



Q&A: Debunking the Myths of Supported Decision-Making and Guardianship
September 8, 2020

Please find responses to questions posted during the 9/8/20 webinar. Questions may have been changed to make them more clear. People asked several questions about guardianship and powers of attorney that will depend on the law in their state. For questions not answered in this document, we encourage you to contact your state's [protection and advocacy program](#).

- 1. What organizations or “experts” provide education and proactive information sharing around guardianship and supported decision-making?**

For national training and resources, please visit the [National Resource Center for Supported Decision-Making](#) and The Arc's [Center for Future Planning](#). For local and state-specific training and resources, we recommend checking first with your state's [protection and advocacy program](#) or your local or state [chapter of The Arc](#).

- 2. Does the term guardianship include conservatorship? How do you view conservatorship?**

States have different laws and procedures regarding guardianship for adults. Some states use the term “guardian,” others use the term “conservator,” and still others use other state-specific terms. Some states separate guardianship into two categories - one for the person's finances (“guardian of the property” or “conservator”) and one for everything else (“guardian of the person”). In the case of this webinar, we used the term “guardianship” to mean all forms of guardianship, including conservatorship.

- 3. Does a parent need to have a guardianship? Is it mandatory?**

No, it is not mandatory to get guardianship over an adult child with a disability. As discussed in this webinar, there are many less-restrictive options that should be explored first.

- 4. Are there ever any circumstances in which you would urge a family to seek guardianship of their adult child with an intellectual disability? Do you believe no person should have a guardian?**

Guardianship is one decision-making option that is available to people with disabilities and their families, and it may be appropriate for some families based on their individual

circumstances. We emphasize, though, that it is not the only option, even though it is sometimes presented to families as their only option. In addition, it is by far the most restrictive of the options, removing a person's ability to make their own decisions and taking away their ability to exert control over many aspects of their life. Therefore, it is important for families to understand that there are many options and that guardianship should be considered as a last resort if none of the other options are appropriate.

5. How can families avoid guardianship for people with severe disabilities?

Many people with significant disabilities can use the less-restrictive options discussed in this webinar. In considering those options, it is important to honor the different ways in which people with disabilities may communicate, such as through augmentative and alternative communication, "behavior," gestures, etc.

6. How can service providers support people with guardians to participate in less restrictive forms of decision-making when guardians typically control all important decisions?

For service providers to confirm the scope of a guardian's authority, they should ask for and review the court order appointing the guardian. The guardian's authority is defined by that order and state law, and there is a role for service providers in supporting the person to dispute guardian's overreaching. In addition, service providers can support people under guardianship in restoration proceedings to get their guardianship limited or terminated. For an example of this team approach, please see [Suzie's Story](#) from Kentucky. It is also important to keep in mind that the [National Guardianship Association](#) has recommended that guardians use principles of supported decision-making within guardianship.

7. What if a guardian is only involved to sign documents annually or lives out of state and is not otherwise involved in the person's life?

This question raises issues as to whether the guardian is adequately fulfilling their responsibilities according to best practices, based on National Guardianship Association [standards](#) and [position statements](#). Depending on state law, the guardian also may not be satisfying their legal responsibilities.

8. Can an individual with a guardian prevent the guardian from accessing their financial records?

The answer to this question depends on the scope of the guardianship and the particular state's law. For example, a medical guardian would likely not be authorized to access financial records without further order of the court.

9. Can an individual who has been appointed a guardian become emancipated from the guardianship? How?

Yes! People under guardianship can seek to have their rights restored by a court. Current guardians, family members, and supporters can help people do this. Exactly how will depend on the state's laws, rules, and procedures. For a resource on legal trends, please see the [report](#) of the ABA Commission on Law and Aging and the Virginia Tech Center for Gerontology. For examples of individual cases, please see ones from the [District of Columbia](#), [New York](#), [Virginia](#), [Massachusetts](#), [Kentucky](#), [Maine](#), and [Indiana](#), among others.

10. For parents who felt pushed into guardianship by schools, is it difficult to restore rights for a young adult as they are still maturing?

While successfully restoring the rights of a person under guardianship who does not need it may take time and legal support, it is worth the effort. For examples of success stories, please see the response to Question 9.

11. What can supporters do if the guardian has Alzheimer's and is no longer appropriate to serve? Is a lawyer necessary?

The answer depends on state law, procedure, and practice, so this question is best answered by someone in your state. In some states, the supporter can file a petition and ask that the guardian be replaced. In states that have guardian monitoring programs, the supporter can notify the monitoring program, and they should take action.

12. Should aging parents who are guardians have their child without a disability appointed as guardian or power of attorney for their child with a disability?

Aging parents should be thinking about their child's future decisions whether they are a guardian or not. Supporting your child with a disability to be as independent as possible and make as many decisions as possible may mean that it makes sense to restore their rights before or after a parent is no longer available to serve as guardian. The person with a disability can then use other, less restrictive options such as supported decision-making or a power of attorney to make their own decisions or voluntarily choose someone to make decisions for them. If restoration of rights is not appropriate, guardianship cannot be transferred to someone else through a power of attorney. The child without a disability or other family member must get permission from the court to be a co-guardian or be appointed as the successor guardian. The new guardian would file a petition with the court, and the court would likely hold a hearing to learn more about the request and then make a decision.

13. If parents are concerned about family members who will take advantage of their child after they pass, how they can plan to express their concerns about giving family members decision-making authority through guardianship, a power of attorney, joint bank accounts, etc.?

Please see the response to Question 12 when parents want to help the court identify who should replace them as guardian when they are no longer available. Parents who are not

guardians can support their adult children during their lives to recognize bad situations and people who mean them harm. They can also help their adult children create supported decision-making agreements and powers of attorney that identify trusted supporters. They also can help their adult children create powers of attorney that include safeguards, such as appointing multiple agents who serve as “checks and balances” to each other to make sure each does not take unfair advantage of their role or the person with a disability. These documents should be widely shared with people who need to know, such as family members, service providers, and doctors. Parents can also document their wishes and concerns for their child in a [Letter of Intent](#), available on The Arc’s Center for Future Planning website.

14. Does a power of attorney require evaluations from a specialist?

No, executing a power of attorney generally does not require an evaluation from a specialist. However, there may be cases where input from a supporting specialist will help enforce a power of attorney, such as when a prior specialist found that the person lacked capacity. In addition, a person cannot give someone authority to make decisions through a power of attorney if the court has already appointed a guardian to make those decisions. Therefore, if a person with a guardian wishes to execute a power of attorney, he/she will likely need an evaluation from a specialist to support a request that a court limit or terminate the guardianship first.

15. Is it best to have a lawyer set up a power of attorney?

A person is not required to have a lawyer to set up a power of attorney (POA). However, it can be helpful in certain circumstances. POA laws vary by state, and publicly available, generic, or on-line POA forms are not always consistent with the law of the state in which the person is seeking to use them. Therefore, problems can arise with trying to legally enforce their use. For local and state-specific training and resources, we recommend checking first with your state’s [protection and advocacy program](#).

16. What kinds of decisions other than financial decisions can be covered by a general power of attorney?

Depending on state law, general powers of attorney can cover decisions relating to insurance transactions, claims and litigation, personal and family maintenance (e.g., housing, education, etc.), services from governmental programs, tax matters, and other non-health-related decisions. State laws generally require a separate power of attorney for health-related decisions.

17. Does a power of attorney for healthcare include authority for requesting and monitoring Home and Community-Based Medicaid Waiver and other support services?

Depending on state law, health care powers of attorney generally cover making medical treatment decisions when a person cannot make those decisions him/herself. Some Waiver services may be considered medical treatment, and so would be covered by the health care power of attorney, but some services may not be considered medical treatment. In practice, if a person wants someone to make decisions about their support services, the person should consider executing a general power of attorney that specifically covers support services.

18. How would a young person set up a power of attorney to allow their parent to participate in IEP meetings?

An educational power of attorney is not necessary for a parent to participate in an IEP meeting. The Individuals with Disabilities Education Act, or IDEA, is the federal law that controls how schools provide special education services. Once a student become an adult according to their state's law, the rights that their parents had in the IDEA transfer to that student. However, even after rights under the IDEA transfer to an adult student, their parents must still receive all the same notices that the student is now required to receive. Therefore, parents should still receive an invitation to all their child's IEP meetings, and parents should still receive a written notice anytime the school wants to change or refuses to change their child's IEP services. These notices ensure parents will know about IEP meetings and can attend meetings with their child's permission. Parents will also know about any changes to their child's services, so they can talk to their child and support their child in discussing any concerns or taking steps to disagree with the school's actions. For adult students who want their parent to make educational decisions for them, students can create a power of attorney for educational decisions. Your state's [protection and advocacy program](#) may be able to help if you have additional questions.

19. Can a power of attorney override the decision of the individual, or does the individual have the right to revoke the power of attorney first?

An "agent" under a power of attorney cannot override the decision of the person appointing them (the "principal"), unless the principal has been formally determined to lack the capacity to make the decision in question themselves. When a person signs a POA appointing someone else to make decisions for them, the person is not giving away their right to make decisions when they can and want to. Rather, they are appointing someone to make decisions for them too. Therefore, third parties should typically respect the decision of the person and not the agent under the power of attorney when there is a dispute between the person and their agent.

20. What can a professional do if they are concerned that a person does not fully understand a consent form and, therefore, questions their ability to sign?

It is important to always start from a place of "presuming capacity," or assuming that a person is able to make his/her own decisions. So, we would encourage the professional to first check themselves and make sure that they are not basing their concerns solely on a

person's IQ or diagnosis or ability to read legal jargon - none of which alone determine a person's ability to make decisions. The professional also should keep in mind that capacity is not "all or nothing." For example, the level of capacity necessary to sign a consent form for a complicated medical procedure would be different (and more) than the level of capacity necessary to sign a consent form for the release of medical information to a trusted supporter. Legal capacity operates along a continuum - some people are able to make certain decisions and not others, at some times and not others, and/or only if they get assistance in understanding the particular decision to be made. In addition, the professional should challenge him/herself and ask "what will it take" to support the person in understanding the consent form enough to knowingly and voluntarily sign it? For example, can it be explained in a different way, such as through pictures or plainer language? Is a trusted supporter better able to describe it in ways the person understands? Is the person being properly supported to ask questions and communicate decisions?

21. What is FERPA?

FERPA stands for the Family Educational Rights and Privacy Act. It is the federal law that says that all school records about an individual student should be kept confidential, with some exceptions, and that parents have the right to access all educational records about their minor child.

22. Can you share the studies related to negative outcomes for people who have decreased self-determination, including negative effects on self-esteem, physical and mental health, and life expectancy?

Some examples include:

- Blanck P., & Martinis, J. G. (2015). The Right to Make Choices: The National Resource Center for Supported Decision-Making. *Inclusion* (3)1, 24-33.
- Bradley, V., St. John, J., Bourne, M.L. (2019). National Core Indicators Data Brief: What Do NCI Data Reveal About the Guardianship Status of People with IDD? Retrieved from: http://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf
- Deci, E. (1975). *Intrinsic motivation*. New York: Plenum Press.
- Powers, L.E., Geenen, S., Powers, J., Pommier-Satya, S., Turner, A., and Dalton, L. (2012). *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes*
- Salzman, L. (2010). *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*. *University of Colorado Law Review* 81: 157-245.
- Salzman, L. (2011). *New Perspectives on Guardians and Mental Illness: Guardianship for Persons with Mental Illness - A Legal and Appropriate Alternative?* *Saint Louis University Journal of Health Law and Policy* 4: 279-329.

- Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Rifenshark, G.G., and Little, T.D. (2015). Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities. *The Journal of Special Education* 48(4): 256-267;
- Wehmeyer, M. and Palmer, S. (2003). Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination. *Education and Training in Developmental Disabilities* 38(2): 131-144.
- Wehmeyer, M., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The Self-Determined Learning Model of Instruction. *Exceptional Children*, 66(4), 439-453.
- Winick, B. (1995). The Side Effects of Incompetency Labeling and the Implications for Mental Health Law. *Psychology, Public Policy & Law*, 1(1), 6-42.
- Wright, J. (2010). Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA. *International Journal of Law and Psychiatry*, 33(5-6), 350-368. <http://dx.doi.org/10.1016/j.ijlp.2010.09.007>.

23. Why shouldn't developmental tests be used as cognitive capability scales for decision-making?

This question was addressed in the 2019 National Council on Disability (NCD) report, "[Turning Rights Into Reality](#): How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities," (see pages 21-25).

24. How can or should states advance supported decision-making (e.g. financial, training, etc.)?

Recommendations for how states can advance supported decision-making are included in the [2019 NCD report](#) (see pages 61-62).

25. How can behavioral health agencies, schools, etc. empower and encourage decision-making as part of their services?

There are many ways that agencies and service providers can encourage decision-making as part of their services. For example, in 2013, D.C. Public Schools incorporated [supported decision-making](#) into its transfer-of-rights policy for adult students in special education and created a supported decision-making form, with no change in state law necessary. It also had an [initiative](#) to include supported decision-making and self-advocacy in school programming, starting as early as pre-kindergarten. In terms of behavioral health services, there are [pilot projects](#) that are focused on strategies for advancing supported decision-making in the area of mental health that may be helpful resources.

26. How can we counsel families around which decision might be best for them when they are unsure if guardianship, power of attorney, or supported decision-making is best for them?

Professionals can help educate families about the options that are available, and then families need to have a conversation about their individual circumstances and what each option might mean for them. Making a choice often does not happen in one conversation and may change over the years, depending on the age and experience of the person with a disability, as well as their available family and caregivers. The Arc's Center for Future Planning has basic information on [decision-making options](#) on its website, and our [Build Your Plan](#) tool helps families think through important questions related to decision-making.

27. What are your thoughts on different people being involved in different ways (e.g. medical v. financial, etc.)?

People with and without disabilities often seek out different people for advice on different topics, so if a person with a disability asks one supporter to attend medical appointments and help explain medical information but asks a different supporter to attend service planning meetings and give advice on picking a service provider, that is fine. Many supported decision-making agreement templates include space where people can identify which people they want to support them in making which decisions.

28. How does supported decision-making work when someone cannot understand the long-term outcomes of their decision or understand people who mean to manipulate or exploit them? Who is responsible for bad outcomes?

This is, obviously, a very tough situation. No one wants to see their loved one or person they support being taken advantage of. As we explained, the guardianship process is different in each state, but a guardian may be appointed if a court determines a person lacks the legal capacity to take care of their basic needs, health, and/or finances, *even with* support from someone they trust. Unfortunately, having a guardian does not stop people from making decisions that have a bad outcome, including injuries, theft, and abuse. In some circumstances, being under guardianship may allow a guardian to invalidate a contract with court approval or take legal action against abuse or exploitation. In other instances, just as for any person who makes a decision with a negative consequence, there may be nothing that the person, their supporters, or even a guardian can do to change it. Regardless of a guardianship, supporters can educate and empower people after a bad situation to help them understand how to make a different choice in the future and how to seek a remedy for the harm done to them, if one is available.

29. Can we share this information with families, guardians, and service coordinators?

Please feel free to share the information in this presentation far and wide. It will also be available on the Center for Future Planning's [Archived Webinars](#) page.

For more information, contact Morgan Whitlatch, Legal Director at Quality Trust for Individuals with Disabilities at mwhitlatch@dcqualitytrust.org or Shawn Ullman, Senior Director of National Initiatives at The Arc at ullman@thearc.org.