The Right to Make Choices: International Laws and Decision-Making by People with Disabilities

Part 5: Guardianship and Supported Decision-Making Law
5. 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.
• For example, 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 has laws for supported decision-making.

• Texas is the only state 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 is the only US state which has 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.
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 make 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.

• You can take these special steps to make sure your Representative does not take advantage of you:
  
  • 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 get 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 public makes the 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 person with a disability.
• The PO cannot make any decisions for the disabled person 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, and Northern Ireland)

• Guardianship and supported decision-making in the United Kingdom 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 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.

• Some are similar to guardianship.

• Others are more like supported decision-making.
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.

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)

• The United Kingdom doesn’t have many official ways to recognize a supported decision-making relationship.

• It is assumed that the person with a disability’s family and friends will act as that person’s representatives and support that person’s decisions.
• If people in the United Kingdom don’t have any family or friends available to help them, they may be able to get an **Independent Mental Capacity Advocate**, or ICMA.

• ICMAs 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.
• The IMCA tells your choice once you make a decision.

• For example, the IMCA tells the doctor what treatment you want.

• If you cannot communicate, the IMCA makes the decision.
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.
- 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.
• Bizchut has made some videos about supported decision-making. You can watch them on YouTube by clicking on the links below.

• **Bizchut’s Article 12 pilot**

• **Dana**

• **Alex**

• **Horesh**

• **Three stories**
• **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 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 the United Kingdom. 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 (UK)

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 People 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.

Court of Protection (UK)

A special kind of court in the United Kingdom. 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 the United Kingdom.

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)

ICMAs 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 person with a disability can also override the mentor’s decisions. 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 the UK. 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.
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.