When a youth reaches the age of adulthood in Pennsylvania (18), they have the legal right to make their own decisions. However, some adults with disabilities lack the capacity to make some or all of their own decisions.

Guardianship is one form of substitute decision-making that grants another individual the legal ability to make decisions for a person who is unable to do so on their own. Guardianship is granted by a court after it first determines that the person is “incapacitated,” meaning they lack the ability to receive and evaluate information to such an extent that they cannot make or communicate their own decisions. After declaring a person incapacitated, if there are no less restrictive alternatives, the court may then appoint a guardian of the estate, a guardian of the person, or both.

A guardian of the estate is empowered to manage the incapacitated person’s finances and make all financial decisions for him or her. A guardian of the person is tasked with managing the incapacitated person’s health and safety, and can, therefore, make all major life decisions for the person (e.g., where they live, what doctors they see, whether they work, etc.)

Guardianship is the most restrictive form of substitute decision-making. It severely limits the rights of the incapacitated person to make his or her own decisions.

Persons who have a guardian of their estate or person may have a hard time gaining employment because they have been labeled “incapacitated” by the court. For example, if the incapacitated person is appointed a guardian of his estate, he may not be able to earn a paycheck in his own name; instead, his paychecks may need to be made out to his guardian. Or, if there is a guardian of the person appointed, the guardian may have to sign documents, such as employment agreements, on the incapacitated person’s behalf. The guardian may even forbid the incapacitated person from working all together. Factors such as these may lead employers to avoid employing persons who have guardians.
Often, educators or doctors tell parents of children who have intellectual disabilities, autism, or similar cognitive disabilities that when their child turns 18, the parents should seek guardianship. However, this is legal advice that educators and doctors are not qualified to give, and it is often bad advice. Many young adults with disabilities have the capacity to make some, many, or even all their own decisions. Even if the young person does not have the capacity to make any of his own decisions, guardianship is usually not needed.

Pennsylvania law states that guardianship should not be pursued unless there are no less restrictive alternatives. Because there are usually viable alternatives to guardianship for persons who are partially, or even completely incapacitated, guardianship is almost never necessary. There are many alternatives to a guardian of the estate and person which allow the incapacitated person to retain more rights than if she had a guardian, and these alternatives make it more likely that she could obtain and keep employment.

**Alternatives to a guardian of the estate include:**

- **Representative Payees:** When a person is not able to manage his own money due to a disability and receives Social Security benefits (SSI or SSDI), the Social Security Administration will name a representative payee to receive and manage their benefits. See: [https://www.ssa.gov/payee/faqrep.htm](https://www.ssa.gov/payee/faqrep.htm).
- **Financial Powers of Attorney:** for those with enough capacity to understand the concept of selecting and allowing another person to make decisions on their behalf.
- **Trusts:** When a person with a disability receives a large sum of money that might jeopardize her eligibility for government benefits, the money can be placed in certain types of trusts that are managed by a trustee; it is important to make sure that the trust protects the benefits, because not all trusts do.
- **ABLE Accounts:** If a person has a qualifying disability that began before age 26, up to $15,000 a year can be put into an ABLE account without the account owner losing their government benefits. If the account owner is not able to manage the account because of their disability, a friend or family member can manage it on their behalf. See: [https://www.paable.gov/overview/](https://www.paable.gov/overview/).
- **Co-Signatory on an Account:** If a person with a disability can make some but not all financial decisions and has their own source of income, they may allow a trusted family member or friend to be a co-signatory on their account, to help them pay bills or make financial decisions when necessary.
Alternatives to a guardian of the person include:

- Health Care Representatives: Pennsylvania law (commonly called "Act 169") allows family members or friends to make most health care decisions for individuals who are not competent to make those decisions themselves. These decisions can include typical health care decisions (e.g., surgery, medical treatment) and decisions relating to disability services. People serving as health care representatives also have access to information under HIPAA. For more information about health care representatives, see: https://www.hhs.gov/hipaa/for-professionals/faq/2069/under-hipaa-when-can-a-family-member/index.html, https://www.disabilityrightspa.org/wp-content/uploads/2018/04/CompleteGuideCapacityConsentSubDecMakingFEB2018.pdf and https://www.pamedsoc.org/detail/article/Act-169-facts

- Health Care Advance Directives (Health Care Powers of Attorney and/or Living Wills): for those with enough capacity to understand the concept of allowing another person to make health care decisions on their behalf and/or making their own choices about medical care at the end of life.

- Supported Decision Making: For some decisions, family and friends of a person with a disability can provide them with the support that they need to be able to make their own decisions without any formal documents in place.

The Protection and Advocacy for Beneficiaries of Social Security Program

The Protection and Advocacy for Beneficiaries of Social Security (PABSS) program in Pennsylvania is tasked with assisting Social Security beneficiaries with return-to-work issues and employment barriers. It also supports the state’s "Employment First” initiative, in that employment in the general workforce should be competitive and integrated for all people, regardless of disability. Find out more information about PABSS, see: https://www.disabilityrightspa.org/wp-content/uploads/2018/03/ServicesForBeneficiariesOfSSSeekingEmploymentJuly2017FinalFEB2018.pdf.

If you are experiencing any barriers to employment, please contact us for assistance.

Contact Information:

If you need more information or help, please contact Disability Rights Pennsylvania (DRP) at 800-692-7443 (voice) or 877-375-7139 (TTY). 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.

The mission of Disability Rights Pennsylvania is to advance, protect, and advocate for the human, civil and legal rights of Pennsylvanians with disabilities. Due to our limited resources, Disability Rights Pennsylvania cannot provide individual services to every person with advocacy and legal issues. Disability Rights Pennsylvania prioritizes cases that have the potential to result in widespread, systemic changes to benefit persons with disabilities. While we cannot provide assistance to everyone, we do seek to provide every individual with information and referral options.

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