



Module 7 – Legal Matters & Self-Advocacy

“To deny people their human rights is to challenge their very humanity.” - Nelson Mandela

Instructions

Please view the Legal Matters and Self-Advocacy video before completing the checklists and worksheets. The video provides a comprehensive overview of the topic. While completing these worksheets, you may need to reference additional resources and reading. We have listed some resources that we have found helpful in the Additional Resources section.

Topic Summary

In the Legal Matters & Self-Advocacy Module, we review a variety of legal considerations and guardianship planning for your child. In addition, we also discuss the importance of self-advocacy and self-determination for individuals with disabilities.

Checklists and Actionables

Only you and your child (with the help of others you trust if you want) can make decisions about what level of legal support s/he may need.

Family and Individual Considerations:

1. Can I prove to a court that my son/daughter cannot make certain DECISIONS on his/her own even if s/he needs help executing those decisions?
2. Do I want the expense of paying court and possibly attorney's or advocate's fees?
3. Do I have a back-up for whatever plan gets put into place?
4. Am I being over-protective?
5. If I am appointed guardian and have a back-up, am I willing to have a court-appointed stranger act as guardian or conservator in the event the people I thought were willing to back me up are no longer willing or can't?



6. Have I empowered my child to make age-appropriate choices, to know right from wrong, to recognize when s/he needs help and who s/he can trust to get that help or have I been doing everything for my child?
7. Have I helped my son/daughter develop a circle of support through my family, friends, faith community, and others who can support his/her decision-making by making sure s/he has and understands all the information needed to make really important decisions?
8. It is important, whatever the result for your family is, that you continue to allow your son/daughter to make as many decisions as s/he can and, to the extent possible, honor his/her choices – even if you end up being a conservator or plenary guardian.
9. For some parents, this means learning to treat their adult son or daughter with a disability in an age-appropriate way!
10. You can also encourage those who know your child to respect his/her decisions. For example, as a guardian or conservator, you may have the power (depending on what powers the court granted you) to sign a photo release so that your child's picture can appear in the news but your son or daughter should be able to override your permission if s/he does not want to do so!
11. Learn about all the adult services agencies in your state. Find out now if your son/daughter is eligible. Do whatever the agency requires to establish that eligibility.

KNOW ABOUT THE RIGHTS YOU AND YOUR SON/DAUGHTER HAVE!

It is important, whatever the choices your family make, that you continue to allow your son/daughter to make as many decisions as s/he can and, to the extent possible, honor his/her choices – even if you end up being a conservator or plenary guardian.

- For some parents, this means learning to treat their adult son or daughter with a disability in an age-appropriate way! For example, if they are older than age 18, are they registered to vote?
- You can also encourage those who know your child to respect his/her decisions. For example, as a guardian or conservator, you may have the power (depending on what powers the court granted you) to sign a photo release so that your child's picture can appear in the news but your son or daughter should be able to override your permission if s/he does not want to do so!



- Enroll your son/daughter in a local self-advocacy group. You can also look for “Self-Advocacy Skills” on line and find suitable videos your child can watch at home.

- Start teaching your child to make choices (and let them make choices that are age-appropriate!) and make sure self-advocacy skills are part of the IEP.

Other Self-Advocacy Resources and Activities

- Disability Rights Day at the Capitol
- On-line advocacy groups
- Self-advocacy groups such as the Autistic Self-Advocacy Network, People First, or SABE (Self-Advocates Becoming Empowered), KASA (Kids as Self-Advocates)
- On-line advocacy and support groups
- Members of your faith community, family, or your own circle of friends and colleagues
- Attorneys
- Legal Aid Clinics
- Advocates
- How to register to vote and actually vote
- Educators or other professionals who can teach your son/daughter self-advocacy skills and about their rights as a U.S. Citizen AND special rights because s/he has a disability.

The following section details legal definitions and requirements as it relates to issues of decision making for health & personal affairs as well as financial affairs.

Special thanks to Kathleen Tetrault of Disability Planning Partners for her assistance with this module. For more information, please contact:

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Table of Legal Definitions and Requirements

Health and Personal Affairs

	Legal Relationship	How achieved	Essential requirements	Results
Most Restrictive	Plenary guardianship	Court appointed individual(s)	Proof of incompetence to make any decisions must be made to the court	Takes away all individual rights
	Limited guardianship	Court appointed individual(s)	Proof of incompetence to make some decisions such as what is adequate care and support, medical decisions, or financial management must be made to the court	Takes away individual rights in the area(s) for which limited guardianship has been granted by the court
	Advocate or Personal Contract (with Advanced Healthcare Directive)	Any person chosen to speak up for the individual (may be paid or voluntary) Healthcare representative(s) appointed by individual with disability in legal document prepared by an attorney.	You or your son/daughter do not have a team to support decision-making but would like some help in formal proceedings to make sure others listen to you. Personal contracts can also apply to assistance in making daily decisions such as how much money to spend on groceries vs. entertainment	The Advanced Healthcare Directive protects the individual's interests in the event he/she loses capacity and cannot express his/her healthcare wishes.
	Supported Decision-making (with Advanced Healthcare Directive)	An individual works with a team/support network to assist him/her with decision-making Healthcare representative(s) appointed by individual in legal document prepared by an Attorney.	Competence of the individual to direct his/her life is presumed even if s/he has difficulty exercising those decisions without assistance. The individual has or is learning self-advocacy skills and has support to use them	The individual retains all rights as an adult, including the right to an Advanced Healthcare Directive, including a Living Will, that will guide the team in making decisions after the person is incapacitated The Advanced Healthcare Directive protects the individual's interests in the event he/she loses capacity and cannot express his/her healthcare wishes.
Least Restrictive				



Decision Making for Financial Affairs

	Legal Relationship	How achieved	Essential requirements	Results
Most Restrictive	Involuntary Conservatorship	Court appointed individual(s)	Proof of incompetence to make personal decisions, financial decisions, or both must be made to the court	Takes away all individual rights in the area(s) for which the conservator was appointed
	Voluntary Conservatorship	Court appointed individual(s)	Individual with a disability voluntarily requests appointment of conservator	Takes away all individual rights in the area(s) for which the conservator was appointed
	Advocate or Personal Contract (with Power of Attorney)	Any person chosen to speak up for the individual (may be paid or voluntary) Power of Attorney document Agent(s) under Power of Attorney appointed by individual with disability in legal document prepared by an Attorney	You or your son/daughter do not have a team to support decision-making but would like some help in formal proceedings to make sure others listen to you. Personal contracts can also apply to assistance in making daily decisions such as how much money to spend on groceries vs. entertainment	No rights are taken away but an advocate's role extends only to formal proceedings. Personal contracts can apply to any decisions written into the contract. The Power of Attorney document protects the individual's interests in the event he/she loses capacity and cannot manage his/her financial affairs.
Least Restrictive	Supported Decision-making (with Power of Attorney)	An individual works with a team/support network to assist him/her with decision-making Power of Attorney document Agent(s) under Power of Attorney appointed by individual with disability in legal document prepared by an Attorney.	Competence of the individual to direct his/her life is presumed even if s/he has difficulty exercising those decisions without assistance. The individual has or is learning self-advocacy skills and has support to use them	The individual retains all rights as an adult, including the right to a Power of Attorney that will guide the team in making financial decisions after the person is incapacitated.



Additional Definitional Information

Many people are confused about the difference between Guardianship and Conservatorship. In general, Guardianship refers to an individual appointed by the Probate Court to manage the personal affairs of an individual with an intellectual disability (IQ of 69 or below). In Connecticut, a Guardian may also obtain special permission to manage the financial affairs of an individual with an intellectual disability whose assets are \$10,000 or less.

Conservatorship generally refers to an individual appointed by the Probate Court to manage the personal affairs (Conservator of Person) or financial affairs (Conservator of Estate) of a person with a disability.

These two concepts are explored in further detail herein.

Guardianship:

In Connecticut, an individual with an intellectual disability (IQ of 69 and below) may have a Guardian appointed for assistance in managing his/her personal affairs and his/her financial affairs for assets up to \$10,000.

There are two types of guardianship for individuals with intellectual disability: Plenary Guardianship and Limited Guardianship. The terms "plenary" and "limited" refer to the level of decision-making authority the Probate Court has given to the named Guardian. Ultimately, it is the Probate Court's decision as to whether to an appointed Guardian should have Plenary or Limited authority. This decision is based upon the best interests of the person with a disability, as well as the stated preferences of the individual with a disability.

What is a Plenary Guardian?

A plenary guardian supervises all aspects of the care of a protected person who, by reason of the severity of his or her intellectual disability, is "totally unable to meet essential requirements for his or her physical health or safety" and "totally unable to make informed decisions about matters related to his or her care."

What is a Limited Guardian?

A limited guardian supervises only certain specified aspects of a protected person's care because the court finds that the respondent is able to do some, but not all, of the tasks necessary to meet essential requirements for his or her physical health or safety or make some, but not all, informed decisions about matters related to his or her care.



Generally speaking, a Guardian does not have the authority to manage the financial affairs of the individual under guardianship. However, if the individual with a disability requires assistance in managing his/her finances, then the Guardian can request that the Court authorize him/her to manage the individual's finances up to the amount of \$10,000. If the individual's assets exceed \$10,000, then the individual would need a Conservator of the Estate to manage his/her finances.

Source: *Probate Court User Guide Persons with Intellectual Disability*
<http://www.ctprobate.gov/Documents/User%20Guide%20-%20Persons%20with%20Intellectual%20Disability.pdf>

What is a Conservator?

A conservator is a person appointed by the Probate Court to oversee the financial and/or personal affairs of an adult who is determined by the Probate Court to be incapable of managing his or her finances or unable to care for himself or herself. A conservator may also be appointed for a person who voluntarily requests such assistance. Source: Probate Court User Guide for Conservators <http://www.ctprobate.gov/Documents/User%20Guide%20-%20Conservators.pdf>

A Conservator of Person manages the personal affairs of an individual with a disability whose IQ exceeds 69 (see Guardianship for individuals with an IQ under 69), and a Conservator of the Estate manages an individual's financial affairs (but see Guardianship for individuals with an IQ under 69 with \$10,000 or less in assets).

What is a Conservator of Person?

A "conservator of the person" is appointed to supervise the personal affairs of an individual who is found by the court to be unable to meet essential requirements for personal needs. These needs may include, but are not limited to, food, clothing, shelter, health care and safety.

What is a Conservator of the Estate?

A "conservator of the estate" is appointed to supervise the finances of an individual who is found by the court to be incapable of doing so himself or herself to the extent that property will be wasted unless adequate property management is provided. This may include, but is not limited to, actions to manage assets, income and public assistance benefits.

Source: *Probate Court User Guide for Conservators*
<http://www.ctprobate.gov/Documents/User%20Guide%20-%20Conservators.pdf>

Conservatorship: Voluntary or Involuntary

Conservatorship may be either voluntary or involuntary. An individual with a disability may voluntarily request that the Court appoint a Conservator to act on his/her behalf with regard to personal and/or financial affairs. When conservatorship is voluntary, the individual with a disability can revoke the conservatorship at any time.



Conservatorship may also be involuntary, which means that the Court has determined the individual with a disability does not have the capacity to consent to the conservatorship. When conservatorship is involuntary, only the Court can terminate the conservatorship.

What is an Advanced Healthcare Directive?

An Advanced Healthcare Directive is a legal document that enables an individual to name a health care representative to speak on his/her behalf with regard to medical decisions, in the event that the individual creating the document is unable to express his/her medical needs or preferences.

This document also contains what is known as a “living will.” A living will sets forth an individual’s preferences for end-of-life care, in the event that the individual is terminally ill or permanently unconscious.

This document does not remove an individual’s ability to make decisions for oneself. It only allows a healthcare representative to if needed. It takes effect immediately and lasts for the remainder of the individual’s life or until it is revoked.

What is a Power of Attorney Document?

A Power of Attorney is a legal document that enables an individual to appoint an agent to carry out legal, financial, and banking tasks for the individual’s benefit. This document does not remove the individual’s ability to make decisions for oneself. It only allows an agent to act on one’s behalf if this is necessary, either because the person creating the document is unavailable to carry out financial tasks or he/she has lost capacity. This document takes effect immediately and lasts for the remainder of an individual’s life or until it is revoked.



This form asks you to list the five steps you will take to support your child legally and maximize his/her ability to self-advocate. These steps can include asking for a PPT to include self-advocacy and self-determination goals and objectives in the IEP, or asking other parents for recommendations about legal issues they have had to address.

Starting small

List the first 5 things you will do/assure gets done to take care of legal matters involving your son/daughter and to facilitate his/her ability to be self-determined and a great self-advocate in order to build a good life!

Action Steps	Who's responsible	Completion date
1.		
2.		
3.		
4.		
5.		