



Alternatives to Guardianship

BY LAUREN AGORATUS, M.A.

How will children with special needs be able to make decisions as an adult?

Families may be concerned about what the future holds for their child with disabilities. Parents may be fearful if the child will be able to live independently and make decisions for themselves. Children with special needs must have input, based on their abilities. Families and professionals need to start at a young age to help the child develop decision-making skills and maximize their potential as adults.

RESOURCES

Resources on Guardianship and Alternatives:

Rural Institute
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Alternatives to Guardianship

www.ruralinstitute.umt.edu/images/archived_publications/Alternatives_To_Guardianship.pdf



Guardianship & Alternatives to Guardianship

www.ridlc.org/publications/RIDLC_Guardianship_Booklet.pdf



Guardianship & its Alternatives

<http://mcdd.kennedykrieger.org/guardianship-and-its-alternatives-handbook-2011.pdf>

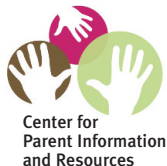


Thinking About Guardianship?

www.disabilityrightsidaho.org/images/content/docs/Self-AdvocacyGuidetoGuardianships.pdf

Helpful Contacts for Families:

Parents may wish to discuss these issues with other family organizations. In each state there is a federally designated Parent Training and Information Center (PTI.) PTIs provide free technical assistance on various topics, including transition to adult life. Transition includes school-to-work, finding adult healthcare providers, post-secondary education, and self-advocacy. The centers can be found at www.parentcenterhub.org/find-your-center



Family to Family Health Information Centers in each state may also provide assistance on transition to adult systems of care issues. You can find them at www.fv-ncfpp.org National Family Voices, which houses the National Center for Family-Professional Partnership, also supports Kids as Self-Advocates, which has developed a series of resources for youth/young adult self-advocacy at www.fvkasa.org/index.php



In every state, there are also Centers for Independent Living (CILs.) These are not residential placements but rather places that teach skills needed for independent living, and maximize the independence of the individual, even if they may not live on their own. Families and self-advocates can find their CIL at:

www.ilru.org/projects/cil-net/cil-center-and-association-directory



Parents of children with special needs and self-advocates need to know that there are various choices, and pick the best option that suits their needs. This will enhance the dignity of individuals with disabilities and maximize their independence. For more information on this topic, see the factsheet from the Statewide Parent Advocacy Network (SPAN) at www.spanadvocacy.org/content/alternatives-guardianship-health-decisions-families-young-adults-special-needs. 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



Resources: Sample Forms

Healthcare Power of Attorney/Advance Directive templates

American Academy of Family Practitioners (AAFP)
www.aafp.org/afp/1999/0201/p617.html

Is Guardianship the Only Way?

Once a child is 18, they are considered capable of making decisions regarding their education, healthcare, etc.— despite having special needs. In fact, shared decision-making is one of the cornerstones of healthcare reform. In addition, one of the Maternal and Child Health core outcomes for children with special needs 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.”

As parents may be unsure about their child's ability to make decisions, some may decide to go through the legal process of guardianship. Some families and self-advocates see this as a civil rights issue as the individual will not legally be able to make decisions about their own life, including where they live, work, or even if they are able to vote, etc. Although some states have limited guardianships, there are other choices available to families which may allow the individual to be more independent throughout their lifetime.

Guardianship Alternatives

There are other options besides guardianship which may work for families and maintain the civil rights of the individual with disabilities. Some families use a Power of Attorney when needed. This allows families to participate in decision-making on healthcare issues for their young adult with disabilities, without the need for guardianship. For young adults with mental health issues, a “durable” Power of Attorney which is revocable may be the best choice to use when the person is temporarily incapacitated, but most of the time otherwise competent to make decisions. Besides Power of Attorney, another type of Advance Directives document is the “Living Will” which includes end-of-life care decisions. Lastly, the publication *Self Advocacy Guide to Guardianship* is also a good resource at:

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

Please note: This information was current at the time of publication. But medical information is always changing, and some that is 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 website.

ABOUT THE AUTHOR:

Lauren Agoratus, M.A. is the parent of a child with multiple disabilities who serves as the Coordinator for Family Voices-NJ and as the central/southern coordinator in her state's Family-to-Family Health Information Center, both housed at the Statewide Parent Advocacy Network (SPAN) at www.spanadvocacy.org