



Medical Decision-Making & Transition Age Youth

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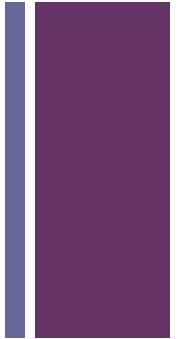
Who is an Adult?

In Pennsylvania, an adult is any individual aged 18 or older.

23 PA Cons Stat § 5101 - Attainment of full age.

(a) Age for entering into contracts.--Any individual 18 years of age and older shall have the right to enter into binding and legally enforceable contracts and the defense of minority shall not be available to such individuals.

(b) Age for suing and being sued.--Except where otherwise provided or prescribed by law, an individual 18 years of age and older shall be deemed an adult and may sue and be sued as such.



+ What is Guardianship?



- **Guardianship** is a legal proceeding in which the court makes a finding of incapacity and appoints someone with capacity to exercise consent on the incapacitated person's behalf.
- A PA court may appoint a **guardian of the person** and/or a **guardian of the estate** for a person who lives in Pennsylvania and has property in Pennsylvania if it finds after a hearing that the individual is “incapacitated” and needs a guardian.



Who is an Incapacitated Person?

- **“Incapacitated person”** means an adult whose ability to receive and evaluate information effectively and communicate decisions in any way is impaired to such a significant extent that s/he is partially or totally unable to manage his/her financial resources or to meet essential requirements for his/her physical health and safety.

20 Pa. C.S.A. §550

- Healthcare practitioners sometimes differentiate between **capacity** to make medical decisions and **competency** make legal decisions.



+ What is Capacity?

Capacity is an assessment of one's ability to give consent. Capacity involves three factors:

- **Knowledge**

An ability to understand situation, risk, alternatives and benefits

- **Intelligence**

An ability to use information logically

- **Voluntary Action**

An ability to communicate the decision



+ What is Consent?

Consent refers to the ability to assent.

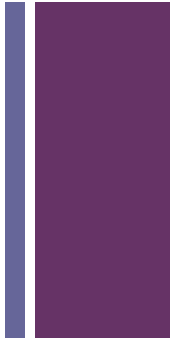
There are two types of consent:

■ Simple Consent

- Assent given based on relatively basic understanding. Reserved for routine decisions.

■ Informed Consent

- Assent given ***voluntarily***, when risks are considered ***knowingly***, and evaluated ***intelligently***. Reserved for decisions with significant consequences.



+ Assessing Capacity

- All clinicians who are responsible for the care of patients should be able to perform routine capacity assessments.
- Decision-making capacity is a clinical assessment of a patient's ability to make a *specific* health care decision.
- Capacity should be assessed on a routine, on-going basis.





When a patient has limited or fluctuating capacity...



- Advance planning by families can often avoid the need for a guardian to manage gifts, inheritances, or other assets.
- Public benefits, such as Supplemental Security Income (SSI), can be managed without a guardian through the appointment of a representative payee.
- Natural support systems - Consent to assistance
Such persons have no legal authority to act on the patient's behalf.



When a patient has some capacity, but cannot consent...



Health Care Advance Directive/Power of Attorney

- Any written statement a competent individual has made concerning future health care decisions. The two typical forms of advance directive are the *living will* and the *health care power of attorney*.

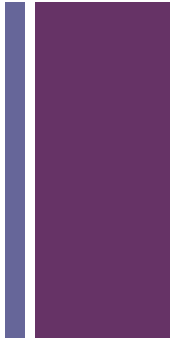
Surrogate decision making by an authorized legal representative, a relative, or a close friend

- In many states, the next of kin are authorized to make some or all medical treatment decisions in the absence of a health care advance directive or appointed guardian.



Health Care Representatives

Act 169 of 2006, 20 Pa C.S.A. Ch. 54



- A framework for substitute health care decision-making for individuals who are “incompetent” to make their own health care decisions.
- Authorizes family members and other individuals who know the incompetent person to act as “health care representatives” to make certain health care decisions when the person did not create an advance health care directive and does not have a guardian.
- If no next-of-kin is available, the Mental Health and Mental Retardation Act of 1966 permits service providers to consent to certain medical treatment on behalf of persons in group homes or other residential facilities.



When May Families Consider Pursuing Guardianship?



- When a minor child with a disability reaches the age of majority and has serious to profound cognitive and communicative impairments.
- When a guardian **would solve the issues** at hand (e.g., access to medical records; communication with insurance providers)
- When there are no less restrictive alternatives.



Guardianship v. Self-Determination

Competing public health goals?



- Guardianship is an attempt to balance two well-being goals:
 - The protection and safety of those with diminished capacity
 - The sense empowerment that comes from autonomy
- Empowering individuals to actively participate in personal decision-making improves life outcomes and can reduce the risk of abuse and exploitation.



Guardianship v. Self-Determination

Competing public health goals?



Supported Decision-Making (SDM)

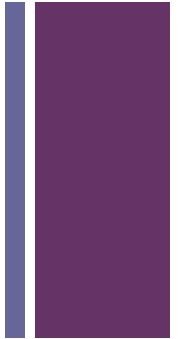
A process in which adults who need assistance with decision making receive assistance in understanding the situations and choices they face, to make life decisions for themselves.

- Removes the need for undue or overbroad guardianship.
- Empowers those with cognitive challenges by utilizing supports to ensure that they can remain the ultimate decision-maker.



Guardianship v. Self-Determination

Competing public health goals?



- There is a risk of abuse and exploitation in all forms of substitute decision-making.
- An overly protective response can stifle self-determination and empowerment.
- Protection must be balanced with opportunities for growth
 - Adults have a basic right to make choices, good or bad
 - An overly aggressive protective response to incapacity can be a form of abuse.



+ Why do some families rely upon a power of attorney/POA?



+ Why do some families
choose Guardianship?

+ Who Can Become a Guardian?

- Any qualified individual, corporate fiduciary, non-profit corporation, or county agency may serve as guardian.
- A proposed guardian must not have interests that conflict with those of the incapacitated person unless no alternative exists.

20 Pa. Cons. Stat. Ann. § 5511(f)

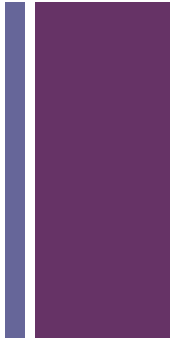
- A guardianship support agency may be appointed by the court.
- If appropriate, the court shall give preference to a person suggested by the incapacitated person.

20 Pa. Cons. Stat. Ann. § 5553(a)

+ What “Type” of Guardian?

Limited or Plenary Guardianship

- A plenary guardianship is a relationship in which the guardian is assigned all duties and powers that an individual with capacity is capable of exercising.
- A limited guardianship is a relationship in which the guardian “is assigned only those duties and powers that the individual is incapable of exercising.”



+ What “Scope” of Guardianship should be pursued?

- If **minimal or no** incapacities, petition not granted, use less restrictive alternative.
- If **severely diminished** capacities in all areas, or if less restrictive interventions have failed, use plenary guardianship.
- If **mixed strengths and weaknesses**, use limited guardianship.





Limits on the Guardian of the Person



Generally, a guardian **does not** have the power to:

- Consent to an abortion, sterilization, psychosurgery, electroconvulsive therapy, or removal of a healthy body organ;
- Prohibit the marriage or consent to the divorce of the incapacitated person; or
- Consent to the performance of any experimental biomedical or behavioral medical procedure or to the participation in any biomedical or behavioral medical experiment.



Limits on the Guardian of the Person



Generally, a guardian **does not** have the power to:

- Admit the incapacitated person to an inpatient psychiatric facility or state center for persons with mental retardation;
- Consent to the termination of the incapacitated person's parental rights; or
- Revoke or amend instructions in a health care power of attorney (POA) or living will without judicial authorization.



In Re D.L.H.,
606 PA 550 (PA 2010)



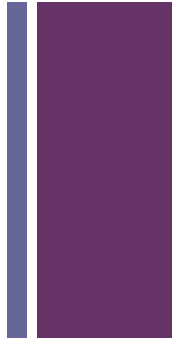
- If an incapacitated person did not execute an advance health care directive and does not have an end-stage medical condition or is not permanently unconscious, ***a guardian may not direct a doctor or other health care provider to withhold life-preserving treatment.***



What if a Guardian passes away?

or

What if the person with a disability wants the Guardianship to end?

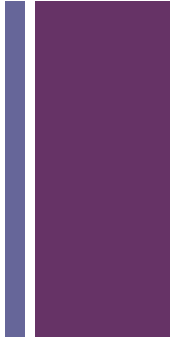


A guardian cannot “transfer” guardianship for a person through a will or other self-directed document.

- Only the court, after a hearing to appoint a successor guardian, can approve a new guardian to take over guardianship of a person and estate if the existing guardian is no longer able or willing to serve in that capacity.

20 Pa. Cons. Stat. Ann. § 5512.2

An incapacitated person, a guardian, any interested person, or the court may petition for a **review hearing**.



The appointment of a guardian for a person with limited or impaired intellectual functioning may, in some cases, be necessary to protect the individual's well-being.

- Alternatives to guardianship may prove equally effective at a substantially lower emotional and financial cost.
- The majority of persons with disabilities live in the community with the assistance of their families or a system of support services without the need for guardians.

A panoramic view of the Pittsburgh skyline at dusk, featuring prominent skyscrapers like the PPG Place and the PPG Field tower, with a bridge visible in the foreground.

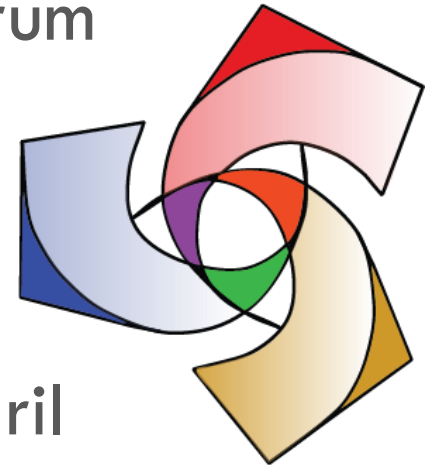
P.A.R.T.S.

Progression of Autism Related Transition
Services



Recommended Resources:

- GotTransition.org
- Aaspire.org ~ Academic Autism Spectrum Partnership in Research and Education
- <https://pittotparts.wixsite.com/partsot>
- *Autism* journal had a special issue in April 2021 on Physical Health Across the Lifespan, vol. 25, issue 3





+ QUESTIONS?



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