

Guardianship Questions and Answers

1. My child has a disability and will soon turn 18. I've heard from their teachers and doctors and from some of my friends that I need to become their guardian. Is that true?

In all likelihood, you will not need to become the guardian of your child when they turn 18.

Guardians are one type of substitute decision-maker who are allowed by law to make some decisions for people who are determined by a court to be “incapacitated” and to need a guardian. Incapacity means that the person’s “ability to receive and evaluate information and communicate decisions is impaired to such a significant extent that [they are] partially or totally unable to manage [their] financial resources or to meet essential requirements for [their] physical health or safety.”

Decision-making is not an all-or-nothing proposition. Individuals with disabilities – even disabilities like intellectual disability, autism, traumatic brain injury, mental illness, or dementia – often have capacity to make many of their own decisions and it is important that they be allowed to exercise their

decision-making abilities to the fullest extent possible. You should encourage your adult child to make decisions if at all possible.

In addition, your child may want to consult you about decision-making – just as we all turn to our family and other supporters. This is a sort of “supported decision-making” that can be effective in helping your child evaluate choices and consequences so they can make sound decisions. See Question Nos. 12, 13.

There also are many alternatives to guardianship that can allow you to act as the decision-maker when your adult child is unable to make their own decisions and the law requires another decision-maker, such as in the health care and financial spheres. See Questions Nos. 5-6, 8-11, 15-18.

Finally, there are protections available for individuals with disabilities who do not have guardianship in the event that they are subject to abuse, neglect, or exploitation. See Question No. 14.

2. My adult child has serious mental illness. Should I become their guardian?

Guardianship for adults with mental illness is usually neither helpful nor necessary. Mental illness is not static or uniform – some people may recover in whole or in part; others may have periodic crises but be well in between; others may be well enough to be able to make many of their own decisions;



others may have serious and more consistent limitations on their capacity that impedes their decision-making ability. The same as for adults with cognitive disabilities, decision-making by people with mental illness is not all or nothing and they should be permitted and expected to make their own decisions to the maximum extent possible.

In addition, just as for adults with cognitive disabilities, there are an array of alternatives to guardianship as well as protections against abuse, neglect, and exploitation. See Question Nos. 5-18. One alternative to guardianship that may be particularly useful in this context is a Mental Health Advance Directive, discussed in Question No. 7, which allows an individual with mental illness to detail their own wishes for treatment and to appoint a decision-maker in the event they experience a mental health crisis.

Many family members of adults with mental illness mistakenly believe that guardianship will enable them to commit them to psychiatric hospitals for treatment or be able to compel them to receive specific types of treatment (such as forcing them to take medication). The Pennsylvania guardianship law specifically prohibits guardians from committing persons in their care to public or private psychiatric hospitals. Instead, the Mental Health Procedures Act governs when and how a person with mental illness can be involuntarily committed to inpatient or outpatient psychiatric treatment and the duration of treatment.

Moreover, it is important to understand that guardianship might undermine your efforts to help your family member with mental illness. Many people with serious mental illness may struggle to trust others. A few might even have delusions that others are trying to harm them. A contentious guardianship hearing could exacerbate those feelings or beliefs, making your family member less likely to turn to you for help or to let you be involved in their lives, much less their treatment.



3. My parent was just diagnosed with dementia. Do I need to become their guardian?

If your parent was recently diagnosed with dementia, it would probably be a good time for him to consider creating documents – if he hasn't already done so – that will help with decision-making as his capacity deteriorates, such as Health Care Advance Directives and Financial Powers of Attorney, which are discussed in more detail in Question Nos. 5-6, 17.

Even if your parent's dementia is at a stage where he does not have sufficient understanding to create those documents and he did not do so previously, he still probably will not need a guardian. As with other disabilities, supported decision making and substitute decision-making alternatives, as well as protective services, are available to help your parent with decision-making and protect him from harm. See Question Nos. 8-9, 14-18.

If your parent has more significant financial assets that are not subject to a Financial Power of Attorney or placed in a Trust and he no longer has capacity to create those documents, a limited guardianship of the estate may be needed solely to handle those assets. This should not, however, require appointment of a guardian of the person for your parent as all personal decisions can be handled through alternative means.

4. If a person with a disability does not have a guardian, who will make health care decisions?

People with disabilities – including intellectual disabilities, autism, traumatic brain injury, and mental illness – can often make some health care decisions that only require simple consent (such as a routine physical exam). Some individuals with those disabilities may also be able to make some more complex health care decisions that require informed consent. But sometimes an individual’s disability may mean that they will not have capacity to give informed consent. In those cases, the doctor will need to have a decision-maker who is legally authorized to give informed consent.

In the past, the need for a legally authorized decision-maker who could consent to health care was one of the main justifications for guardianship. It is no longer. Now, there are several options for health care decision-making that preclude the need for guardianship – Health Care Advance Directives; MH/ID Facility Directors; and, perhaps most significantly, Health Care Representatives. These are discussed in Question Nos. 5-6, 8-9, 11, 14.

5. What is a Health Care Advance Directive?

A Health Care Advance Directive is a document that is created by an adult when they have capacity to do so that will govern health care decisions affecting them in the event that they lose the capacity needed to make those decisions. Health Care Advance Directives can be either a Living Will, a Health Care Power of Attorney, or a combination of the two documents.

A Living Will generally only covers decisions for people when they are at the end of life or permanently unconscious. They often just reflect “yes” or “no” decisions about specific types of treatment or care (such as cardiopulmonary resuscitation, nutrition, hydration) and they may or may not appoint a “health care agent” to make decisions.

In a Health Care Power of Attorney, the person who creates it (called the “principal”) appoints a “health care agent” to make all health care decisions for them in the event they become incapacitated and cannot make those decisions. The Health Care Power of Attorney can provide specific instructions as well as more general guidelines as to the principal’s wishes and values so that the health care agent will make decisions that reflect what the principal would have done if they had the capacity to make the decisions themselves.

Because Health Care Advance Directives allow principals to exercise the greatest control over decision-making, they are the most preferable form of substitute decision-making.



6. Can a person with a disability make a Health Care Advance Directive?

It depends. In order to make a Health Care Advance Directive, an adult must be “of sound mind.” This means that the person can make an informed decision about the matters covered in the document. Some people with disabilities – including those with cognitive disabilities – will have capacity to execute Health Care Advance Directives and, if they do, they should be encouraged to do so.

7. Would a Health Care Advance Directive cover mental health treatment? If not, are there other options?

Health Care Advance Directives would not apply to most mental health treatment. Pennsylvania, however, has a law that allows individuals to create Mental Health Advance Directives that can impact both treatment and non-treatment choices in the event that the person who creates it loses capacity to make those decisions. By giving people with mental illness more control over their treatment, Mental Health Advance Directives can encourage such individuals to seek treatment.

An adult may create a Mental Health Advance Directive if they are not subject to a guardianship order and not currently subject to involuntary commitment under the Mental Health Procedures Act. Unlike Health Care Advance Directives, Mental Health Advance Directives have a limited duration – two years (subject to certain exceptions).

A Mental Health Advance Directive can be either a Declaration or a Mental Health Power of Attorney or a combination of the two. A Declaration identifies specific treatment preferences, such as location of treatment and medication. These are not legally binding but can be useful to help guide treatment. In a Mental Health Power of Attorney, the individual appoints an “agent” to make mental health treatment decisions but gives guidance to the agent. Both a Declaration and Mental Health Power of Attorney can also include instructions unrelated to mental health treatment, such as dietary requirements, religious preferences, temporary custody of children or pets, and who should be notified. A Mental Health Advance Directive cannot prevent involuntary commitment but can impact treatment post-commitment.

8. If my adult child's or parent's disability does not allow them to make a Health Care Advance Directive, who would make health care decisions if they do not have a guardian?

Since 2006, Pennsylvania law has allowed Health Care Representatives to make health care decisions for adults who lack capacity to make such decisions, who do not have a Health Care Advance Directive (or whose agent under the Health Care Advance Directive is unavailable or unwilling to act), and who do not have a guardian with authority to make health care decisions. The availability of Health Care Representatives means that guardianship is almost never required to make health care decisions. No court needs to authorize Health Care Representatives to make health care decisions allowed by law, so it is a much less burdensome option than guardianship.

If an individual has capacity to do so, they can designate their own Health Care Representative by writing and signing a document with the designation or telling their physician. This is somewhat easier than executing a Health Care Advance Directive but will provide far less guidance to the person designated as the Health Care Representative than a Health Care Advance Directive would provide to the designated agent.

In most cases, Health Care Representatives are used by individuals who did not or could not designate a Representative. In such case, the law identifies who can serve as the Health Care Representative and the order of priority to select the Representative: (1) spouse and adult children (if the children are not the children of the spouse); (2) adult children; (3) parents; (4) adult siblings; (5) adult grandchildren; and (6) any other adult with knowledge of the individual's preferences and values. The law forbids the individual's attending physician, health care provider, and any employee of a health care provider to serve as the individual's Health Care Representative.

Health Care Representatives, as valid decision-makers under Pennsylvania law, are authorized to access the individual's records under HIPAA and should review them when making health care decisions for them.



9. Are there any limits on the ability of Health Care Representatives to make decisions?

Yes. The law prohibits Health Care Representatives from refusing or withdrawing life-preserving treatment (which is treatment that is needed to save the life of someone who is not at the end of life or permanently unconscious). Health Care Representatives can refuse or withdraw life-sustaining treatment for individuals who have end-stage medical conditions or are permanently unconscious, though the individuals in their care can override those decisions (even though they lack capacity) by telling their treating physicians.

Health Care Representatives also should not be able to make those health care decisions that court-appointed guardians are unable to make with or without court oversight and approval. See Question No. 20.

10. Would a guardian have more authority than a Health Care Representative to make health care decisions?

No. Even a guardian who has authority to make health care decisions (and not all do) is prohibited from refusing life-preserving treatment, just like Health Care Representatives. Guardians' authority to make certain other types of health care decisions is also limited. See Question No. 20.

11. I'm older and my child has an intellectual disability and lives in a group home. There is no other family to make decisions for them. What will happen when I die?

Under Pennsylvania law, directors of facilities for individuals with mental illness or intellectual disabilities ("Facility Directors") are authorized to make certain health care decisions for individuals in their care who do not have family members or guardians if they have the approval of two independent physicians. Facility Directors cannot refuse or withdraw life-preserving treatment and they should even seek judicial approval before they refuse or withdraw life-sustaining treatment.

12. My loved one receives Medicaid Waiver services. Do I need to be the guardian to participate in meetings to develop their service plan?

No. Pennsylvania allows individuals' family members, friends, and advocates to participate in developing service plans as long as the individuals want them to participate. In addition, if the individual is not opposed, they can have a family member or friend help them to manage the services and supports they receive through a waiver. These are examples of informal "supported decision-making."

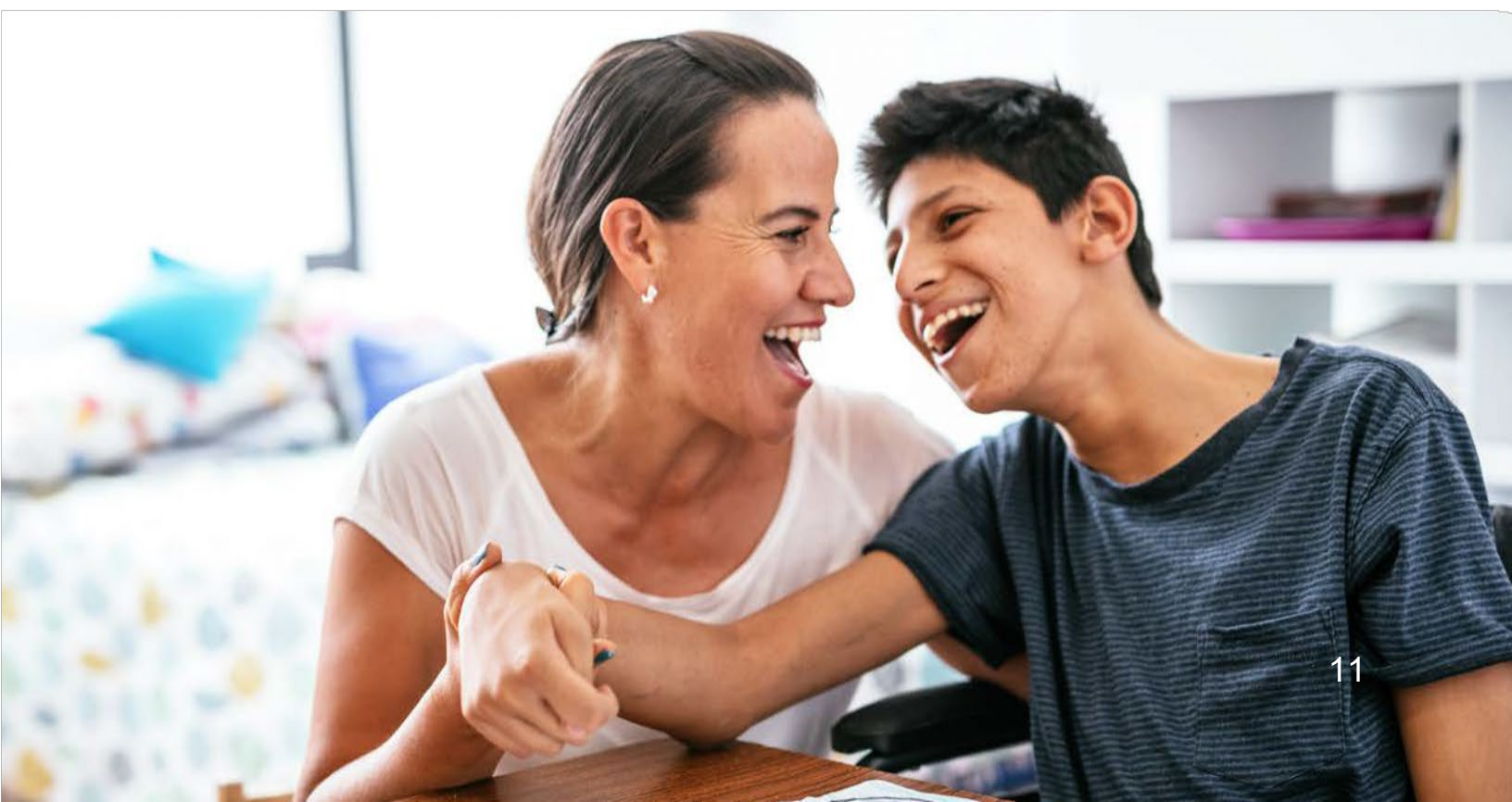
13. What is supported decision-making and how does it differ from guardianship or other kinds of decision-making?

Most people turn to family, friends, and professionals for advice and guidance about important decisions. Supported decision-making essentially recognizes that people with disabilities can use the same process. It allows people with disabilities to use family members, friends, advocates, and professionals to help them understand the situations and choices they face so they can make their own decisions. There is no single model of supported decision-making – it can be formal or informal – but it should identify a network of people with an established, trusted relationship with the person with a disability who are able to help the person understand the choices and consequences of decisions. Ultimately, though, it is the person with the disability who is the decision-maker.

Because it is the person with the disability who is the decision-maker, supported decision-making differs from guardianship, Health Care Advance Directives, Health Care Representatives, Financial Powers of Attorney, Representative Payees, or Trusts which are all forms of “substitute decision-making” (sometimes called “surrogate decision-making”). In substitute decision-making, another person has legal authority to make decisions on behalf of the person with a disability.

While Pennsylvania law does not formally recognize supported decision-making, disability service systems in the Commonwealth often look to members of the individual’s natural support system – family, friends, and advocates – to support the individual in making decisions about services. In addition, like all of us, many people with disabilities naturally look to their family and friends to help with decision-making.

For more information about how you can use supported decision-making, there are resources at <http://www.supporteddecisionmaking.org/> and <https://supporteddecisions.org/>.



14. I'm concerned that my relative with a disability may make bad decisions or be exploited by people who don't have their best interests in mind. Shouldn't I become their guardian to prevent that from happening?

Your fears are not uncommon, but they are not a reason to secure an anticipatory guardianship. Remember that most people with disabilities live their entire lives without having guardianship and do not suffer adverse consequences. To the contrary, they often thrive.

This is not to say that people with disabilities will not make bad decisions sometimes. People without disabilities make bad decisions as well. The "dignity of risk" is part of the human experience and self-determination. And, like everyone else, sometimes a bad decision can be a learning experience that helps them to make better decisions in the future.

In addition, in the event that your family member is at serious risk, the Adult Protective Services system (for adults ages 18 through 59) or the Older Adult Protective Services system (for adults age 60 and older) can help. These protective service systems can be reached 24 hours a day at 800-490-8505. They can investigate allegations of abuse, neglect, or exploitation and offer services to assist your family member and, in certain circumstances, can seek an emergency order to intervene to compel your family member to cooperate with services.

15. My adult child has a disability and receives Supplemental Security Income. They need help to make sure their bills are paid. Do I need to become their guardian to do that?

No. When an individual's only source of income is from Social Security – either Social Security Disability Insurance ("SSDI") or Supplemental Security Income ("SSI") – and they are unable to manage their benefits, the Social Security Administration can appoint a "Representative Payee." It is not necessary to get guardianship to become a Representative Payee. The Social Security

Administration will prefer a family member or other person who knows the beneficiary to serve as the Representative Payee. The Representative Payee is obligated to use the individual's funds for the benefit of the individual and can be removed if they do not.

16. My relative with a disability works and has money in a bank account but they need some help to manage their funds. Do I need to become the guardian to do that?

No. There are several options. First, consider this an opportunity to use "supported decision-making" to help them make sound decisions about their money. You and others who they trust can work with them on a regular basis to review what money is coming in and what their options are for saving and spending. This will enable you to offer guidance but continue to allow them to make decisions. Second, your family member could authorize you to become a co-signatory on their bank account which would be another way to help them to manage their funds while giving you more direct control over the funds.

If your family member is earning and saving money and receives government benefits that may be jeopardized if their income or resources are too high, you should work with them to consider alternatives, such as an ABLE account or special needs trust. See Question No. 18.

17. My parents are getting older and have various financial resources, including bank accounts, investments, and property. Will I need to get guardianship when they are no longer cognitively able to handle those matters?

With proper planning before an individual loses capacity, guardianship generally will not be necessary. There are several options.

First, your parents can consider making you or another trusted and reliable relative, a co-signatory on their accounts, which would enable you to help

manage the accounts and pay bills in the event that they become unable to do so. This would not strip them of authority over their own accounts and enable them to continue making their decisions and handling their finances for as long as possible.

Second, just as your parents should consider creating Health Care Advance Directives before they lose capacity to do so, they also should consider creating Financial Powers of Attorney before they lose capacity to do so. In a Financial Power of Attorney, the person who creates it (the “principal”) appoints another person (the “agent”) to manage some or all of their financial affairs. The scope of a Financial Power of Attorney is up to the person who creates it. The person who creates it will determine when it will take effect, usually choosing to make it effective only when they no longer have capacity to manage their own affairs.

It is important to understand that if your parents simply transfer certain assets it could impact their eligibility for some government benefits that they might need. Your parents might want to consider consulting with an attorney who specializes in financial planning for older adults who can help determine the best strategy for managing their resources in the event they become incapacitated.

18. I want to make sure that my adult child with a disability has the things they need but know that if they receive money directly from me it could jeopardize their important government benefits. What can I do?

Many people with disabilities rely on government benefits, such as SSI or Medicaid, that can be terminated if their income or resources exceed a certain amount. The loss of those benefits can be extremely detrimental, especially the loss of Medicaid that can pay for home and community-based services as well as health care.

Yet, family members and friends might want to be able to give their loved one funds to assure they have what they need without risking their loss of government benefits. Giving the money outright – even through an inheritance or bequest following death – can jeopardize their benefits. But, there are several ways for people with disabilities to have access to resources without risking their eligibility for benefits – ABLE accounts and special needs trusts.

ABLE accounts are available for individuals who receive SSI or SSDI benefits due to blindness or disability (or who self-certify that they have a similarly severe disability) that arose prior to age 26. The individual with the disability and their family and friends can contribute up to \$17,000 a year to the ABLE account (possibly more if the individual earns income). An individual will lose SSI eligibility (but not Medicaid) if the account exceeds \$100,000, but it can hold as much as \$511,758. Account funds can be used for “qualified disability expenses,” such as housing, education, vocational training and support, and transportation. Individuals with disabilities can have fiduciaries manage their ABLE accounts. If there is a 529 account that was prepared for the person with a disability, the funds from that account can be transferred to an ABLE account.

Trusts are another option, particularly but not exclusively for large amounts of funds, such as an inheritance or court judgment or settlement. A person can put funds in a trust and appoint a trustee to manage the funds and distribute them to designated beneficiaries. But, you must be careful. Only certain types of trusts, such as pooled trusts, will shield the individual’s eligibility for government benefits. You will need to consult an attorney with expertise in trusts, and especially how trusts impact eligibility for government benefits, or one of the non-profit groups that operate these types of trusts for more information and advice.



19. I understand that there are many alternatives to guardianship but am still considering it. What are the downsides to getting guardianship over a loved one with a disability?

One practical downside is the cost. To obtain guardianship, you will need to go to court which usually requires hiring a lawyer and an expert, and paying for a criminal background check. And, the court may not grant your guardianship petition. Pennsylvania law does not allow appointment of a guardian if there are less restrictive alternatives available, including family and friends who can support the individual informally. Given the many alternatives to guardianship that exist, you may not prevail on your guardianship petition.

Perhaps just as important is the cost to your family member in their loss of autonomy. Decision-making is a core aspect of adult life. Stripping an individual of their right to make decisions is a drastic step that undermines their right to self-determination.

Relatedly, guardianship may cause a rift between you and your family member if they perceive the action to be intrusive and limiting. It can also create dissension among the family more broadly if different people have different ideas about whether guardianship is necessary and who should serve as guardian. Encouraging your family member with a disability to work cooperatively with you and other family members to help them with decision-making can yield better results than forcing them to do what you want.

20. Are there limits on a guardian's authority?

Yes. Guardians of the person are required by law to respect the person's preferences and wishes to the greatest extent possible and to encourage them to participate in decisions that affect them and to act on their own behalf when they can.

There are other limits as well. A guardian of the person cannot make certain decisions – including consenting to sterilization, electroconvulsive therapy, prohibiting marriage – without a specific court order following a hearing about the issue. A guardian of the estate is not permitted to spend the person’s savings without judicial authorization. There are other decisions that a guardian can never make and cannot be authorized by a court, including consenting to admission to psychiatric treatment, consenting to relinquish parental rights, withdrawing or refusing treatment life-preserving treatment, and compelling an abortion.

21. I was appointed as the guardian for my adult child, but now I’m not sure that it’s necessary. What can I do?

You can request a “review hearing.” Pennsylvania law allows the person subject to guardianship, the guardian, the court, or any interested party to ask for a review hearing. At a review hearing, the court will assess if the person still needs a guardianship and, if so, whether the guardianship can be limited in any way. The court will also assess whether the guardian is acting in the person’s best interest and, if not, who should be appointed as the new guardian. Different courts have different procedures for initiating review hearings so you should contact the Orphans’ Court in the county which has jurisdiction over the guardianship of your child.

22. Where can I get more information about the information discussed here?

DRP has information on its website about many decision-making issues, including those involving health care, financial decisions, guardianship, and estate planning. You can find these materials at <https://www.disabilityrightspa.org/resources/#estate-planning-substitute-decision-making-guardianship>.

Stay Connected

If you need more information or need help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TDD). Our email address is: intake@disabilityrightspa.org. DRP's live intake line is open Monday - Friday from 9:00 a.m. to 3:00 p.m.

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