



DISABILITY RIGHTS
PENNSYLVANIA

Introduction

What is DRP?

Public interest law firm

- Non-profit, 501(c)(3) corporation
- Independent
- Statewide

Designated as the federally-mandated
Protection & Advocacy agency in
Pennsylvania



What is a Protection & Advocacy Agency?

- Provides legal and advocacy services to protect the rights of individuals with disabilities
- Established by Congress
- P&As in every state and U.S. territory = 57
- National Disability Rights Network (NDRN)



What does DRP do as a Protection & Advocacy Agency?

DRP staff works statewide on behalf of individuals with disabilities to:

- improve services and social systems
- ensure civil rights and empower the community
- provide technical and training assistance



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What is DRP's philosophy?

- **EQUALITY:** People with disabilities are full and equal persons under the law and are entitled to equal access
- **SAFETY, RESPECT, AND DIGNITY:** People with disabilities are entitled to be free from abuse, neglect, exploitation, discrimination, segregation, and isolation
- **INDIVIDUALIZED, CLIENT-DRIVEN:** People with disabilities should have access to appropriate services and supports that are shaped by the unique needs and preferences of each individual



What is DRP's philosophy (cont.)?

- **INDEPENDENCE, SELF-DIRECTION, INCLUSION:** Such service and supports are designed to foster an independent, productive and integrated community life
- **AUTONOMY:** People with disabilities have the right to make choices about all aspects of their life including daily routines and major life events



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What is DRP's mission & vision?

MISSION

- Protects and advocates for rights of people with disabilities so that they may live the lives they choose, free from abuse, neglect, discrimination, and segregation.

VISION

- A Commonwealth where people of all abilities are equal and free.



What areas of disabilities does DRP provide advocacy and legal services?

Protection & Advocacy for all disabilities:

- Developmental Disabilities (1975)
- Mental Illness (1986)
- Individual Rights – everyone else! (1993)
- Assistive Technology (1994)
- Barriers to Employment for SS beneficiaries (1999)
- Traumatic Brain Injury (2000)
- Voting Accessibility (2002)
- Representative Payee (2018)



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What are DRP's priorities?

Goals and Objectives

1. Stop the abuse, neglect and rights violations of people with disabilities
2. Address the segregation, institutionalization, and treatment issues of people with mental illness and developmental disabilities.
3. Promote consumer-driven, person-centered planning and recovery-oriented services to enable people with disabilities to live in home and community-based settings.
4. Eliminate discrimination against people with disabilities.
5. Conduct rights training and outreach in Pennsylvania.



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What advocacy tools can DRP use?

Systemic change through core functions:

- Intake and Case Services
- Litigation
- Policy Advocacy
- Investigations and monitoring
- Education and outreach



Does DRP
provide self-
advocacy
tools?

Guides for Self-Advocacy

- Currently 26 topics, including:
 - Resource Guide for Veterans with Developmental Disabilities
 - Assistive Technology
 - Access to public/private commercial facilities
 - Mental Health
 - Estate Planning/Substitute Decision-Making/Guardianship
 - Housing
 - Rights of Deaf and Hard of Hearing People
- <https://www.disabilityrightspa.org/resources/>



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Freedom to Make Decisions

- Historically, people with disabilities were presumed unable to make decisions
 - Many people with disabilities lived in institutions
 - Decision-making in institutions is usually unnecessary
 - Institutional care perpetuated dependence on others to make decisions
- Today, integration is the norm
 - Most people with disabilities live in the community
 - Decision-making by people with disabilities – everyday decisions, personal decisions, financial decisions, healthcare decisions – has become an issue of increasing concern

Freedom to Make Decisions

- Adults – even adults with disabilities – have the right and are presumed to have the capacity to make their own decisions
- Freedom to make decisions is fundamental to personal autonomy and self-determination
- An adult’s right to make their own decisions can sometimes be limited
 - People with disabilities may need supports to help them understand and make decisions and, often, “supported decision-making” will be effective
 - Sometimes, however, people with disabilities may need others to make a decision for them. These are often called “substitute decision-makers”

Alternatives to Guardianship

- Health Care Representatives
- Health Care Advance Directives
- Supported Decision Making
- Representative Payees
- Financial Powers of Attorney
- Trusts
- ABLE Accounts
- Co-signatory on an Account

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.

Health Care Representatives

- A health care representative can make health care decisions for an individual if all of the following circumstances are met:
- (1) the individual's attending physician has determined the individual to be incompetent to make a health care decision;
- (2) the individual is at least 18 years old or has graduated from high school or is married or is an emancipated minor;
- (3) the individual does not have a guardian who is authorized to make health care decisions; and
- (4) the individual either does not have a health care POA or he or she does have a health care POA but the appointed health care agent is not willing to act and there is no alternative health care agent previously designated by the individual
- An attending physician or health care provider can require a person claiming the right to act as a health care representative to provide a written declaration made under penalty of perjury.

Limits to Health Care Representatives

- Limits on health care representatives' authority
 - Cannot refuse life-preserving treatment for person who does not have end-stage disease or who is not permanently unconscious, 20 Pa. Cons. Stat. Ann. § 5462(c)
 - There may be other limits similar to limits imposed by law on guardians, see 20 Pa. Cons. Stat. Ann. §§ 5521 (d), (f), including:
 - Removal of healthy bodily organ
 - Experimental treatment
 - Commitment to psychiatric hospital or state center

Health Care Advance Directives

- An "advance health care directive" is a health care power of attorney (POA), a living will, or a combination of those two documents.
- 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.

Health Care Advance Directives

- Any individual who is of "sound mind" can make an advance health care directive as long as he or she meets one of the following criteria:
- (1) he or she is 18 years of age or older;
- (2) he or she has graduated from high school;
- (3) he or she has married; or
- (4) he or she is an emancipated minor

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.

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/faqrep.htm>;
- It is not necessary for a Beneficiary to be adjudicated incapacitated to have a Representative Payee appointed
- Representative Payees must use the benefits to:
 - first, pay for the individual's current needs (e.g., housing, food, utilities, health care, clothing, personal care)
 - second, once those expenses are paid, pay any past-due bills, to support any dependents, or pay for entertainment for the individual
 - third, save any funds remaining after those expenses are paid for the individual

Financial Powers of Attorney

- Financial Powers of Attorney are governed by 20 Pa. Cons. Stat. Ann. §§ 5601-5614
- 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
- A trust is a legal instrument where a person (the settlor) places money or other property (the trust assets) in a special account for the benefit of one or more persons (the beneficiaries). A third-party (the trustee) is designated to control the assets in accordance with specific directions in the trust
- Trusts can be important for individuals to qualify for or maintain needs-based government benefits, such as SSI or Medicaid
 - Not all trusts will protect an individual's eligibility for government benefits
 - Important to have careful legal advice, particularly for older adults where placing money in a trust may have negative consequences related to asset transfers

ABLE Accounts

- PA ABLE accounts allow individuals with qualifying disabilities to save without risking loss of their SSDI, SSI, Medicaid, and certain other benefits
- To qualify, a person must receive SSDI or SSI due to blindness or disability (or self-certify that they have a similarly severe disability) and the disability must have started before age 26
- Individuals, family members, and friends can contribute to ABLE accounts
- Up to \$16,000 a year can be added to ABLE accounts (though that a total of \$28,880 can be contributed if the individual contributes earned income) but accounts cannot exceed \$511,758 and if accounts exceed \$100,000 the individual will lose SSI eligibility
- There are various investment options available
- Account funds can be used for “qualified disability expenses,” which include, among other things, education, vocational training and support; housing; transportation; healthcare; and legal fees
- Account holders may have fiduciaries manage their accounts for them if they choose
- More information about PA ABLE Accounts can be found at <https://www.paable.gov/>

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 cosignatory on their account, to help them pay bills or make financial dec

Protective Services

- Protective services are available to assist people with disabilities who are victims of abuse, neglect, or financial exploitations and may be a way to avoid guardianship
- Pennsylvania has 3 protective services laws:
 - Child Protective Services Law (CPSL), 23 Pa. Cons. Stat. Ann. §§ 6301-6388 – Covers children under 18
 - Adult Protective Services Act (APS), 35 P.S. §§ 10210.101-10210.704 – Covers adults ages 18 through 59 who have disabilities
 - Administered by PA Department of Human Services
 - Investigations conducted by private agency
 - Older Adult Protective Services Act (OAPSA), 35 P.S. §§ 10225.101-10225.5102 – Covers adults ages 60 and older who are incapacitated
 - Administered by the PA Department of Aging
 - Investigations conducted by local Area Agencies on Aging (AAAs)

Protective Services: Reporting

- Hotline for APS and OAPSA: 800-490-8505
- Voluntary reporting
 - Anyone who has cause to believe that an adult with a disability or an older adult needs protective services can make a report by calling the hotline
- Mandatory reporting
 - Employees or administrators of certain facilities (e.g., nursing homes and personal care homes) and providers (e.g., home health agencies) are required to make reports when they suspect that an adult with a disability or an older adult has been a victim

Why guardianships are not the best option:

- Financial costs
 - Guardianship requires a court hearing, so a lawyer and expert are usually needed.
 - Guardians are obligated to file annual reports and filing fees must be paid unless waived by the court.
- Guardianship is the most restrictive form of substitute decision making and significantly limits the individual's autonomy.
- Guardianship can create divisions or cause dissension among family members.

How to contact DRP?

- Website: <https://www.disabilityrightspa.org/>
 - Intake Form
 - Request Training/Education Form
 - General Inquiries Form
- Call Intake: (800) 692-7443
- Email Intake: intake@disabilityrightspa.org



Questions?

