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 his right to make his 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.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](https://www.disabilityrightspa.org/wp-content/uploads/2018/04/CompleteGuideCapacityConsentSubDecMakingFEB2018.pdf), and [https://www.pamedsoc.org/detail/article/Act-169-facts](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 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 their benefits. See: [https://www.ssa.gov/payee/fagrep.htm](https://www.ssa.gov/payee/fagrep.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 his eligibility for government benefits, the money can be placed in a certain 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 the disabled person’s 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.

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.

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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