

What Happens When My Child with a Disability Turns 18 Years Old? Supports for Decisions in Adulthood

Key Words to Know in Massachusetts

Guardianship

Guardianship is a legal term. If a court decides that an adult is “*incapacitated*,” the court can give someone else (called a *legal guardian*) the power to make decisions for that adult. When a court determines someone needs guardianship, it decides what types of decisions the person cannot make. If the court decides the person cannot make most decisions, it can place the person under general guardianship. If the court decides that the person can make some decisions, but not others, it can limit the guardianship to only cover the decisions that the person cannot make. Only the court can change or end a guardianship.

Legal guardian

When a court decides that an adult needs a guardianship, the court gives legal authority to someone else, called a legal guardian, to make decisions on behalf of the adult. The legal guardian has responsibilities and reports to the court. If the court believes the legal guardian is not doing a good job, it can replace them with a different legal guardian. While a guardian makes decisions for a person, the person should still be included in decision-making as much as possible.

Incapacitated

Massachusetts law defines an “incapacitated person” as an adult who has a clinically diagnosed condition that makes the person unable to receive and evaluation information or make or communicate decisions necessary to meet the person’s essential requirements for physical health, safety, or self care – even with help.

Supported Decision-Making

Supported Decision-Making (SDM) is a way of making decisions that people with disabilities can use to make choices about their own lives. People with disabilities can choose other people that they know and trust – or *supporters* – to be part of a support network to help with decision-making. Instead of having a guardian make decisions *for* the person, Supported Decision-Making allows the person with the disability to make decisions with help. Supported Decision-Making can be used with or without a written agreement in Massachusetts. For a sample Supported Decision-Making Agreement form, see: <https://supporteddecisions.org/getting-started-with-supported-decision-making/sdm-agreement-form/> (English, Spanish, and Khmer instructions)

Supporter

When people with disabilities use Supported Decision-Making, the other people that they choose to be part of their support network and help them understand their choices are called their “supporters.” Supporters provide assistance, information, and guidance, so the person with disability can make decisions. Supporters do not make decisions for the person with a disability.

Self-determination

Self-determination is having the ability and power to make choices in your life and act for yourself. It includes the ability to choose and set your own goals and work to reach them. Studies have shown that people with disabilities who exercise self-determination have better life outcomes, including in education, community living, and general quality of life.

Shared Educational Decision-Making

In Massachusetts, when a student turns 18, the student can choose to share educational decision-making authority with one or more parents or other adults. This means that the adult student and their trusted shared decision-maker make choices together about the student's Individualized Educational Program (IEP) and educational services. The student's choice to share decision-making must be documented and witnessed by representatives of the school district. The student or parent can obtain the necessary form through the school district. The student can revoke or cancel the shared decision-making agreement at any time. If a disagreement arises between the student and the other shared decision-maker, the choice of the adult student rules.

Delegated Educational Decision-Making

An adult student can choose to delegate educational decision-making authority to a parent(s) or other adult. This means the parent(s) or chosen adult makes all the choices about the student's IEP and educational services, because the student picked them to do so. The student or parent can get the necessary form through the school district. Students can revoke or cancel this arrangement, if they want to make their own educational decisions.

Health Care Proxy

A health care proxy is a legal document that an adult can sign to choose a trusted person to make medical decisions when the adult cannot make them. The adult must understand what a health care proxy is and does in order to be able to sign it. The adult can also revoke or cancel a health care proxy. An adult does not need to go to court to use a health care proxy. For health care proxy forms in nine languages (including English and Khmer) see: <https://www.honoringchoicesmass.com/multilingual-planning-documents/>

Durable Power of Attorney

A "power of attorney" is a legal document that allows an adult to choose a trusted person to manage the adult's money, property, and business affairs. The document can specify exactly when the trusted person has that power – either right away or only in certain circumstances, such as when the adult becomes unable to make decisions. A "durable power of attorney" allows the **agent** to continue acting for the person, even after the person has become incapacitated. The adult signing the power of attorney must understand what it is and what it does first. The adult may also revoke or cancel the power of attorney. An adult does not need to go to court to use a power of attorney. Powers of attorney can be complicated, depending on the situation, so consider talking to a lawyer before using one. For more information, see: <https://www.honoringchoicesmass.com/dpoa/> (in English)

Agent or Health Care Agent

When signing a power of attorney or a health care proxy, the adult picks a trusted person to make decisions if the adult is unable or unwilling to do so. That trusted person is called an agent. When the adult signs a health care proxy, sometimes the agent is called a health care agent.

Representative Payee

A representative payee is someone who manages another person's social security benefits. The Social Security Administration (SSA) will appoint a representative payee for someone if they think that person cannot manage or tell others how to manage their social security benefits. A person does not need to be subject to guardianship to have a representative payee. To apply to become someone's representative payee, contact your local SSA office <https://secure.ssa.gov/ICON/main.jsp> (type in your Zip Code).

Release of Information

A release of information form is a legal document that an adult can use to let service providers – like doctor's offices or school – share private information with others.

- For health care information, the adult should complete a release form under the Health Insurance Portability and Accountability Act (HIPAA). For a sample HIPAA form, see: <https://www.mass.gov/files/documents/2016/07/rh/model-authorization-eng.pdf> (in English). However, many health care providers have their own HIPAA forms that will want to be filled out as well.
- For educational information, the adult should complete a release form under the Family Educational Rights and Privacy Act (FERPA). Ask the school for the FERPA release form it uses.