

Committee on the Rights of Persons with Disabilities

What living independently and being included in the community means

Plain English version of:

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**Article 19: The right to live independently and be
included in the community**

Note: Please note this is not a United Nations official document.

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1. About this paper

The **United Nations** (UN) is a place where all the countries of the world come together.

They meet to agree how to make the world a better and safer place for everyone.

Many countries sign the United Nations **Convention** on the Rights of Persons with Disabilities. This is an agreement that says persons with disabilities should have the same support and treatment as everyone else.

We are the UN Committee on the Rights of Persons with disabilities. Our job is to check that persons with disabilities all over the world get their **rights**. We help countries understand what to do to make sure persons with disabilities get their **rights**.

This paper tells you more about the Convention. It explains the part about living independently and being included in the community. This is Article 19 in the Convention.

The Convention says persons with disabilities have the same rights as other people and should be able to use them. Being independent and being part of society are important **human rights**. But many persons with disabilities face **discrimination** that takes away this **right** and choice and control over their lives.

This paper does not give persons with disabilities new **rights**. But it says what this right means and what should happen for them.

2. Living independently and being included in the community

For many years persons with disabilities had no choice and control over their lives. Other people thought they were not able to live independently in a place they chose. So countries spent money on special services away from other people, instead of support to live in the community.

Many persons with disabilities still have to live with their families or in big services away from home. When this happens, they **depend** on other people and have little freedom. This can lead to **discrimination**, bad treatment and abuse when other people do not respect them and their rights.

Persons with disabilities and their families fought to change things and asked for:

- homes in the community
- support to live in their home and community
- better **access** to services and buildings that other people use

Many persons with disabilities live in **poverty**. When countries support them to live independently and be part of the community it can help them have better lives.

Human rights law and the Convention say that everyone with a disability has the right to live independently and be included in the community. This should happen wherever people are and wherever they live. It gives them freedom, choice and control over decisions that affect their lives.

When persons with disabilities live and work with other people it breaks down **barriers** and people get to know and understand each other. This can help stop **discrimination** and abuse against persons with disabilities.

Persons with disabilities have the right to a good standard of living. This means the same right as everyone else to have:

- enough food
- a home they can get in and out of
- the basic things they need in life
- support services
- **assistive technology**

Things are getting better but people with a disability still do not have this right when:

- laws or plans take away **legal capacity** and the right to make decisions about your own life
- there is not enough support or protection to live independently in the community
- countries do not have the right laws, rules or enough money to give people the support they need
- they are forced to live somewhere they do not choose or have treatment they do not agree to

- countries keep spending money on large services away from other people and have no plans to close them
- other people think they do not have the right or the ability to live in the community
- there are not enough services like transport, housing, health, schools, theatres or public buildings that persons with disabilities can use
- countries do not involve organizations of persons with disabilities in checking that people get this right
- countries do not think about supporting persons with disabilities when they plan how to spend money
- different parts of a country do not work together to plan things

3. What should be happening

Independent living

Independent living means you have everything you need to help you have control over your life and make decisions about your life:

- somewhere to live
- information
- support to communicate
- support to care for yourself
- daily routines
- relationships with other people
- food
- clothing
- health care
- transport
- **sexual and reproductive rights**
- the chance to get involved in religious or social activities

It means you decide things such as who you live with, what you eat, when you go to bed and what you have in your home. These decisions let you be who you want to be.

Living independently does not mean doing everything on your own. It means making choices about what you want and having the support to put these choices into action.

Being included in the community

This means having a good life and spending time with other people, using the services they use and getting involved in the things they do. This includes **voting** and getting involved in **politics**.

Independent living arrangements

Independent living means you can choose who supports you, control your life and spend time with other people. Just living in your own home in the community is not necessarily **independent living**. Countries must make sure persons with disabilities can choose the support they need to make decisions and be part of the community.

Personal assistance

A **personal assistant** is someone you choose to help you live independently.

You are in control of this support because:

- you have an **assessment** to find out how much your support will cost and you decide how to spend that money to get the support you need
- you choose which organization or person supports you

- you **recruit**, train and manage your personal assistant. You only share their support with someone else if you choose to
- you choose how much support you have and when you have it. You can have support to make these choices if you need it. This includes other people thinking about what is important to you and how this might affect your choices

Sometimes services say they are 'independent', 'community living' or 'personal assistance'. But if you cannot choose who supports you, other people control your life, or you are kept away from other people then this is wrong.

What should happen for you to live independently and be included in the community

These things should happen:

- however much support they need, every person with a disability has the choice and support to live in the community and be involved in the community
- countries get rid of things that take away this right or **discriminate** against some groups of persons with disabilities
- persons with disabilities have lots of different things to choose from in the community because services, housing and buildings are **accessible** to them

- persons with disabilities have support and information to make choices and there are no rules or laws to take away their **legal capacity**
- individual support inside and outside your home is a right, not something other people decide you can or cannot have
- countries make sure there are enough people who are trained to support persons with disabilities to be part of their local community and not kept apart from other people
- persons with disabilities live side by side with other people in the local community, not in buildings or areas that are just for persons with disabilities
- it is easy for everyone with a disability to use good affordable services near their home
- children with disabilities live with and grow up with a family

Countries understand and respect that persons with disabilities only have this right when:

- they have the right to **legal capacity** to choose where they live, who they live with and how they live
- there is lots of **accessible** housing with no **discrimination** against persons with disabilities
- persons with disabilities have other choices if they want to live in the community but not with their family

- persons with disabilities can communicate, get information and use the same buildings and services as other people. Countries take action against people who do not make buildings or services **accessible**
- countries have an action plan for good **personalised** services
- countries do not go back to old ways of working unless there is a very good reason for this and they keep to international laws
- countries collect good information about the numbers of persons with disabilities who live in different places and what they think about them
- countries use any funding they can to build more independent living services where anyone can live

4. What countries must do

Countries that sign the **Convention** must understand the different types of **human rights**.

Some rights must happen for everyone without delay. Others need more planning and bigger changes to make them happen.

As soon as countries sign the Convention, persons with disabilities who live in these countries have the right to choose where they live and who they live with. Countries must get rid of laws or plans that take away this right.

It will take longer to make all services, buildings and information accessible and to set up good **personal assistance** services. But countries must have plans about how to support persons with disabilities to live independently and make communities **accessible**. If people live independently but cannot do things like use the library, go shopping or meet other people, then they are still kept apart from other people.

Countries should work on these plans with persons with disabilities and their organizations.

Countries must:

- **respect** the right for persons with disabilities to live independently and be included in the community
- get rid of laws or rules that **discriminate** against people by taking away their choices or freedom or stop them using buildings or services. This includes not building any more institutions or services that keep persons with disabilities away from other people

- protect persons with disabilities by stopping families or other people taking away their right to live independently in the community. This includes making sure 'community living' services do not take away people's freedom, choice or control in any way
- protect persons with disabilities from **discrimination** and get rid of rules or other barriers that stop them living in the community, having their own home and using all the services other people use
- carry out everything they need to do to make sure persons with disabilities can live independently and be included in the community. This means having a timed plan for closing large separate services and involving persons with disabilities and all parts of government in these plans
- set up **assessments** and the support people need to live in the community. **Assessments** must include **human rights** and how to get rid of the **barriers** that stop people doing the things they choose to. Support must be affordable and right for the person
- make sure people have **benefits** or **allowances** to help them pay for things that cost more when you have a disability. If countries have to make cut backs, they cannot give persons with disabilities less money if it means they lose their **human rights**
- give persons with disabilities clear, up to date information to help them make choices about independent living. Have rules (standards) for anyone who sets up a service to support people and make sure staff are trained about community living and **inclusion**

- make sure persons with disabilities can use the law and courts to complain or get the right to live independently in the community
- support families and carers so they can help their relative to live in the community. This includes things like childcare, respite or **benefits** if they have to stay home and care for someone instead of going to work
- keep asking persons with disabilities about the things that stop them living independently in the community and what would make things better

5. How this links with other parts of the Convention

The right to live independently and be included in the community leads to other rights such as being involved in plans for the community.

It also links with these other rights:

- To be treated equally and not **discriminated** against
- For women and girls to be treated equally with men and boys and to feel safe from abuse and violence
- To live in the community and be involved in your community and workplaces
- To have the care and support you need – including **assistive technology**
- To use public services, buildings and transport
- To travel about freely
- To be equal under the law and have **legal capacity**
- To have **accessible** information in ways you can understand – including **Braille**, sign language and EasyRead
- For other people to know it is wrong to treat persons with disabilities unfairly or badly
- To have a full life and a good standard of living
- To be part of a family

- To have good health care
- To **vote**, be on a **jury** or stand for **election**

6. How countries can make this happen

We understand that some countries will have to make lots of changes to make sure persons with disabilities can live independently and be included in the community.

Countries that sign the **Convention** can make this happen for persons with disabilities if they:

- Get rid of laws that stop people with any disability choosing where they live. This includes laws that say they can be forced to live somewhere they do not choose because of their disability
- Have laws that support the right for persons with disabilities the right to live in the community
- Tell persons with disabilities about their rights in ways they can understand
- Have laws that say buildings, services and information must be accessible to persons with disabilities. Take action against people and organizations that break these laws
- Have laws and rules to make sure all new building work is **accessible** and check this is happening
- Make sure plans for **social protection** treat people with all types of disability fairly
- Have clear, timed plans for closing down big institutions or services that keep persons with disabilities away from other people. Particularly for children with disabilities, people with learning disabilities or mental ill health

- Take action against **discrimination** by helping other people understand and respect persons with disabilities and their rights
- Work on plans for community services with persons with disabilities and their organizations
- Set aside money to pay for **accessible** and affordable, housing, transport and support in the community
- When they choose services to support people in the community make sure they know how to give people freedom, choice and control
- Set up checks to make sure they are closing large services away from other people and building new services in the community
- Involve persons with disabilities and their organizations in checking whether things are changing

7. Word bank

Access - whether something is easy to get into, understand or use.

Allowance - money that is paid to you regularly to help pay for things

Assessment- a way to find out what support you need

Assistive technology- a piece of equipment or computer programme that makes it easier for a person with a disability to do something or be independent. For example, alarms, special switches or voice operated computers.

Barrier - something physical or a rule or law that makes it difficult or impossible for you to do something

Benefit- money a government pays to someone with a disability to help them pay for things

Braille- a way of writing things so blind people can feel the words under their fingers.

Convention - an agreement between different countries

Depend - to need someone else or rely on them for help or support

Discriminate- treat someone worse than other people because of who they are.

Election - an organised way to choose members of local or national government.

Human rights - basic rights and freedoms that should happen for every person in the world.

Inclusion - being able to use the same buildings and services, take part in the same activities, and enjoy the same experiences as other people.

Independent- making choices about what you want and having the support to put these choices into action. Being independent does not mean doing everything on your own

Independent living - you have everything you need to help you have control over your life and make decisions about your life.

Legal capacity - means that anyone over 18 years old can make legal agreements or decisions

Personal assistance - support to live your day to day life and take part in everyday activities that other people take for granted.

Personal assistant- someone you choose to help you live independently

Personalized - designed or planned just for you.

Politics - being involved in local or national government.

Poverty - not having enough money to pay for the basic things in life

Recruit - a formal and organised way of choosing staff.

Respect - admire someone for who they are or what they can do.

Sexual and reproductive rights - the right to enjoy safe sexuality and keep well and healthy. The right to decide whether or not to have children and support to have healthy children

Social protection - things that give everyone the same chances in life. For example, having enough food, basic healthcare, going to school or having money to help pay for things.

United Nations - a group of 193 different countries that work together to try to make the world a better and safer place for everyone.

Vote - an organised way to choose between one or more people.