

Guardianship, Supported Decision-Making, And People With Disabilities In Medical Settings

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Guest Speakers

Outcomes for Today

- A brief explanation of the differences between SD-M and Guardianship
- More in depth look at tools to address medical decision-making concerns
- Hear directly from people with disabilities about their experiences in seeking medical treatments
- See where this information can show up on an IEP

Tash Connection, 2017

“We all make decisions-big and small-every day. We may take for granted that we have the right to exercise such autonomy over our lives and that we often have a network of trusted friends and allies with whom we consult to make the important decisions that affect our lives. This is not always the case for people with disabilities.”

What Is Guardianship?

A legal guardian is a person who has been appointed by a court and has the legal authority (and the corresponding duty) to care for the personal and property interests of another person, called a ward. Guardians are typically used in four situations:

- Seniors
- Minors
- Adults with developmentally disabled
- Adults found to be incompetent

How does guardianship impact medical rights?

- A person with IDD can lose her/his/their rights to:
- Contract
 - Attend education programs including sexuality education
 - Attend medical appointments including those pertaining to sexual health
 - Obtain reproductive health information
 - Have health information kept confidential

All of which are critical to human dignity and personhood.

How does guardianship impact medical rights?

There are many reasons why parents may consider obtaining guardianship for a young adult with an intellectual or developmental disability (IDD), but parents are also, frequently unaware that guardianship results in the loss of a person's legal and civil rights. This is why alternatives to guardianship are so important.

Why Is Guardianship The Least Preferred Model?

Being connected to supporters protects people against the kind of exploitation or abuse That can occur when a person is isolated and powerless.

Supporting people with IDD to make their own decisions is the best way to carry out the purpose of laws like:

- Americans with disabilities act (ADA)
- Individuals with disabilities education act (IDEA)

Why Is Guardianship The Least Preferred Model?

Making one's own decisions fosters self-determination and teaches people to learn from bad choices and to make good choices in a way that will serve and protect them when their family is no longer able to do so.

Why Is Guardianship The Least Preferred Model?

New research shows that people who lead more self determined lives are not just emotional healthier, but physically healthier.

<https://pubmed.ncbi.nlm.nih.gov/27630254>

<https://pubmed.ncbi.nlm.nih.gov/22385839>

What is Supported Decision-Making anyways?

We all need supporters, helpers and consultants in our lives in order to make good decisions, whether we have a disability or not.

This really is no different for people with IDD!
So why then have we created a whole separate system for this population?

What is The Difference Between Guardianship and Supported Decision-Making

Substituted decision-making = guardianship, which limits rights, choices and freedom

Supported decision-making = a process that enables people with disabilities to retain and exercise their rights and make and communicate choices in regard to, personal and legal matters

Who Might These Supporters Be For People With IDD?

- Friends
- Families
- Neighbors
- Colleagues
- People from my place of worship
- Doctors/Nurses
- Health classes

We all build social capital throughout our lives.

Meaningful Connections In The IEP

Clear and meaningful connections must be established between what the student is learning in high school and what he or she will be doing after leaving high school.


- Postsecondary goals are outcomes. They are age-appropriate and measurable.
- Align annual goals with adult outcomes (postsecondary goals)
- Transition Services are activities.
- They assist the student in reaching the goal.

Individuals with Disabilities Education Act (IDEA)

§300.320(b) *Transition services.* Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include—

- Appropriate measurable postsecondary goals based upon age appropriate, transition assessments related to training, education, employment, and, where appropriate, independent living skills; and
- (2) The transition services (including courses of study) needed to assist the child in reaching those goals.

Office of Special Education Training



- The student is presumed to be competent to act on their own behalf
- The district is presumed to have been, and is continuing to, educate the student to live a self-determined life
- School personnel should NOT try to persuade the parents to obtain legal guardianship over the student

Medical Needs at School

Transferring responsibility for self-care to a youth is a complex process dependent on factors such as the youth's health needs and cognitive abilities, as well as family and cultural factors.

Health Can Be Addressed in the Transition IEP: Present Levels of Academic Achievement and Functional Performance is the place where the student's baseline performance is documented.

Health issues, can describe the current impact of the student's health in relation to the disability or condition.

A description of the student's current knowledge and skills around recognition and management of their health needs.

IEPs and 504 Plans

IEPs and 504 Plans are federal regulations put in place to guarantee an education for children with disabilities(which includes medical issues).

Each plan creates a legal document which outlines the student's specific needs and accommodations while at school.

The plan can include:

- taking medication at school
- meeting dietary requirements
- safety issues (like accommodations for allergies)

These may all be affected by the student's knowledge of their rights.

Informed Consent

Permission granted in the knowledge of the possible consequences, typically that which is given by a patient to a doctor for treatment with full knowledge of the possible risks and benefits.

One Persons' Experience with Medical Issues

- Izzie lived experiences with medical concerns
- Reflections on how a different result could have happened with a public guardian



Stories From The Streets



- Jan will share some stories from her work as an advocate
- Reflections on how a different results very with or without guardianship

When the Main Concern are Medical Decisions

- Like ALL people, it is likely that young people with disabilities will experience the need for medical care at some point in their lives.
- Like ALL young adults, youth with disabilities should learn to seek accurate information and weigh options
- Like ALL young adults, youth with disabilities need time to take on successively more responsibilities and when needed, have support to make these decisions

What Is A Healthcare Power Of Attorney

A healthcare power of attorney (HCPA) is a legal document that allows an individual to empower another person to make decisions about their medical care. A healthcare power of attorney refers to both a legal document and a specific person with legal authority.

What Is A Patient Advocate?

An individual, such as an attorney, friend, nurse, ombudsman, physician, or social worker, who pleads for and preserves a patient's rights to health care. Patient advocates address many common and important health care issues, including the right to access a health care provider, the right to obtain confidential care, and the right for the patient to work after diagnosis or treatment.

Advanced Directives

A Michigan advance directive is a document that lets a person select their end-of-life treatment options in the chance they cannot speak for themselves. This includes an agent that can be nominated to make health care decisions on the person's behalf in addition to treatment options and organ donation selections.

What We Have Seen With Covid

We have seen issues arise that have adversely affected people with IDD throughout the pandemic.

Refusal of medical staff to allow a supporter at appointments.

- Lack of access to virtual health care
- Lack of prioritization for medical services
- Lack of prioritization for vaccines
- Lack of access to vaccinations

National Guardianship Association/2015

“Supported decision-making should be considered before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”

Real Life Stories



<https://youtu.be/IREiWxNel7g>

Organization Resources

DD Council Webpage
www.michigan.gov/ddcouncil

Arc Michigan
<https://arcmi.org/>

Quality Trust
dcqualitytrust.org

National Resource Center for Supported Decision-Making
www.supporteddecisionmaking.org

Speaker Contact Information



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