



Statewide Parent  
Advocacy Network

## **Alternatives to Guardianship for Families of Children with Special Healthcare Needs**

Parents of children (and adults) with disabilities, and self-advocates, need to know that there are alternatives to guardianship. While parents may have legitimate concerns about their youth/young adult's ability to make decisions about their own healthcare, education, finances, living situation, etc., youth and young adults with disabilities have the right to be involved in and make their own decisions. This factsheet supplies tips and resources for families who have a loved one with special needs to help them maximize the participation of their youth/young adult in their own decision-making.

Shared decision-making is one of the key concepts in healthcare. When patients and their families partner with health providers, they get better outcomes. One of the six key core outcomes for the Maternal/Child Health Bureau highlights the importance of shared decision-making: "Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive." One of the main ideas behind another core outcome for children with special needs, the medical home, is that care needs to be patient and family centered. *Children with special needs should have as much input as they can based on their capacity. Parents must begin at an early age to help their child, regardless of their disability or special healthcare needs, to engage in decision-making about their own care and prepare them to make independent decisions as they become adults.* To protect the civil rights and dignity of youth and young adults with disabilities and special healthcare needs, it is critical that parents use alternatives to guardianship for their young adults with special needs. Even if parents decide that guardianship is the only alternative that will work for their family, it is important that they minimize the extent of their guardianship and use options such as limited guardianship, so that their young adult with special needs can make as many of their own decisions as possible.

In terms of healthcare decision-making, an important alternative to guardianship is a healthcare power of attorney, which allows parents to participate in healthcare decision-making for their young adult with special needs without guardianship. Links to relevant forms are provided below.

### **Forms:**

Sample healthcare power of attorney & Advance Directive forms:

American Academy of Family Practitioners (AAFP)-Advance Directive/Power of Attorney

<http://www.aafp.org/afp/1999/0201/p617.html>

Palliative and End of Life Care: What is an Advance Directive (see Healthcare Proxy)

NJ Department of Health

<http://www.state.nj.us/health/advancedirective/whatis.shtml>

"Self Advocacy Guide to Guardianship" (see chapter 2)

Disability Rights Idaho

<http://www.disabilityrightsidaho.org/images/content/docs/Self-Advocacy%20Guide%20to%20Guardianships.pdf>

## Resources:

Alternatives to guardianship resources can be found at:

- Alternatives to Guardianship  
[http://ruralinstitute.umt.edu/images/archived\\_publications/Alternatives\\_To\\_Guardianship.pdf](http://ruralinstitute.umt.edu/images/archived_publications/Alternatives_To_Guardianship.pdf)
- Guardianship-Family Options (see Power of Attorney)  
<http://nj.gov/humanservices/ddd/services/guardianship/>
- Guardianship & Alternatives to Guardianship  
[http://www.ridlc.org/publications/RIDLC\\_Guardianship\\_Booklet.pdf](http://www.ridlc.org/publications/RIDLC_Guardianship_Booklet.pdf)
- Guardianship and its Alternatives – (see Chapter 3)  
<http://mcdd.kennedykrieger.org/guardianship-and-its-alternatives-handbook-2011.pdf>
- Thinking About Guardianship? <http://www.gcdd.org/images/Reports/guardianship%20guide%20-%20gcdd.pdf>

Please also see SPAN's transition materials for health care practitioners, including power of attorney for medical decisions, at [www.spannj.org/keychanges/TransitionResourcesHealthPractitioners.pdf](http://www.spannj.org/keychanges/TransitionResourcesHealthPractitioners.pdf)

## Helpful Contacts:

**Centers for Independent Living (CILs)** maximize skills needed for independent living, supports needed to achieve this goal, and maximize potential of individuals who may not live independently. County CILs can be found at <http://www.njsilc.org/>

### **SPAN Family Voices/Family-to-Family Health Information Center**

<http://www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj>

(800) 654-SPAN

Families of individuals with disabilities and self-advocates need to be aware of the alternatives to guardianship to make the choice that best fits their needs and maximize the dignity and independence of their youth/young adults with special needs.

**Please note:** This information was current at the time of publication. But medical information is always changing, and some information given here may be out of date. For regularly updated information on a variety of health topics, please visit [familydoctor.org](http://familydoctor.org), the AAFP patient education Web site.

---

**Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and education of children, to enable all children to become fully participating and contributing members of our communities and society.**