



Ministry of Culture and Equality

EasyRead version

Meld. St. 8 (2022–2023) Report to the Storting (white paper)

# Human rights for persons with intellectual disabilities

“It’s about being seen and heard”







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“It’s about being seen and heard”



# Introduction

In November 2022, the Norwegian government sent a report to the Storting (Norwegian Parliament). The report concerned human rights for persons with intellectual disabilities. The report was presented in format known as a white paper (stortingsmelding). The report was called Meld. St. 8 (2022-2023) *Human rights for persons with intellectual disabilities – It is about being seen and heard.*

This is an EasyRead version of the white paper.



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# 1

## About the white paper

### In short

In this chapter, you will read about why the government created this white paper:

- The government wants persons with intellectual disabilities to have their rights respected and fulfilled.
- The government wants to listen to persons with intellectual disabilities.
- The government held a seminar where persons with intellectual disabilities could talk about what was important to them.

### The policy is about everyone being seen and heard

The government wants everyone to be included in society. Therefore, the policy must apply to everyone, regardless of disabilities. The policy should ensure that persons with intellectual disabilities can live just as good a life as everyone else. It should also safeguard their human rights.

Human rights are important in all parts of society. Policy about persons with intellectual disabilities must therefore cover all areas of society, such as health, work, and privacy.

Everyone is different and requires various kinds of help. The government wants everyone to get the help they need. Everyone should be able to live good lives and spend their time in the best way possible. That is also what is best for society.

Policy about persons with disabilities is based on a United Nations convention. The UN convention concerns the rights of persons with disabilities and is known as the *Convention on the Rights of Persons with Disabilities* (CRPD). We need extra awareness of the rights of persons with intellectual disabilities. This white paper is a way of creating this awareness.

### **What is the purpose of the white paper?**

The white paper shall explain the rights that persons with intellectual disabilities have. It shall also explain what is currently working well and what is not working. The parliament (Stortinget) can use this knowledge to create new policies or services. It can also ensure that the services for persons with intellectual disabilities work better together.

Persons and organisations can also use this white paper. People can use it to tell the people helping them what they want and what they are entitled to. The white paper shall contribute to ensure that persons with intellectual disabilities get the same rights and opportunities as everyone else.



#### **What are rights and human rights?**

**A right is something someone is entitled to. For example, you have the right to the healthcare that you need.**

**A human right is something everyone in the world is entitled to, regardless of who they are and where they live. No one can lose their human rights, nor is it possible to give them up. An example of a human right is the right to freedom of speech.**

### **How was the white paper made?**

CRPD states that persons with disabilities shall be consulted about issues and decisions that concern them. Persons with intellectual disabilities and their representatives have therefore given input to this white paper.

The government worked with Bufdir (The Norwegian Directorate for Children, Youth and Family Affairs) and Stiftelsen SOR. They invited 16 persons with intellectual disabilities to a seminar. The seminar was held in autumn 2019 and was focused on human rights. At the seminar, the participants spoke about things that were important to them. They spoke about health, school, and work, as well as other issues. They spoke directly to the Minister of Culture and Equality. In 2019, this was Trine Skei Grande.

### **The government wants to have more seminars**

The government wants persons with intellectual disabilities to be part of the decision-making process. Therefore, the government wants to arrange more seminars like this in the future. The government wants to speak to both persons with intellectual disabilities and organisations working in their interest. These organisations can often do a good job in protecting the rights of their members.

## Human rights, the law and society

### In short

In this chapter, you will read about what Norway and the UN says about persons with intellectual disabilities:

- The UN says that persons with disabilities have the same rights as everyone else.
- The government wants the UN convention to be a part of Norwegian law.
- Norway has its own Equality and Anti-Discrimination Act.
- Some people need help to get the same rights as others.

### The Constitution and the CRPD

It is said in the Constitution of Norway that the Norwegian state is responsible for everyone's human rights being respected. Human rights apply to everyone. However, society must take extra care to ensure that the human rights of persons with disabilities are respected. This is what the UN wanted to achieve when it created the CRPD.

### What does the CRPD say?

The CRPD states that society shall ensure that everyone's human rights are respected. The countries should ensure that rules and laws give persons with disabilities their rights. The authorities should listen to persons with disabilities and their organisations. If the state does not act as it should under the CRPD, it is failing in its duties.

## **More people should know about the CRPD in Norway**

The government wants employees at the state and municipal level to know more about the CRPD. Bufdir has created a project to improve the way municipalities understand human rights and equality. This can improve the services and the cooperation between services.

The government wants CRPD to be a part of Norwegian law. The government is receiving help from experts to find out how they can do this in the best way possible.



### **The Equality and Anti-Discrimination Act**

The Equality and Anti-Discrimination Act is a law saying that there must be equality in society. It also says that it is illegal to discriminate against people.

It is not legal to treat people differently due to

- a disability
- the gender they have, feel they are or want to be
- who they love
- how old they are
- their religion or beliefs
- a pregnancy or being on parental leave after having given birth or adopting a child
- someone looking after sick or ageing family members
- where someone's family comes from

In addition to this law, there are also what are known as regulations. These regulations give more detail about the obligations to help people and use universal design.

When the law says something about persons with disabilities, this also applies to persons with intellectual disabilities.

## Society's view of persons with intellectual disabilities

### **Before the 1900s**

Very little is written about persons with intellectual disabilities in world history. There was lots of prejudice, and many people were hidden away.



### **Up to the 1940s**

Persons with intellectual disabilities were viewed as being different. They did not have the same rights as others.



### **1950s and 1960s**

Norway created institutions for persons with intellectual disabilities. Those living in institutions lived differently than everyone else. They were not allowed to decide over their own lives.



### **1980s**

Norway discovered that it was not good for people to live in institutions. The state decided that municipalities should manage services for persons with intellectual disabilities. This is called the Responsibility Reform (ansvarsreformen).



### **1991**

The institutions were shut down. Municipalities were given responsibility for ensuring a good life for persons with intellectual disabilities. This was a positive step for equality and human rights.

## **People believed that persons with intellectual disabilities were sick**

In the past, persons with intellectual disabilities did not have the same rights as others. At that time, this was not seen as discrimination. Instead, people believed that it was natural because persons with intellectual disabilities were sick or damaged. This way of thinking is known as the *medical model*.

We think differently today. Today the goal is that everyone shall have the same rights. Society must help to make this happen. This way of thinking is known as the *human rights model*.

## **How can persons with intellectual disabilities be heard in a democracy?**

In a democracy, it is important that persons with intellectual disabilities get to express themselves, and to be heard.

Democracy is a way of governing a country where everyone can take part in the decision-making process.

Norway is a democracy.

Many people need extra help in order to be heard.

Organisations for persons with intellectual disabilities can help more people to be heard. These organisations can tell politicians about issues that are important for persons with intellectual disabilities.

Many persons with intellectual disabilities need extra help to understand issues in society. Adapted information can make it easier to understand. When someone understands what an issue is about, they can tell their organisation and those around them what they think about the issue.

## **What rights do people in Norway have?**

Everyone who lives in Norway has many rights whether or not they have any disabilities.

### **Equality**

Equality means that everyone is able to participate in society in the same way and have the same rights. This is because each individual has the same worth as everyone else.

Real equality exists when everyone is seen and accepted for who they are.

The CRPD says that the countries shall work to make sure that people with disabilities are treated equally.

### **Deciding for oneself**

Everyone has the right to decide over their own life. This is called self-determination.

Every person knows what they like and do not like. Also, what they think is important and unimportant. Therefore, no one should lose the right to decide for themselves because of an illness or injury nor if there is something they are not able to do themselves.

### **Contributing and being included**

It is important for people to be a part of society, and to do something meaningful together with others. When everyone is included in society, more people are able to speak up if their rights are not being respected.

It is difficult for people to take part in society if they live, work and spend their entire time in an institution. Persons with intellectual disabilities must have the opportunity to live and work in the same places as others.

### **There are various reasons for discrimination**

Persons with intellectual disabilities are just as different as everyone else. They can be discriminated due to different reasons. For example, a person can be discriminated due to both an intellectual disability and the colour of their skin.

It is important to remember that everyone is different when helping persons with intellectual disabilities. Also, it is important that groups working against discrimination make sure that persons with intellectual disabilities are not discriminated. For example, those working against discrimination against Sami people must also think about Sami people with intellectual disabilities.

# 3

## What are people entitled to?

### In short

In this chapter, you will read about the rights that persons with intellectual disabilities have:

- Everyone has the right to manage their own life and to learn and work.
- Everyone has the right to live where they want and enjoy leisure activities.
- Not everyone has their rights respected.
- The government wants everyone to have their rights respected.

### The right to manage your own life and health

Everyone has the right to decide over their own life. Everyone also has the right to know about their own health.

### The right to get help to take part and to make decisions

Persons with intellectual disabilities often need help to live independently and to take part in the activities they like. In law, this help is known as *personal assistance*.

People can have right to personal assistance regardless of their living situation. Some may be entitled to user-controlled personal assistance (BPA - Brukerstyrt personlig assistanse). People who receive this assistance can decide when and how their help is provided.

## **Right to healthcare**

According to the human rights, no one should be discriminated against when accessing healthcare. Everyone has the right to the healthcare they need, and the service should be close to their home. There should not be a separate system for persons with intellectual disabilities.

Persons with intellectual disabilities may require healthcare because of many reasons. The people who are helping them need to co-operate. Those giving help must know the person they are helping. The government wants to make this a reality.

The law states that everyone has the right to accept or reject healthcare if they

- understand what they are choosing between
- understand what the alternatives will mean for them

The law states that everyone has the right to say how they want the help to be given before they receive it. If someone needs a lot of help from different helpers over a long period of time, they have the right to receive a specific plan for this help. This is known as an *individual plan*.

## **The right to know about your own health**

Everyone has the right to know about their own health, so that they can decide on what help they want.

Healthcare workers should show consideration when they speak to someone about their health. They should speak about it in a manner which

- is suitable to the age of the person they are talking to
- is easy to understand for the person they are talking to
- is suitable for how much the person they are talking to knows from before

Healthcare workers should speak about these things in a language that the person who is listening can understand.

Family members can be told about someone's health if

- the person says it is OK
- the person needs help to decide for themselves

### **It is difficult to assess mental health**

Everyone has mental health. The term refers to thoughts and feelings, and how you are doing. Persons with intellectual disabilities have illness related to thoughts and feelings (these are known as *mental illnesses*) more often than others. Examples of such illnesses are depression and anxiety.

It is often difficult to assess the mental health of persons with intellectual disabilities. Persons with intellectual disabilities can find it difficult to explain what they are thinking and feeling. It can also be difficult to understand why some things feel different than usual.

### **Why are the health services not good enough?**

Persons with intellectual disabilities do not always get the help they need. The four most important reasons for this are:

1. Health services are not adapted for everyone.
2. The person getting help is not asked what they want.
3. The people working in the health services do not know enough.
4. The municipalities do not check whether the health services are good enough.

We will now examine these four reasons in more detail.

#### **1. Health services are not adapted for everyone**

Persons with intellectual disabilities require different amounts of help. They also need and want different types of help. However, many persons with intellectual disabilities often receive almost the same help. This means that the help is not suitable for everyone.

The government wants services to be suited for the person receiving them. This means that everyone should get the help they need and the help they want.

## **2. The person getting help is not asked what they want**

Healthcare personnel often give too little information about the help they are providing. They also often share too little information about the health of the person receiving help. This makes it difficult for the person or the family members to find out what help they should say yes or no to.

Everyone is entitled to tell what sort of help they want. This can make the services better.

Personal assistance is help a person receives to daily activities. This gives the person the opportunity to take part in activities and work, and to manage their own life.

The government wants people receiving help to be part of the decision-making process. They also want people to know more about their own health.

## **3. The people working in the health services do not know enough**

The people who help must know the person receiving help. Otherwise, they will not know what the person needs or wants.

The people working in the health services must have good knowledge about intellectual disabilities. They must also know how to collaborate with persons with intellectual disabilities.

The people who give services must know what the law says. They should also know how to find out what is right and wrong in difficult situations.

1 in 3 people working in the healthcare services do not have enough education to know what people with intellectual disabilities need. The government wants those giving help to receive training so that the services can be improved.

## **4. The municipalities do not check whether the health services are good enough**

The municipalities can decide how they organise services for persons with intellectual disabilities. The people who are

making decisions in the municipalities must ensure that the services are good enough. However, they do not control often enough. That makes it difficult to improve services that are not good enough.

The government wants the municipalities to have better systems in place to ensure that persons with intellectual disabilities have access to good services. The managers in the municipalities need to learn to be more attentive.

### **What does the government want to do?**

The government wants that

- services are adapted to the person receiving them
- persons receiving help is part of the decision-making process, and that they know about their own health
- persons who are giving help get training, so that the services can be improved
- the municipalities have better systems, to ensure that persons with intellectual disabilities access good services

The government's aim is that everyone should live an independent life. In addition, everyone should know that public authorities will look after them when they need help.

### **Coercive measures**

The government believes that everyone should be able to decide for themselves. In addition, those who need help should receive what they need in order to decide for themselves. Sometimes, however, someone will need to decide for others so that they do not harm themselves, for example. This is known as *coercive measures*.

#### **Coercive measures are a last resort**

Those working in the services can use coercive measures against someone to prevent them from harming themselves or others. The law states that coercive measures can only be used when all other avenues have been tried first. Those deciding on coercive measures must, however, have the

correct training in order to make this decision. In addition, this must have been decided with a *court order*. In addition, an administrative decision must be made.

### **Being able to decide more for oneself can make coercive measures unnecessary**

Some people can harm themselves or others if they feel that they are not able to decide in their own lives. In these cases, the persons may need help to be able to decide more themselves. If someone regains the feeling of being able to choose and decide for themselves again, it can reduce the need for coercive measures.

To avoid coercive measures being used, the law states that there must be:

- skilled people on the job
- good managers
- good services that follow all laws

### **It is possible to appeal against coercive measures**

It is possible to send an appeal if someone uses coercive measures. It is also possible to receive help in writing down what is being appealed against. Coercive measures are often used against persons with intellectual disabilities. However, persons with intellectual disabilities almost never raise an appeal.

Coercive measures are used more in some parts of the country than in others.

### **A new act on coercion and coercive measures**

In 2016, the government commissioned a report to explain whether they should change the law about when the use of coercive measures is allowed. The report also explored what the UN CRPD had to say about coercive measures.

The report was published in 2019. It proposed a new law relating to the use of coercion in the health and care sector. One of the most important proposals was that people should get to decide more for themselves. Diagnoses should not by themselves be a reason to use coercive measures.

Coercive measures should only be used if the person really needs help but does not understand enough to accept or reject this help.

The report is called NOU 2019: 14 *Limitation of the use of coercion act – Proposal for common rules on coercion and intervention without consent in health and care services*. The body that proposed this was called the Coercion Act Commission.

## **Right to education**

Everyone has the right to education. Everyone should have a good experience at school.

### **Everyone shall be included in kindergarten and school**

All children and young people should experience that they belong together with others. They should feel included, and that they are worth something. No one should be excluded or discriminated against. Kindergartens and schools are responsible for everyone being included.

All children and pupils should be included in decisions on how they want to experience kindergarten and school. They should feel that they are being heard. They should also feel that they can influence things that affect them.

Pupils with intellectual disabilities may require extra help to be able to take part in the decision-making process. They have a right to this help.

### **Children should be prepared for adult life**

One goal of the school is to prepare the pupils to take part in working life and society, so that they can live a good life when they become adults.

Another goal is to prepare the pupils to be involved in making decisions in society when they are adults. Some pupils can get extra help in school to achieve this.

Children who need extra help before they start school have the right to get this extra help. They have the right to extra

help regardless of whether they go to kindergarten or not. This kind of help is known as *special pedagogical help*.

### **Everyone should have the opportunity to go to a local school**

Everyone has the right to go to school in their neighbourhood. At school, persons with intellectual disabilities should go in the same class as the other pupils. They should receive the facilitation they need in order to be included.

### **The right to go to upper secondary school**

Everyone who has finished at a lower secondary school has the right to start at an upper secondary school. It should be possible to apply on different educational programmes, and to say which one the person would prefer to attend.

A queue system has been created to decide where people can go to school. Those who are entitled to special education and facilitations are placed at the front of the queue. This is known as a *preferential right*.

### **Some schools do not provide pupils with what they are entitled to**

Many kindergartens, schools and after-school programmes provide children with what they are entitled to. However, there are many that do not.

Many children must wait for a long time to receive the help they need. There are also many children that do not get to learn everything they need to know. Sometimes this is because the schools believe they cannot learn it. Many are able to learn if the school facilitates and gives them a chance to learn.

### **It is important to be included in the school environment**

Many pupils get their special education outside of the classroom. This can make them feel excluded.

It is important that all pupils are included in the school environment and that they feel that they belong to a group.

## **What does the government want to do?**

### **Increase the knowledge among the people working with children and pupils**

The government wants to increase the knowledge among the people working in kindergartens, schools and educational and psychological counselling services. Kindergartens, schools, after-school programmes and others providing help should cooperate better.

### **Make it easier to transfer between schools**

The government wants to find out whether it is possible to prepare better for pupils when they finish primary school and begin at lower secondary school. Also, when they finish lower secondary school and start at upper secondary school. It may be that schools can share information and talk more about pupils so that the new school is better prepared.

The government also wants to find out how lower secondary and upper secondary schools can work together better.

### **After-school programmes should include everyone**

The government wants that pupils who need facilitations should get the same services as others at after-school programmes. The after-school programmes must include all children in the same way as schools have to.

### **More people should be able to recognise that children need help**

The government wants to have more adults at kindergartens and schools. These adults shall be able to recognise when children need facilitation. Children should receive the help they need faster than today and should not have to seek it out. This is part of what is called early intervention at kindergartens and schools.

## **Right to work**

Everyone who can and wants to work should be able to do so. Persons with intellectual disabilities may need facilitation and help at work. If people receive this, many more can be able to work.

### **Facilitation at work**

Employers and others must take responsibility for giving more people the opportunity to work. People work in different ways. Persons with intellectual disabilities have the right to an assessment of their job opportunities.

For some, it will be most proper to work at a place where the entire workplace is adjusted. These workplaces are known as inclusive enterprises. These companies shall include people who cannot work elsewhere.

Proper facilitation is important to make it possible for more people to get into work. Facilitations must be better. Different services must also co-operate better.

### **Permanent work adjustment works for many people**

Most persons with intellectual disabilities work through permanent work adjustment (VTA – varig tilrettelagt arbeid). Permanent work adjustment is found in most inclusive enterprises. However, it is also offered in ordinary enterprises. If everyone who wants VTA is to get a job, there is a need for many new VTA places.

### **The transition from school to work is important**

Many persons with intellectual disabilities do not get a job when they finish school. It is important with good facilitation when someone has finished at school and wants to start working. If people are out of work for a long time after they finish school, it is more difficult to start a job later on.

### **Persons with disabilities are more often out of work**

We do not know exactly how many persons with intellectual disabilities who have a job. However, we do know that persons with intellectual disabilities are more often out of work than others.

It is difficult to get a job when you do not have proof of what you have learned. Many people believe that persons with intellectual disabilities cannot do much. This belief can

make it more difficult for people with intellectual disabilities to get a job.

Schools and families may also believe that the person cannot do much. A result of that can be that the person does not learn enough.

### **What does the government want to do?**

#### **Everyone should have the opportunity to work as much as they can**

The government wants the whole society to help to facilitate so that everyone who wants to work, get the opportunity to work. The government also wants that more people get to learn new things when they are adults.

The government believes that it is important that people who receive disability benefits should have the opportunity to work at the same time. Everyone should feel included in society through participation in the labour market.

#### **Research on how pre-employment training programmes function**

The government wants to find out whether pre-employment training (AFT- arbeidsforberedende trening) is functioning properly. That is a service for those who need to work on a facilitated enterprise before they start work training in a regular business.

#### **Find out how permanently adapted work can be better**

The government wants to find out how permanently adapted work can function better. The government wants to evaluate whether receiving more assistance in VTA helps. The government want to assess this in some counties.

### **Right to live how you want**

To decide how you want to live is an important part of deciding over your own life. In a good home, people are able to do more without help. It also gives more freedom.

When persons with intellectual disabilities become adults, they should be able to move away from their family and into a home they have chosen for themselves. The government wants everyone to live well and securely, and for more people to be able to own the home they live in. The government also wants a good rental market.

### **Most persons with intellectual disabilities live alone**

Persons with intellectual disabilities want to live the same lives as others. They want to have a partner, family and maybe children.

However, most persons with intellectual disabilities live alone, and not with a partner. In contrast, 4 in 5 people who do not have intellectual disabilities live with someone.

It is difficult to move in together. It is also difficult to find someone to move in with. These are two of the reasons why most persons with intellectual disabilities live alone.

Persons with intellectual disabilities often do not have many close relations. In addition, many live in a shared house with many others. That makes it difficult to have a private life and find a partner.

### **It should be possible to live in ordinary homes**

Persons with intellectual disabilities should be able to live in ordinary apartments or houses in regular residential areas. They should be able to live independently in these places, like everyone else.

Homes for persons with intellectual disabilities should not look like institutions. The people living there should be involved and participate in decisions.

There should not be too many homes for persons with intellectual disabilities in the same building. This can lead to those living there not being fully included in society.

## **The government's goal for housing**

The government wants everyone to live well and securely.  
They want

1. more people to be able to own their own home.
2. better residential environments.
3. more houses to be built.
4. new housing to be built in an environmentally-friendly manner.

## **Ability to apply for a start-up loan**

The Norwegian State Housing Bank offers a product called a *Start-up loan* (Startlån). The Housing Bank loans money to municipalities, which in turn loan it out to people in financial hardship. People can use the loan to buy a home, or to get enough money to keep the home they are living in.

Almost all municipalities offer a start-up loan. However, start-up loans for persons with intellectual disabilities are not used by all municipalities.

In many places, persons with intellectual disabilities and their families have bought homes together with others. Sometimes, they have worked together to organise a housing co-operative with multiple homes for persons with intellectual disabilities.

This can be a good way for persons with intellectual disabilities to own their own home. However, this can also lead to those living there not being included in society.

## **What does the government want to do?**

The government wants

- to make it clear what responsibilities municipalities have to help people struggling in the housing market
- to help more persons with intellectual disabilities to buy a home instead of renting
- to know more about how people with intellectual disabilities live



### **How do persons with intellectual disabilities live?**

Before a reform in 1991 (ansvarsreformen), many adults with intellectual disabilities lived in institutions or with their parents.

With this reform, persons with intellectual disabilities were able to live in regular homes. From 1990 to 1996, 3,500 homes were built for persons with intellectual disabilities. However, among persons with intellectual disabilities only 1 in 4 persons own the home they live in.

A shared house is the most normal way of living for persons with intellectual disabilities.

## **Right to leisure activities**

Everyone has the right to

- participate in culture
- have hobbies
- get involved in festivals and camps
- participate in sport
- be involved in activities about religion and other beliefs

Leisure activities must be organised and planned so that everyone can be involved. It must also be easy to get help to be involved in activities about religion and belief. Help to take part in such activities should be a part of the service offers, in line with other activities.

The government wants all children to be able to take part in at least one leisure activity together with others. They also want it to be easier for persons with intellectual disabilities to participate.

## **Why are leisure activities important?**

Being involved in culture and sport makes people feel included. It makes leisure time feel meaningful. It is also a way to make friends.

It is therefore important that persons with intellectual disabilities are able to participate in culture and sport like everyone else. If there are only separate activities for persons with intellectual disabilities, it is more difficult to get included.

## **Many people cannot participate in the activities they want to**

Persons with intellectual disabilities cannot always participate in the activities they want to. This is also case for children with other disabilities.

It may be because others think that they are not able to perform these activities. It may also be because the accessibility or facilitation is not good enough. For example, the person does not have enough time with a support person, or the person cannot get to, or enter the activities.

It is important that persons with intellectual disabilities and other disabilities are included just like the others. This makes it possible to make more friends. Physical activity may also help to avoid many illnesses.

## **A support person may make it easier for people to participate**

Municipalities are responsible for making it possible for everyone to take part in activities. Persons with intellectual disabilities may require help from a support person to participate.

A support person can help people to decide for themselves which activities they want to take part in. Municipalities must offer a support person.

## **There are many different activities to participate in**

Persons with intellectual disabilities take part in many cultural activities, such as music, dance, and visual arts.

Over the last twenty years, more sporting activities have been offered to persons with intellectual disabilities. Most persons with intellectual disabilities take part in sport with their local sports team.

Not all sports offer inclusive activities. Persons with intellectual disabilities are therefore not always able to choose which sports they participate in. Children can feel excluded when they are not able to participate in sports together with their classmates.

### **What does the government want to do?**

Persons with intellectual disabilities should have the possibility to take part in leisure activities in the same way as others.

The government wants

- to work towards everyone being included when they participate in art, culture, volunteering, and sport
- to ensure that carer certificates are digitalised, and that events offer free tickets to carers
- to work towards all children being able to participate in at least one leisure activity together with others
- to make the service from the Norwegian Library of Talking Books and Braille better known so that everyone has access to books
- to continue to work to make sure that people can participate in religion and other beliefs when they are at hospitals and other healthcare settings.

# 4

## Who are responsible for the rights?

### In short

In this chapter, you will read about the responsibilities for rights and services to persons with intellectual disabilities and their families:

- Both the state and the municipality are responsible for getting everyone what they need.
- Many do not get what they have a right to.
- Parents of children with intellectual disabilities have more responsibility than other parents.
- Politicians have to listen to persons with intellectual disabilities.

### The ministries are responsible for equality

The state is divided into many ministries. The ministries are responsible for their own subject fields. For example, the Ministry of Education and Research handles issues relating to schools.

All ministries are led by a Minister. The ministries are responsible for equality within their field. The Ministry of Culture and Equality should also help other ministries in their work on equality. There should be equality everywhere.

The Ministry of Culture and Equality has an extra responsibility to ensure that other ministries work towards

- everyone being included
- everyone participating
- no one being discriminated against

Persons with disabilities should be a part of policy-making. For example, there should be persons with disabilities in councils and committees working on issues that are important to persons with disabilities.

### **Municipalities have a great responsibility**

Municipalities are responsible for many services for their inhabitants. They can decide on many different things. For example, municipalities decide where new houses can be built. They also decide on the types of buildings that can be built in specific places.

It is good that municipalities get to decide over lots of things. They have best knowledge of the local context and people living in the municipality. Therefore, they know what people in their municipality need.

It is important that the people living in the municipalities take part in decision-making in their municipality. This is called *local democracy*.

### **Municipalities are responsible for citizen services**

Municipalities should provide the welfare services that persons with intellectual disabilities need. The services should be a part of the same system as the services for everyone else living in the municipality. There should not be a separate system with services only for persons with intellectual disabilities.

Persons with disabilities shall be consulted about issues and decisions that concern them, and municipalities and county authorities should appoint councils for persons with disabilities. These councils should know about all issues relating to persons with disabilities and ensure that persons with disabilities are able to say what they think about these issues.

### **Not everyone currently receives their rights**

It varies between municipalities whether persons with intellectual disabilities receive their rights. In some

municipalities, they do not receive the services they are entitled to, or the services they need.

### **Persons with intellectual disabilities are forgotten in policy**

When politicians make policy for persons with intellectual disabilities, they often make policy about health. However, persons with intellectual disabilities should be a part of all policies. Policy for persons with intellectual disabilities should focus on equality.

There are not many persons with intellectual disabilities who work with persons without intellectual disabilities. Therefore, people do not think that much about persons with intellectual disabilities.

### **Politicians must listen to persons with intellectual disabilities**

It is only persons with intellectual disabilities who know how their lives are. It is therefore important that councils and committees listen to and include people with intellectual disabilities.

To create this white paper, the government arranged a seminar where persons with intellectual disabilities spoke about their situation. This is an example of how persons with intellectual disabilities can be heard.

### **Persons with intellectual disabilities should get to tell which services they need**

It is important that persons with intellectual disabilities get to speak about the kinds of services they need. It is the persons themselves who know their own situation best. They can also get their representative organisations to give input.

Persons with intellectual disabilities rarely get to speak about what they need. The municipalities who handle the services often lack a good system to involve people.

Not all the people who are working with persons with intellectual disabilities know which rights they have.

Many also believe that persons with intellectual disabilities are able to do less things than they actually are.

### **The services must co-operate better**

Persons with intellectual disabilities often receive help from many different places, for example at home, school or at work. However, the different people and services supplying them help do not always work together well. This makes it difficult for persons with intellectual disabilities when they start something new. For example, if they need to change school, or when they are finished at school and need to start working.

### **Persons with intellectual disabilities do not always get BankID (electronic ID)**

Not everyone with intellectual disabilities gets BankID (electronic ID for secure information). This makes it impossible for them to use all state and municipal websites. Many websites have strict login requirements. The government is looking into a solution with something similar to BankID to make it possible for more people to log in to these services.

### **The COVID-19 pandemic had major consequences**

During the COVID-19 pandemic, many services were closed. This was to prevent people from getting infected.

Many persons with intellectual disabilities need help to take part in society. They also need help to do things in their leisure time and to live good lives. When the services closed, they could no longer do these things. Therefore, the COVID-19 pandemic had a worse impact on many persons with intellectual disabilities than others.

In addition, some of the services were worse when they reopened after the pandemic.

The government believes that persons with intellectual disabilities must keep their rights if a new pandemic occurs. If we need to avoid infections in the future, we will need to do things a little differently.

## Help in making decisions

### A guardian can help

Everyone should get to decide for themselves. However, some people will need a bit of help to do so in one or more areas of life. In this case, they can have a guardian to help.

A guardian may, for example, help to

- ensure that they receive their rights
- handle money and loans
- find out whether they should sign a contract
- find out whether they should end a contract

Since everyone should be able to decide for themselves, a guardian cannot make decisions for a person against their will. In an ordinary guardianship the guardian's job is to help the person make decisions and conduct necessary actions to help realise the person's own wishes.

An ordinary guardianship is voluntary, and a person must agree to have a guardian. The person must also agree to who their guardian will be.

There are around 42,500 adults with a guardian in Norway. Many of these are persons with intellectual disabilities.

The scheme where someone has a guardian is called a *guardianship*.

### Guardianship order

If it is absolutely necessary to help someone have their rights respected, a court can decide that there are some things the persons cannot decide for themselves. For example, the person cannot take out a loan on their own behalf.

In such cases, the person may have to get a guardian even though the person does not agree to this. This is known as a guardianship order. It can only be ordered by a court, and only if the person is not able to take care of themselves. For example, if someone gives all their money away or uses it on gambling instead of paying for food, clothes and

accommodation. It is very rare that someone has to get a guardian against their will.

The guardian shall always listen to the opinions of the person the guardian is helping. This also applies if the person has been ordered to have a guardian against their will. The guardian shall always help make decisions so that the person is able to live the life they want to the greatest extent possible.

It is possible to complain to the county governor if the person who has a guardian disagrees with the guardian's actions.

### **Some people do not understand what a guardian is**

Some people do not understand what it means to have a guardian, regardless of how much help they receive to understand it, or they do not understand what the guardian can decide. It can also be difficult for some people to clearly explain what they mean. These people may need more help because it is difficult to find out what the person agrees or disagrees with. It may also be difficult to find out whether the person wants to have a guardian.

When a person does not understand what a decision means, we sometimes say that this person lacks capacity to make decisions.

These people should be able to decide as much as they can, just like everyone else. However, they often need even more help to make decisions than other people who need the help of a guardian.

### **The Guardianship Act is being changed**

The government is working to change the Guardianship Act. The law should be clearer that receiving the help of a guardian is voluntary. It should be clearer in both the rules of the law and through the wording of the law.

In addition, it will be made clearer that guardians in ordinary guardianships cannot do something the person disagrees with.

The law will also be made clearer when it comes to guardians for people who do not understand what a guardian is, or what the guardian is there to help with (those who lack capacity to make decisions). The law will be changed to say more clearly that these guardians must also make decisions so that the person is able to live their life how they would like to.

The law relating to guardians is called the Guardianship Act.

## **Help for parents of children with intellectual disabilities**

All children and young people should have a safe and good childhood. The government wants to listen to the families about what they need.

The government wants all children and young people to receive better services. That shall make differences in society smaller. That shall also give the families more freedom.

### **Parents of children with intellectual disabilities have more responsibility than others**

Having a child with intellectual disabilities can be difficult. Research shows that parents of children with intellectual disabilities have a tougher time than other parents. It takes a lot of time and energy to ensure that these children receive what they need.

Parents of children with intellectual disabilities often continue to look after their child once they are an adult. 1 in 5 adults with intellectual disabilities still live with their parents.

### **The parents are not always satisfied with the services**

Some families move to different municipalities or neighbourhoods that have better services for persons with intellectual disabilities. These are so-called *social care refugees*.

Parents of children with intellectual disabilities often have a different impression of the public sector than other

parents. They often lack the information they need. They also often apply for things that they do not get approved. This makes them have less trust in the state and municipalities than others.

Equality between parents is also worse in families where a child has intellectual disabilities. This is because the mother in the family often quits her job or works less to look after their child.

## **Protection against violence, abuse and exploitation**

### **Who are the victims of violence, abuse and exploitation?**

Some people are more likely to be victims of violence, abuse and exploitation than others. It happens more often with

- very young or very old people
- women
- persons with disabilities

A person who is a member of more than one of these groups is in even greater danger of being a victim of violence, abuse or exploitation.

Women with disabilities are more likely to be victims than men with disabilities.

We do not know how many persons with intellectual disabilities are victims of violence, abuse or exploitation. Many speak up when something like this happens. However, there are just as many who do not say anything. This makes it difficult to know how many are victims of these issues.

### **Persons with intellectual disabilities are at a higher risk of violence and abuse**

Many persons with intellectual disabilities live in a way that makes the risk of violence and abuse higher. Some things can make this risk higher are if

- their home is similar to an institution
- their home situation is rarely checked by anyone

- they do not know enough about self-determination
- they are not allowed to decide for themselves
- the employees quit after a short time and new employees frequently come along
- the employees only work for a few hours per week
- the employees are not trained

### **How can we avoid violence and abuse?**

To avoid the risk of violence and abuse, there should be someone checking in on how things are going. They should also check that there are good employees who understand the law, and that the service is well designed.

It is also important that everyone learns about what violence and abuse are at school. Everyone should also learn about sex.

The law states that municipalities should take extra care to ensure that those receiving help from others do not become victims of violence. They should also make sure that they are not coerced or tricked into having sex. Municipalities should have good plans in place so that they can uncover abuse when it occurs.

### **What does the government want to do?**

The government wants to protect persons with intellectual disabilities against violence and abuse.

The government wants

- to continue working on co-operation between different services and agencies that are meant to protect adults against unlawful events – this co-operation is called TryggEst
- to teach the employees at crisis centres so that they know more about persons with disabilities (a crisis centre is a place someone who is in danger can turn to for safety)
- to teach the employees in health services about violence and abuse

- to continue offering a service that parents can call when they are struggling with their children – this service is called Foreldresupport (Parental Support).

## Right to help in interaction with the police

When someone finds it difficult to understand things that most others do understand, the person may have what is known as a cognitive impairment. Intellectual disabilities are an example of a *cognitive impairment*. When the police arrest someone with cognitive impairments, the person has the right to facilitations and help when the police work on the case. It may be difficult for the police to know whether the person they are arresting has a cognitive impairment.

If the police are not sure, they should use facilitation when they question the person. Questioning refers to explaining to the police what has happened.



### What is violence, abuse and exploitation?

***Violence* is when someone harms someone else.**

**The most common example is when someone hits someone else. This is an example of physical violence.**

***Abuse and exploitation* are when someone forces or tricks someone into doing something they do not actually want to do. If someone forces a person to work without pay, they are exploiting them. If someone uses someone else's ID to pretend that they are that person, they are abusing the other person's identity.**

***Abuse* is when someone does something that denies someone else their rights. Violence, abuse and exploitation are all different forms of abuse.**

**When talking about this, it is most common to hear about sexual abuse. This is when someone uses someone else's body for their own pleasure when they have not received consent to do so.**

Around 1 in 10 people in prison have cognitive impairments. However, there are undoubtedly more, as the prisons know very little about this topic. These people do not receive the facilitations they need.

### **What does the government want to do?**

The government wants

- to work for adapted activities for persons with intellectual disabilities in prison
- to work to find good solutions so that persons with intellectual disabilities in prison have access to good services.

## Fight against hate crime



### **What is a hate crime?**

Hate crime is when someone does something illegal because they do not like specific groups of people.

A hate crime against a person may involve

- where someone or their parents come from
- the religion or other beliefs they have
- who they love
- the gender they feel they have
- the gender they would like to be
- whether they have a disability

Examples of hate crime against specific groups:

- saying something that shows hate or discrimination
- harming someone
- threatening someone
- damaging someone else's property
- trying to make someone else do something illegal
- trying to get others to hurt someone

### **People do not believe that there is hate crime against persons with disabilities**

Very few persons tell the police about hate crimes when they occur against persons with disabilities

Many people think that it does not happen very much as they do not hear much about it. However, their organisations say that people do not speak up when hate crimes occur. This is often because they do not understand that a hate crime is occurring.

### **We should use a word for hate against persons with disabilities**

People have a good understanding of hate crimes when it concerns the colour of someone's skin. This is because we have the word "racism". We also have the word "homophobia" when people do not like gay people. We also have "islamophobia" when people do not like Muslims. The English word for hatred towards persons with disabilities is "ableism".

However, there is no specific word for this concept in Norwegian, though the Swedish word "*funkofobi*" has started to be used in Norway.

### **The fight against hate continues**

The government wants to continue its work against people saying hateful things.



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