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Empowered Families: Educated, Engaged, Effective!

Supported Decision-Making/Alternatives to Guardianship for Families of Children with Special Needs

Parents of children (and adults) with disabilities, and self-advocates, need to know that supported decision-making is a positive alternative to guardianship for young adults with disabilities. This factsheet supplies tips and resources for families who have a loved one with special needs who is reaching, or has reached, the age of majority.

Shared decision-making is one of the key concepts in healthcare. When patients partner with their health providers, they get better outcomes. This is one of the key core outcomes of the Maternal/Child Health Bureau which states “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 the medical home concept is that care needs to be patient and family centered. *Children with special needs should have as much input as they can based on age and ability.* Parents need to decide if and when their children are capable of making medical decisions. The individual with disabilities should maximize their independence, including medical decisions. One of the most difficult decisions for parents of children with special needs is how much they need to be involved in medical decisions as their child grows older. Besides guardianship (which could also be limited), there are other tools such as power of attorney that parents can use-see Resources below.

There is even information on Palliative and End of Life Care: What is an Advance Directive (see Healthcare Proxy) available from the NJ Department of Health at <http://www.state.nj.us/health/advancedirective/whatis.shtml>. Lastly, but perhaps most importantly, there is a guide for self advocates “Self Advocacy Guide to Guardianship” (see chapter 2) from the Idaho Disability Rights available at <http://www.disabilityrightsidaho.org/images/content/docs/Self-Advocacy%20Guide%20to%20Guardianships.pdf>. Children and adults with special needs should have input into their medical care to the best of their ability.

Forms:

Sample healthcare power of attorney forms

American Academy of Family Practitioners (AAFP)-Advance Directive/Power of Attorney
www.aafp.org/afp/1999/0201/p617.html

Sample Advance Directive Form (AAFP)

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

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, the AAFP patient education Web site.

Resources:

Alternatives to guardianship resources can be found at:

- Alternatives to Guardianship
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
- 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

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

www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj
(800)654-SPAN

Families of individuals with disabilities need to be aware of what options are available, as do self-advocates, to make the choice that best fits their needs.

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