

A photograph showing two men in conversation. One man is seen from the back, wearing a light-colored shirt, while the other man, a young Black man in a dark t-shirt, looks towards him. The background is a bright, out-of-focus indoor setting with large windows.

Less Restrictive Alternatives to Guardianships

People with intellectual disabilities, autism, or similar cognitive disabilities do not necessarily need to have a guardian of the person or estate to help them make medical, financial, or other decisions. Most people with these disabilities live their whole lives without guardianship. Many have capacity to make some, perhaps many or even all, of their own decisions. Even if they do not have capacity, guardianship is usually not needed.

Why guardianships are not the best option:

- It is often unnecessary (there are usually viable alternatives);
- It is burdensome and expensive (there are legal fees and detailed annual filing requirements with accompanying filing fees for the guardian);
- It takes away the rights of the person with the disability by limiting their right to make their own decisions.

Alternatives to guardian of the person for someone who is incapacitated include:

- **Health Care Representatives**– Pennsylvania law (commonly called “Act 169”) allows certain family members or friends to make health care decisions, when they do not have capacity to make those decisions themselves. These decisions can include regular health care decisions (e.g., surgery, medical treatment) and decisions relating to disability services. Health Care Representatives have access to information through HIPAA. 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 or Health Care Powers of Attorney**– Those with sufficient capacity to understand documents designating others to make decisions for them can create these documents which would take effect in the event that they lose capacity to make their own decisions.
- **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.

Alternatives to guardian of the estate for someone who is incapacitated include:

- **Representative Payees** – When a person is not able to manage their 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 their benefits. See: <https://www.ssa.gov/payee/faqrep.htm>.

- **Financial Powers of Attorney** – For those with sufficient capacity to understand the concept of allowing another person to make decisions for them, they can create financial powers of attorney to identify another person to make some or all of those decisions.
- **Trusts** – When a person with a disability receives a large sum of money that might jeopardize their eligibility for government benefits, the money can be placed in a certain trust that is 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 \$17,000 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 the disabled person's behalf. See: <https://www.paable.gov/overview/>. 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.
- **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.



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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PLEASE NOTE: For information in alternative formats or a language other than English, contact Disability Rights Pennsylvania at 800-692-7443 (voice) or 877-375-7139 (TDD). Our email is: intake@disabilityrightspa.org.

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