



ASAN

AUTISTIC SELF ADVOCACY NETWORK

The Right to Make Choices:

**International Laws and
Decision-Making by People
with Disabilities**

Introduction

Freedom to make choices is a human right.

- International human rights laws protect people's right to decide how to spend their money, make their own health care decisions, work for a living, and have relationships with friends and family.

Adults without disabilities take freedom of choice for granted.

- But people with disabilities cannot take freedom of choice for granted. People with disabilities often do not make their own choices.
- People with disabilities – especially people with intellectual, developmental, or mental health disabilities – often do not get to make their own choices.
- Often, if a family member thinks the person with a disability cannot make good choices, the person with a disability is no longer in charge.

People with disabilities can make their own decisions with the right supports.

What is this guide?

This guide helps people with disabilities understand decision-making laws.

- Every country has different laws. This guide explains the different types of laws and how they work.

The guide explains how international law protects people with disabilities' freedom of choice.

- International laws are laws between countries.
- International law also involves agreements with international organizations, such as the United Nations and the European Union.
- International organizations create laws all member countries who vote for them must follow.
- Sometimes there is conflict between international law and a country's laws. Conflicts lead to lawsuits. This conflict can lead to changes in the laws.

What is Supported Decision-Making?

“Supported Decision-Making” gives people with disabilities the help they need to make choices about their own lives.

- These choices could be about where to live, what to do during the day, how to spend money, or when to see a doctor.
- Everyone needs supports to make decisions. But people with disabilities may need more or different kinds of supports.
- For example, people with disabilities may need help to understand information about choices we need to make.

- **Examples of help include:**
 1. Plans for the future
 2. Help us get our ideas across
 3. Keep us on task.

- The person with a disability chooses a person that helps with decisions. This is supported decision-making.
- With supported decision-making, the supporter gives advice, but the person with a disability makes the final decision.
- A good supporter respects the wishes of the person with a disability.
- A good supporter listens and suggests ways to make the person’s wishes happen.

Example - A good supporter

- For example, imagine that you want to find a place to live, but don't know how to make decisions about what you can afford, or what kind of house would be a good place to live.
- You ask your sister for help.
- Your sister comes to your house and asks you questions about what kind of apartment you want.
- She listens to you about how much money you get each month and how much you spend on other things like food and clothes.
- She helps you figure out how much money you can afford to pay in rent each month. Then she helps you look at apartments.
- Maybe she helps you understand that an apartment with all of the things you want – for example, a big house close to the middle of town – would be too expensive for you to afford.
- She helps you figure out which of the things you want in an apartment are most important to you.
- You visit apartments with your sister.
- You then decide which apartment you want and sign a lease.
- At the end of this process you have received a lot of support, but you still **made all your decisions yourself.**

How to name a supporter using a form

- Most supported decision-making happens without any special legal process. Your sister helps you find an apartment without a special form or going to the court.
- There are only a few states that have true supported decision-making laws on the books.
- But sometimes, people decide to sign a form that lets other people know that a supporter is helping them.

- There are a couple of different types of these forms, and they all do different things. Here, we're going to list a few of the different types of forms and what each of them do.
- The forms have names such as **"Power of Attorney," "Health Care Proxy," "Representative Agreement,"** or **"Supported Decision-Making Agreement."**

"Power of Attorney" gives someone else the right to do things like take care of your money for you or make legal decisions for you.

- "Attorney" is a word that means "lawyer." But the person making decisions for you does not have to be a lawyer.
- This person can only make decisions at certain times. The times depend on the agreement.
- You can take this power away at any time.
- The person has the right to use the power of attorney to show that they can make decisions for you unless a court finds that you can't make decisions on your own anymore.
- The court might find that if you got really sick. So a power of attorney stops working if you can't make decisions by yourself, unless it's a special kind.

Durable power of attorney is that special kind of power of attorney.

- It keeps working even if you get sick.
- It keeps working even if you can't make decisions by yourself anymore.
- Sometimes it does not start working unless you stop being able to make decisions by yourself.

A "Health Care Proxy" is the same type of agreement for health care.

- A **health care proxy** or **health care power of attorney** puts someone else in charge of your health care decisions if you are unable to make them yourself.
- The document only takes effect if you are ill and can't make decisions by yourself. A team of doctors must determine if this is the case.
- Health care power of attorney is hard to cancel after you get sick.
- Even though these forms usually let people make decisions for you, you can sometimes write them in a way that lets you make all the final decisions.

“Representation Agreements” and “Supported Decision-Making Agreements” tell people who supports you.

- You remain in charge.
- The supporter helps.
 - The supporter takes these forms to doctors, bankers, landlords, or other people who might give services to a person with a disability.
 - Once the doctor, banker, landlord, or other person sees the form, they know that the supporter is helping the person with the disability.

If you are not interested in giving someone any decision-making power and are only interested in telling people what health care you want while you are sick, you can sign an advance directive.

- These are documents that tell people what you want them to do if you can't tell them what to do.
- They can be for medical care or for mental health care.
- However, these documents usually aren't **legally binding**.
 - This means that even though the advance directive tells the doctor what you *want* the doctor to do when you can't tell them (because you're sick or knocked out), the doctor **doesn't** legally have to do it.
 - An advance directive can be helpful if you trust your health care provider.

Powers of attorney and advance directives don't work if a court thinks the signer didn't understand what they were signing.

- This means that sometimes, a court will say a power of attorney or advance directive isn't valid because the signer had a disability.
- In those cases, the court will often put the person under **guardianship** instead.
- Sometimes the court will pick a guardian who is different from the person named in the power of attorney or advance directive.

How to name a supporter using a bank

- In most countries, people who need help with money can set up bank accounts that let another person help them.
- Bank accounts with partners give another person access to the account.
- You must trust the person because they can take money out of the account.

You can create an authorized signatory so that it takes two signatures – yours and your supporter – to take any money out.

- This works if you worry about money.

You can also create a trust.

- Other people help manage the trust. The managers are **trustees**.
- The trust has rules for when you can use the money.
- These rules are set when the trust is set up. The trustees have to follow the rules.
- These strategies let a person with a disability get help with money.
- Another person does not have full control with these strategies.

What is Guardianship?

Guardianship is a system that allows one person to make decisions about another person's life.

- These decisions can include where you live, your friends, your money, and your health care.
- Sometimes, people under guardianship are not allowed to vote, get married, or take care of their children.
- In most countries, children have guardians. A parent takes responsibility for a child.
- Sometimes grandparents, step-parents, godparents, or someone else takes responsibility.
- Under the law, children cannot make important decisions without approval. As children grow older, they make their own decisions.
- Legal adults do not have guardians. Legal adults make their own choices.

People with disabilities under guardianship do not have the same rights as other adults.

- The person with a disability cannot make their own decisions under guardianship. **Another person is the guardian.**
- The guardian makes the decisions.
- For a guardianship you must go to court. A judge must declare guardianship.
- **Full guardianship** means the guardian makes every decision.
- **Limited guardianship** means the guardian only makes certain decisions. Examples include healthcare and money management.

Guardianship takes choices away from people with disabilities.

- For example, imagine that you want to find a place to live and are under guardianship.
- If you are using **supported decision-making** instead of guardianship, you could simply call up your sister and have her help you through the process.
- If you have a **guardian**, you could not get an apartment without your guardian's consent and assistance, even if you would rather have someone else help you instead of your guardian.
- Even if your guardian could only make decisions about how you spend your money, you wouldn't be able to pay the rent for your apartment without their help.
 - This means the guardian has a lot of power to say where you can or can't live.
 - Some countries' laws say that a guardian must consider your wishes when they make a decision.

It is hard to make sure your wishes are considered by a guardian.

- You may have to go to court to complain about your guardian's decisions.
 - This may be expensive and hard.
 - In some countries, you cannot even go to court on your own to complain about a guardian – someone else has to make the complaint for you.
- Guardianship frustrates people because they cannot make their own choices.

Guardianship VS Supported Decision-Making: An Illustration

DIFFERENCE BETWEEN
GUARDIANSHIP
AND
SUPPORTED DECISION
MAKING



Illustration by Pip Malone

Abuse can happen under guardianship.

- For example, a guardian might:
 - Refuse to let you spend time with friends or family
 - Force you into an institution or group home
 - Make healthcare choices you do not want
 - Steal or misuse money (this is illegal!)
 - Take away your right to marry or have children
 - People under guardianship cannot always protect themselves from what the guardian might do.
 - They may not know the situation they are in.
- Guardians can spend a person's money without telling them.
- Sometimes guardians have made health care decisions without telling the person under guardianship.

Guardians can make choices about a person without getting to know them.

- This is especially common if the guardian is the government itself or is a stranger appointed by the court.
- They may make the same choices for many people with disabilities under guardianship, even though those people all want different things.
- Even if the guardian knows the person very well, that guardian still has the power to do anything they want with that person's life without talking to the person at all.

Sometimes guardians can commit neglect.

- In this situation, the person with a disability cannot legally make decisions for himself or herself, but also cannot get the guardian to act on his or her behalf.
- As a result, the person may not be able to spend money to buy food or pay rent, and may face serious problems as a result.
- People with disabilities should have the right to make their own choices, rather than having someone else making choices for them.

Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) is an agreement by many countries to respect the rights of people with disabilities.

- The word “convention” here means “treaty” or “agreement,” not “conference.”
- “Persons” is another word for “people.”
- **The CRPD includes:**
 - the right to make choices.
- **The CRPD also includes:**
 - freedom from discrimination or violence,
 - the right to have a family,
 - the right to live and work in the community,
 - and the right to accessible roads, schools, information, housing, and other resources.

Article 12 of the CRPD says that:

- 1. Judges and courts must recognize people with disabilities as people.**
- 2. Governments must recognize people with disabilities as people.**
 - People with disabilities can make decisions for themselves.
- 3. People with disabilities need some help or supports. Governments must make sure that support is available.**
- 4. Governments must protect people with disabilities from abuse.**
 - Governments cannot give authority to someone who might abuse their power.
 - Governments need to respect a person's decisions.
- 5. Governments need to make sure that people with disabilities have the same right to:**
 - own money or property
 - inherit money or property from their relatives
 - and do all the same things with their money that people without disabilities can do.

For example, take out loans or use credit cards.

- People with disabilities should not have their money or property taken away from them for no reason.

Almost every country in the world has signed the CRPD.

- Almost every country in the world has signed the CRPD, and most countries have “ratified” it.
 - “Ratifying” something means that the country now has to follow the rules that are in the CRPD.
- Some countries have **signed** the CRPD but have not “**ratified**” it, which means that they agree with the idea of respecting the rights of people with disabilities but don’t have to follow its rules.
- The names of the countries on the CRPD are here: <http://www.un.org/disabilities/countries.asp?navid=17&pid=166>
- Many of the countries that signed the CRPD have guardianship laws.

Many countries’ guardianship laws break the CRPD, because they allow the court to take away the rights of people who could make their own decisions if they had the right supports.

- Some countries have already started trying to change their guardianship laws to respect people’s rights under the CRPD.
- In other countries, people with disabilities have sued in court, saying that under the CRPD, they have the right to be free from guardianship.

The CRPD: An Illustration



Illustration by Pip Malone

Guardianship and Supported Decision-Making Laws

- All countries make their own laws.
 - In the United States and Canada, guardianship and supported decision-making laws vary by state or province.
 - Other countries have different laws.
 - Countries can have different types of laws about guardianship and supported decision-making.

Guardianship laws allow other people to make life choices for a person with a disability.

Supported decision-making laws allow people with disabilities to make their own choices with support.

- Some countries have **more specific laws** that allow people with disabilities to make some choices but not others, which will be discussed individually in the country sections.
- Often, countries have a combination of these three things.

The United States of America

- All 50 States have laws about guardianship. Each state has different laws.
 - Massachusetts, for example, might have very different rules about how the court decides who needs a guardian than Alabama does.

Different states have different rules about:

- How the court supervises the guardian
- How easy or hard it is for somebody to get put under guardianship in that state
- How the court decides who needs a guardian

Because different states have different laws about guardianship, which state a person with a disability lives in can change their whole life.

- For example, a person may be put under guardianship because they lived in a state where it was very easy to put someone under guardianship.
- If the person lived in a different state, they might not have been put under guardianship.
- Instead, they would be able to keep making their own choices. If a person with a disability moves from Virginia to Maryland and is under guardianship, the guardianship might change or completely disappear simply because of the move to Maryland.

Most states have laws saying that guardianships should be limited to just the parts of life that the person needs support with.

- But despite these laws, most people in most states get put under full guardianships like the ones described earlier.
- They lose the ability to make decisions for themselves.

Disability advocates want supported decision-making laws.

- These laws reduce the number of people under guardianship.

Supported Decision-Making Laws in the United States

Texas and Delaware have laws for supported decision-making.

- Texas and Delaware are the only states where these laws exist.
- In Texas, courts have to think about supported decision-making options for you before they can assign you a guardian.
- Guardianship is the final option if supported decision-making doesn't work.
- In Texas, an adult with a disability signs a **supported decision making agreement**.
- The agreement is legal as long as the person with a disability understands the agreement.
- You sign the agreement in front of people or witnesses.

Reform in the United States

Even though Texas and Delaware are the only US states which have passed a supported decision-making law, advocates across the United States are trying to get supported decision-making laws passed in their home states.

- There have also been many conferences on supported decision-making where people could talk about these laws.
- Many disability rights and disability self-advocacy groups have said that supported decision-making should be used whenever possible instead of guardianship.

ASAN wrote model supported decision-making laws that let people sign special supported decision-making agreements for health care.

- “Model laws” are designs for a law. A model law is not an actual law. People use model laws for ideas.
- ASAN’s model law lets the person with a disability make decisions, with help from a supporter. ASAN’s model law only works in healthcare situations.
- It is easy to prove you understand the agreement under ASAN’s model law: you just have to say you want a supporter.

The Constitution and the Americans with Disabilities Act make guardianship hard.

- Guardianship takes away rights guaranteed by both the Constitution and the Americans With Disabilities Act.
- The Constitution says that freedom is a right. Guardianship takes away freedom.
- People with disabilities could also use the Americans with Disabilities Act to challenge guardianships.

It is possible to challenge guardianships and win.

- Jenny Hatch, a 29-year-old woman with Down Syndrome, went to live with friends after she won in court.
 - She chose her friends as her supporters. She has choices now.
 - Advocates hope more courts follow this decision.

Canada

Several Canadian provinces have supported decision-making laws.

- In British Columbia, for example, people with disabilities enter a **Representation Agreement**.
- You name people you trust (or group of people) who help with the decisions.
 - This person is called the Representative.
 - You can sign a representation agreement even if the court says you cannot sign a power of attorney.
- You have control over the decisions you make.

The Representative sometimes makes decisions for a person with a disability in some special cases.

- This can happen when the Representative doesn't have the chance to talk to the person with a disability before making a decision.
- The Representative also can sometimes go against the person with a disability's wishes if their wishes do not seem "reasonable."

In most Representation Agreements, there are some choices that the Representative can't make for the person with a disability, no matter what.

- These include:
 - refusing medical treatments that you need to live,
 - abortion,
 - restraint,
 - experimental medical treatments,
 - forcing you to take medications,
 - using pain or unpleasant things to try and change the person's behavior,
 - making parenting decisions for a person with a disability who has children,
 - or buying or selling the person with a disability's house.

A Representation Agreement with Broader Powers lets the Representative make more decisions.

- But even in that case, a Representative can't consent to things like:
 - taking away the ability to have children (unless it's medically necessary)
 - or suicide with medical help.
- If a person with a disability signs a Representation Agreement, they have **legal capacity**.
 - **Legal capacity** means you can make decisions without your Representative.
- A person with a disability can stop or change a Representation Agreement any time.

Even without a Representation Agreement, you can get some kinds of help from your friends and family.

- They can remind you to do things you have to do, help you understand your choices, and come with you to the bank or doctor's office.
- Without a Representation Agreement, they cannot always do things like talk to your bank or your doctor when you can't talk to them yourself.
- Some Representation Agreements allow a Representative control over money.
- Special steps make sure the person with the disability is not taken advantage of:
 - You name a spouse as your Representative;
 - You name a group who serves as Representatives. The group must all agree before it can spend your money.
 - You name a **monitor**. The monitor make sure the representatives follow your wishes.

Anyone can report the representative for abuse and neglect. The government investigates.

- Yukon and Saskatchewan have similar Representation Agreement laws.
 - Only British Columbia's law allows people with significant disabilities to sign Representation Agreements.

In Canada, you can sign an Enduring Power of Attorney.

- An **Enduring Power of Attorney** is like a **durable power of attorney** in the United States.
- It is like a Representation Agreement, but not everyone can sign it.

A notary public puts a stamp on an Enduring Power Of Attorney. A notary republic makes a document legal.

- The notary public may choose not to make the document legal if the notary public believes you did not understand the document.
- Also, if another person believes you did not understand the document and complains to the court, and the court agrees, the court cancels the Enduring Power of Attorney.

Finally, Canada also has a guardianship system. A court appoints a guardian for you.

Sweden

Sweden has a supported decision-making law that is very different from Canada's.

- You must ask the court for a supporter in Sweden. The court appoints a legal mentor or administrator.
- No guardianship system exists in Sweden.

A legal mentor helps the person with a disability make decisions.

- The legal mentor can be a friend, family member, professional supporter, or even a community member such as a teacher or social worker.
- The legal mentor gives advice.
- If the person with a disability wants, the legal mentor manages money.
- If the person with a disability is ill, the legal mentor acts without approval.
- People with disabilities make decisions with the legal mentors, with or without help.
- The person with a disability can also cancel the legal mentorship at any time.

The court can also appoint an administrator, who acts more like a guardian.

- This only happens when appointing a legal mentor would not be enough to help the person make decisions.
- An administrator can make decisions for a person with a disability without first asking for the person's approval.
- The administrator can also undo decisions that a person with a disability made, if the administrator thinks they seemed wrong.
 - For example, if a person with a disability buys a car that the administrator thinks that the person cannot afford, the administrator can take the car back to the seller.
 - They can get the person's money back – even if this means the seller will lose money.
- The person with a disability still has some decision-making rights, such as the right to vote.

Sweden also has programs to give people professional help to make decisions.

- For example, instead of choosing a person like a friend or family member, a person with a disability can get a professional supporter called a **Personal Ombudsman** from an agency.
- They do not have to go to court to get the Personal Ombudsman.
- The Personal Ombudsman (PO) spends a lot of time reaching out to and meeting with the disabled person.
- The PO cannot make any decisions for the person with a disability but can help the disabled person make his or her own choices.

Personal Ombudsmen work with people who have psychiatric disabilities, not intellectual or developmental disabilities.

- People with intellectual or developmental disabilities hire a personal assistant who helps with decisions and daily living.
 - The government pays for the assistant.

United Kingdom (England, Scotland, Wales, & N. Ireland)

- Guardianship and supported decision-making in England and Wales are now both governed by the same important law: **The Mental Capacity Act of 2005.**
- The United Kingdom is made up of England, Scotland, Wales, and Northern Ireland.
- The Mental Capacity Act of 2005 only is law in England and Wales. Northern Ireland and Scotland have different laws.

The Mental Capacity Act has a few important rules to follow.

- These rules are:
 - Assume a person with a disability makes their own decision unless proven otherwise.
 - The court must try supported decision-making before guardianship.
 - Bad decisions are not a reason for guardianship.
 - If people can't find any way for someone with a disability to communicate what choice they want to make or make a decision, all decisions made for the person must be in that person's "best interests."
 - Even a decision made in the best interest of a person with a disability must protect them and accomplish their goals.
 - This protection cannot restrict a person with a disability.

No guardianship under the Mental Capacity Act can take away your right to:

- Marry whoever you want
- Have relationships and friends
- Place a child up for adoption
- Vote
- **People with disabilities who need support have options under The Mental Capacity Act.**
- These options range from supported decision-making options to guardianship options.

Deputies

Deputies are the British term for guardians.

- A court appoints a deputy.
- The court appoints a deputy when the court thinks you cannot make decisions.
- A person must apply to the Court of Protection to be a deputy.
- The Office of the Public Guardian oversees deputies.
- The court order lists what the deputy is in charge of.
- The deputy must act in the best interests of the person with a disability.

A deputy must keep five things in mind with any decision.

1. Do not make assumptions about the person with a disability.
2. The deputy must wait to make a non-urgent decision if there is a chance the person with a disability will be able to decide for themselves later on.
3. The deputy must wait on any noncritical decision if there is a chance the person with a disability gets to make decisions themselves again.
4. The deputy must involve the person with a disability as much as possible in decisions.
5. Deputies cannot stop life-saving medical treatment.

Lasting Power of Attorney and Advance Decisions

In England when you create a power of attorney, you can create two types:

- an ordinary power of attorney and
 - a Lasting Power of Attorney (LPA).
- An ordinary power of attorney gives someone the same kinds of powers as a normal power of attorney in the United States.

A Lasting Power of Attorney gives someone the power to make decisions for another person who is no longer able to make decisions for themselves.

- It is like a durable power of attorney in the United States or an enduring power of attorney in Canada.

Lasting Powers of Attorney grant a person (called the attorney, even if they are not a licensed attorney) the right to make one of two specific types of decisions on behalf of another.

- One type of decision is health care and welfare.
 - The other type of decision is about property and financial decisions.
 - These two types can't be combined.
 - If someone wants to give another person the ability to make decisions about both health care and money, they would have to sign two different forms.
- Lasting powers of attorney can be **created** at any time when the person granting another power over their life is seen as having the ability to make their own decisions.
 - The lasting power of attorney only **takes effect** when the person loses this ability.
 - A lasting power of attorney could be used as a plan for how to make decisions in case of a future illness or disability.
 - It can also be a way to appoint a supporter for times when you have more support needs than usual.

Advance statements say what you want in the future.

- Advance statements cover any subject.
- Advance statements are **not** legal documents.

An advance decision is like an advance statement, but specifically covers unwanted medical treatment.

- Unlike an advance statement, **it is a legal document.**
- It only works if it is signed when the person is seen as having the ability to make decisions.

- A doctor in England absolutely has to do what the **advance decision** says.
 - For example, an **advance statement** could say that the person with a disability doesn't want to go to a certain hospital but the person's doctors **don't have to listen**. They could still take the person to that hospital.
 - If an **advance decision** said that the person didn't want to go to that hospital, the doctors would have to not let that person go to that hospital no matter what.
 - This means that people have to think very carefully before signing an advance decision.

Independent Mental Capacity Advocates (IMCAs)

There are not many ways to use supported decision-making in the United Kingdom (U.K.).

- It is assumed that a family member or friend is your guardian, or that they can help you make decisions.
- England and Wales are part of the U.K. Some people in England or Wales do not have any family or friends that can help them. People in England or Wales may be able to get an Independent Mental Capacity Advocate, or IMCA.
- You cannot get an IMCA if you've been placed in a mental hospital under a law called the Mental Health Act of 1983.

British courts can decide that some people can't make important decisions on their own. IMCAs help these people.

- IMCAs can only help with health care, abuse and neglect, or when the person is changing where they live.
- The IMCAs know how to talk to people who have trouble communicating.
- The IMCA finds out from the person what they want and tells other people what they want.
 - For example, the IMCA tells the doctor what treatment the person wants.
- If the IMCA can't find out what the person wants, the IMCA makes a guess.
- The IMCA does not make the final decision. Whoever called the IMCA makes the final decision. This person is called the decision-maker.

- Sometimes an important decision has to be made. If there are no friends or family to help, the decision-maker **has** to give you an IMCA.
- The decision maker is chosen by the NHS or the local government. The NHS is the U.K. agency that does health care. Sometimes a doctor is the decision-maker.
- The IMCA can challenge the final decision if it is not what you want.
- They can also argue that you are able to make decisions, even if the British court said you can't.

Bulgaria

Guardianship in Bulgaria

Guardianship in Bulgaria limits choices even more than guardianship does in other countries.

- Very few laws on guardianship exist in Bulgaria. The ones that do exist take most choices away from people with disabilities.

Advocates think guardianship in Bulgaria is outdated, used too much, and based on stereotypes about people with disabilities.

- About 7,000 people with disabilities are under guardianship in Bulgaria.
- Most of these are the “full” guardianships we explained earlier.
- There are “partial” guardianships in Bulgaria, but even these take away many rights.
- People under full or partial guardianships in Bulgaria can’t sign a contract with someone else without help of the guardian.
- People under guardianship in Bulgaria don’t have control over their property or where they live, either.

Bulgarian guardianship law grants the guardian the power to control the person under guardianship’s property and the power to decide where the person under guardianship lives.

- The person cannot even complain to the court if they think they shouldn’t have a guardian.
- Only their guardian can go to court to complain if the person is not getting any or enough services.
- This is a serious problem because sometimes the person’s guardian does not want the same things the person wants.
- For example, if guardian takes a person’s money away or puts them in an institution, the person can’t go to court and complain unless the guardian agrees to let them go to court.

The European Court of Human Rights says Bulgaria's guardianship laws are illegal.

- The European Court on Human Rights hears cases inside the European Union.
- Bulgaria is a member of the European Union.
- Bulgaria must listen to the European Court on Human Rights.

In *Stankov v. Bulgaria* and *Stanev v. Bulgaria*, the European Court of Human Rights listened to complaints by people with disabilities who had been put into institutions by their guardians.

- The guardians had not asked them where they wanted to live.
- In Stanev's case, he had never even met his guardian.
- The conditions in the institutions were also very bad.

The European Court of Human Rights said that this violated European Convention on Human Rights.

- It was illegal because the people with disabilities had no way of arguing they shouldn't be institutionalized if that was what the guardian wanted.
- To obey these court decisions, Bulgaria will have to change its guardianship laws.

Supported Decision-Making in Bulgaria

- Right now, there are very few options in Bulgaria for people with disabilities who want to live independently but with supports.
- A national program called Assistants to People with Disabilities was created in 2003.
 - This program hires previously unemployed people and teaches them to support people with disabilities.
 - A program called **Help at Home** helps pay assistants or family members of people with disabilities to give people supports.

However, some advocates have said that these assistants sometimes don't have enough knowledge and experience about the needs of people with disabilities.

Reform Efforts in Bulgaria

Advocates in Bulgaria really want to make guardianship laws there better.

- Advocates created a supported decision-making model in Bulgaria.
- They're also trying to get laws passed that create supported decision-making for people with disabilities there.

The Minister of Justice wants to bring Bulgaria's laws in line with the CRPD.

- In Bulgaria, The Minister of Justice deals with human rights issues.
- The Minister of Justice wants supported decision-making.
- Progress is slow.

Reform Efforts in Bulgaria: An Illustration

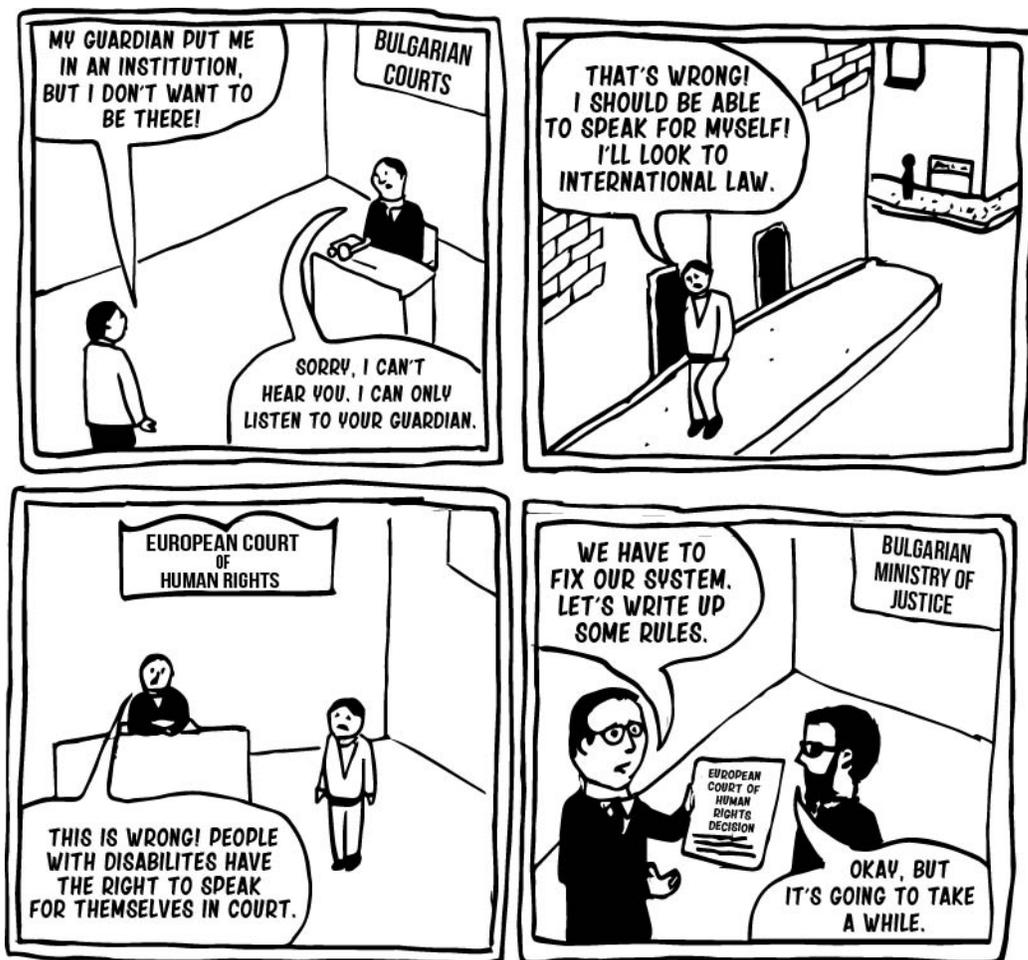


Illustration by Pip Malone

Israel

Guardianship

- Guardians in Israel are called **apotropos**, which is a legal term there.
- Originally, Israel made guardianship for the elderly.
- Now, Israel uses guardianship a lot.
 - In Israel, 50,000 people are under guardianship.
 - Guardians in Israel are always appointed by the courts.
 - They are often family members.

Guardianships in Israel are fairly similar to guardianships in other countries, in that the person with a disability loses power over their own decisions and daily life.

- The guardian gets the right to make those decisions.
- There is one interesting exception. In Israel, it is possible to be put under guardianship while still keeping the theoretical, legal ability to make your own decisions as well.
- This happens when a court appoints a guardian but does not specifically say that the person with a disability is “legally incompetent.”

In this case, the person under guardianship can still make decisions about health care and money or sign contracts without telling the guardian, but the guardian in practice still controls the person’s life.

- The guardian still does control the major choices that need to be made by the person with a disability because if people know you have a guardian, they probably won’t ask for your opinion in Israel.

If the court says you cannot make choices, you can argue against guardianship in court.

Supported Decision-Making

- Israel just started to use supported decision-making.
- The first person in Israel moved from guardianship to supported decision-making two years ago.

Advocates want Israel's guardianship laws in line with the CRPD.

- **Bizchut** is a disability rights organization that helps with supported decision-making.
- Right now, 22 people with disabilities use supported decision-making.

Israel Unlimited gives people with disabilities a care coordinator and a mentor.

- The care coordinator and mentor help make decisions.
- The care coordinator and mentor also help the person with an independent living skills.

Israel agreed to the CRPD.

- This means that it should let people use supported decision-making instead of guardianship.
- But there is still no official government program to promote supported decision-making.

Other Guardianship Alternatives

- People in Israel can sign documents to name supporters.
- They can use a **power of attorney** to get support with health care and money.
- Powers of attorney in Israel are like powers of attorney in the US, Canada, or the UK.

A psychiatric advance directive says what mental health treatment you want if you have a mental health crisis.

- It is not a legal document. Doctors do not have to follow it.

- Some people who own property – like a house – worry that they will make a bad decision and sell the house.
- People can prevent this using something called a **caveat**.
 - A caveat prevents you from making certain kinds of decisions about land without the court's approval.
 - The caveat *can* also prevent a guardian or supporter from selling land without court approval too, although usually it isn't used like that.

A person can also name a trustee over his or her land, money, and other property.

- The person with a disability can put a bank account or land into a "**trust.**" The **trustee** is the person who takes care of the **trust**.
- The trustee is like a power of attorney but can only make decisions about money or property in the trust.

The trust can have rules about what the trustee can or can't do.

- For example, the trustee may not be able to sell the land.
- For a bank account, the trustee may be allowed to spend only a certain amount every month.
- The person with a disability can put only some of their property in the trust.
- For example, they may put their house in a trust but keep control over their bank account.

Glossary

Advance decision (UK)

- An **advance decision** is like an advance directive, but specifically covers unwanted medical treatment. Unlike an advance directive, **it is a legal document**. It only works if it is signed when the person is seen as having the ability to make decisions. A doctor in England absolutely has to do what the advance decision says.

Advance directive

- A kind of form you can sign. Also called an Advance Statement in England. It tells people what you want if you become unable to make decisions or to tell them what you want. It is usually used to show the doctors what kind of health care you want, or what kind you don't want. An advance directive is usually not legally binding. This means that doctors don't always have to listen to what it says.

Advance statement

- *see Advance directive*

Apotropos (Israel)

- The word for guardians in Israel.

Assistants to People with Disabilities (Bulgaria)

- This program hires previously unemployed people and teaches them to support people with disabilities.

Bizchut (Israel)

- A disability rights organization that helps with supported decision-making.

Caveat (Israel)

- A caveat in a legally-binding document can prevent a guardian from making certain kinds of decisions about land.

Convention on the Rights of Persons with Disabilities (CRPD)

- An agreement among countries about the rights of people with disabilities. It is an international law. Article 12 protects people's right to make decisions about their own lives. Most countries have agreed to follow the CRPD, but not all. Many countries that agreed to follow it are still not fully protecting the decision-making rights in Article 12. Those countries that have agreed to follow the CRPD, but are not following Article 12, may risk being taken to court. "Persons" is another word for "people."

Court of Protection (UK)

- A special kind of court in England. It can decide what kind of help a person needs to make decisions. It can appoint a deputy for a person with a disability.

Deputy

- The word for guardians in England.

Durable Power of Attorney

- A power of attorney that keeps working if you become unable to make decisions without help. Sometimes this kind of power of attorney only starts working if you become unable to make decisions without help. Usually, doctors have to say that you can't make decisions. Once you're seen as unable to make decisions, you may not be allowed to cancel the power of attorney.

Enduring Power of Attorney (Canada)

- see *Durable Power of Attorney*

European Court on Human Rights

- The European Court on Human Rights hears cases from countries that are inside the European Union.

Full Guardianship

- Guardianship where the guardian makes decisions involving every, or almost every, part of a person's life – including health care, money, where a person lives, and what a person does during the day.

Guardianship

- An arrangement where someone is appointed by law to make decisions about another person's life. In many countries, guardians will be appointed for disabled adults who are seen as unable to make their own decisions. Guardianship could be a Full Guardianship or a Limited Guardianship.

Help at Home (Bulgaria)

- This program helps pay assistants or family members of people with disabilities to give people supports.

Independent Mental Capacity Advocates (IMCAs) (UK)

- ICMAAs are people paid to help the person who has trouble making important decisions on their own, like their future health care plans or their finances. The IMCAs receive training to help them communicate with the person they support and find out what that person wants to do.

Israel Unlimited (Israel)

- An organization that gives people with disabilities a care coordinator and a mentor. The care coordinator and mentor help the person with disabilities with independent living skills.

Lasting Power of Attorney (UK)

- see *Durable Power of Attorney*

Limited Guardianship

- Guardianship where the guardian makes decisions about some parts of a person's life, such as money and healthcare, but not others.

Legal capacity

- A person's ability to have their decisions recognized legally. This can include whether a person can sign a contract, set up a bank account, sue in court, or make a decision about health care. If a person does not have legal capacity, then a banker or a doctor would not be allowed to follow the person's decision alone. They would need permission from a guardian or family member. Different countries or states might have different rules about who has legal capacity and who does not.

Legal mentor

- The Swedish equivalent of a supporter. The mentor has some ability to make decisions for a person. The person with a disability can fire the mentor at any time. The mentor can make decisions for the person with a disability that person becomes unable to say what they want.

Mental Capacity Act of 2005 (UK)

- This law governs both guardianship and supported decision-making in England and Wales. The Mental Capacity Act has important rules to follow about when guardians can be assigned and what guardians can and cannot do.

Model Legislation

- An idea for how a law could work. It is written to look like a real law. Lawmakers can use it as a model for laws to pass. It does not become a real law unless lawmakers vote to make it a law.

Notary or Notary Public

- This word means different things in different countries. In many countries, notaries are people who have special stamps or seals. Sometimes they are also lawyers. A notary might need to put the stamp or seal on a power of attorney or health care proxy. The stamp or seal means that the notary is sure that the people signing the document are who they say they are. The notary may also make sure the person signing the document knows what they are signing. In some places, a power of attorney or health care proxy won't work unless a notary puts a stamp or seal on them.

Ordinary Power of Attorney

- A power of attorney that stops working if you become unable to make decisions without help. Also called Normal Power of Attorney.

Personal assistant or Personal Ombudsman

- A Swedish type of supporter. A person can get one from an agency. Usually a personal ombudsman works with people with psychiatric disabilities. A personal assistant works with people who have intellectual or developmental disabilities.

Psychiatric Advance Directive (Israel)

- An advance directive about mental health. For example, it can say that you don't want a certain medication. It is not a legal document. Doctors do not have to follow it.

Ratification

- This is what happens when a country agrees to follow the rules of an agreement or treaty created by multiple countries. If a country ratifies an agreement, they can be called into court if they break the rules of the agreement.
- Countries that agree with the treaty or agreement but don't want to follow the rules have not ratified it. They can't get called into court over it.

Representation Agreement (Canada)

- A kind of supported decision making agreement in British Columbia, Canada. It allows people with disabilities to name a Representative. The Representative helps make decisions. The person with a disability usually keeps the ability to make their own decisions.
- Sometimes a Representative may make decisions for the person with a disability. This can happen if the person with a disability can't make the decision for some reason. It could also happen if the Representative thinks the person with a disability is being "unreasonable."

Representation Agreement with Broader Powers (Canada)

- A special Representation Agreement. It gives a Representative the ability to do things that they normally could not. For example, the Representative could help make decisions about buying or selling a person's house. A person with a disability can't sign a Representation Agreement with Broader Powers if the court thinks they do not completely understand it.

Supported Decision-Making

- A way to make decisions. A person with a disability chooses someone to help them understand or communicate a decision. The person with a disability is free to make their own decision but has help from the supporter.

Supported Decision-Making Agreement

- An agreement that a person can make with a supporter. The supporter helps the person make decisions. The supporter usually can't make decisions for the person with a disability. In some places, an agreement just needs to be signed by the person with a disability and the supporter. In other places, they also need to be stamped by a Notary. In some places, they may even need to be approved by a court.

Trust

- A trust is a legal arrangement that lets someone else manage money or property. The manager, or trustee, has to follow special rules that you set. For example, there might be a rule that you get a certain amount of money each month. Or there can be a rule that the money can be spent for certain things. The trustee can only manage the money or property that's been put into the trust.

Trustee

- A trustee is someone who manages money or property that's in a trust. A trustee could be a person you know. Or it could be a bank or a lawyer. A trust can have more than one trustee.

