

Consider the Alternatives: Decision-Making Options for Young Adults with Intellectual Disabilities

By Deborah Leuchovius and Barb Ziemke

As youth with intellectual and developmental disabilities (IDD) are making plans to attend college, it is more important than ever that families become fully informed about guardianship as well as less-limiting alternatives. This brief defines some of the options and possible ramifications. It also presents special circumstances for consideration, and suggests ways to promote self-determination no matter which option is chosen.

THE TRANSFER OF RIGHTS AT THE AGE OF MAJORITY

When schools notify families and youth with IDD of the coming [transfer of rights at the age of majority](#), typically 18, they often present parents with only two alternatives: 1) transfer decision-making rights to the student, or 2) petition the court to become their child's guardian to continue to be the educational decision-makers.

However, if there is uncertainty about whether or not a child is capable of making educational decisions, guardianship is not the only choice. There are other viable alternatives for families to consider. Because these options vary from state to state, parents are encouraged to contact their state's [Parent Training and Information Center](#) for information.

Reaching the age of majority affects more than educational and due process rights in special education. At the age of majority, young adults are "presumed competent" and are normally granted legal rights such as the right to vote, marry, obtain a credit card, consent to medical treatments, make living arrangements, and sign contracts. All of these rights can be impacted by the decision of parents to become guardians of their son or daughter because adults under guardianship are considered to be legally "incompetent" or "incapacitated." Once made, the guardianship decision is not easily undone.

However, some students at age 18 may not be able to recognize when an important decision needs to be made, consider the possible options, or foresee the consequences

of their decisions without support. Understandably, many parents are concerned about putting their son or daughter into a position where they could be pressured into making decisions they are not capable of handling.

Often, the question is not *if* support for decision-making will be needed, but rather *what level* of support is required and appropriate for the individual. It is important for parents to consider the kinds of support they can provide that are respectful of a young adult's autonomy, and recognize the youth's potential for future growth and development.

There are many different variations of substitute or supported decision-making. This brief takes a closer look at three options:

- **Power of Attorney:** A written document where a competent adult voluntarily grants authority to another competent adult to act and make decisions on his or her behalf.
- **Supported Decision-Making:** An agreement whereby an individual with a disability chooses a team of people to assist them with obtaining and understanding information, considering alternatives, executing a decision, and expressing it to third parties.
- **Guardianship:** A court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom a court has deemed to be "incapacitated" or "incompetent."

Often, the question is not *if* support for decision-making will be needed, but rather *what level* of support is required and appropriate for the individual.

Laws, processes, and terminology on this topic vary by state as well as individual circumstances. This brief presents a basic overview of a complex topic with legal implications. It provides general information to families and connects them to additional resources that can help them make well-

informed life planning decisions for their son or daughter with IDD. [The University of Montana Rural Institute for Inclusive Communities 2018 Alternatives to Guardianship Toolkit](#) provides comprehensive, family-friendly information about decision-making and support options.

Will guardianship, once disclosed, limit perceptions of, and expectations and opportunities for, an individual with IDD?

EXPLORE OPTIONS

Power of Attorney

One of the alternative approaches to the transfer of rights at the age of majority in some states is to allow students to sign a Power of Attorney (POA) form that names their parents as educational decision-makers. A POA is a written document where a competent adult grants authority to another competent adult to act and make decisions on their behalf. An educational POA allows a parent to represent a student's educational interests, communicate with schools, give consent for evaluations, receive notices, attend IEP meetings, and assist with making decisions related to school.

When a POA has been granted, the student does not give up decision-making authority; rather, the student shares that authority with another. Beyond educational matters, POAs may focus on finances, health, or other matters.

Although families are encouraged to consult with a legal professional regarding requirements and specifics of the document, a POA does not generally involve the court, and an attorney is not necessary to complete a form. Check what is required by reviewing your state's laws and sample form online, or by contacting your state's [Protection and Advocacy Agency](#).

Supported Decision-Making

Many families of teens with and without disabilities are already using supported decision-making informally in their everyday lives. Helping a person learn decision-making skills by making their own choices with guidance is supported decision-making (SDM).

Formal SDM allows individuals with disabilities to make choices about their lives with the support of a team of competent people they know and trust. Individuals receive help with obtaining and understanding information, considering available alternatives, executing the decision, and expressing it to third parties.

District of Columbia schools offer supported decision-making as an option for students to consider at the transfer of rights at the age of majority. D.C. law states that "student[s] who have reached 18 years of age may receive support from another competent and willing adult to aid them in their decision-making" and created the option for supported decision-making agreements with a [codified form](#). Other states may present parents with similar options, but this practice is not commonplace.

Beyond educational decision-making, the person-centered approach of supported decision-making is being increasingly used as an alternative to guardianship, as it is seen to have far fewer negative consequences in terms of future legal ramifications for young adults. When adults are able to use friends, family members, and professionals to help them understand situations and choices they face, they may make their own decisions without the "need" for guardianship.

Supported decision-making is an emerging approach to providing decision-making assistance without imposing any long-term limitations on rights or personal liberties. For a better understanding of how this may be carried out, see Wisconsin's recent [Supported decision-making law](#) and [Supported decision-making agreement form](#). To learn about supported decision-making laws, policies, and organizations in your state, visit the [National Resource Center for Supported Decision-Making](#).

Guardianship

Before becoming their child's legal guardian, parents should carefully consider the impact of this decision on the future of their child. While there is no one-size-fits-all solution, and guardianship may be necessary based on the unique needs of the individual, many in the disability community feel guardians are regularly appointed for individuals with IDD when a less drastic legal intervention may have sufficed.¹

Some families pursue guardianship because they mistakenly believe or have been told that it's required in order to show their youth's eligibility when being assessed for developmental disabilities services, other governmental programs, or medical care. However, guardianship severely limits an individual's right to make independent decisions. Sometimes, less restrictive alternatives or a limited guardianship can be adopted to address specific concerns.

Parents are encouraged to think about the particular areas their son or daughter needs help with. Is it primarily their finances, medical decisions, or something else? If the

young adult is able and willing to provide consent, could a POA, joint bank account, health care directive, or pulling together an SDM team be less restrictive options?

CONSIDER UNINTENDED CONSEQUENCES

As more and more youth with IDD are going on to postsecondary education and employment, it is worthwhile to consider the consequences of guardianship in postsecondary and employment settings. Will guardianship, once disclosed, limit perceptions of, and expectations and opportunities for, an individual with IDD?

Many college programs for students with IDD, for example, ask students who apply to their programs about their guardianship status. A recent internal survey of programs indicates that guardianship status may affect how students are perceived or supported. Schools may have higher expectations for achievement and autonomy of youth without guardianship.

If a student does have their parents as guardians, the program may make certain assumptions about that young adult – possibly that they are less competent, need more help, are more dependent on their families, and are not capable of living on campus. It has been reported that a small number of college programs do not admit students who are under legal guardianship due to concerns about their legally determined “incapacity.”

PROMOTE SELF-DETERMINATION AND AUTONOMY

Many parents feel their child is not ready to become responsible for all their health, financial, educational, and other decision-making when they turn 18. This is true for parents of youth with and without disabilities. Although students who do not receive special education services are not officially informed of a “transfer of rights,” they too become legal adults at the age of majority. Yet, without having to become guardians for their children, parents of students without disabilities naturally continue to influence and guide their children and be consulted by them after they reach this age.

Parents want their children to learn the skills they need to be successful adults, and they also want them to be safe from harm. This is important for all youth, but may be especially relevant for families of youth with IDD. Key among essential adult skills are good decision-making and self-determination skills. These take repetition and experience to develop and mature.

It is important for parents to consider the kinds of support they can provide that are respectful of a young adult’s autonomy and recognize their potential for future growth and development.

Students need opportunities to practice and apply these skills to the maximum extent of their abilities, regardless of their guardianship status. To learn more about the research supporting self-determination for youth with IDD, [review this research summary from A National Gateway to Self-Determination](#).

Although perhaps less mature than their peers at age 18, individuals with IDD continue to learn new skills well into adulthood.² Rather than making decisions for their child, parents can intentionally step back and help their young adult become more comfortable with making good choices and decisions.

Tips to help parents develop their child’s decision-making skills:

- Be sure youth are actively involved in setting their high school goals and planning their transition to adulthood during high school.
- Prepare students to actively participate in and perhaps lead their IEP team meetings.
- Gradually increase the level of difficulty of choices to be made as youth get older.
- Discuss pros and cons of potential decisions with them.
- Help youth identify other trusted people they can go to for advice about difficult decisions.
- Allow youth to take responsibility for some decisions.
- Whenever possible, let youth learn from their mistakes rather than trying to protect them from the consequences.
- Do not interfere with the young person’s desires when it is not truly necessary.

Ideally, “each individual with IDD should receive preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.”³ Finding the least restrictive way to support young adults in making good decisions represents a positive approach that can help foster self-determination and personal autonomy, and can prepare youth for learning, working, and living in their community.

Endnotes

- 1 National Council on Disability. (2019). Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities. Retrieved from https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf
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- 3 American Association on Intellectual and Developmental Disabilities and The Arc. (2016). Joint Position Statement on Autonomy, Decision-Making Supports, and Guardianship. Retrieved from <http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship>



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PACER's National Parent Center on Transition and Employment is a partner of Think College. We work together to develop materials to help families and others better understand opportunities in postsecondary education for students with intellectual disabilities. This brief was created by PACER's National Parent Center on Transition and Employment and is based on a review of existing guidance documents and discussions with experts in the field.