

Preparing for the Transfer of Rights: Taking a Closer Look at Guardianship and its Alternatives

*This brief was compiled by Massachusetts Advocates Standing Strong (MASS)
and Self-Advocacy Association of New York State (SANYS).*

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Introduction

We believe people need to know what information is available related to guardianship and alternatives to guardianship. This brief is for parents and supporters of youth with disabilities in transition. It is also for those who are new to the transition process as well as those who have experience with the transition process.

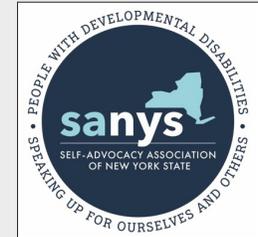
The transition process is very significant. Our goal in conducting our research and creating this brief is to educate parents and supporters of youth in transition about guardianship and alternatives to guardianship. We believe this will help parents and supporters of youth better support their children/young adults and improve the transition process for everyone involved. This project explored the literature and resources currently available to students with disabilities and their parents to help educate them about their options once their child turns 18.

Although the topic of transfer of rights was a focus area in our research, very few of our sources covered the topic in detail. There was not much literature about the connection between the discussion of transfer of rights and the topic of guardianship and its alternatives. Instead, most of the literature we reviewed focused on the areas of guardianship and supported decision-making, an alternative to guardianship. We would like to see more information on transfer of rights available to parents, supporters, and students so they can have the best outcomes.

In this brief, we will present the main themes from the literature, including:

- » the reasons people pursue guardianship
- » the negative effects of guardianship on the lives of people with intellectual and developmental disabilities (IDD)
- » the strategies and recommendations about alternatives to guardianship

This brief is the result of countless hours of research and discussion. We hope that our hard work and dedication will make things easier for others doing their own research in this field.



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[Watch the researchers present on the findings of this brief.](#)



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Method

To conduct our literature review, we identified a number of sources that we believed to be accessible, and that covered the topics of guardianship, alternatives to guardianship, and/or transfer of rights. We reviewed sources targeting youth, parents, and supporters, which covered different perspectives and may have included people's opinions and personal experiences. We also used sources that were in a variety of formats (e.g., videos, websites, printed materials).

There were many more sources for parents than for students. Some of the sources for students were not written in accessible formats or in plain language for students to easily understand. In addition, the tone was also different based on the intended audience. These differences all played an important role in how we determined and collected our findings. Sources that were more accessible ended up being cited more in support of our findings.

Due to the ongoing COVID-19 pandemic, most of our group's research and discussion happened on Zoom. While not meeting in person presented challenges, Zoom allowed our different teams to connect with each other easily even though we were physically separated. Of course, the process was a big learning experience for all of us. In the next section, we have listed the themes of our findings.

Findings

This section presents the main themes we found in the literature we reviewed.

Theme 1: The reasons that parents and other supporters pursue guardianship

Parents and other supporters fear losing access to education and health information of their youth and are concerned about their youth with disabilities being taken advantage of.

Parents usually have good intentions behind getting guardianship.⁷ Parents and supporters may get guardianship because of pressure from schools and doctors, often out of their fear of persons with IDD being taken advantage of, or out of their fear of being left out of important decisions.^{6,7} In some cases, parents have been told that guardianship is the best option, and they don't know of any other options.^{6,8}

Guardianship can be suggested by the medical community and sometimes by the school system.

Parents and supporters may receive a lot of pressure from many places, including doctors, lawyers, and schools, to get guardianship over their children with disabilities.⁶ Seeing people with disabilities as "perpetual children" in need of guardianship moves doctors, lawyers, and other professionals to routinely advise parents and supporters to get guardianship.⁶ Their biased views pressure parents and supporters to become guardians.^{6,8}

People make assumptions about the capabilities of people with IDD, such as lack of skills to make decisions, inability to communicate, and lack of competence.

Guardianship is often based on the assumption that people with IDD are unable to make decisions for themselves.^{1,7,8} Some people think individuals with disabilities can't articulate their own thoughts and may think they are not able to make decisions without a guardian.^{1, 3, 6, 10} Some people are biased and make assumptions that people with disabilities can't do things or be capable just because of their appearance.^{6,8}

Theme 2: Guardianship limits self-determination and has long-term consequences

Guardianship limits youths' decision-making opportunities and abilities. It can take away rights and freedoms.

When thinking about their disabled child's future, parents are often told their best option is to obtain legal guardianship of them when they turn 18. Unfortunately, guardianship can have many negative impacts on a person with disabilities. Guardianship limits individual decision making; guardians can make decisions for [the person].^{1, 2, 4, 10} It also takes away a

person's rights, independence, and freedom.^{1, 2, 9} When a parent tries to get guardianship without talking with the youth about it first, the parent is assuming that the youth's decisions are not important. People with disabilities are not always taken seriously.

Guardianship can also have a negative emotional impact.^{6, 8} People with IDD feel they need to fight for respect, and they want to be heard and seen as individuals. Under guardianship, abuse can happen, and can be hard to prevent and prove.^{1, 2}

Guardianship can have a long-term impact on many choices later in life.

Guardians can make decisions about a person's life without discussing the decisions with the person. If a person has a guardian, the guardian can make major decisions that affect the life of the person under guardianship. Guardians can receive personal information about the person, make educational decisions, control their right to contract, control their marriage and reproductive rights, decide their place of residence and travel, decide who the person can spend time with, make health care decisions, and make financial decisions.^{5, 6} "The person loses complete control over some or all parts of their lives.^{1, 2}"

"The act of being put under guardianship felt dehumanizing and degrading⁶"

~John McCarty

Theme 3: Strategies and recommendations from the literature to increase choice in supported decision-making

The sources emphasized that it is important for parents and supporters to understand the range of alternatives that are available beyond guardianship to help support people in making decisions, and to help youth be independent. Too often, people immediately pursue guardianship over a person with a disability without thinking about possible alternatives to guardianship. This can be especially true for people with IDD.⁹ Parents and supporters don't always know what is available to explore prior to deciding if someone can make decisions on their own.⁶ There are a number of less restrictive alternatives to guardianship, including supported decision making, power of attorney, representative payees, trusts, and health care proxies.^{1, 3, 5}

Youth and families should choose supporters who treat people with IDD with respect.

A support team can include friends, family, community members, teachers, helpers, and self-advocates. The team can help a person with a disability do what they want with their life.^{2, 6} A good supporter is one who treats people with respect, understands them, and supports their decisions. Individuals have the right to be treated with respect by supporters, and they also have the right to choose and change supporters at any time if they do not feel respected.^{2, 10} It makes a big difference if a supporter treats a person with respect. If they do, the person is more likely to feel happier and more confident. If the supporter does not treat the person with respect, the person is more likely to feel alone and invisible.⁶ It is important for supporters to be good for the person's future and respect what the person wants, even if there is disagreement.^{1, 2}

Parents and others can support youth to practice self-advocacy skills, which allows them to use their voice and has many benefits.

Exploring alternatives to guardianship like supported decision-making helps the voices of young people be heard and communicated. This approach can be a game changer because it puts the supporters (parents, doctors, educators) in the role of listening to the preferences of the person with a disability.^{3,8}

People should have the support they need to feel they have a voice and to feel empowered.

People may need help in many ways, but it doesn't mean they need a guardian.¹ People with greater self-determination are healthier, more independent, more well-adjusted, more integrated into communities, and better able to recognize and resist abuse.⁷ It's better for people and they are happier and more confident if they are involved in decisions about their lives through options like supported decision-making. If people are respected and taken seriously, they are more empowered and able to do more things independently.^{3,8}

Conclusion/Implications

Considering alternatives to guardianship benefits the person with disabilities and their parents. By considering alternatives to guardianship, parents are supporting their child to live the life their child wants. If parents work together with their child to consider alternatives, the person with disabilities can live a life with a sense of dignity and respect.

We hope this brief provides useful information for parents and supporters about the need to consider alternatives to guardianship. With this information, we hope that parents and supporters can potentially be more involved in the transition process in a productive way.

Through our research, we have found that information regarding transition, guardianship, and alternatives to guardianship can either be complicated or very hard to find. Therefore, we hope that this brief will be accessible to everyone. We realize that every person's situation may be different, and hope that our brief will encourage others to start their own conversations surrounding these important issues.

Finally, we want people to realize that changes surrounding guardianship and other social issues are possible - nothing is set in stone! History has shown that changes can be made when everyone has a voice at the table.

In addition to our roles as researchers we also have lived experiences with transfer of rights conversations and alternatives to guardianship. The quotes below highlight our perspectives:

“Guardianship can create conflicts between the child and the parent.”

- Shameka Andrews, Self-Advocacy Association of New York State (SANYS)

“From a parent’s perspective, guardianship can feel like the only option to keep their child safe. For the individual under guardianship, though, they can feel limited or stuck. Individuals under guardianship may feel they have to ask for everything, and they can have rights taken away like living independently, having children, or meeting friends.”

- Kamisha Heriveaux, Massachusetts Advocates Standing Strong (MASS)

“I think we need to protect our own rights and each person has their own rights to learn how to grow and become independent. Learning about different options like your rights and guardianship helps you learn more about how it affects your life and about other people. I would feel hurt if someone made a decision without asking me because I would want to be part of decisions about my life.”

- Cynthia Goldberg, Massachusetts Advocates Standing Strong (MASS)

Resource List

This list is a useful resource for parents, supporters, and youth who are interested in learning more about supported decision-making, alternatives to guardianship, and transfer of rights. The resources with footnotes were cited by researchers to write this brief.

- ¹ [The Right to Make Choices: International Laws and Decision-Making by People with Disabilities](#)
Autism Self-Advocacy Network--Easy Read Paper from 2016
- ² [Roadmap to Transition: A Handbook for Autistic Youth Transitioning to Adulthood](#)
Autism Self-Advocacy Network and the Family Network on Disabilities--Handbook from 2016
- ³ [Supported Decision-Making](#)
Center for Public Representation--Webpage
- ⁴ [Supported Decision-Making in Action: Dawn and Belinda's Story](#)
Disability Rights Texas--Video from 2018
- ⁵ [Coming of Age in Massachusetts](#)
Frederick M. Misilo Jr.--Booklet from 2017
[A Legal Guide for Individuals with Developmental Disabilities and their Families Transitioning to Adult Services](#)
Frederick M. Misilo Jr.--Guide from 2014
[Supported Decision-Making Resources](#)
Georgia Advocacy Office & John McCarty
List of resources from 2020
[Supported Decision-Making and Guardianship Termination](#)
Institute on Disability/UCEDD & John McCarty
Webinar recording from 2019
- ⁶ [The Process of Terminating Guardianship Using Supported Decision-Making](#)
John McCarty--Video from 2020
- ⁷ [Who's in Charge Here?](#)
John McCarty--PowerPoint from 2020
[Why Supported Decision-Making Matters and How to Get Started](#)
John McCarty--Video from 2020
[Age of Majority](#)
Federation for Children with Special Needs
Brochures about transition
- ⁸ [Supported Decision-Making: Gabby's Story](#)
Lynne O'Hara--Video from 2016
- ⁹ [Self-Advocacy Materials: Guardianship and Alternatives to Guardianship](#)
Massachusetts Disability Law Center--Paper from 2017
- ¹⁰ ["My Voice Counts" Supported Decision-Making, An Alternative to Guardianship: A Self Advocate's Guide to Supported Decision-Making](#)
Self-Advocacy Speakers Network, Utah--Guide from 2017



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