

Closing institutions and living in the community

Global self- advocate report

2021

Inclusion
international



Contents

Section 1 - Background information	Page 1
• Important words and ideas	Page 2
• Introduction	Page 5
• How we ran our meetings	Page 7
Section 2 - Self-advocate experiences of closing institutions and living in the community	Page 10
• North America	Page 11
• Latin America	Page 14
• Europe	Page 17
• Middle East and North Africa	Page 20
• Africa	Page 23
• Asia	Page 26
• Australia and New Zealand	Page 29
Section 3 - Global Recommendations	Page 32
Section 4 - Glossary and Thank You	Page 39

Section 1

Background information

Important words and ideas

There are some important words and ideas that we should understand so the information in this report is clear to everyone. At the end of this report there is also a glossary with other words and ideas you may find useful.



Inclusion

- Inclusion is when all people are valued, respected and treated equally.
- We all have the right to be included.
- In an inclusive community we all;
 - have the support that we need,
 - have choice and control over our lives,
 - have the same opportunities as others to take part.
- People with intellectual disabilities and their families face many more barriers to being included in their communities.
- When people are separated from the rest of a community they are excluded. This is the opposite of included. For example in institutions.



Self-advocacy

- Self-advocates are people with intellectual disabilities who work on inclusion.
- Self-advocates work on inclusion by:
 - understanding about rights and decision making;
 - speaking up for themselves and others;
 - working together in groups;
 - taking action to make inclusion happen.

Important words and ideas



Institutions

- An institution is **any place** where people with intellectual disabilities:
 - are separated from the community;
 - cannot leave if and when they want to;
 - live together in large groups;
 - do not have control or choice about their lives.
- Across the world institutions come in many different forms and are called lots of different names.
- Sometimes people with intellectual disabilities are institutionalised in their own homes if they do not have choice and control over their lives.



Closing institutions

- Closing institutions is sometimes called **deinstitutionalization**.
- It is when people who live in institutions move into living in the community
- People must have choice and control about their lives and be supported to make their own decisions.
- When people move they must also get the services they need to be included in the community.
- The process for closing institutions can be very difficult.

Important words and ideas



Convention on the Rights of Persons with Disabilities

- The Convention on the Rights of Persons with Disabilities is also called the CRPD.
- It is a United Nations agreement between many countries around the world.
- The CRPD is about protecting and respecting the human rights of people with disabilities.
- Our countries should be following what the CRPD says.



Article 19

- Part of the CRPD is called Article 19.
- Article 19 is about making sure people with disabilities have choice, control and support and are included in the community.
- Article 19 says countries should make sure **all people with disabilities** have the same opportunities as everyone else to live independent lives in the community.
- Article 19 says that if people need support to make a decision they should get this support.
- There must be different services available in the community so people with disabilities can choose what is right for them.

Introduction



The Committee on the Rights of Persons with Disabilities are a group of experts who check how countries are doing on the CRPD.

The CRPD committee are writing guidelines for countries on how to close institutions and make sure everyone can live in the community.

They are writing these guidelines because countries are not doing enough to close institutions and make sure everyone can live in the community.

Introduction

In 2018 at the Inclusion International Global Self-Advocacy Summit self-advocates created Calls to Action for Inclusion.

Two of the Calls to Action were:

We demand that all institutions are closed and that no new institutions or institutional type settings are built again.

We demand to be included and be part of our communities.



Introduction

To make sure that the voices of self-advocates are part of the CRPD Committee's guidelines, Inclusion International ran meetings during 2021 for self-advocates.

In this report we will share:

- what self-advocates said about the situation on institutions and living in the community;
- what self-advocates have worked on and good examples of this work;
- the recommendations self-advocates have, these are the most important things that we think should happen to close institutions and make inclusion in the community real.

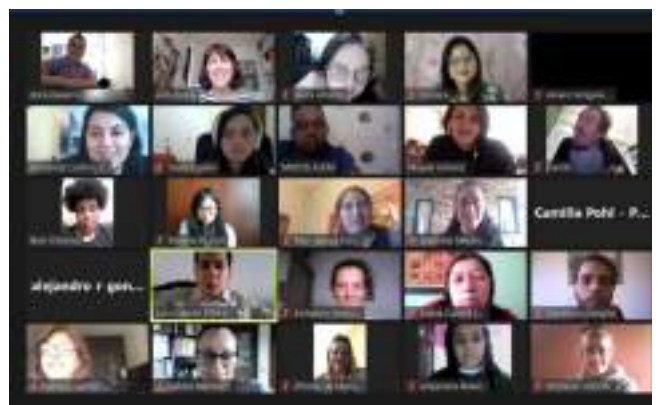


How we ran our meetings

Inclusion International worked with a team of self-advocate leaders through our Empower Us programme to create a plan to meet with self-advocate members around the world.

At each meeting we talked about:

- the work self-advocates have done on closing institutions;
- the work self-advocates have done on making communities inclusive;
- the services or support that should be available so people with intellectual disabilities are included;
- what governments should do to make sure all types of institutions are closed.



How we ran our meetings

Regional meetings



- **North America** - Canada and USA
- **Latin America** - Mexico, Colombia, Brazil, Argentina, Peru, Spain
- **Europe** - Belgium, Hungary, Romania, Austria
- **New Zealand and Australia**
- **Middle East and North Africa** - Egypt, Palestine, Sudan, UAE

Country meetings



- Hong Kong, China
- Malaysia
- Mauritius
- Benin
- Tanzania
- Moldova

To write this report we also looked at other information self-advocates shared with us about closing institutions and living in the community, including our [2012 Global Report on Living and Being Included in the Community](#).

Section 2

Self-advocate
experiences of
closing institutions
and living in the
community

North America



What is happening?

There are many active self-advocacy organisations and networks in North America. Closing institutions has been an issue that self-advocates have worked on for a long time.

Self-advocates said that there are still many large institutions where people with disabilities live. Awareness of institutions is not good.

Self-advocates said institutions are hard to close because:

- there are few good places for people to move into;
- governments think moving people will be too expensive;
- staff who work at institutions want them to stay open so that they can keep their jobs;
- families think their children are safest in institutions, they do not know about other options.



Institutions are not going away. Unfortunately, it's an industry. Even if they close the big ones, you have to keep watching. They are opening up, under different names.

Self-advocate, Canada

North America



Self-advocates said institutions are hard to close because:

- families may not know that institutions under different names are still offered as places for their children to move to;
- governments and other people in the community do not understand about institutions and the rights of people with intellectual disability, so there is not much pressure from the public to close institutions.

Self-advocates said that they face discrimination in the community which means they are not included. Self-advocates talked about the lack of job opportunities as a big issue.

Self-advocates said that support workers and caregivers in the community are not trained about human rights and are paid badly. This means that there is often not good support to help people be part of the community.

People need their own individual services. Not be stuck with 5 or 6 roommates. No one else is required to do that apart from the disability community. We want our own space. Our system does not allow that.

Self-advocate, USA



North America



What are self-advocates doing?

Activity

Example



- Self-advocates are part of decision making about services in the community for people with intellectual disabilities.
- In Canada the Deinstitutionalization Task Force brings together families, service providers and self-advocates to monitor and give advice to government.



- Self-advocates are sharing their stories to raise awareness of their human rights.
- In Illinois, USA the Going Home Coalition encourages advocacy and shares success stories from people who have moved out of institutions.



- Self-advocates are supporting people to leave institutions and move into the community.
- Self-advocates from SABE member groups have worked on helping people in institutions to develop self-advocacy skills such as decision making.



- Self-advocates are advocating, using the law and are part of campaigns calling for the closure of institutions
- People First of Canada supported self-advocates to use the law to defend their rights. A recent case was about discrimination and people being forced to live in institutions.

Latin America



What is happening?

Self-advocacy in Latin America is growing quickly.

There are many active groups in the region. Self-advocacy groups often work closely with family organisations.

Self-advocates said that there was little awareness and understanding of institutions in Latin America. There are large institutions which are often a last resort for poor or desperate families. People who live in institutions rarely leave. Self-advocates said there is very little work done by governments to support people with intellectual disabilities to leave institutions.

Most people with intellectual disabilities live and are supported by their families. However self-advocates said that families can be overprotective of their children with intellectual disabilities and need more information and services to support their children's rights.



If we don't have a family that is well prepared, that is well informed, life for us is difficult. If we have a family that can support us, we are able to go out into the world and live actively in society.

Self-advocate, Brazil

Latin America



Self-advocates said that they face many barriers to being included in the community:

- attitudes in the community towards people with intellectual disabilities are not good;
- legal capacity and guardianship laws stop people from living the lives that they choose;
- discrimination and exclusion especially in education and employment;
- information and communication about community services are often not accessible, this means that people with intellectual disabilities are left behind.

For a 100% independent life, you need a job and, at least here in Mexico, opportunities for jobs are few. I think we need to concentrate on employment inclusion.

Self-advocate, Mexico



Latin America



What are self-advocates doing?

Activity

Example



- Self-advocates are working together to understand rights and develop advocacy skills.

- IJC in Brazil developed a programme with self-advocate leaders to help people with intellectual disabilities understand their rights and challenge legal capacity laws.



- Self-advocates are sharing their stories to raise awareness of human rights.

- In Colombia through Asdown self-advocates lead training for university students on the rights of people with intellectual disabilities.



- Self-advocates are campaigning for information and services in the community to be accessible.

- In Argentina self-advocates are employed with Fundación Visibilia to create accessible information for all. This includes information about local services.



- Self-advocates are advocating, using the law and are part of campaigns calling for inclusion in the community.

- SPSD self-advocacy group in Peru meet regularly and have successfully campaigned for change of laws, including the right to vote.

Europe



What is happening?

Across Europe there are many self-advocacy groups. Some belong to national networks and the European Platform of Self-Advocates (EPSA). Closing institutions is an important issue that self-advocates work on.

Self-advocates in Europe said that although closing institutions is happening in many places, the situation in Europe is still not good. People moving out of institutions do not have real choice about where they live, who they live with and what they do with their time.

Self-advocates were worried that people in the community do not have control of their lives, they said supported living homes or group homes are often the only option for people with intellectual disabilities to live with support.



Its not getting any better for me. I have been waiting over two years for independent living. There are so many people on that waiting list. I want my own future. I want my own space.

Self-advocate, Ireland

Europe



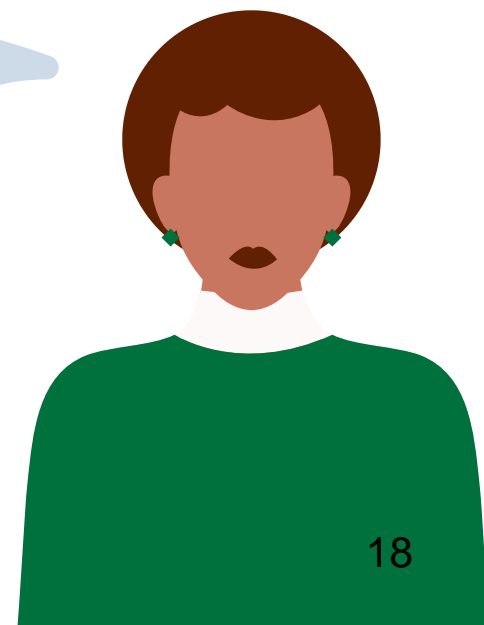
Self-advocates said day centres, special college courses and sheltered workshops are often the only places where people can spend their time.

Self-advocates said that it is difficult for all people with intellectual disabilities to live independently because:

- there is no good housing to rent or buy;
- individual budgets and personalised support are hard to get;
- legal capacity and guardianship laws mean that people are not allowed to make their own decisions;
- finding a job is difficult, it is hard to earn money to support yourself and manage bills;
- people leaving institutions need a lot of extra support to move from life in institutions, like mental health support.

Persons with disabilities were abandoned in institutions so they do not know how to be included. They have different needs than the persons that lived with their families. They need a lot of support.

Self-advocate, Romania



Europe



What are self-advocates doing?

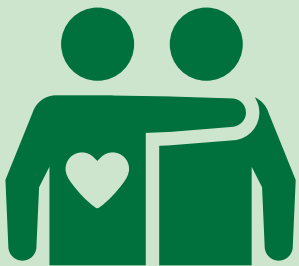
Activity

Example



- Self-advocates are part of decision making about services in the community for people with intellectual disabilities.

- In Romania self-advocacy organisation Ceva De Spus and a national disability service provider worked to develop a community housing service for people leaving institutions.



- Self-advocates are supporting people through leaving institutions and moving into the community.

- In Moldova self-advocates who have moved out of institutions speak to people still in institutions, to help people who are afraid to move understand about community living.



- Self-advocates are sharing their stories to raise awareness of their human rights.

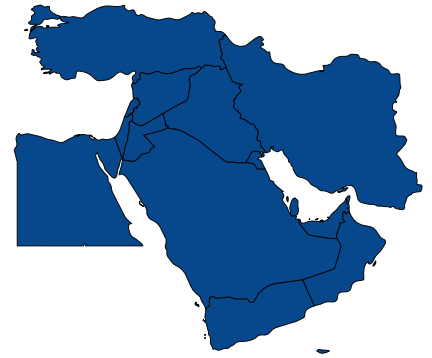
- The Hidden Now Heard project from Mencap Cymru resulted in a museum exhibition and a podcast.
- Inclusion Europe's Life After Violence report was based on the experiences of women who had lived in institutions.



- Self-advocates are advocating, using the law and are part of campaigns calling for the closure of institutions.

- In the UK the #right2home campaign demands inclusion and shares good examples of people living in the community.

Middle East and North Africa

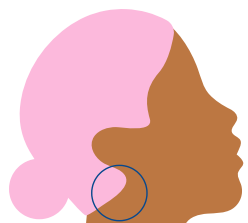


What is happening?

There are a few well supported self-advocacy groups in the Middle East and North Africa . Recently there have been regional self-advocate events that have helped self-advocates to connect.

Self-advocates said that there was little awareness and understanding of institutions in the Middle East and North Africa.

Self-advocates said that most people with intellectual disabilities live with and are supported by their families. There are large institutions in the region which are run by private organisations and by governments. People who live in institutions rarely leave. Self-advocates said they had not been part of any work on closing institutions.



I suffered a lot. I spent years moving from one institution to another. I was beaten. The food was very bad. My dream is to find a place where I can be comfortable.

Self-advocate, Egypt

Middle East and North Africa



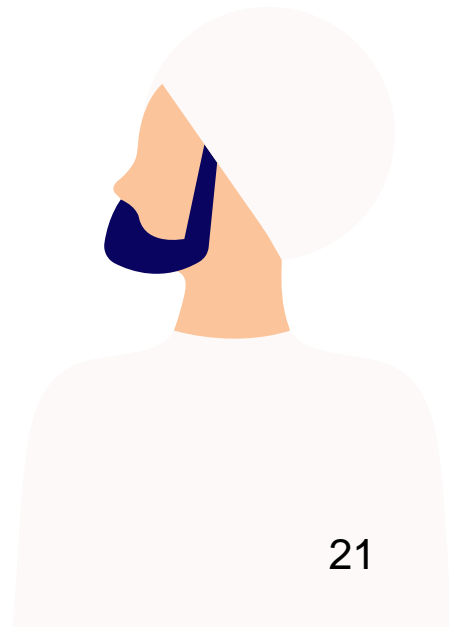
Self-advocates said that there were other places where institutionalisation happened. For example, day services that are far away from the cities. The people using the service have no choice or control about how they spend their time and are not included in community life.

Self-advocates spoke about the discrimination they face in the community. Self-advocates said that there are few options available to live independent lives. In particular self-advocates spoke about the exclusion they face in education and employment and information on services not being accessible.

Self-advocates also spoke about the lack of support for their families from governments and services.

I want support that respects my choices.

Self-advocate, UAE



Middle East and North Africa



What are self-advocates doing?

Activity

Example



- Self-advocates are working together to understand rights and develop advocacy skills. Strong self-advocates advocate for inclusion in their community.

- In Egypt the Alexandria Self-Advocacy Resource Centre run regular sessions on the CRPD. The group have created an Easy Read Arabic version of the CRPD to support self-advocates to understand rights.



- Self-advocates are advocating, using the law and are part of other campaigns calling for inclusion in the community.

- In Lebanon through the Lebanese Association for Self Advocacy self-advocates have campaigned on inclusion in the community for refugees with intellectual disabilities who are at extra risk of exclusion.



- Self-advocates are campaigning for information and services in the community to be accessible.

- In UAE through SCHS self-advocates have been part of recent campaigns on accessible information and creating some Arabic standards for accessible information.

Africa



What is happening?

There are a some well organised self-advocacy groups in Africa. Many work with local or national family organisations. Recently there have been some regional events that have helped self-advocates in the region to connect.

Self-advocates said that there is a lack of understanding about people with an intellectual disability. People face discrimination and prejudice in the community. Self-advocates said there is not good information on how many people with disabilities there are so this makes it hard to check if they have good lives.

Self-advocates said that families get very little support from governments. Sometimes this means that families will lock their children away at home or abandon their children. Self-advocates said children with intellectual disabilities who have been abandoned by their families often live in institutions like orphanages.



Families locked away their children for many reasons. We should understand the reasons so we can address these barriers so people with intellectual disabilities can be free.

Self-advocate, Tanzania

Africa



There are other places other than housing where institutionalisation happens.

For example, prayer camps where people with intellectual disabilities are sent to be 'cured' of their disability. Self-advocates said there is little work being done by governments to help people leave these places and have choice and control in their lives.

Many of the self-advocates said that they did not feel like their rights were respected in the community. Self-advocates said more needed to be done to make sure families and people with intellectual disabilities understood their rights, and can get the services and support they need.

In particular self-advocates spoke about the importance of education, training and employment and community healthcare services like nurses.

Parents in Benin suffer a lot because they often do not have state support in the education or care of their children. So I think the question is how to help these parents to be independent so that they can help their children to be independent as well.

Self-advocate, Benin



Africa



What are self-advocates doing?

Activity

Example



- Self-advocates are working together to understand rights and develop advocacy skills. Strong self-advocates advocate for inclusion in their community.

- In Zanzibar, Tanzania self-advocates are trained on the CRPD and work with ZAPPD to raise awareness and advocate for inclusion.
- In Mauritius a network of self-advocacy groups supported by Inclusion Mauritius develop self-advocacy skills.



- Self-advocates are supporting people through leaving institutions and moving into the community.

- In Benin through La Chrysalid self-advocates speak to families on rights of their children with intellectual disabilities to stop families locking or hiding children away in their homes.



- Self-advocates are part of decision making about services in the community for people with intellectual disabilities.

- In Kenya self-advocates from KAIH have met with government officials to share recommendations on different issues. For example on how education should be inclusive of people with intellectual disabilities following COVID 19.

Asia

What is happening?



Across Asia there are many local and national self-advocacy groups and networks.

Self-advocates said that governments, professionals and families often think institutionalisation is what is best and safest for people with intellectual disabilities. Few governments are working on closing institutions. Self-advocates were not aware of any work happening on closing institutions in the region they were part of.

Self-advocates said that in the community there was a lack of understanding about people with intellectual disabilities. People with intellectual disabilities are not supported to make decisions and have very little choice or control over their lives.



People in the community need to know that people with learning disabilities are natural, it's not something to be afraid of.

Self-advocate Malaysia

Asia



Self-advocates said that inclusion in the community is difficult because:

- governments do not understand the rights of people with disabilities and the CRPD;
- there is a lack of good housing and little choice for people;
- families get poor social protection services from governments;
- 'special' services are common and community services are not inclusive, in particular self-advocates mentioned education and employment;
- information about community life is not accessible.

I want to be independent but the services are not accessible!

Self-advocate, Hong Kong



Asia

What are self-advocates doing?



Activity

Example



- Self-advocates are working together to understand rights and develop advocacy skills. Strong self-advocates advocate for inclusion in their community.

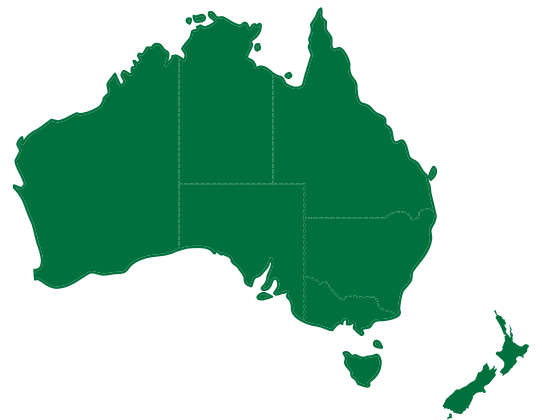
- In Hong Kong self-advocacy group Chosen Power have run training on the CRPD and Article 19 for self-advocates. Chosen Power have also ran supported decision making training for families.
- In Nepal self-advocates meet regularly through PFPID and Association of Persons with Intellectual Disabilities Nepal to speak about rights and run training sessions to develop advocacy skills.



- Self-advocates are sharing their stories to raise awareness of their human rights

- Self-advocates from United Voice in Malaysia have shared their experiences through radio shows and created information for people in the community to raise awareness of their rights
- In Bangladesh self-advocates from SEID have started a YouTube channel to share their stories of being included in the community.

Australia and New Zealand



What is happening?

Self-advocacy in Australia and New Zealand is well organised with many local and national level organisations. Closing institutions has been an important issue that self-advocates have successfully worked on.

Self-advocates said that they were concerned that small group homes and supported living services have replaced larger institutions, which have almost all closed.

Self-advocates felt that many people with intellectual disabilities, including people who live in the community do not have any choice in the support that they receive or control about how they spend their time.



I live in my own home with government support. We need to decide what works for us.

Self-advocate, Australia

Australia and New Zealand



Self-advocates spoke about how special schools, respite care and sheltered workshops could also be described as institutions because people with intellectual disabilities do not have choice and control.

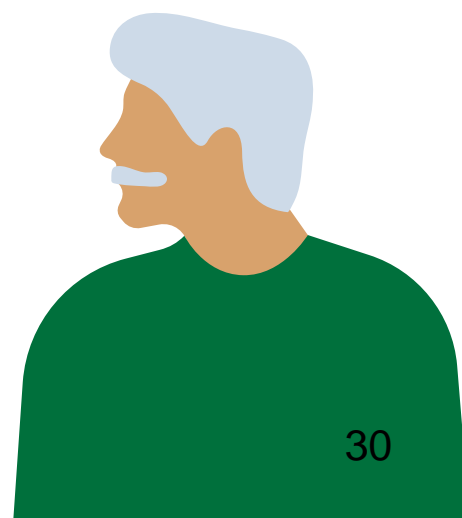
Self-advocates talked about why stopping institutionalisation in services was difficult:

- Governments do not understand the issue and human rights of people with intellectual disabilities are not respected.
- People with intellectual disabilities are not listened to by services.
- People who have been institutionalised for a long time can be scared of change.

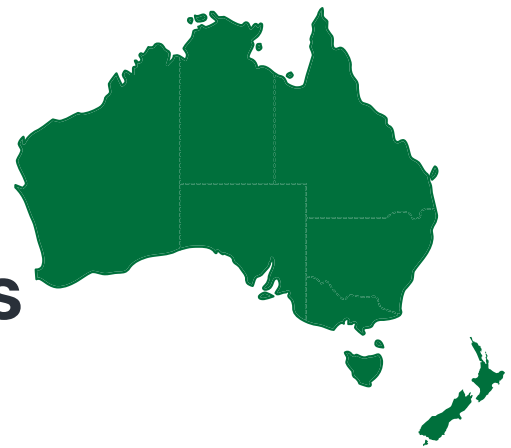
Self-advocates also spoke about discrimination and exclusion they faced in community services, in particular health services.

They have cut the big institutions down to smaller ones

Self-advocate, New Zealand



Australia and New Zealand



What are self-advocates doing?

Activity

Example



- Self-advocates are sharing their stories to raise awareness of their human rights.

- Self-advocates from People First New Zealand worked with the Royal Commission looking into abuse. Self-advocates shared their stories and gave recommendations so that abuse in care does not happen again.



- Self-advocates are advocating, using the law and are part of campaigns calling for inclusion in the community.

- Self-advocates at VALID in Australia come together to work as community Peer Action Groups to advocate for inclusion in their communities.



- Self-advocates are part of decision making on services in the community for people with intellectual disabilities.

- Self-advocates in Australia are trained through VALID to check group homes and other services to make sure that residents have choice and control in their lives.



- Self-advocates are working together to understand rights and develop advocacy skills. Strong self-advocates advocate for inclusion in their community.

- People First New Zealand work with their member groups across New Zealand to train self-advocates on the CRPD and advocacy.

Section 3

Global recommendations

Recommendations

These are the most important things that, we, self-advocates from around the world say need to happen to make sure that we can leave institutions and live good lives in the community.

Close institutions



- Institutions deny us our basic rights.
- We demand that all institutions are closed.
- We demand no new institutions or institutional type settings are built again.

Include us in the community



- We demand to be included and be part of our communities.
- To be included we need:
 - affordable, accessible and safe housing;
 - the right support, information, and transportation;
 - to vote and be active citizens.

Recommendations

Understanding and Awareness



- Build awareness of institutions and institutionalisation, especially in organisations that provide services to us.
- Support communities and services to understand our rights and how they are protected by the CRPD.
- Help our families and the services we use to understand about supported decision making. This is when we get help from people we choose and trust to understand our options and make decisions about our own lives.

Self-Advocacy and Empowerment



- Fund and support our self-advocacy organisations and activities so we have the skills to advocate for closing institutions and inclusion in community.
- Developing self-advocacy skills helps us to speak up for our rights. Support people with intellectual disabilities who live in institutions to develop self-advocacy skills such as:
 - decision making;
 - confidence building;
 - understanding of rights.

Recommendations

Laws and Policies



- Include us in making the laws about closing institutions.
- Include us in the committees that governments and services are accountable to.
- There should be no guardianship or legal capacity laws that stop us from having control of our own lives. Every person with intellectual disabilities should be supported to make decisions about their own life.
- Make sure laws to close institutions and to protect people from being institutionalised are followed. If services do not follow the law there should be consequences.

Funding



- Governments should not fund any organisations that run institutions or institutional type services. This includes places like:
 - Special schools,
 - Sheltered workshops.
- Each person moving from institutions to the community should have their own budget to pay for individual support based on their needs.
- Make sure the money follows us from the institution when we are moving into the community.

Recomendations

Moving into the community



- Make sure we have the support we need to make decisions about our lives in the community.
- Include us in the planning and decision making of projects on closing institutions and moving into the community from the start.
- The process for closing institutions should be planned well. Big changes too fast and not well planned can lead to more harm. Make sure there is time:
 - for us to learn the skills we need to live in the community;
 - to have good options and support to choose;
 - to have the support that we need ready for us.
- Provide training on independent living skills based on each person's needs, so that we are not dependent on support service organisations.

Housing



- Build safe and affordable housing in the community.
- Our housing needs to be close to health services, shops and accessible transport.
- Be aware that places where groups of people with intellectual disabilities live together such as group homes are likely places for us to experience institutionalisation. Pay extra attention to these places to make sure we have choice and control over our lives.

Recommendations

Families



- There should be social protection support for our families to make sure they can support us as we grow up. For example; caregivers allowances, respite services and early years services.
- Provide education for our families on rights and advocacy so they understand the type of services we should receive.

Services in the community



- Make sure there are employment services and opportunities in the community so we can earn money to support ourselves.
- Social protection services, like health services should understand about our rights and be accessible.
- Make sure there is good mental health support in the community for people leaving institutions.

Information



- Provide training and information about community services so that we can understand how to get the support we need.
- All information should be accessible. For example information should be available in Easy Read, or video.
- Information should be shared in accessible places. For example through organisations that represent us, with our families and support workers and through social media.

Recomendations

Support workers and caregivers



- Include us in the recruitment and training of support staff and care workers.
- Pay our support workers and caregivers a good wage so that they are happy at work. They do an important and difficult job.
- Make sure there are options of support or care services so that we can choose what is best for us.
- Make sure support workers and care givers understand we should make decisions about our own lives. They need to understand about about supported decision making.
- Support workers or care givers who work with people who have moved out of institutions should have extra training on how to support people to live in the community.

Checking and evaluation



- Include us in checking and evaluating services and service providers.
- Government representatives and decision makers should spend time in institutions and talk directly with people who have survived institutionalisation so that they understand what life is like.
- The CRPD committee should develop a stronger way of monitoring institutionalisation in countries.
- Encourage supported decision making across all services.

Section 4

Glossary and Thank you

Glossary

A glossary is a list of words. It explains the meaning of words that can be difficult to understand.

Accessible - is when something is easy for everyone to understand or use. If people with intellectual disabilities can do something with the same amount of time and effort as people who do not have a disability, we describe that as 'accessible'.

Advocacy - is what a person or group does to try to influence or change big decisions. For example a group may advocate together to change a law that is unfair.

Campaign - is organised work to achieve a goal. For example a group may run a campaign on social media to raise awareness of an issue.

Community - is a group of people who are connected to each other. For example, people who live in the same town are a community.

Discrimination - is when you are treated badly because of who you are. For example, this could be because of your disability, race, religion, or gender.

Governments - are the official group of people that lead and make decisions about our lives. Governments are often decided by public votes.

Guardianship laws and legal capacity laws - are laws that mean other people can make decisions for you. People with intellectual disabilities are often under these laws because law makers think we are not able to make our own decisions.

Glossary

Rights - Human rights are the freedoms that belong to every person in the world. Human Rights are there to help make sure we are safe, happy, part of our communities and are able to achieve our best.

Service providers - are organisations that give services to people. For example housing, support or care, or activities.

Sheltered workshops - are places where all of the workers are people with disabilities. Usually the people who work at sheltered workshops get very low pay or no pay. They are not inclusive.

Social protection - is about how governments support people to be part of communities and overcome challenges. Social protection is especially important for people who may face more barriers to inclusion like people with disabilities, or people who are poor.

'Special' schools or colleges - are places where children or people with disabilities are taught separately. 'Special' schools or colleges and other 'special' places where people with disabilities are separated from other people in the community are not inclusive.

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