Supported Decision-Making and Guardianship For Families and Students

Overview

Just like people without disabilities, individuals with disabilities must make many daily and major life decisions, both on their own and with support. Being able to make decisions about one's own life is a fundamental right and critical to community living. There are many options for creating an ongoing system of support that preserves maximum autonomy for individuals of all ages, with and without disabilities. Students and their families must understand the options and make a plan that works best for the student before they reach adulthood.

- Informal support refers to the everyday, casual ways people seek advice and input from trusted individuals like friends, family members, colleagues, or even neighbors before deciding. They rely on personal connections rather than formal legal arrangements to help them weigh options and make choices. In addition to family and friends, people can use technology and community-based services to provide guidance.
- Supported decision-making (SDM) is an alternative to guardianship that should be considered if complete independence is not an option. Supported decision-making maintains a person with a disability's right to make their own decisions but provides for the help of trusted people. Friends, family, or professionals can assist the person to understand, make, and communicate their choices. Supported decision-making can be informal or formal, depending on whether there is a written agreement or not. For more information, see the IDR Options for SDM and Independence.
- Health Insurance Portability and Accountability Act (HIPAA) Authorization allows a person to share their medical information with whomever they choose. This can help individuals make informed decisions about their health care.
- Health Care Representative is a person the individual chooses to make medical decisions if they are unable to do so. This can include end-of-life decisions, but also decisions about care at other times. A health care representative is also known as a health care agent, surrogate, or proxy. It is a good idea to choose a trusted person and to discuss healthcare preferences with them in advance.
- **Power of Attorney (POA)** is a legal document that gives one or more individuals (person or non-profit) the power to act for another person. The designated person(s) can make

decisions about the individual's property, finances, or medical care. An individual may assign POA responsibility to more than one individual.

• **Guardianship**, the most restrictive option, is a legal process that gives someone else the authority to make decisions for a person with a disability. Guardianship can be full or partial, depending on how much decision-making power the guardian has. Guardianship can affect the person's right to choose where to live, work, receive medical care, marry, and more. Guardianship can affect an individual's right to vote in many states. However, Indiana does permit individuals under guardianship to vote.

Supported Decision-Making (SDM) in Indiana

Indiana's new SDM law became effective on July 1, 2019. It establishes the option for supported decision-making and requires that SDM and/or other less restrictive alternatives be tried before a court grants guardianship. With SDM, the person is still in charge of their own life. They can decide who will be involved in supporting them. The supporters must also agree to provide guidance and assistance and not make decisions unless requested to do so by the person. This can include finances, healthcare, education, employment, housing, etc.

Assessing Decision-Making Support Needs

Discussing and determining an individual's strengths and needs related to decision making is a collaborative approach. The Individualized Education Program (IEP) teams are required by Indiana law to discuss supported decision-making as an option during meetings, particularly those related to transition planning. When deciding on SDM, it is strongly encouraged that:

- The person and their team seek input from trusted individuals familiar with their needs and abilities.
- Decision-making authority should only be granted to someone trustworthy, as exploitation is always a possibility when an individual is given authority to make decisions on behalf of someone else. This information is sourced from the Indiana Disability Rights on the Indiana Department of Education (IDOE) website.

Disability Rights/Law

While not required, in a SDM scenario, the individual and the trusted person can create a document that outlines how the individual will be supported, called a Supported Decision-Making Agreement. This agreement can be changed at any time.

• Agreements are individualized. It identifies decisions and the supporters a person chooses for each of those.

- Trusted people sign off on their commitment to support the person in the designated decision-making area(s).
- A Supported Decision-Making Agreement can help reassure physicians and other medical providers that a patient with a disability has the needed support to execute informed consent regarding their health care, even if they are using accommodations in the decision-making process.
- A court does not have to oversee a Supported Decision-Making Agreement.

Alternatives to guardianship are important because they allow individuals to maintain as much autonomy and decision-making power as possible, respecting their choices and preferences, while still providing necessary support, instead of completely removing their legal rights and independence that a traditional guardianship often does; it prioritizes a person-centered approach to decision-making.

Resources

- Indiana Medicaid for Providers: <u>Health Insurance Portability and Accountability Act</u> (HIPAA)
- ✓ Charting the LifeCourse: <u>Tool for Exploring Decision-Making Supports</u>
- Indiana Disability Supports: <u>Sample Self-Determination and Supported Decision-Making</u> <u>Documents</u>

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