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Guardianship and Alternatives for Decision-Making Support

Written by: Got Transition Staff with support from Tina Campanella, Quality Trust for Individuals with Disabilities

HEALTH CARE TRANSITION AND DECISION-MAKING

For a youth or young adult who has intellectual disabilities, his or her health care transition often raises questions for health care providers and families about guardianship. This brief provides a high level look at guardianship and other decision-making supports as well as resources that will provide more in-depth information.

Photo courtesy of Colorado's Children and Youth with Special Health Care Needs Unit

Guardianship Issues

Reaching the age of 18 — Opportunities and Challenges for Young Adults with Disabilities

Reaching the age of majority (18 years, in most states and jurisdictions) means, under state law, an individual is no longer a "minor." As such, the person has the right and responsibility to make certain legal choices that adults make. For some young adults with intellectual disabilities, this may be an exciting opportunity for increased independence. However, there may also be family concerns about how to best support that person's self-determination in making life decisions such as for health care or in financial management.

This brief provides a broad outline of decision-making support options, both informal and legal, that may assist a young adult with an intellectual disability. States and jurisdictions may have different laws and options. Each state defines the categories and rules for guardianship in its laws. It is important to know all of the options before deciding which one to pursue since every young person has a unique situation and individual needs for support.

Got Transition, The National Health Care Transition Center, is a resource for health care professionals, families, youth, and state policy makers focusing on a young adult's transition from pediatric to adult health care.

Decision-Making — A Skill that Requires Practice and a Variety of Experiences

Decision-making is a learned skill. Children and youth who have support and experience choosing what to wear, eat, who to socialize with etc., will approach adulthood having exercised this skill early on. On-going decision-making experiences lead to confidence and a self-awareness that "I am able make decisions that direct my life." When a youth or young adult is denied the opportunity to make decisions or to participate in a shared decision-making process, this lack of skill building may lead to a perceived "incapacity" either by the family or by the young adult him/herself.

Despite having opportunities for decision-making early in life, not all young adults with intellectual disability are able to make all decisions especially those choices with

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more far reaching impact on their lives. In these situations, the right amount of support at the right time can help build on early decision making experiences.

The Right Support at the Right Time

"Informal" support from a young adult's circle of friends and family may be enough to help the young adult talk over life decisions while maintaining the young adult's unrestricted self-determination.

When it comes to issues such as health care decisions or money management, there may be legal options available to assist the young person to "share" decision responsibilities with a trusted friend or family member. Joint or trust fund accounts, financial powers of attorney, health care durable powers of attorney, conservatorships or "waivers of confidentiality" for individual health care issues are options that can support a young person's decision making while providing timely guidance, as needed, for important issues.

IN FOCUS

There may be forms of guardianship that can provide specific decision-making support while not completely denying the young adult's participation in that decision.

Guardianship — More Restrictive Option with Alternatives

Guardianship is a formal, legal process in which a court is requested to assume responsibility for a person as a "ward" and then may appoint an "agent" to act as guardian. The guardian may or may not be a parent or family member, and the guardian's authority is determined by the judge's order or state law. The guardian may have certain responsibilities to the court i.e. submit written reports, attend additional hearings as needed, and maintain standards that preserve the ward's decision-making process, as much as possible.

Some families pursue guardianship because they believe or have been told that it's the only legal answer to concerns they may have about their young adult's ability to handle money or access and stay connected to adult or health care services. While some form of legally arranged guidance may be called for, full guardianship may not be the

PROTECTING EVERY YOUNG ADULT PATIENTS RIGHT TO PRIVACY AND CONSENT

Health care providers, especially those accepting a young adult with intellectual disability into their primary care practices, must protect every patient's right to privacy and consent.

Along with past medical records and health-related information, the health care provider in this situation will need accurate information regarding the individual's independent decision-making status and the names of anyone who has been appointed or identified to support decisions on the young adult's behalf.

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only option. There may be forms of guardianship that can provide temporary or specific decision-making support while not completely denying the young adult's participation in that decision. When it comes to determining what is the best option, the "least restrictive" ones may best support and promote the young adult's decision-making skills and rights.

Each state will have their own definition of guardianship options as well as laws to govern them and every young person has a unique situation and needs. In researching options, families may want to consider availability and appropriateness of options for "emergency," "temporary," "limited," or "provisional" guardianship, 90-day health care guardians, or conservators. Sometimes a combination of different and least restrictive options may be required in order to provide the best assistance.

Guiding Questions to Ask in Considering Decision-Making Support Options

In summary, in considering what the right decision making support for a young adults may be, here are some key questions families may ask:

1. What kind of decision is being made?
2. Has the person made a decision like this before?
3. Has the person been assisted to understand the risks and benefits?
4. How big is the impact of this decision in the person's life?
5. How long would the person live with the decision?
6. How hard would it be to undo?
7. Most important: What is the least restrictive level of support that might work.

Decision-making is a skill that requires practice and a variety of experiences.

Resources

RESOURCES FOR MORE INFORMATION ON GUARDIANSHIP AND DECISION-MAKING ALTERNATIVES:

http://www.gottransition.org/about-us-news/24 An archived broadcast of Got Transition's 2012 webinar, "Understanding Guardianship" is available from the Got Transition website.

dcqualitytrust.org: Quality Trust for Individuals with Disabilities

thearc.org: "The Arc" for People with Intellectual and Developmental Disabilities.

acf.hhs.gov: U.S. Dept. of Health and Human Services: Administration for Children and Families: State Protection and Advocacy Agencies

www.ndrn.org: National Disability Rights Network: Protection & Advocacy for Individuals with Disabilities

http://www.guardianship.org/ NGA, the National Guardianship Association is a resource for volunteer, family and professional guardians

Florida HATS Health and Transition Services

For more information about decision-making options in Florida, visit FloridaHATS.org at www.floridahats.org/?page_id=614. Also learn about the Center for Guardian Advocacy at www.centerforguardianadvocacy.com.

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