

Choice and control:

the right to live independently

Experiences of people with intellectual disabilities and people with mental health problems in nine countries in Europe

A summary

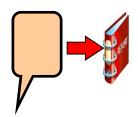


What is in this summary

Inside this summary you will read about:



Who wrote this summary? Why was this work done?



How was the work done?



How life is for: people with intellectual disabilities people with mental health problems



What did the work find out?

What will be done next?

Who wrote this summary?



The European Union Agency for Fundamental Rights wrote this summary.

The European Union Agency for Fundamental Rights is called FRA for short.

FRA is an organisation.

An organisation is a group of people working together.



The FRA has looked at what life is like for people with intellectual disabilities and people with mental health problems.



People with mental health problems sometimes find it hard to cope with the stresses of life.

People with intellectual disabilities find it hard to learn new things.



This summary will tell you about FRA's work on the right to live independently.

Living independently means that everyone has the right to choose how they want to live.



Rights are things all people are entitled to.

Another word for entitled is allowed.

For example, the right to be part of a community.

This means that all people have the right to join in things in your community along with everyone else.

Why was this work done?

Most people can:



- Grow up with their own family
- Choose where they live
- Choose who they live with
- Make decisions about their life.



People with disabilities sometimes cannot make choices about these things.

People with disabilities sometimes do not have control over their life.



The United Nations created an important document in 2006.

The document is called

the Convention on the rights of people with disabilities. It is also called Convention for short.

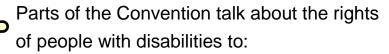


Countries who agree with the Convention must make sure people with disabilities also have the same rights as everyone else.





- People with disabilities are free to make choices about their lives.
- Everybody should be treated fairly.
- People with disabilities have the same rights to be included in society as everyone else.



- Live independently
- Be part of the community they live in







People with disabilities must be treated the same as other people by law.



People with disabilities have the same right as everyone to live where and with whom they want.



This study looked at people with intellectual disabilities and people with mental health problems.

People with intellectual disabilities and people with mental health problems are different.



Laws in Europe say that the rights of people with mental health problems and the rights of people with and intellectual disabilities must be protected.



Both groups of people are in this study because they:

- Have similar problems with their rights
- Are treated unfairly across the EU.

How was the work done?



FRA talked to people with intellectual disabilities and people with mental health problems.

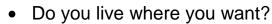
FRA also talked to:

- Politicians
- Non-governmental organisations
- Organisations that support people with disabilities
- · Families of people with disabilities.

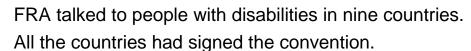
FRA asked about

the lives of people with intellectual disabilities and the lives of people with mental health problems.

For example, we asked:



- Do you get the support that you want?
- Can you do what other people living around you do, like finding a job or going to cinema?
- Have you been treated unfairly?



The 9 countries were:

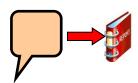








The results of the study were discussed in a meeting with people who have disability and their supporters.



This summary tells what the study says.

First we talk about people with intellectual disabilities.

After that we talk about people with mental health problems.

How is life for people with intellectual disabilities?



People with intellectual disabilities often cannot choose where to live and who to live with.



It is often difficult for people with intellectual disabilities to live in the community.

There are not many apartments where people with intellectual disabilities can live on their own or with the support they choose.



People with intellectual disabilities do not have enough money to rent or to buy somewhere to live on their own.

People with intellectual disabilities have problems finding paid jobs.

People with intellectual disabilities are often treated unfairly or discriminated against.

Discrimination is when someone is treated worse than someone else

just because they are different in one way or another.



It is hard to get a paid job for them because:

- Separate schools for people with disabilities do not give them the skills they need to find work.
- Many employers do not give them a chance.
- Work places can be difficult
 for people with disabilities to work in
 because the right equipment is not there.
 For example, information is not available
 in an easy to read format.



When people with intellectual disabilities do not work they need other places to go to, like day centres.

But places like day centres

are often just for people with disabilities and they do not meet people without disabilities.

People who work in these places do not want to take a risk with people with disabilities.

They think people with disabilities cannot do much so they choose simple things in case something happens.

This means people with disabilities may not be able to choose or decide what they want to do.

Sometimes, people with intellectual disabilities have problems to have:



- boyfriends/ girlfriends
- children

Official rules can cause these problems.

Parents can also cause these problems.

If people with intellectual disabilities

have a boyfriend/ girlfriend or

want a family this can cause arguments in a family.

Many people with intellectual disabilities cannot vote.



Many do not know how to take part in politics.

Help to take part in politics can come from groups that speak for people with intellectual disabilities and groups that let people with intellectual disabilities speak.



Laws can stop people with intellectual disabilities from making choices and deciding what to do.



There is little official information in easy to read format.



The law and courts are not easy to understand for people with disabilities.



Many people with intellectual disabilities live in institutions and care homes.

People living in institutions and care homes often do not have privacy.

Sometimes, they are not treated with respect.

People without disabilities are often not friendly to people with intellectual disabilities.



They can shout at people with intellectual disabilities.

They can hit people with intellectual disabilities.

Some parents and professional staff, like doctors, tend to think people with intellectual disabilities cannot do much on their own.

Governments have less money at the moment.

So governments have less money to help people with intellectual disabilities.

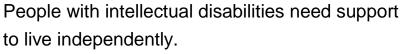


Groups that can help people with intellectual disabilities are also getting less money.

This means it is more difficult

for people with intellectual disabilities to have support to live independently.





People with intellectual disabilities should be able to choose what support they need.

In this way, they learn to live independently.



To choose the support they need to live independently, people with intellectual disabilities need to have control over their money
If people with intellectual disabilities
do not have control over their money
they do not learn how to live independently

How is life for people with mental health problems?



It is often hard for people with mental health problems to live in the community.

People with mental health problems have problems finding a job.

This is often because the mental health problems started when they were at school.



This sometimes they stopped going to school early.

Employers also do not give

people with mental health problems a chance to work.

Work places can be difficult

because the right equipment is not there. For example, information is not available in an easy to read format.

for people with disabilities to work in

People with mental health problems often do work which is not paid.

They also often work in workshops with other people with disabilities.



These workshops often do not have people without disabilities
Working in these workshops
helps people with mental health problems feel better.
But working in these workshops does not help people with mental health problems

find paid work or become part of a community.



People with mental health problems can have problems with doctors and mental health support.

Doctors say that medical problems of people with mental health problems

are because of the mental health problem even if they are separate.

People with mental health problems often get little information about medicines and treatments.



People with mental health problems think it is important to have support from groups that speak for people with mental health problems and that let people with mental health problems speak.

In some countries, these groups need support as well.



Laws also stop people with mental health problems from making choices and decisions.

This means they cannot sign work contracts or takes decisions about money or houses.



Guardians make these decisions for them.

Guardians are people who make decisions for others.

Sometimes people with mental health problems cannot choose their guardian.



People with mental health problems who have a guardian can have problems with treatment in hospitals.

They can go to hospital or

have a treatment against their will.



The law and courts are not easy to understand for some people with mental health problems.

Often they do not know if they can complain about courts.

Often they do not know how to complain.



People with mental health problems do not have privacy and are not treated with respect in institutions or care homes.



Sometimes, people without disabilities are not friendly to people with mental health problems.

They can shout at people with mental health problems. They can hit people with mental health problems. Parents and professional staff, like doctors, do not think people with mental health problems can do much.

They treat people with mental health problems as if they cannot do much.



That is why people with mental health problems often do not tell others that they have a mental health problem.

This means people with mental health problems do not get the help they need.



People with mental health problems often do not have paid jobs.

This means they need money and help from the government.

This money and help is often not enough to live the way they want.



Governments have less money at the moment.

So governments have less money to help people with mental health problems.

This means it is more difficult for people with mental health problems to have support to live independently.

People with mental health problems need different types of support to live independently. This can be:

- advice on how to live independently in the community
- support to handle money
- support to check things are safe at home, for example that the lights are off
- support when a mental health problem happens
- advice from family and friends
- support from groups that speak for people with mental health problems and that let people with mental health problems speak.
 They can help people with mental health problems decide what support is best for them.



People with mental health problems need houses in communities and they need support.
Without this they need to live with families or in institutions.

They also need help from governments or money to buy or rent somewhere to live.

What did the work find out?



From what people told us there is a lot of work to be done.

It is still hard for people with intellectual disabilities and people with mental health problems to live independently.

This means joining communities is hard.

The main problems are:

- Laws and policies do not help people to live independently.
- There are not many places
 where people with intellectual disabilities and
 mental health problems can live
 included in the community
- People with intellectual disabilities and people with mental health problems get little support to live in the community.
- People without disabilities think people with disabilities cannot do much.
- It is hard for people with intellectual disabilities and people with mental health problems to find paid jobs.
- Jobs do not pay much money.

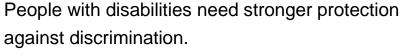


Closing institutions will only work if people with disabilities get enough support to live in the community.





To live independently and be part of society, people with disabilities need chances and help to learn how to be independent.



People with disabilities who cannot work are poorer.



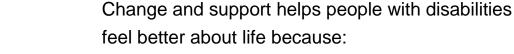
Poorer people with disabilities cannot live independently in the community.

Not being in a community means people without disabilities treat people with disabilities differently, sometimes badly.



Some countries are changing laws.

This means things are getting better for some people with disabilities.





- they are part of a community and
- they have control over their lives and
- they can make decisions about themselves.



Support can be from people like themselves or from organisations that speak for people like themselves.

This type of support has helped people with disabilities understand when they are treated unfairly and that they should be treated better.



Very often, the support comes from families. Even in families, people with disabilities need to be able to control their lives and make decisions.



Families need support to take care of their relatives with a disability and to help them live independently.



What will be done next?



People with mental health problems and people with intellectual disabilities can live independently. They need:



 Laws and different ways of helping people with intellectual disabilities and people with mental health problems make decisions.



Good support for each person
 with an intellectual disability
 or with a mental health problem.
 This does not depend on the type of place
 they live in.



 Help for families of children with intellectual disabilities and children with mental health problems.



Help not to need money from others.
 This can be through better jobs,
 or money from governments
 or paid services from governments.



 An end to discrimination so people with disabilities can work and spend their free time like people without disabilities, for example go to the cinema or play sports.







Better access to information
 that is easy to read and understand for people with
 intellectual disabilities and
 people with mental health problems.



 Support for groups that speak for people with intellectual disabilities and for people with mental health problems.
 Support for groups that let people with intellectual disabilities and people with mental health problems speak.
 These groups need to be in all countries in Europe.



 More mental health centres in the community and more mental health services.



 Help to make sure that people with intellectual disabilities and people with mental health problems can take part in politics and vote.



 More information about where to complain and about how to complain about courts.
 People with intellectual disabilities and people with mental health problems need more support when they go to court and talk to a judge.

This summary was developed thanks to the support of Inclusion Europe.