

Guardianship/Supported Decision-Making



Above: Micah Fialka-Feldman with his sister, Emma Fialka-Feldman (right) and his parents Janice Fialka and Richard Fialka. "I talk to my parents about...like big decisions and stuff," Micah says. "But it's my final decision of how I want to live my life." **Below:** Naieer Shaheed gets guidance from his history teacher, Matthew Reggiannini.

As children with disabilities enter their teenage years, we start to think about how they will navigate the responsibilities of adulthood (managing money, being in relationships, voting, self-advocating, etc.) and legal rights (IDEA, Section 504, ADA, etc.). Who is going to make those decisions? Is it the person with disabilities by themselves? Their family members? Friends? Professionals? Some combination of all of these people?

When a person with significant intellectual or developmental disabilities approaches the age of 18 (the legal age of adulthood), families are often presented with only one option—full guardianship, which gives the parent/guardian legal decision-making power across all aspects of a person's life.

But there are many other options which preserve a person's self-determination



and control over aspects of their own life while continuing to provide supports and protections to help make decisions around education, employment, finances, housing, healthcare, and relationships.

ALTERNATIVES TO FULL GUARDIANSHIP

Some alternatives to full guardianship that can preserve at least some of the legal decision-making rights of the person with a disability are:

	Education	Employment	Finances	Housing	Health Care	Relationships
Limited Guardianship	X	X	X	X	X	X
Supported Decision-Making	X	X	X	X	X	X
Health care proxy					X	
Case management	X	X	X	X	X	X
Durable powers of attorney (individually determined)	X	X	X	X	X	X
Joint checking accounts/trusts	X		X	X	X	

Enabling Self-determination

Full guardianship should not be the first choice and is not the only choice for people with disabilities when they reach adulthood. If we believe that people with disabilities have hopes and dreams (like all of us), then taking away all their rights to make their own decisions leaves them at the mercy of what other people think their hopes and dreams should be. One of the hardest parts of maintaining an individual's rights to

make decisions is it may feel like they are operating without a safety net (e.g., choosing to live independently rather than with a family member). But if we believe that people with disabilities should make their own life decisions, we can find ways to support them, possibly through limited guardianship options, even if we don't always agree with those decisions.

Being able to make your own decisions does not happen overnight and without practice. That's why it is so important to

start early by having young children make everyday decisions that are appropriate for their chronological age and then respecting those decisions. Sure—they will make mistakes, but everyone makes “bad” decisions sometimes; that is one way we all learn. However, it is never too late to support self-determination. Nor is there anyone who is “too disabled” to be able to have a say in their own lives. Be sure to read the [Intelligent Lives brief on self-determination](#) because self-determination is the basis of decision-making.

Supported Decision Making

Using person-centered planning approaches like “[circles of support](#),” “[MAPS](#),” or other strategies to identify and use natural supports, individuals with disabilities can use “Supported Decision-Making” to be in charge of their own lives. Supported Decision-Making is a process in which people with disabilities still have all or some of the legal rights and power to make their own life decisions. Just as it is for all of us, those decisions may be made with input and help from supporters who may be trusted friends, family members or other relatives, and even professionals. These supporters help the person understand the decision, provide guidance, and assist the person to clearly communicate their decision.

Some things to help prepare for Supported Decision-Making are:

- Learn about the legal options available (they vary from state to state).
- Determine what supports are needed and how they can be made available.
- Create an agreement and map out how this would look to everyone involved.

The ACLU’s tool [How To Make A Supported Decision-Making Agreement](#) helps explain supported decision-making. During *Intelligent Lives*, you see examples of Supported Decision-Making as Naieer considers his options after high school and as



Steven Monplaisir is the legal guardian of his younger sister Naomie. “I think Naomie could definitely live on her own if she had like a good set-up and had someone coming in, checking in on her,” Steven says in the film. “You know, kind of putting a blueprint to her.”

Supported Decision-Making is a process in which people with disabilities still have all or some of the legal rights and power to make their own life decisions.

Naomie and her support team have a meeting to talk about who is in her social capital circle(s) and the support they can provide across her life. Micah works with his supported decision-making team as he talks about his girlfriend, work, healthcare choices, and living arrangements. His journey of supported decision-making is further detailed in Janice Fialka’s book, *What Matters: Reflections on Disability, Community and Love*.

Writer

Deborah Taub, Ph.D., OTL Education Solutions

Contributor

Ann N. Butenhof, Esq., Butenhof & Bomster, PC

Resources

American Civil Liberties Union, “Beyond the Binary: Using a Supported Decision-Making Lens in Evaluating Competence,” retrieved from the web 2/9/18. <https://www.aclu.org/other/beyond-binary-using-supported-decision-making-lens-evaluating-competence>.

How to Make a Supported Decision-making Agreement, retrieved from the web 2/8/18. <https://www.aclu.org/other/how-make-supported-decision-making-agreement>.

Supported Decision Making & the Problems of Guardianship, retrieved from the web 2/9/18. <https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making>.

Center for Health Care Transition Improvement, “Guardianship and Alternatives for Decision-Making Support,” retrieved from the web 2/9/18. <http://www.gottransition.org/resourceGet.cfm?id=17>.

Webinar: Understanding Guardianship and the Alternatives for Decision Making Support, retrieved from the web 2/9/18. <https://www.youtube.com/watch?v=0xXELClMHHE&feature=youtu.be>.

Center for Parent Information & Resources, Getting Ready for When Your Teen Reaches the Age of Majority: A Parent’s Guide, retrieved from the web 2/8/18. <http://www.parentcenterhub.org/age-of-majority-parentguide/#transfer>.

Friendship Circle “When Your Child Turns 18: A Guide To Special Needs Guardianship” retrieved from the web 2/9/18. <http://www.friendshipcircle.org/blog/2012/10/16/when-your-child-turns-18-a-guide-to-special-needs-guardianship>.

National Caregivers Library, “An Overview of Guardianship,” retrieved from the web 2/8/18. <http://www.caregiverslibrary.org/caregivers-resources/grp-legal-matters/hsgrp-power-of-attorney-guardianship/an-overview-of-guardianship-article.aspx>.

National Guardianship Association, “An Overview of Guardianship,” retrieved from the web 2/9/18. <https://www.guardianship.org/what-is-guardianship>.

National Health Care Transition Center, (2012). “Guardianship and Alternatives for Decision-Making Support,” retrieved from the web 2/9/18. <https://vafamilysped.org/Resource/JWHaEa5BS77XPTgr7N2FWQ/Resource-guardianship-and-alternatives-for-decision-making-support-2012>.

National Resource Center for Supported Decision-Making, retrieved from the web 2/9/18. <http://supporteddecisionmaking.org>.

PACER: National Parent Center on Transition and Employment, “Helping Your Young Adult Learn About Accessing Accommodations After High School,” retrieved from the web 2/9/18. <http://www.pacer.org/parent/php/PHP-c165.pdf>.