

Guidelines on Closing Institutions

Plain Language transcript of accessible
videos



Based on the "Guidelines on
deinstitutionalization, including in
emergencies" written by the Committee on
the Rights of Persons with Disabilities (2022)

Introduction

Welcome to the guidelines on closing institutions. These guidelines are about what countries must do to close institutions and make sure everyone has good lives in the community.

The guidelines were made by the United Nations Committee on the Rights of Persons with Disabilities. This is a group of experts who make sure that countries are respecting the rights of people with disabilities.

These guidelines were made because countries around the world have made an agreement called the Convention on the Rights of Persons with Disabilities. This agreement and other laws say that countries must close institutions.

But, many people with disabilities are still in institutions.

These guidelines explain what countries need to do to close institutions. You can use these guidelines to understand what your country should be doing!

We hope you find these guidelines useful.

Parts of the Guidelines

There are different parts to these guidelines, each part covers a different topic.

The parts are:

- [What is an institution?](#)
- [What happens when people live in institutions?](#)
- [What does deinstitutionalization mean?](#)
- [What do governments need to do to close institutions?](#)
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What is an institution?

Institutions are places where people with disabilities have to live or spend a lot of time because of their disability.

Institutions are supposed to provide people with disabilities with care or treatment.

An institution is any place where people with disabilities:

- live together in groups;
- do not have a choice about who they live with;
- are not part of the day-to-day life in their neighbourhoods;
- do not have control over their daily decisions;
- do not choose the people who are supposed to care for them;
- do not choose how they are cared for;
- do the same thing every day.

- do activities with lots of other people with disabilities in the same place. These activities are decided and controlled by other people, like the staff.

There are many types of institutions.

There are many different names. They could be called:

- Long stay hospital
- Nursing homes
- Special boarding schools
- Group homes
- Homes for children
- Sheltered or protected living homes
- Treatment centres

But these are just a few of the names

Even when a place is not described as an institution by the people who work there, it can still be an institution.

Institutions are often separate from our communities.

Communities are places where people live, go to school,

work and have fun together. A town or a neighbourhood is a community.

People with disabilities have the right to take part in the community just like any other person.

What happens when people live in institutions?

All around the world people with disabilities are suffering because they live in institutions.

- People who live in institutions are treated badly. For example, they may be hit, locked in rooms, and called names.
- People who live in institutions face sexual abuse, this is when someone touches your body without your permission.
- They may be forced to take drugs.
- People who live in institutions cannot leave the institution and go where they want to in their neighbourhoods.
- People who live in institutions are forced to do things they do not want to do.
- People who live in institutions cannot make their own decisions and live the lives that they want to. They

cannot have their things. They have to share their space.

The human rights of people with disabilities are not respected when they live in institutions.

This is why living in institutions must end.

What does deinstitutionalization mean?

Deinstitutionalisation is a long word that means that people leave institutions.

When people with disabilities leave institutions, governments must make sure they:

- are safe;
- are not poor or homeless;
- have money to pay for the things they need like food;
- are respected and are treated well by others;
- have information about services they can use, for example, easy information about healthcare;
- have the support they need to live their lives have choice and control of their own lives;
- can decide where and with whom they want to live.

What do governments need to do to close institutions?

The first thing governments must do to start closing institutions is change the laws

Laws should make sure people with disabilities:

- can make their own decisions;
- have the support they need to make these decisions;
- be treated the same as everyone else by the law. For example, they must have the same right to open a bank account, sign a contract or buy a house if they want to.

Laws should help people with disabilities to get help if crimes have happened to them or if their human rights have not been respected. This is called Access to Justice.

There should not be any laws that allow people with disabilities to be placed somewhere that they cannot leave.

There should be laws that make sure services, like schools or healthcare include everyone.

When governments are planning the new laws they should include people with disabilities. People with disabilities know what services and support governments need to provide so people can live good lives in the community.

People who want to keep institutions open, like doctors and lawyers, should not be part of the process of closing institutions.

After changing the laws, the next thing governments must do is understand the institutions in their country.

They must find out about where the institutions are, the number of people who live there, where they get their money, and who works there.

Governments should find out about each person living in an institution and what is important to them.

They should find out about the different support and services available in communities, so they can offer people what they need to live good lives.

What are some of the problems with closing institutions?

Closing institutions can be very difficult. This is because there are often no good services or support in the community

governments do not always know how to create good laws and services for people.

Sometimes governments do things like:

- 'improve' institutions, like making changes to the building;
- add more beds to institutions;
- replace a large institution with smaller ones;
- rename an institution.

But this is not the same as closing institutions!

Governments should not:

- Build new institutions

- Improve institutions
- Move new people into institutions

Another problem is that for many people with disabilities in institutions, the institution is the only place they have lived. They might feel very worried about leaving a place they know to live in the community where they have never been.

Sometimes governments:

- say that is a person's choice to live in an institution;
- say that an institution is the only place where a person can be protected;
- say that some people are too disabled, too challenging, too weak or in too much of an emergency to live in the community.

But this is not right!

People cannot choose to live in an institution. When people choose to live in an institution, this means that there was not enough support to help them to understand their choices or not enough support provided for them to live in the community.

Some people with disabilities may have emergencies in their life but this should not be a reason to put them in institutions or force them to take drugs.

The right to be included in the community

All people have the right to live and be included in the community.

Communities are places where people live, go to school, work and have fun together. A town or a neighbourhood is a community.

People with disabilities have the right to take part in the community just like any other person.

Institutions are often separate from communities

When people leave institutions, governments must make sure every person with a disability has:

- choice and control of their lives;
- the support they need to live good lives in the community;
- be able to use services that everyone else uses;
- have the money to pay for the things that they need.

The right to make decisions

Every person has the right to choose and make decisions about their own life. This includes people who are leaving institutions.

People with disabilities must be able to choose from different options when they leave institutions. They must choose the place they will live. They must choose the support they will get.

If the person needs help to understand the options and make decisions they must get that support.

Other people must respect the choices and decisions of people with disabilities, even if they think they are unwise.

Governments must make sure every person with a disability has their legal capacity so that they can control their own life.

Legal capacity means people with disabilities are treated the same as everyone else by the law and can make their own decisions. For example, people with disabilities must

have the right to open a bank account, sign a contract or get married if they want to.

The right to support

Support is the help that every person gets to live their lives. We all get support at different points in our lives. This may be from our family, from our friends or from people who are paid to help us.

Every person has the right to the support that they need to be part of their communities.

People may need support to:

- Make decisions
- Live independently
- Travel around in their neighbourhoods
- Talk with others
- Go to school
- Do their jobs
- Use services, for example, healthcare

People with disabilities should get support based on what each person needs.

Decisions about what support people with disabilities need should not be made by healthcare professionals like doctors.

Each person with disabilities should be part of planning and making decisions about what they want and need.

Governments must make sure that there are different types of support available.

When governments are planning support services they should talk to people with disabilities to find out what is needed.

Support can be provided through services, for example, paid personal assistants or support workers.

Support can also come from friends or family in their community or through groups of other people with disabilities.

Governments should make sure families who are giving support also have access to the support they need, like respite or counselling so they can stay healthy and give good support to their family members with a disability.

Supporting families should not include placing family members with disabilities in institutions.

Support should:

- be available wherever people live, including in small towns or countryside areas;
- be flexible;
- be accessible to all people with disabilities;
- be right for the different places people live and the different cultures people have;
- not be expensive;
- have ways for people with disabilities to report if support is not good for example if they are being abused.

The right to use services the same as everyone else.

When people leave institutions they should be able to use the same services as everyone else.

Services are the places we all use in our communities. They help us to live good lives.

Services are places like:

- Healthcare services like dentists or the doctors
- Employment services, where people find jobs
- Education services like libraries or colleges
- Leisure facilities like sports clubs
- Transport services like busses or trains
- Cultural places like churches or temples
- Social protection services, which are places we can get help so we do not become poor or homeless.

Governments should make sure all services are easy for people with disabilities to use and get to.

Government should make sure there is easy-to-understand information about services

Governments should make sure the people who work in these services understand how to support people with disabilities.

Special or segregated services are **NOT** inclusive. This is places like:

- “Special” schools or colleges
- Sheltered workshops
- Day centres
- Hospitals or centres for people with disabilities

Paying for the closure of institutions

Funding is the money that pays for the support and services that people need when they leave institutions.

Governments must make sure there is enough funding to make sure people with disabilities live good lives.

Funding should be available for people when they need it.

People with disabilities should get the funding they need to pay for the extra costs that come from having a disability.

For example, to pay for medication.

People with disabilities should get-funding to help repair the harm caused by institutions.

Technology that people with disabilities may need, like communication devices or wheelchairs should be available and affordable.

People with disabilities who have jobs should also get the funding they need, they should not have to choose between having a job or getting funding.

Governments should make sure that people with disabilities can manage their funding, for example, to buy the support services they may need.

The rights of different groups of people leaving institutions

All people with disabilities have the right to be included in the community.

But people with disabilities can face more barriers to being included in communities. This is called discrimination.

Other groups of people can also face discrimination. People are more likely to face discrimination if they:

- Are an older or younger person
- Of a different race
- Are a woman
- Are gay or have another sexual orientation
- Are religious
- Speak another language.

People with disabilities can also belong to these groups. When this happens they may face more discrimination.

For example, a gay woman with a disability may face discrimination because she has a disability AND because she is a woman AND because she is gay.

Different groups of people may face extra barriers when they are leaving institutions.

- Women and Girls with disabilities are more likely to face violence and abuse when they are in institutions. Women and girls may need more support when they leave institutions.
- Older people with disabilities may have extra health problems. Even if older people with disabilities are unwell they should not have to stay in institutions. They should also not have to move into an institution because of their age. governments should make sure older people get the support they need in the community.

The rights of children leaving institutions

All children have the right to grow up in a family, including children with disabilities. For children, an institution is any place that is not a family.

A family can be different for different people:

- Married and unmarried parents
- Single parents
- Same-sex parents
- Adoptive families
- Extended family
- Foster care.

Support for children with disabilities and their families should be made as early in a child's life as possible

Children with disabilities should be included in the same services as all other children. They should be included in schools and receive an inclusive education. Services that

support children with disabilities must be inclusive and caring places.

When children are separated from their own families, for the short or long term, they should be placed within another family.

Children and young people with disabilities cannot choose to live in an institution.

Children and young people should be listened to on the support they need. They should get the support they need that is right for their age, gender and disability.

Children with disabilities should have access to support from other children.

Children with disabilities and their families should have access to easy information on their rights, so they understand what institutions are and why they should not have to live in institutions.

If a person with a disability is a parent, governments should give them the support they need so that they can look after their children.

Closing institutions in emergencies

Emergencies are things like:

- Health emergencies, for example, the COVID-19 pandemic
- Natural disasters like earthquakes or heat waves or floods
- Conflicts and wars.

During emergencies people with disabilities are more likely to be at risk of bad things happening to them. For example during an emergency people with disabilities may be given treatment last by hospitals. The human rights of people with disabilities should always be respected.

Closing institutions should still happen during emergencies. It should happen more quickly so that people with disabilities who have been forced to leave their homes because of an emergency do not end up in institutions. This includes women, children and older people.

When there is an emergency sometimes organisations and other countries help by sending people or giving money.

This is called aid.

Aid workers should understand closing institutions. Aid should help all people, including people with disabilities. Aid money should not go to institutions.

During emergencies, governments and aid workers should talk to people with disabilities to find out what they need to get through the emergency.

After emergencies, institutions should not be rebuilt. People who have moved out of institutions should not have to go back.

All people with disabilities should have support so that they can rebuild their lives

Preparing to leave an institution

People leaving institutions should be respected as the decision maker and be involved in planning for when they leave an institution.

The people who work in institutions should get training on Human Rights so that they understand why closing institutions must happen.

Each person's plan should be just for them. Their plan should be about their personal choices and decisions.

A person leaving an institution can decide if they want to include family members, friends and other trusted people in their planning.

Family members and friends should get information and support so they can help the person leaving the institution.

As people are getting ready to leave an institution they should get information about houses, transport, employment and other services.

People must have enough time and support to prepare for living in the community. Preparing could be about getting ready physically, like building up their strength or it could be about getting ready emotionally like talking through their worries.

People may face problems getting important documents. For example birth registration or identity documents.

Governments must make sure these problems are solved for people leaving institutions.

When people with disabilities leave an institution, they should get all their personal information. For example their administrative documents and their medical documents.

Governments should make sure people leaving institutions can access justice.

Accessing justice is what happens when people get help if a crime has happened to them, laws have been broken and their human rights have not been respected. For example, if a person with a disability was treated very badly by a staff person in an institution the staff person should answer for

their crime. If this happens the person with a disability gets justice.

There should be support and easy-to-understand information about getting justice. The process of accessing justice should be easy

People who have left institutions and people living in institutions should be able to be witnesses of a crime. This means that they should be allowed to call the police, explain what happened, and be heard and respected by the justice system.

Governments should apologise to people leaving institutions.

Governments should raise awareness about how bad institutions are and how people who have lived in institutions have suffered.

Governments should try and “repair” some of the hurt that was caused by institutions. This is called Reparations.

Reparations could be payments of money or other support or services.

Checking how countries are closing institutions

We must keep checking how our countries are doing on closing institutions.

We need to make sure that our governments are following the guidelines.

To make sure the plans to close institutions are happening, governments should collect information.

governments should collect information about how many people have moved from institutions and what type of places they have moved to.

governments should find out if people with disabilities are living good lives in the community.

People with disabilities and their organisations should be part of planning how to collect information and be part of collecting the information

When governments collect information about people with disabilities they should keep personal information private.

But governments can share general information so that people with disabilities, decision-makers and other interested organisations can check how closing institutions is happening.

governments should make sure that the information is shared in an accessible way.

Experts must check the process of closing institutions. This is also called monitoring.

The experts should be independent. This means that they are not controlled by the Government.

The experts should check to make sure that the rights of people leaving the institutions are respected and that no mistakes are made.

People with disabilities and their organisations, including survivors of institutions should be part of monitoring.

Staff who work in institutions should not be part of monitoring closing institutions.

Monitoring should continue during emergencies

Countries often help one another. This is called development.

Development help might be giving money towards a project, or advice and support through a project.

When countries help each other the development money or projects that they give should not encourage keeping institutions open. Any development money or projects should encourage institutions to close.

Development projects that are about closing institutions should be done with persons with disabilities and their organisations, including survivors of institutions.



Watch the video playlist of the
accessible guidelines here:
bit.ly/3pMHnFC

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