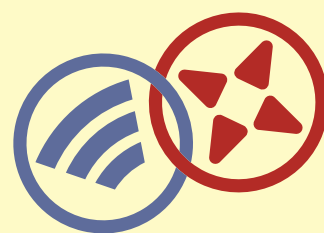


Exploring Alternatives to Guardianship: A Brief for Youth with Intellectual and/or Developmental Disabilities and Their Supporters

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Introduction

Do you want to know how many people with Intellectual and/or Developmental Disabilities (IDD) have guardians? We talked with people with IDD about making important life decisions. We talked with people who have guardians. We also talked with people who don't have guardians.

Here is what we learned from the National Core Indicators (NCI). The National Core Indicators is a survey. Thousands of people with IDD are invited to answer questions in the National Core Indicators survey each year.

This brief will tell you what we learned about guardianship for people with IDD. It will show you some differences between people with IDD who have guardians and people with IDD who do not have guardians.

This brief will also describe *alternatives to guardianship*, including supported decision-making. At the end, the brief lists resources such as the [Center on Youth Voice, Youth Choice](#). It also offers questions that you can ask your parents and teachers so you can learn more about alternatives to guardianship. Let's start with defining some terms!

What is guardianship?

Guardianship is a legal term. Guardianship is when a court decides that a person cannot make their own decisions. The court then gives someone else (a guardian) the power to make decisions for the person. Guardianship is often used in the United States to try and protect people with disabilities. But guardianship also takes away the person's legal rights and ability to make decisions.

Many adults with disabilities have guardians that they do not need, and this can be bad for them. Sometimes, people with IDD have guardians, even though they can make their own decisions and choices.

What are alternatives to guardianship?

Many people with IDD do not need guardians. The term "alternatives to guardianship" means choosing something different instead of guardianship. Alternatives to guardianship are tools other than guardianship that people can use to get the support they need to make tough decisions about their lives.

What does the National Core Indicators survey tell us about guardianship?

The National Core Indicators (NCI) survey tells us that about half (53%) of adults with IDD have a guardian. That means they might not be able to make important decisions about their own lives.

People with IDD who have guardians are less likely to make important life decisions than people who do not have guardians. This includes making decisions about:

- where to live
- who to live with
- how they spend their time
- what they buy

[For more information about these differences in decision-making between people with IDD who have guardians and people who don't, check out our infographic here.](#)

How can having a guardian make people with IDD feel?

Research shows that people with IDD who have guardians may feel:

- helpless or hopeless
- not good enough
- tired or sick
- sad or depressed
- dependent on others

From: National Council on Disability. (2018). [Beyond guardianship: Toward alternatives that promote greater self-determination](#), Washington, D.C.

What are some alternatives to guardianship?

Some alternatives to guardianship include *health proxies* and *powers of attorney*. Another alternative to guardianship is supported decision-making. *Supported decision making* is a way for people with IDD to make decisions about their own lives, with help from good friends and family members who create a circle of support.

Research shows that people with IDD who have used supported decision-making say they:

- are more independent
- feel good about making decisions
- are able to make important decisions
- feel good about their lives

From: "[I learned that I have a voice in my future](#)" Summary, Findings, and Recommendations of The Virginia Supported Decision-Making Pilot Project by Martinis, J. & Beadnell, L. (2021)

Do you want to learn more about alternatives to guardianship?

Youth with IDD and their families should learn about alternatives to guardianship when they are making the transition to being an adult. This is the time *before you turn 18*.

Here are some questions you can ask your parents and teachers about alternatives to guardianship:

- *Do you know about alternatives to guardianship?*
- *Do other people in my school know about alternatives to guardianship?*
- *Can you tell me about alternatives to guardianship?*
- *Can you tell my parents about alternatives to guardianship?*
- *Can you tell me more about supported decision-making?*
- *Can you tell my parents about supported decision-making?*
- *Do you know what the [National Guardianship Association](#) says about alternatives to guardianship?*
- *Do you know what the American Bar Association says about alternatives to guardianship?*
- *What are the laws in my state about supported decision-making?*
- *What are the laws in my state about alternatives to guardianship?*

- *What does the Protection and Advocacy organization do?*
- *Does the Protection and Advocacy organization work with people who don't want guardians?*
- *Are there other groups that work with people who don't want guardians?*
- *Are there self-advocates and advocates I can talk to about alternatives to guardianship?*
- *Do judges in courts understand alternatives to guardianship?*
- *Do judges in courts have to mention alternatives to guardianship?*

Are you a youth or a supporter looking for more resources?

The **Center on Youth Voice, Youth Choice** is a resource center for youth with disabilities. We help you learn how you can have control over your decisions after you become a legal adult. One of the ways you can do this is by using alternatives to guardianship.

[This publication offers a clickable list of accessible resources](#) designed for youth with IDD and their supporters.

For more information on alternatives, including Supported Decision-Making:

- Georgia Advocacy Office. [Advocate John McCarty talks about supported decision making, how he used it to terminate guardianship, and includes perspectives from his parent.](#) (2020).
- Georgia Advocacy Office. [Shining a Light on the Inner Workings of Supported Decision-Making.](#)
- American Bar Association. (2016). [Practical tools for lawyers: Steps in supporting decision-making.](#) Chicago, IL.
- Center for Public Representation. [Supported Decision-Making Gives People with Disabilities a Voice.](#)
- Disability and Health Information Center (n.d.). [Missouri Guardianship: Understanding Your Options & Alternatives.](#)
- Georgia Advocacy Office. [Supported Decision-Making Resources.](#) The Georgia Advocacy Office
- [National Resource Center for Supported Decision-Making.](#)



The [National Core Indicators](#) (NCI) project talks with people with IDD around the country about the services and supports they receive. Almost all state intellectual and developmental disabilities (IDD) agencies in the US collect this information and they use this to make the services they provide better. One of the questions they ask people with IDD is whether they have a guardian.



About

The Center is a project of the Institute for Community Inclusion at UMass Boston (ICI)
in partnership with:

Center for Public Representation (CPR)
Self Advocates Becoming Empowered (SABE)
Human Services Research Institute (HSRI)

in consultation with experts from:

Harvard Law School Project on Disability
Georgia Advocacy Office

Funding

This project was supported, in part by grant #90DNM0004, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Suggested Citation

Bonardi, A., Bradley, V. & Timmons, J. (2022). Exploring Alternatives to Guardianship: A Brief for Youth with Intellectual and/or Developmental Disabilities and Their Supporters. Center on Youth Voice, Youth Choice Brief #1. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

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