



How Self-Advocacy Groups Form and Make a Difference

Case Study



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This report shares what we learned from a project that supported self advocates in Southern Africa. The project focused on groups in Angola and Zambia. The work was funded by the Government of Finland (MFA Finland) through the International Disability Alliance (IDA).



Ministry for Foreign
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Inclusion International is the international network of people with intellectual disabilities and their families.



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What is this report about?

The report talks about different ways that self-advocacy groups can come together.

By "self-advocacy groups," we mean groups of people with intellectual disabilities who come together to advocate for their rights.

This report shares real examples of self-advocacy groups from Inclusion International's network.

This report also tells the story of how self-advocacy groups started in Zambia and Angola.

Examples from their self-advocacy groups show us how people with intellectual disabilities build confidence, learn leadership skills, and work together to make change.

At the end of the report, there are worksheets that can help you start or strengthen your own self-advocacy group.



Who did we talk to?

We talked to two different organisations.

Friendly Barn Development Foundation in Zambia (FBDF)

- This is a cross-disability organisation
- This means they work with people with many different disabilities

APEGADA in Angola

- This is a family-led organisation
- This means families of people with intellectual disabilities started it and run it

Both organisations are members of Inclusion International.

They worked to form self-advocacy groups as part of a project with Inclusion International.

We also talked to other organisations in our network in Uganda, Egypt, and Canada for examples of different kinds of self-advocacy groups.



What will you learn from this report?

This report explains what starting self-advocacy groups can look like in different types of organisations:

- Cross-Disability Organisations
- Family-Led Organisations
- Self-Advocate-Led Organisations
- Other Types

It also shares stories from Zambia and Angola.

These stories show how the groups started, what they did, and what they learned along the way.

Why does this matter?

Self-advocacy groups help people with intellectual disabilities become leaders.

Self-advocacy groups support people to speak up for their rights and be included in their communities.

When self-advocates come together in groups, they are stronger. They can make real changes in their own lives and in their communities.

What is self-advocacy?

Self-advocates are people with intellectual disabilities who know about their rights and speak up for themselves about what matters to them.

Self-advocacy means:

- understanding your own rights and the rights of other people with intellectual disabilities,
- sharing experiences and learning from each another,
- building confidence and power, and
- taking action to make sure organisations and governments do what they promise.

We use the word self-advocate because, in the past, other people spoke for people with intellectual disabilities. When that started to change, people wanted a new word to show that this was something different - speaking for ourselves.

Calling ourselves self-advocates showed that people with intellectual disabilities were leading the conversation about our own lives.

Some other disability groups have started using the word *self-advocate* too. But this word comes from our movement.

Introduction

It has a history. It means something to people with intellectual disabilities. We don't want that to be forgotten or taken away.

Not all people with intellectual disabilities are, or want to be, self-advocates.

Another important part of self-advocacy is coming together to give each other support.

When self-advocates do this, we call it a **self-advocacy group**.



What are self-advocacy groups?

A self-advocacy group is a group of people with intellectual disabilities that come together to do advocacy work as a group.

They speak out on the problems they face and:

- Push for changes for people with intellectual disabilities
- Share knowledge with the community and government
- Build each others self-advocacy skills and knowledge
- Support each other
- Have a stronger voice together



What is *not* a self-advocacy group?

Sometimes organisations talk about their "self-advocacy work" but the activities are more social or fun, not about rights.

For example, some organisations call their exercise or drama groups "self-advocacy."

Many self-advocacy groups start as social groups. But people in those groups may not have learned about their rights or about speaking up for others.

These activities are fun and important, but they are not self-advocacy.

Our self-advocacy group was created 13 years ago with a small group of people with intellectual disabilities who barely knew about their rights. Over time, the group grew, and we learned about our rights, the importance of having autonomy, and places of social participation that we could engage in.

Self-Advocate, Brazil

Why are self-advocacy groups important?

Self-advocacy groups give people with intellectual disabilities a stronger voice.

Introduction

The self-advocates create one clear message when speaking up about issues.

Organisations that have self-advocacy groups can learn from them, because self-advocates are experts on our own lives.

Self-advocacy groups help people with intellectual disabilities to:

- Speak up on issues that are important to them
- Share their experiences and stories
- Speak up against unfair treatment and ask for equal rights
- Develop their skills and confidence
- Feel part of a community
- Challenge stereotypes and discrimination

By working together, self-advocacy groups make real change happen.

When I joined, I felt very happy and free—like a heavy burden I had been carrying for years was finally removed. Before this, I had a lot of thoughts but no platform to speak.

Joseph, Self-Advocate, FBDF

Ways Self-Advocacy Groups Form

There is no single way to start a self-advocacy group.

Each group starts in its own way, depending on where it happens, who is involved, and what support is available.

Some groups begin with support from families.

Others start within organisations that already work on disability issues.

Some are created and led by self-advocates themselves outside of an organisation.

The way a group starts can shape how it grows. It can impact who makes decisions, what kind of support they get, and how much space self-advocates have to lead.

In this section, we will talk about some of the common ways that self-advocacy groups form.



Family-Led Organisations

Family-led organisations are started by families of people with intellectual disabilities.

The families support one another and fight for people with intellectual disabilities to be included.

These groups also play an important role in supporting people with intellectual disabilities, especially where self-advocacy is still growing.

Many self-advocacy groups begin inside a family organisation, with support from families.

Over time, family organisations help people with intellectual disabilities take charge and form their own self-advocacy groups.

Many organisations that used to be only led by families are now led by people with intellectual disabilities and our families together, because families have supported a self-advocacy movement within the organisation.



How Self-Advocacy Groups Develop

Self-advocacy groups in family-led organisations often start because families want a better life for their family member with an intellectual disability.

Families help bring people with intellectual disabilities together and encourage them to speak up for themselves.

I started from my own personal experience as the father of a person with an intellectual disability and approached parents of children in similar situations.

- Antonio F Teixeira, APEGADA Staff

At first, families help gather people with intellectual disabilities and their families to organise friendly meetings or activities. These early meetings help people with intellectual disabilities get to know each other and build confidence.

Then family organisations usually give training to help future self-advocates learn about their rights and how to speak up. This helps them gain skills to take part in decisions and lead their own work.

The family organisation continues to support by:

- Finding training opportunities
- Offering support and guidance
- Linking the group with other organisations or networks.

Over time, families move from leading the group to supporting from the side. Self-advocates begin to lead their own meetings and speak for themselves with government and community leaders.

Families stay involved by offering advice and support for the group, while leadership of the group shifts to the self-advocates themselves.

How does family support help a new self-advocacy group?

Family organisations provide structure and resources in the early stages. They help find money, materials, and training to get the group started.

Family organisations can help organise the group so it can talk with government officials and other decision-makers.

Family support helps build confidence. Parents, siblings, and other family members are usually self-advocates' first, and most important, supporters. They help build up people's

confidence and keep encouraging self-advocates to join meetings and training, reminding them that their voices matter.

What challenges are there for self-advocacy groups working within a family organisation?

Parents and staff sometimes find it difficult to stop protecting and start supporting. This can make it hard for self-advocates to make their own choices. It takes time for everyone to learn to share power and work together.

Family-led organisations also face outside challenges. Limited resources can mean slow progress, especially when families are seen as troublemakers who expect too much or when funding is scarce.

Real change takes time, patience, and learning from others.



Cross-Disability Organisations

Cross-disability organisations are groups that include people with many kinds of disabilities, including people with intellectual disabilities.

They work on big issues for *all* people with disabilities.

These organisations don't focus only on self-advocacy for people with intellectual disabilities, but they can help a self-advocacy group get started.

They might help self-advocacy groups get started because they know that strong self-advocates make the whole disability movement stronger.

People with intellectual disabilities can share important experiences and ideas that are often left out, which will make their organisation more inclusive.

When self-advocates are involved and have leadership roles, cross-disability organisations can better represent the whole disability community.

How Self-Advocacy Groups Develop

Self-advocacy groups often begin inside a cross-disability organisation when people with intellectual disabilities come together to talk about their rights and experiences.

To make this work, the organisation needs to believe that people with intellectual disabilities can make their own decisions and lead.

This works when the organisation has moved away from the idea that they need to “protect” people, and instead is ready to support people with intellectual disabilities to take the lead.

To start a self-advocacy group, cross-disability organisations usually bring people together by:

- Reaching out to people with intellectual disabilities and families from their members to invite them to take part
- Offering clear information about what the group will be and why someone might want to take part
- Providing a safe and accessible meeting space
- Using their staff to coordinate the group's work

Once the group begins meeting, the organisation supports them by offering training about rights, easy-to-understand materials, and chances for self-advocates to practise leadership.

Staff should always take a supporting role in self-advocacy groups, while the self-advocates decide what the group should focus on, their big messages, and what activities to do.

Cross-disability organisations also use their experience to help the self-advocacy group get connected. For example, helping self-advocates to share their messages in the media, meet government leaders, and link with other disability groups.

This kind of support helps self-advocates build confidence, gain skills, and take their place as leaders in the wider disability movement.

How does cross-disability support help a self-advocacy group?

Cross-disability organisations help new self-advocacy groups have access to resources and knowledge from across the disability movement. This can mean good advocacy support and ideas for the self-advocacy group.

In cross-disability organisations, self-advocacy groups can also have wide leadership opportunities. For example, the change for self-advocate leaders to represent not only people with intellectual disabilities, but the whole disability movement.

Having self-advocacy groups within a cross-disability organisation helps makes those organisation more inclusive.

We use resources and knowledge from working with different disability groups. This helps us provide better support and ideas for self-advocates.

- Amos Muselema Chileshe, FBDF Staff

What challenges are there for self-advocacy groups working within a cross-disability organisation?

It can take time for an organisation to shift its priorities and attitudes towards including people with intellectual disabilities, who are often excluded in the cross-disability movement.

Some staff may still hold old ideas about people with intellectual disabilities, and it can take time to change those attitudes.

Many policies are often not already in easy-to-understand language to start, and ways of working might not be easy to understand. This means they must be updated to make self-advocate leadership possible.

Finally, there can be some resistance. Some disability organisations still do not see why including self-advocates is important.

We have heard from our members in Zambia that they have been having trouble with the Zambian cross-disability federation in the capital who doesn't want to include their new self-advocates. We need to think about adding in more support to organisations to advocate specifically to their cross-disability federation.

- Amos Muselema Chileshe, FBDF Staff



Self-Advocate-Led Organisations

Self-advocate led organisations are founded and led by people with intellectual disabilities themselves. In them, self-advocates take charge of their own advocacy.

Some self-advocacy groups start on their own, not as part of an existing organisation. People with intellectual disabilities might know each other through their school, through services they use, or through their community.

They come together as a group because there is something missing or not working in their community, and they want to speak up about it.

They might start by talking about issues that matter most to them, such as education, employment, accessibility, and human rights.

These groups connect with other self-advocates and speak with organisations or government officials.



They do this to make sure people with intellectual disabilities are included when decisions are made.

Sometimes a group that is brought together by people with intellectual disabilities may also start by being centred on fun and social activities within a local neighborhood, and then it grows into a self-advocacy group over time.

How Self-Advocacy Groups Develop

Self-advocacy groups usually start when they have good support.

For example, in People First Canada, the group received funding and guidance from a partner organisation.

This organisation helped connect local groups to self-advocates and provided structure in the beginning.

That support helped self-advocates learn new skills, build confidence, and do their own planning about how to work together across the country.

In this type of self-advocacy group, people with intellectual disabilities are in charge from the start.

They lead their own group, with help from other groups, their peers, families, or other organisations that share their goals.

What are the benefits of this type of self-advocacy group?

Self-advocate-led organisations offer a strong sense of ownership. This means self-advocates feel like they are in control and the group really belongs to them.

Because the groups are built and led by people with intellectual disabilities themselves, members learn by doing. This helps them grow in confidence, get leadership skills, and make sure the group's goals reflect their experiences.

These self-advocate-led groups are also fully independent from the beginning. They are not shaped by parents' or professionals' priorities.

Instead, they set their own agenda. The group can become recognised experts on disability rights and equal partners in advocacy work.

What are the downsides of this type of self-advocacy group?

This type of self-advocacy group also comes with challenges.

Because self-advocate-led groups often start without the same resources or structure as groups that grow out of a

bigger organisation, they can struggle with money, management, and planning.

They may also face stigma or doubt from people who are not used to seeing people with intellectual disabilities in leadership roles.

The voice of self-advocates was weak then, and we were committed to making it stronger. People were being identified as leaders in the self-advocacy movement, and these leaders formed People First Canada.

- People First Canada, History

Other Ways Self-Advocacy Groups Come Together

Some self-advocacy groups develop from unique or mixed setups.

Other Ways Self-Advocacy Groups Develop

Groups might form because people share a common experience, like going to the same school or having the same service provider.

For example, the Alexandria Self-Advocacy Resource Group in Egypt was inspired by a suggestion from the Interact organisation to create a self-advocacy group.

Interact is a service provider in the Middle East. They have programmes that support people with disabilities and their families, helping them get the services they need.

Interact invited young people with intellectual disabilities from organisations in Egypt to attend training on self-advocacy in Beirut in 2013.

Following this training, Interact suggested they form a leadership group in 2014 to start an Egyptian self-advocacy movement.

In some cases, self-advocacy groups are formed not by a single service provider, but through the efforts of several different organisations and their supporters.

Some self-advocacy groups start as part of a project run by another organisation. These projects aim to help the group become independent over time.

Self-advocacy groups form in many different ways, but they can all be successful if they get good support!



Case Studies

A case study is a short story that shares how people or organisations did something in real life.

It explains what they did, what challenges they faced, and what they learned.

Case studies can help us learn how self-advocacy groups grow.

These case studies are important because self-advocates and organisations can learn how others created self-advocacy groups, which can help them create groups in their own communities.



Zambia

The Friendly Barn Development Foundation (FBDF) is an organisation in Zambia that advocates for the rights of people with disabilities.

Friendly Barn is a cross-disability organisation, which means they work with people with a range of disabilities, not just those with intellectual disabilities.

Friendly Barn decided to start a self-advocacy group after joining Inclusion International as a member.

Before we learned about self-advocacy, we didn't work with self-advocates as people who could actively contribute. Instead, we viewed them as a vulnerable group who needed protection and couldn't speak up for themselves. We were overprotective and always spoke for them.

- Amos Muselema Chileshe, FBDF Staff

The self-advocacy group at Friendly Barn started through a project funded by the Finnish Ministry of Foreign Affairs, which helped Inclusion International members in Zambia and Angola to start self-advocacy groups.

In response, Friendly Barn searched for people with intellectual disabilities in Zambia by talking to families in their organisation and community.

The people they found volunteered to come together and create the group.

The group was trained by Inclusion International. A self-advocate leader from Southern Africa ran the Empower Us programme for the group as a part of the project. 15 people with intellectual disabilities took part, including people with multiple disabilities.

The [Empower Us programme](#) is a training focused on self-advocacy skills, leadership, and understanding of the Convention on Rights of Persons with Disabilities (CRPD). It is a training programme created by self-advocates, and the trainers are self-advocates.

The Empower Us training taught me that I have a right to speak up—not only for myself but for other people with intellectual disabilities too.

- Charity, Self-Advocate, FBDF

I learned that being Deaf does not mean I cannot speak out. I use sign language, and during the training, there was support to help me understand and contribute.

- Joseph, Self-Advocate, FBDF

Friendly Barn staff were also trained on how they could use the [Listen Include Respect guidelines](#) to include the future self-advocates in their organisation better.

After learning about self-advocacy, the people in the group thought about what was important to them and discussed key issues.

They chose topics that matter most and began working together to bring about positive change - they chose the right to work and the right to health as the big topics they wanted to do advocacy about.

I now know I have the right to good healthcare and should be included in the community. At the clinic, I make sure I receive proper care. It was hard to claim my rights before becoming a self-advocate.

- Jabulani Jay Boy, Self-Advocate, FBDF

Leadership and decision-making processes

The self-advocacy group at Friendly Barn Development Foundation in Zambia is led by self-advocates who hold formal positions, such as the Chairperson, Vice Chairperson, and Secretary.

These leaders are elected by the group members themselves.

Additionally, the group created a paid Project Coordinator role to help coordinate the group. This job is also held by a self-advocate.

The self-advocates and their group leaders make decisions together.

They decide what issues to work on, what messages to share, and how to carry out their advocacy.

This approach to decision-making means that self-advocates choose their work plans and the topics they advocate for. Self-advocates making decisions was new to Friendly Barn when the group started.

Being a leader means that I represent others, not just myself. Leadership is not just about talking—it's about listening, guiding others, and being an example.

- Ruth, Self-Advocate, FBDF

Activities

After completing the Empower Us training, the self-advocacy group in Zambia began a wide range of activities focused on awareness, inclusion, and influencing policy.

They meet twice a month to decide what issues to focus on, what messages to share, and how to reach people in their communities.

Leaders collect ideas from members and include them in the group's plans. Together with staff, they also help manage logistics, like buying materials and preparing reports.

As a self-advocate leader, I take part in planning what our group should focus on — whether it's community awareness, attending meetings, or reaching out to leaders.

- Ruth, Self-Advocate, FBDF

The group also runs community programmes to raise awareness about the rights of people with intellectual disabilities.

They meet with government officials to talk about improving policies and support systems for people with intellectual disabilities.

The group uses local radio and television to share their message. Members are now well known in their communities and are regularly invited by organisations like YWCA, Radio Mano, and Sightsavers Zambia to speak about disability issues.

The self-advocates work with other organisations and take part in workshops to improve their advocacy, leadership, and communication skills. They also meet families to share knowledge and build understanding.

Within the group, members teach each other new skills and reflect on what's working well.

Group members shared their knowledge and skills with each other, helping to build a supportive network where everyone could learn and grow.

- Amos Muselema Chileshe, FBDF Staff

Challenges and Lessons Learned

The creation of the Friendly Barn Development Foundation self-advocacy group in Zambia faced several challenges.

Many of these challenges were because the organisation was new to focusing on people with intellectual disabilities and self-advocacy.

It was also hard to select members, manage limited resources like transportation for those in far areas, and address the different needs of the self-advocates.

Staff found it difficult to recognise accidental barriers within their own organisation. Embracing the idea that self-advocates should determine their own work plans was also a new idea for them.

Some things about Listen Include Respect took a bit more time to introduce. For example, the idea that an organisation can accidentally create barriers in their work. Part of the introduction to Listen Include Respect is talking about what barriers are in your organisation. We had a hard time with this, we were thinking only of barriers outside of our organisation.

- Amos Muselema Chileshe, FBDF Staff

Many parents and supporters doubted that members could become effective leaders or advocates.

The organisation learned to overcome these challenges by providing training through the Empower Us programme and accepting a shift in power where self-advocates were the decision-makers.

FBDF has since seen expectations change, realising people with intellectual disabilities can be leaders and direct the work. The organisation created a role for a self-advocate on their Board.

After seeing the benefits, families have begun to change their perspective and now feel proud, offering support to the self-advocates.

Impact

Changes in personal lives

Since the group started, self-advocates have seen big changes in their lives.

They feel more confident, active, and free. Many said they used to stay at home and feel lonely, but now they have purpose and connection.

Self-advocates have learned about their rights and how to speak up for themselves.

Self-advocates like Charity now ask to be included in social protection programmes. Ruth went from thinking she could

not talk to officials to becoming a leader with recognised skills. Jabulani, a deaf person with an intellectual disability, now feels strong enough to make sure he gets good care at the clinic.

I used to feel lonely and lacked confidence. After becoming a self-advocate, I've gained confidence and motivation. I can now handle any situation.

- Pelekelo, Self-Advocate, FBDF

Together, self-advocates say they feel valued and respected. They take part more in meetings and move more freely in their communities.

The group has helped them feel seen, capable, and included.

Community impact

The self-advocacy group's work has changed not only members' lives, but also their families and communities. The self-advocacy group has created a big impact on the community and families across Northern Zambia.

Through activities like Road Shows, Village Outreach Programmes, and appearances on local radio and television, the self-advocates have made the community more aware of the rights and needs of people with intellectual disabilities.

These efforts have challenged stereotypes and misconceptions. There is now more respect and inclusion within the community.

The group's work has affected families, who now feel proud and supported, and have gained knowledge to better advocate for their loved ones. This means the community has become more supportive as well.

Policy influence

The self-advocates have a better understanding of the Convention on the Rights of Persons with Disabilities (CRPD) and other important laws, helping them to better advocate for their rights. They have been meeting with important people in government departments like health, education, and other key sectors.

I had a chance to speak to the Permanent Secretary of the Northern Province... I told him how people with intellectual disabilities are often left out of important services. He listened to me seriously and promised to consider us in all future policy decisions.

- Ruth, Self-Advocate, FBDF

The self-advocates have shared ideas with government officials to change policies that are not working for people with intellectual disabilities.

The group has even been recognised internationally, where a self-advocate was nominated to represent the entire disability movement in Zambia at the CRPD Committee meeting in Geneva. Self-advocates from Zambia have become active in Inclusion International's network of self-advocates, sharing their experiences and connecting with peers internationally. Both Ruth and Charity have been speakers at Plena Internacional sessions and Ruth was a speaker at the 2025 Global Self-Advocacy Summit



Angola

APEGADA (Associação Angolana de Apoio à Pessoas Autistas e Transtornos Globais de Desenvolvimento) is a family organisation in Angola that supports people with autism, developmental disabilities, and intellectual disabilities.

A family organisation is a group started by families of people with disabilities. The families work together to help their children and other people with disabilities be included and supported.

Before working with Inclusion International, APEGADA had a group of people with intellectual disabilities who were meeting but they were not yet self-advocates.

To start, it was a small group of people with intellectual disabilities who met to paint and make music, but it was not a large or organised group at the time.

The group did not have any knowledge about advocacy or the CRPD, or any formal leadership.

After joining Inclusion International, APEGADA's leadership attended meetings in Mozambique and Ethiopia to learn more about the CRPD.

Inspired by other self-advocates in Africa that they saw at these meetings, they wanted to support new self-advocates in Angola.

When APEGADA started working with Inclusion International, they learned about self-advocacy groups.

The group started with 17 young people from Angola.

Through Empower Us, people with intellectual disabilities learned that they are citizens and have rights like anyone else. The training helped them understand what it means to be a self-advocate.



Activities

Since participating in the Empower Us training, the organisation has become more actively involved with self-advocates in their advocacy work.

We are able to take [self-advocates] and go to ministries so that they can advocate for themselves.

- Antonio F Teixeira, APEGADA Staff

Today, self-advocates are involved in planning, leading group meetings, and deciding what to do next.

The group focuses on meeting with government officials and doing public campaigns to make sure their rights are respected.

Self-advocates went to the national parliament to hold meetings where they presented their concerns directly to government officials.

They also met with the General State Attorney to propose the translation of the national constitution into easy-to-understand language so that people with intellectual disabilities could understand it.

Self-advocates also met with the Labour Ministry to explain that people with intellectual disabilities have often been left out of work opportunities. They asked the ministry to include and support people with intellectual disabilities in all its programmes.

In public, self-advocates distribute pamphlets in easy-to-understand language to explain their rights to the community.

Leadership and decision-making processes

The group has developed strong self-advocate leadership.

APEGADA has elected a self-advocate President and a Vice-President of the group.

Now, self-advocates are the ones speaking in meetings, advocating for the group, and helping to run the organisation.

The basic idea is that [the self-advocates] are not just passive agents, they play an active role in the work that the organisation does in helping to come up with plans and agendas. Also they are the ones that present and speak for themselves in those meetings.

- Antonio F Teixeira, APEGADA Staff

Challenges and lessons learned

The self-advocacy group still faces stigma, which is a big challenge.

People in the community often do not understand intellectual disability. Changing mindsets was difficult to do.

The group started small and informally, focusing on activities like painting and music, which helped build trust with families who were nervous at first

Many self-advocates still feel shy about talking in public, so it can be hard for them to share what they've learned.

The organisation has learned a lot. To start, they did not know how to work with self-advocates, but through training, they have begun to include self-advocates in their work.

Training on rights, focused on the Convention on the Rights of Persons with Disabilities (CRPD), was really important. It empowered members to advocate for themselves without being instructed on what to say by supporters.

By actively involving these newly trained self-advocates, the group achieved big impacts, such as training new members, meeting with national government officials and ministers, and contributing to actual changes in government policies and practices.

At first, we didn't know how to work with self-advocates. Through training, we learned that support means helping them speak for themselves, not telling them what to say.

- Antonio F Teixeira, APEGADA Staff

Impact

Changes in personal lives

APEGADA has seen a lot of changes in self-advocates after the training. Many used to stay at home, now they take part in their communities.

Training, especially about the Convention on the Rights of Persons with Disabilities (CRPD), helped build their confidence. They learned that they have rights like everyone else.

For instance, 20-year-old Jorgina joined the group in February 2024. At first, she was silent and seemed unsure of her role in the group. However, as the training progressed, she participated actively in activities. Today, she confidently speaks about her rights in public without hesitation.

They also moved from being told what to say by supporters to speaking for themselves. Today, they talk directly with

government leaders and are recognised as the voice of people with intellectual disabilities in Angola.

I am a self-advocate, and since I became a self-advocate, many things have changed in my life... I now feel like a woman, I feel like a Jorgina, and any question a person asks me I can answer; I feel that I can, and I really can, today I know that I am different

- Jorgina Monteiro, Self-Advocate, APEGADA

Community impact

The self-advocacy group in Angola has helped change how communities see people with intellectual disabilities.

Group members work to raise awareness and promote inclusion. They share easy-to-understand pamphlets on the streets to explain their work and the rights of people with intellectual disabilities.

By being visible and active, the group is changing negative attitudes and making sure people with intellectual disabilities are heard and seen. Their work has also encouraged local organisations to offer more support and resources.

Policy influence

The self-advocacy group in Angola has made a difference in government policy and practice. Members have met directly with government leaders, including people from parliament, the justice system, and several ministries.

They asked for clear changes, like translating the national constitution into easy-to-understand language so everyone can understand it. They also pushed the labour ministry to include people with intellectual disabilities in job training and programmes.

Because of their work, different parts of the government, including courts, health, and education, have started to change how they support people with disabilities.

There have been all sorts of changes in the way the government has handled people with disabilities. There have been changes in courts, in the health ministry, in the way hospitals handle people with disabilities. The same with the ministry of education. Classrooms have been changing, they are now making sure new classrooms are multifunctional so that people with intellectual disabilities can learn properly with the right kind of assistance.

- Antonio F Teixeira, APEGADA Staff

Tools for Building Self-Advocacy Groups

Building a strong self-advocacy group takes time, planning, and the right kind of support.

This section helps you think about what makes a self-advocacy group work well.

It gives you space to reflect and write down your own ideas.

You will find questions about what to think about before starting a group, what kind of support is needed, and what steps help a group grow and lead its own work.

Use these worksheets to learn from the examples in this report and to plan how you could support or start a self-advocacy group in your own context.

Who are these tools for?

We made these tools for anyone who wants to help a self-advocacy group grow. They are mostly for staff and leaders at organisations that work with people with intellectual disabilities. These tools show you how to support people to lead their own work and speak for themselves.

Tools

Self-advocates can also use these worksheets to plan their own meetings and activities.

Facilitators and support people will find them helpful to check if their support is working well. Whether you are just starting a group or trying to make one stronger, these tools help you work together.

The tools in this section

1. Planning your Self-Advocacy Group
2. Checklist for Strong Self-Advocacy Group
3. Steps to Start a Self-Advocacy Group
4. Our Advocacy Plan
5. Support Person Guide



Planning your Self Advocacy Group

What should you think about before starting a self-advocacy group?

Why do we need self-advocacy groups?

- We need self-advocacy groups because...

Write your thoughts here:

What kind of support does the group need to be successful? Think about...

- Who will do meeting logistics?
- Who will take notes during the meetings?
- Who will pay for meeting space?

Write your thoughts here:

Tools

What will make it difficult for group members to meet when they need to? How can we plan to avoid this? Think about...

- Distance
- Data connection
- Travel costs
- Family responsibilities
- Work commitments

Write your thoughts here:

What group size will make it easy to include everyone and manage the work? Think about...

- Resources required
- Making sure everyone has space to speak
- Meeting space

Write your thoughts here:

What factors like age, gender, or other factors should we think about to create a balanced group? Think about...

- Gender
- Age
- Education
- Where people live

Write your thoughts here:

Checklist for Strong Self-Advocacy Groups

What does a successful self-advocacy group look like?

A group of people with intellectual disabilities want to share their experiences and stand up for their rights.

People with intellectual disabilities feel safe, welcomed, and like their stories and ideas are valued.

Self-advocates lead their own work - support people and organisations help, but do not control.

How do you make that happen?

Try starting with a smaller group of motivated individuals and invite others gradually as confidence grows.

Try creating clear group rules, using icebreakers, and having trusted supporters present to make everyone feel comfortable.

Set clear roles and boundaries for supporters, communicated by the self-advocate leaders themselves.

Train supporters in what good support looks like. This training should be led by experienced self-advocates if possible.

What does a successful self-advocacy group look like?

Meetings, materials and activities are easy-to-understand and accessible for everyone.

There should be some support from families, peers, and community partners for the group's work.

Members need chances to learn about their rights and build skills in communication, leadership, and advocacy.

How do you make that happen?

Make sure materials like meeting agendas, notes, and advocacy resources are in easy-to-understand language.

If materials are made by supporters or by the organisation, always check them with self-advocates to make sure they are accessible.

Think about other forms of accessibility that members of the group might need.

Engage with families in the process. Help families understand why self-advocacy matters and how they can support.

Encourage the self-advocacy group to connect with other groups in the community.

Make sure self-advocates get access to accessible training.

Make sure that there are roles available within the group for self-advocates to build their leadership skills.

Steps for Starting a Self-Advocacy Group

What are the steps for starting a successful self-advocacy group?

1

Commit to self-advocacy

- Look at the [Listen Include Respect principles](#) that explain what makes an inclusive organisation.
- Think about what barriers exist that might make it difficult for self-advocates or a self-advocacy group to be fully engaged in the organisation.
- Think about accessibility - what needs to change if you commit to engaging self-advocates?

2

Bring people together

- Find people with intellectual disabilities and their families. Look within your members, people in the community, in local organisations, and check with partners.
- Make sure you have clear and easy-to-understand information about why you are bringing people together. This will help people understand how a self-advocacy group is different from a social group.

3

Learn about rights and get basic training

- Help the group learn about the CRPD, self-advocacy, and how to speak up.
- Help supporters learn about how to support without taking control.

4

Organise meetings and find resources

- Plan a meeting schedule - the group should decide if they want to meet weekly, monthly, or on a different schedule.
- Find a meeting place, materials, and think about any funding needed. Organisations that are supporting self-advocacy groups to start usually help fund this.

5

Choose leaders and plan activities

- Self-advocacy groups should choose their own leaders. This can be one leader for the group, two co-leaders, or a team of people with different roles. Many self-advocacy groups decide they want to vote on leaders.
- It is up to the group how they choose their leaders!

6

Plan Activities

- Self-advocacy groups decide their own activities. A good place to start is for the group to choose two or three topics that matter to them.
- Agree on what the big messages are - what does the group want to say about the topics that are important to them?

7

Accessibility check

- Do a check to make sure you're still following your commitment to inclusion now that the group has started working. Look back at the [Listen Include Respect principles](#) and see if they match up with how the self-advocacy group is being supported.
- Check the accessibility of how the group works - make sure you are still using easy-to-understand language, visuals, and clear agendas. Get feedback from the group to make sure everyone can understand.

8

Get support

- Look for local networks or organisations that want to work with the self-advocacy group.
- They can help with coordination, information, or relationships - but it is important that partners understand that the self-advocacy group makes their own decisions about what work they do.

9

Stay active and grow

- Grow membership - find new people with intellectual disabilities who want to join the group and become self-advocates.
- Support the current members of the group to grow - think about what leadership roles people can take on and how they can keep growing their skills.

Our Advocacy Plan

Self-advocacy groups can use this worksheet to plan what work they want to do on issues that are important to them.

1. What is a big issue we care about?

*Example:
The right to have a job*

2. What needs to change?

*Example:
We don't get jobs because people think and say that we are not able to work. This needs to change*

3. What are our rights on this issue?

*Example:
We have the right to work and have a job. This is Article 27 of the CRPD.*

4. Who is responsible for this issue? Who are the decision makers?

Example:

People who own businesses are deciding not to hire us.

5. What do we want the decision makers to do differently?

Example:

We want people who own businesses to hire us for jobs. We want them to learn about us, about our rights, and how we can work.

6. How can we get decision makers to listen to us?

Example:

We can go on TV and talk about the problem. We can talk to businesses and have a meeting about how to include us at work.

7. What are our big messages?

Example:

We have the right to get a job. We are ready for work.

Support Person Guide

What is a support person?

A support person is someone who helps self-advocates do their work and reach their goals.

They do not speak for self-advocates. Instead, they make sure self-advocates have what they need to speak for themselves.

Support people might:

- help prepare easy-to-understand materials,
- assist with communication or technology,
- make sure meetings are accessible, and
- provide encouragement and guidance.

Support people can be staff members, family members, or volunteers from partner organisations. Their job is to make leadership possible, not to take over.

Support for Support Persons

Support people help self-advocates lead, speak up, and make decisions.

They also need support to do this well.

Support people need support like...

- Training to understand what self-advocacy is and how to support without taking over.
- Time to prepare materials and make meetings accessible.
- Clear roles so everyone knows that self-advocates make the decisions.
- Connection with other support people to share what works and learn from each other.

It would help support people if...