowerment), that shift depends on building up the roles of others in our community to be inclusive; supports to families and their organizations; and the continued inclusion of families as a part of the support network.

What self-advocates say about families...

- Self-advocacy starts at home.
- Families can support us to feel confident about speaking up.
- By helping us build relationships in the community, families can help to support us to become self-advocates.
- By promoting inclusion, choice and speaking up, families can support us to be a part of a self-advocacy group that is working for change.



What is happening for families and self-advocates?

Families and self-advocates around the world want the same things for people with an intellectual disability:

- Communities which are inclusive of people with disabilities.
- Communities where people are valued.
- A society where they and their families are given equal chances to live good lives.

In the past, family organisations have done a lot of campaigning work on this. Today, self-advocates are the people who are speaking up and making change happen. Families understand that this is fair and right. People with an intellectual disability should be the ones speaking up about their lives.

For most people with an intellectual disability their families are their first and most important carers, advocates and guardians.

Family involvement in supporting a person should always be valued. Self-advocates have said that how a person's family feel and act can be the make or break factor for self-advocates. How a young person is raised by their family will make a big difference to their confidence and the way they live as an adult.

But, things like poor attitudes, misunderstanding of disability, lack of support in their community and financial pressures can make raising a young person with an intellectual disability a difficult task for families all around the world. These things can make families feel over-protective and distrustful.

Self-advocates say the same thing; that families need to support and encourage us to be independent. Families that are overprotective or controlling of their family member



limit and isolate the person. This stops us from living a full and good life.

Families need to be supported to shift from being the protectors and carers of people to the enablers of people.

Families who encourage and support their family members with an intellectual disability to take risks and make choices help us to learn and develop. Experiencing failures and challenges in life, just like everyone else, is a big part of being independent.

What can a family do to help a person become a self-advocate?

There are many small and big ways a family can work with us to gain the skills and abilities to become a self-advocate. Families are often busy and overworked, but supporting us to develop the skills we need will help us to live a full and included life.



- The family can make sure that we are always included in family and community life. This makes sure we feel valued, accepted and part of the world. It helps us to understand our rights and responsibilities as a member of society and helps others in the community to understand and accept disability.
- Often a family has been advocating for their family member since they were young. They have helped people like doctors, teachers or service providers know what kind of support the person needs. Always including us in conversations will make sure that we understand about the need to speak up for ourselves.
- A family can learn all they can about intellectual disability, and spend time speaking to their family member with an intellectual disability about it. This supports the person to understand about their disability and what it means for them.
- Families can listen to what having a disability makes us feel like. This will help us to understand about how to speak about our disability. Being able to speak about disability will help us feel comfortable with our identity and how other people may relate to us.

- Making time to speak and listen to a family member with an intellectual disability will also help us to develop our communication skills and learn how to understand and ask for support we may need.
- Listening to us also shows that the family value what we have to say which builds confidence – another important skill for self-advocates.
- Families may need training themselves in order to understand the principles of self-advocacy and to support us to learn about the skills we need to be a self-advocate.
- Families can find out about groups or organisations that provide support or services. Sharing information and experiences with other families can help the family and the person to be part of a larger community. It can help the family and person to know that they are not alone and that they have peers that can support them. Organisations may also be able to help a family get information and support.
- Families should allow us to receive independent self-advocacy support. In many cases this may not be possible but when there is an option of a self-advocate being able to choose a supporter will help the person with being independent.



How can a family encourage self-advocacy

These are some more of the many ways self-advocates and families have said families can support a person in order to become a self-advocate.

- Accept the person
- Be Patient
- Be positive
- Build skills in the person
- Create opportunities to do new things
- Encourage the person
- Promote independence
- Ask for help and support when you need it
- Have high expectations of the person
- Build self esteem
- Give choices and encourage decision making
- Share information
- Role model self advocacy
- Allow risk taking
- Encourage independence

Inclusive Organizations

Inclusion International has many different kinds of organizations in our global network. In some places these are large service providing agencies, in others they are small parent or self-advocacy groups. In different parts of the world these organizations campaign and advocate for human rights and inclusion; they provide support to people with intellectual disabilities to live in the community. They provide advocacy support: to families to get their children into school; to self-advocates to access health care, employment; access to community services.

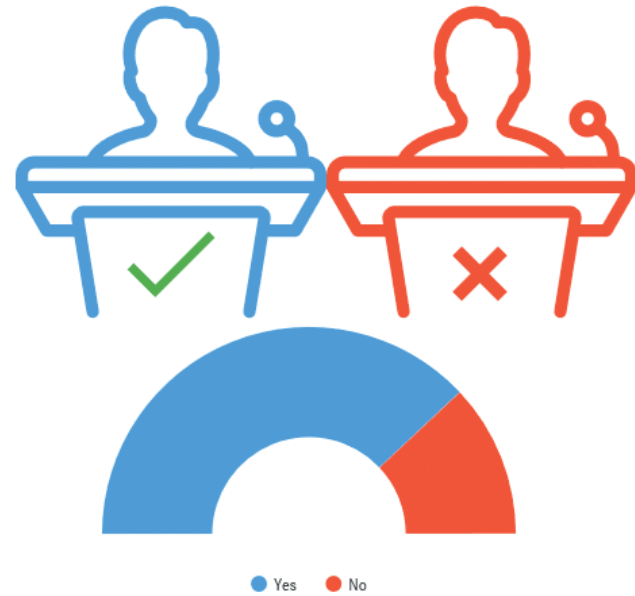
They also in some places provide direct support to people with intellectual disabilities for employment, personal assistance, housing support, etc. Many of these organizations are over 50 years old and have changed over time the way they work. Others are new organizations or groups that have been started by self-advocates and families to support people with intellectual disabilities to be heard.

All of these organizations have an important role to play in supporting self-advocacy. By taking an inclusive approach to these roles organizations help to change the way communities and society include people with intellectual disabilities. From our survey and interviews we learned about ways that organizations are involving self-advocates in:

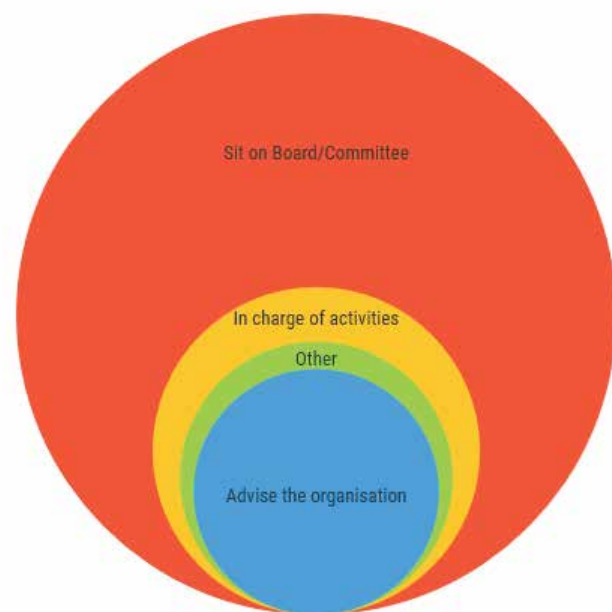
- leadership and running of organizations (participation on boards and as employees)
- campaigning
- building self-advocacy skills and supporting self-advocacy groups
- delivering services

Leadership and running of organizations:

Most of the survey respondents (76%) told us that self-advocates are involved in running their organizations.



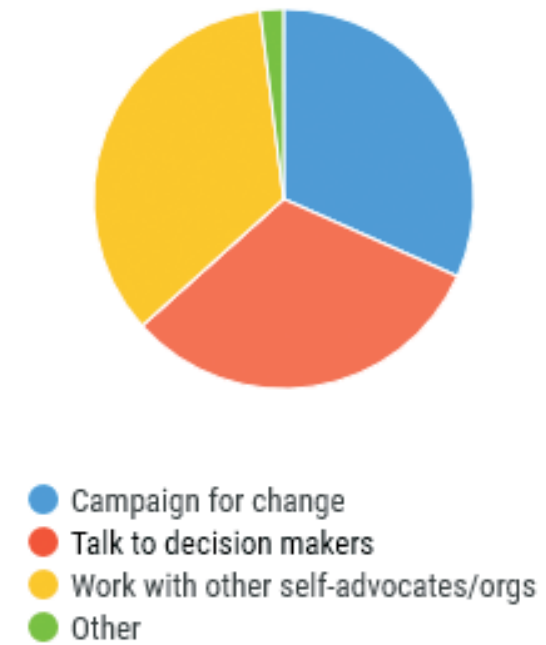
Many organizations include self-advocates on their boards, advisory groups and committees. They also involve self-advocates in activities of the organization (community events etc.).



Campaigning

As well as advising or leading organisations, self-advocates play an important role in helping organisations achieve their goals: by talking to leaders, empowering other self-advocates or campaigning for change.

“People with disabilities support and participate in opportunities provided by the Director and participate to national and international invitations, opportunities such as panels, and forums to represent the group” COLOMBIA

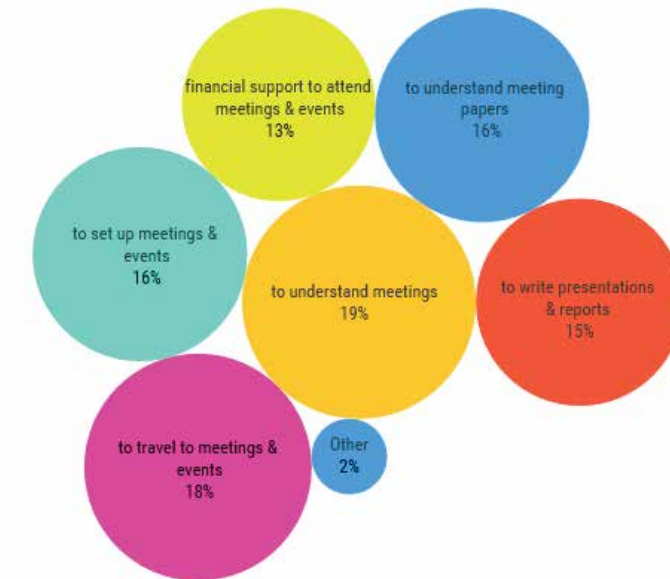




Making the involvement and leadership of self-advocates in these organizations meaningful and inclusive requires adaptations and changes to how the organization works and specific supports to self-advocates. We heard about different ways that organizations support people in their different roles:



Self-advocates say they get support to...



Building Skills and supporting self-advocacy groups

A growing number of organizations are developing strategies to support self-advocacy groups to organize and build their strengths to make change in the community.

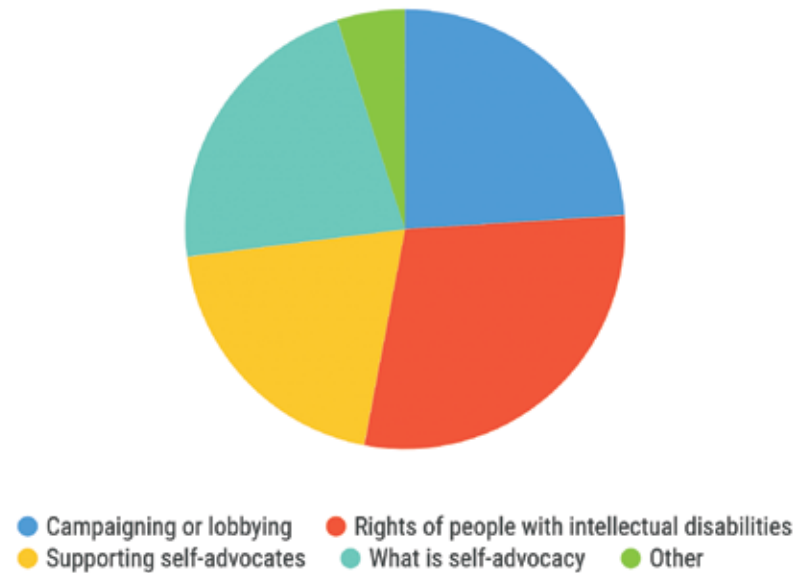
These strategies include supporting self-advocates to build their skills and confidence; developing support groups to identify issues that are important in their lives and planning activities for campaigning and advocacy.

89% of organisations told us that support for self-advocates is often focused on developing skills, knowledge and confidence:



Inclusive Organizations

The role of organisations also involves enabling self-advocacy, campaigning on human rights and community advocacy.



We heard about a range of issues and priorities that are identified by self-advocacy groups working on campaigning and actions.



Inclusive Organizations

“We fight to become self-advocate to defend our rights based on CRPD UN mainly in Articles 12 on our legal capacity and Article 19 on our right to live included in the community and not be institutionalized in dangerous places that threaten human rights, also work with the government to comply with the convention to create services in the community and create reasonable adjustments for people with psychosocial disabilities.”

MEXICO

The view of society toward disability, their environment, the respect to identify that we are not less valuable than anyone else and we are able to respect, improve and love as anyone else.

SPAIN

“Closing institutions, to have people in my community think of me as a person, better housing, more support and help with employment.”

CANADA

Delivering Services:

For those organizations that provide support to people with intellectual disabilities through services, the challenge is how to shift from making decisions for people with intellectual disabilities to supporting them to make decisions and choices themselves. Many of Inclusion International's member organizations are working to adapt their mandates and strategies to manage this shift:

- From being paternalistic and assuming that families or service providers always know best, to being person-centred and respecting the will and preference of the person.
- From being "custodians" on behalf of parents (concerned about safety) to being "facilitators" of participation in the community based on people's preferences and choices.
- From providing specialist services, usually in separate programs and facilities to harnessing social supports and building inclusive communities.

In our interviews with organizations there was a consistent message. They want to share what they are doing and they want to learn about how others are including and supporting self-advocacy in their work.

What self-advocates say about families...

- Organisations that work with people with an intellectual disability can play a big part in including people and supporting self-advocacy.
- By supporting inclusion, choice and by working with self-advocates, organisations can encourage changes in society.



What type of organisation supports self-advocacy?



There are lots of types of organisations that work with people with an intellectual disability.

Organisations give services, support, care and information to people with an intellectual disability and their families. Organisations may provide more than one service to a person and their family and are often a very important part of a person's life.

We know organisations that work with people with intellectual disabilities get

money from lots of different places; this can make it difficult for the organisation to try different ways of working.

Some organisations have found it hard to move away from seeing people with an intellectual disability in need of care rather than as individuals who have the right to decide and a voice they should be able to use.

All organisations can make changes to be more inclusive and supportive of people with an intellectual disability.

An organisation that supports self-advocacy understands that making sure we can speak up for ourselves about things that are important to us helps build strong inclusive communities.

These organisations encourage, train and support the people they work with to understand about self-advocacy. They work alongside self-advocates in making change happen.

What do inclusive organisations do?

- The organisation understands, promotes and works to remove barriers to inclusion in society.
- Organisations that work this way understand that they play a big part in promoting a world where barriers do not have to exist. All their work shows this.

- An organisation that provides services makes sure that the people who use its services always have choice, support and inclusion. Services are creative and there are lots of options to suit a person. People are encouraged and supported to have their say.
- The organisation has an inclusive way of making its big decisions. This is called inclusive governance. For example an organisation may have trustees or directors with an intellectual disability.
- If the organisation campaigns, they work alongside self-advocates to campaign for inclusive policies that promote the rights of people with a intellectual disability.
- Organisations are happy to take risks. They don't think that they are 'responsible for' the person they are working with. They understand and support the people they work with to risk take and make their own choices.
- The organisation is the bridge between people with an intellectual disability, families and society. It promotes inclusion and relationships between all people.
- Organisations that fund or provide supporters to self-advocacy groups understand that self-advocacy is not about what the organisation thinks.
- Organisations that provide support to people with intellectual disabilities value the people who give the support. They are respected and are treated well. They are encouraged to not be care givers but supporters who can help people to understand their rights and their place in a community.



What is good practice for inclusive organisations?

There are ways of working that show a commitment to being an inclusive organisation.

Inclusive decision making

Organisation can make sure they have inclusive ways of making big decisions. This is called Inclusive governance.

Inclusive governance is a big step for an organisation in including and valuing our decisions.

Inclusive governance shows that an organisation understands that self-advocates are the ones that know what is important in our own lives.

Inclusive governance means recruiting people with an intellectual disability who have the right skills and values to make decisions on behalf of the organisation. It also means providing ongoing and well managed support for the person or people.

Making sure Inclusive governance is done right may mean:

- Changing the organisations rules on who makes the big decisions and how they are made.
- Changing how meetings are run, changing how often and how long the meetings are, or how decisions are made in the meeting.
- It may mean providing training and support to the people who already make the big decisions.



Inclusive meetings

Inclusive meetings make sure that self-advocates can be truly involved and have their say. Some ways to make sure a meeting is inclusive are:

- Make sure that all information about the meeting is shared beforehand, for example the agenda or any presentations.
- Make sure that support people are invited and have all the same information.
- Have a contact person for the meeting that people can get in touch with to ask questions.
- Provide papers or information in plain language, easy to read, or in any other format that a person may need.
- Offer a phone call or meeting before the actual meeting to help people to go through the agenda and understand what the meeting is about.
- At the meeting encourage the group to set ground rules at the beginning. For example, one speaker at a time, respect one another, keep to time, etc.
- Make sure agendas and timings are followed and there is plenty of time for questions and for breaks.
- Include creative activities that help people to think about things in different ways.
- Recap what has been spoken about and agreed before moving on to the next part of the meeting.
- Include time at the end of a meeting for people to think about how the meeting went and if anything needs to change for next time.



Inclusive recruitment and training

An inclusive recruitment and training process makes sure that people with the right skills work for an organisation, but also the right values and attitude.

An inclusive recruitment process helps new staff to learn about inclusion and enabling people.

Having well trained staff with the right values means that their work with people with an intellectual disability will be inclusive. They are not ‘care givers’ but enablers.

All staff, not just those who work directly with people with an intellectual disability can be recruited in an inclusive way. This makes sure that an inclusive way of working runs all the way through an organisation.

People with an intellectual disability should be involved in every step of the recruitment process from checking job descriptions, shortlisting candidates and interviewing.

Once recruited staff should be trained or co-trained by people with an intellectual disability. As well as organisational training, helpful training sessions for new starters could be on

- Human rights of people with disabilities.
- The principles of person centred support.
- How to support people to make choices.
- Communication.
- Self-advocacy.



Employing people with an intellectual disability

Hiring people with an intellectual disability will show that an organisation is inclusive. Hiring people shows that an organisation does what it says and is representative of the community it supports.



- Jobs and the work of people must be meaningful and useful. There should be chances for development.
- All employment contracts and conditions like wages should be fair and equal.
- Creating roles just to look inclusive are not helpful.
- Support for people in work must be considered from the very beginning and should be well managed.

Campaigning for inclusive community

Being part of a community that values and listens to all of its members makes people stronger. It helps people with intellectual disabilities and their families to feel confident to speak up, make choices and get information and support.

Organisations should understand the importance of their role in supporting people to find and make relationships in the community, for example, through working with educators or employers.

Investing in community work supports the wider community to understand, value and listen to what self-advocates want and need to live good lives.

Tips for supporting groups

Getting started

- Organisations may know interested people and/ or active self-advocates and can support them to come together and plan for a group.
- If people do not have much experience of self-advocacy or speaking up for themselves organisations can arrange training sessions about self-advocacy.
- Organisations can support the group to think about how they will work, how decisions will be made and how the group will be led.
- An organisation can also help the group with developing plans and goals for their work. Depending on how experienced group members are, the organisation can support the group to understand about wider policies, laws, or issues that are going on for people intellectual disabilities.

Practical arrangements

- Organisations may have meeting spaces that they can let self-advocacy groups use.
- The organisation can provide the group with supporters or facilitators. Either volunteers or staff members.
- Organisations can provide support by coordinating the group, being the point of contact for people and helping with practical arrangements. For example arranging the dates and times of meetings, arranging travel for people or with writing accessible papers and information.

Other ways organisations can support groups

- Self-advocacy is about what self-advocates think and feel. Organisations need to make sure that the group can speak up about what the important issues are for them. The group should not feel it has to agree with what the organisation says.
- Organisations should make sure that the support that they give to the group encourages self-advocate leadership. Groups should be supported to look for opportunities to use and develop its skills
- Groups that are active within the community will succeed. Organisations can help with bridging the gap for self-advocates and society and role model inclusion.
- Helping the group to find ways of funding itself is an important step in encouraging independence.
- There may be more self-advocacy groups across a region or country that groups can build relationships with. Sharing good ideas, for example funding ideas, will help the self-advocacy movement to become strong. Organisations should encourage the group to build relationships.
- In some cases groups feel confident enough to break away from the organisation and become independent groups. Organisations can support a group to make this change.



The Way Forward



From the stories and experiences we have collected, we have a picture of the growing number and forms of self-advocacy around the world. We know that self-advocacy means:

- **Personal Empowerment:** *individuals being supported to make choices and expressing themselves;*
- **Peer support:** *listening and supporting each other;*
- **Advocacy for action:** *Coming together to set priorities for action and advocacy in our communities.*

The UN Convention on the Rights of Persons with Disabilities guarantees that people with intellectual disabilities have the **right to be heard** in their own lives and to be heard and included in our communities. They also have the **right to be supported** to have choice and control in their lives and to be activists and advocates for inclusion.

For people with intellectual disabilities to build the skills and confidence to express themselves, have their choices and opinions heard and to mobilize and take actions to make change in their communities, self-advocate leaders, families and organizations, governments and communities must work together.

Throughout Inclusion International's global network we have many good examples, tools and resources that support self-advocacy. The challenge is in mobilizing those resources and making them easily available to self-advocates, families and organizations.

Under the direction of self-advocate leaders, Inclusion International will launch **Empower Us: A global resource to support self-advocacy**. The resource will support:

Self-advocates to:

- ✓ Encourage each other
- ✓ Learn together
- ✓ Share experiences
- ✓ Organize and support groups

Supporters to:

- ✓ Understand their role
- ✓ Share experiences and information
- ✓ Learn from self-advocates
- ✓ Develop skills

Families to:

- ✓ Understand and support self-advocacy
- ✓ Share strategies for building support
- ✓ Find support they need
- ✓ Learn together

Organizations to:

- ✓ Be inclusive
- ✓ Support self-advocacy
- ✓ Deliver supports based on choice and inclusion
- ✓ Share strategies with other organizations

Empower Us will be organized and run by self-advocates and will include an online platform for sharing tools and resources as well as a program of activities to support exchanges; workshops and forums. By bringing together individuals and organizations throughout our global network this initiative will help to grow and build self-advocacy and inclusion around the world.

Notes

Notes

