

CESDM

CENTER FOR EXCELLENCE
IN SUPPORTED DECISION MAKING



Guardianship & Transition Age Youth with Intellectual / Developmental Disabilities (IDD)

For years parents and caregivers of young adults with intellectual and/or developmental disabilities have been instructed to obtain guardianship for the person when they turn 18. Families are often told that once their child is legally an adult, they will no longer be able to participate in medical, education, or social service conversations with providers: they are told the remedy is to seek guardianship.

This fear-based approach also fails to acknowledge that almost all young people, including those without disabilities, still rely on their parents and families for decision making. It is the rare 18-year-old who is ready to be completely independent from family, never needing further guidance and assistance to address some poor choices or lack of skill or knowledge. In fact, it is now well known that the human brain is not even fully developed until at least 25 years of age, yet families of young people with disabilities are often pressured to seek guardianship; it is assumed they are not fully capable of exercising good decision making and thus need a guardian. Yet, young people without disabilities are usually not expected to be fully independent and capable of consistently good decision making until they are in their twenties.

Another fear some families have is whether they have liability should the person engage in illegal activity. Is a guardian legally responsible for the person's illegal activity?

Similarly, some families have questions about criminal court and whether a guardian is needed to have authority or ability to "protect" the person from criminal charges, or to be involved in the criminal process. These are very real and concerning scenarios, as well as very nuanced and complicated. Consulting an experienced attorney is the best course of action to ensure appropriate steps are taken.

GUARDIANSHIP MYTHS & FACTS

Myth: *Guardianship is required for a person with an IDD once that person turns 18.*

Fact: Guardianship is not required by MN law or policy to receive county, state, or federal services, to sign an Individualized Education Plan (IEP), or to move into to a residential home. Families and individuals are often told this, even by professionals, but that is a mistake of professionals, and often a misinterpretation of the Individuals with Disabilities Education Act (IDEA), not a statement of law. Many individuals and families in this situation find it works very well for the person to sign a Release of Information consent form once the student turns 18, which enables the family's continued involvement in the educational planning conversations.

Myth: *If a person has a disability and can't make decisions independently, that person must have a guardian appointed to make decisions for them.*

Fact: Many people are willing to have help making decisions. This can be very successful way to support individuals with help from trusted supporters. The ability to complete tasks independently is not a requirement for anyone, and young people with disabilities should not be expected to be independent either. Needing help does not mean a person needs a guardian.

Myth: *Doctors won't talk to me as a parent once my child turns 18, so I need to obtain guardianship.*

Fact: Consider having the individual sign a Consent for the Release of Information form if the person understands the form when someone explains it to them. This will allow health care professionals to talk to supporters and involve them in decision making. (Note: If a person's physical disability prevents them from being able to sign, an x or witnessed verbal consent is suitable.) The person can also simply inform their providers that they want their supporter to be involved in discussions and decision-making. Ideally, the person will complete a Health Care Directive, appointing a health care agent to make medical discussions if the person is unable to do so even with help. Even a person with significant disabilities who can't understand complicated

medical treatment decisions may still be capable of appointing a health care decision-maker.

Myth: *Guardianship is required for a person with an IDD to prevent them from making bad choices.*

Fact: Guardianship does not remove all risk; it is a power of consent, not a power of compliance. Short of placing a person in an overly secure living environment that removes all risk (and places excessive restrictions on the person), guardianship rarely is an effective tool in preventing a person from making any bad choices. Even though this is a well-meaning desire to remove all chance of harm, this may offer a false sense of security, and will also very likely lead to a poor quality of life for the individual. Instead, recognize that decision-making is a skill. People with disabilities should receive guidance, coaching, and support to learn to recognize risk, develop good life skills, and maximize independence at levels reasonable to their disability. The person and their support team (families, professionals, trusted others of their choosing) can work together to identify areas of risk and vulnerabilities and develop plans to avoid trouble spots and ways to address the trouble when it does arise. No one is exempt from making poor choices; everyone makes bad, or risk, choices, and often people learn from their mistakes. Families and other supporters should work with people with disabilities to learn about good decision-making the same way they work with others without disabilities when they make bad choices: to learn from it and find ways to prevent it from happening in the future.

Myth: *Guardianship/Conservatorship is required for a person with an IDD to prevent the person from being financially exploited.*

Fact: Unfortunately, even people under guardianship/conservatorship may be financially exploited. This intrusive court action should not be engaged simply because of something that may happen; instead, professionals, families, and other supporters should work with the person and the situation to put measures in place that will address vulnerabilities to financial exploitation, such as a representative payee, power of attorney, trust, or utilizing banking tools such as on-line monitoring to enable a trusted person to keep an eye on financial transactions. Another approach would be developing

systems where the person has access to less cash on hand, to minimize giving away or losing all their money; utilizing debit or store gift cards is an excellent way to ensure the person still has ability to make purchases while protecting overall assets. It may also be advisable to contact the credit companies to flag inquiries and require alerting the person or their financial supporter so that others don't try to take out credit cards in the person's name.

Myth: *Guardianship can change behaviors, prevent bad decisions, or make the person do something or stop doing something that others want them to do or not do for care and safety reasons.*

Fact: Since guardianship is a power of consent, not a power of compliance, it is rarely able to address behaviors. Instead, behaviors or "bad choices" should be addressed in creative ways seeking solutions that are meaningful to the person / applicable to the situation such as learning why the person is behaving the way they are, addressing the underlying emotions, or understanding what life skills the person needs help developing to seek behavioral change.

Myth: *Guardianship is required in case the person engages in criminal activity and is responsible for the illegal activity of a person subject to guardianship.*

Fact: Another fear some families have is whether they have liability should the person engage in illegal activity. Is a guardian legally responsible for the person's illegal activity? Similarly, some families have questions about criminal court and whether a guardian is needed to have authority or ability to "protect" the person from criminal charges, or to be involved in the criminal process. These are very real and concerning scenarios, as well as very nuanced and complicated. Consulting an experienced attorney is the best course of action to ensure appropriate steps are taken.

Guardianship Information Line

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