

When Young Adults Turn 18 – Considerations for Supported Decision Making

Wisconsin Statewide Transition Academy

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CYSHCN Regional Centers

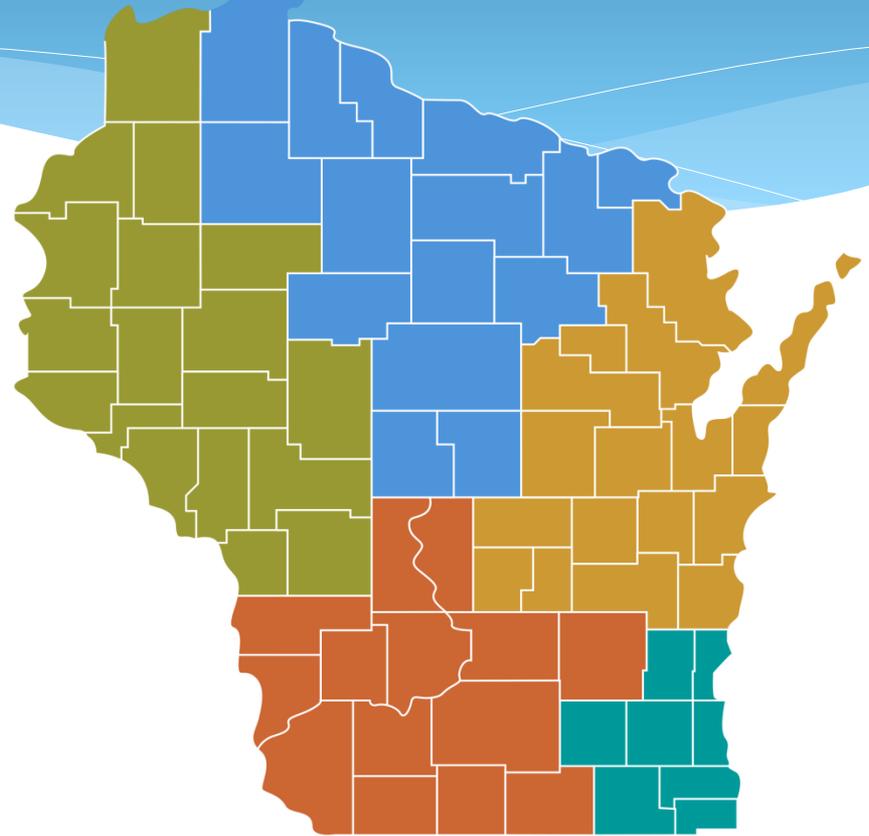
Need some help?

Wisconsin has five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them.

Call us!

¿Necesita algún tipo de ayuda?

Hay cinco centros regionales dedicados a apoyar a las familias con niños y jóvenes con necesidades de atención médica y a los proveedores que los atienden.



<http://www.dhs.wisconsin.gov/health/children/resourcecenters/index.htm>



What Happens at Age 18?

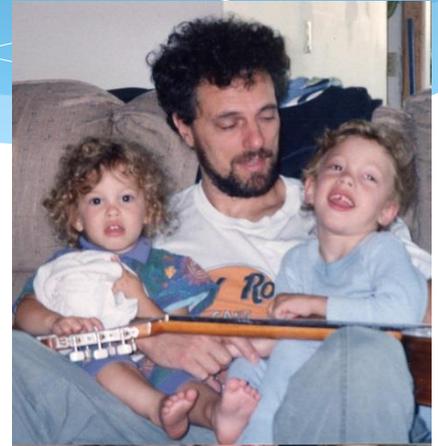
- * Any person in Wisconsin over the age of 18 is legally an adult, and is presumed to be able to manage his or her own financial affairs, choose where to live, consent to medical treatment, vote, make contracts, marry, and exercise his or her own legal rights as an adult. This presumption does not change because a person has a disability.
- * When a person is unable to do some or all of these, some form of supported decision making is needed.

Legal Tools to Support Decision-Making

- * Release of information
- * Power of Attorney for healthcare, finances or education
- * Limited Guardianship or Full Guardianship of the person and/or estate

Making Decisions is a Learned Skill

- * Families do the best they can to raise & support their children based on:
 - * Strengths and resources
 - * Cultural beliefs and values
 - * History and experience
- * Typical families and children have access to everyday experiences that prepare them for self-determined lives.
- * Families and children with disabilities have fewer opportunities to have self advocacy experiences.
- * Families who have children with disabilities may need help teaching decision-making skills.
- * Families and youth need information and experiential opportunities develop these skills.

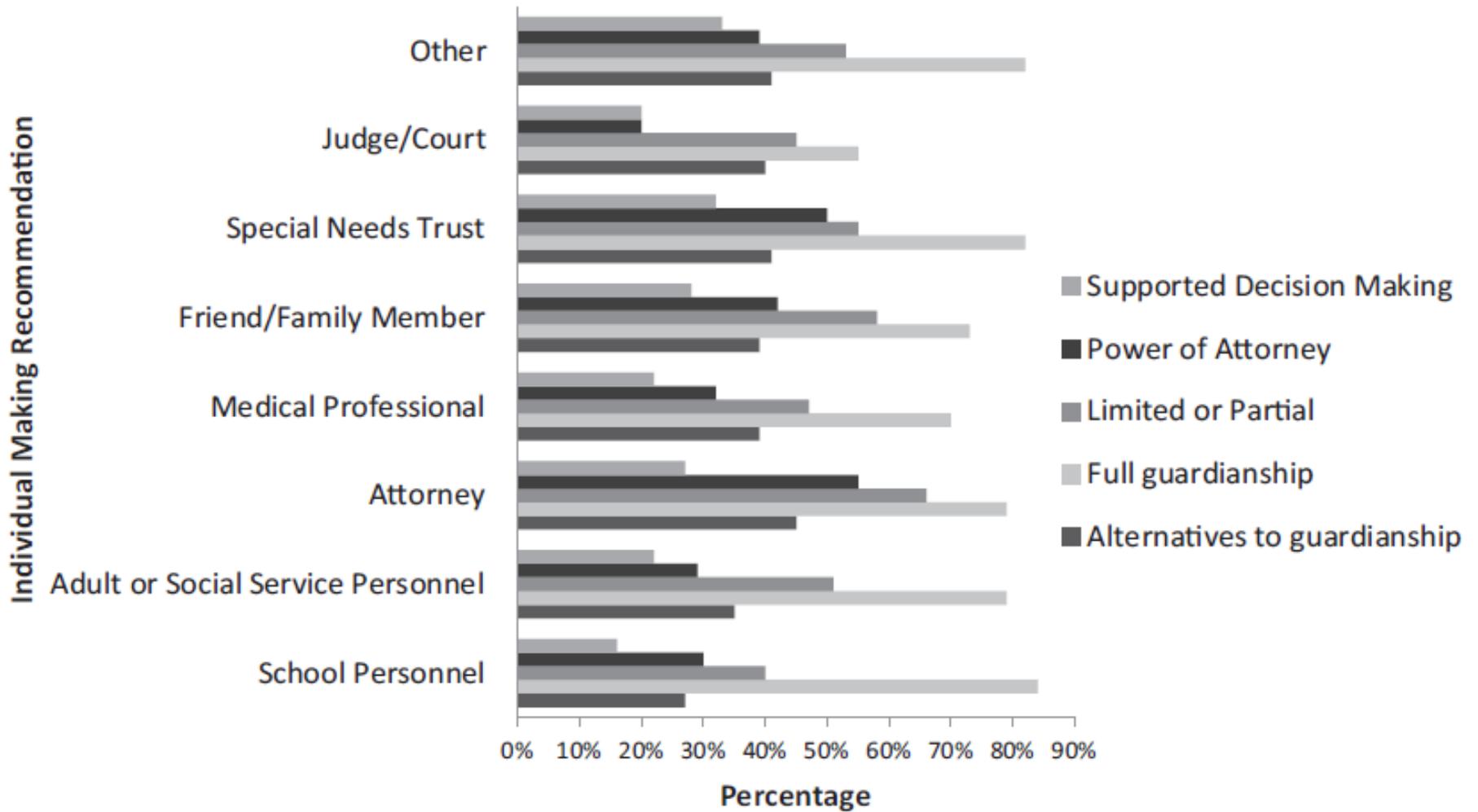


Families Need Information

- * Start a conversation well in advance
- * Ask if the family has thought about the need for decision making supports
- * Share information
 - * Family Voices Fact Sheet
 - * Regional CYSHCN Center brochure
- * Connect families and youth to learning opportunities

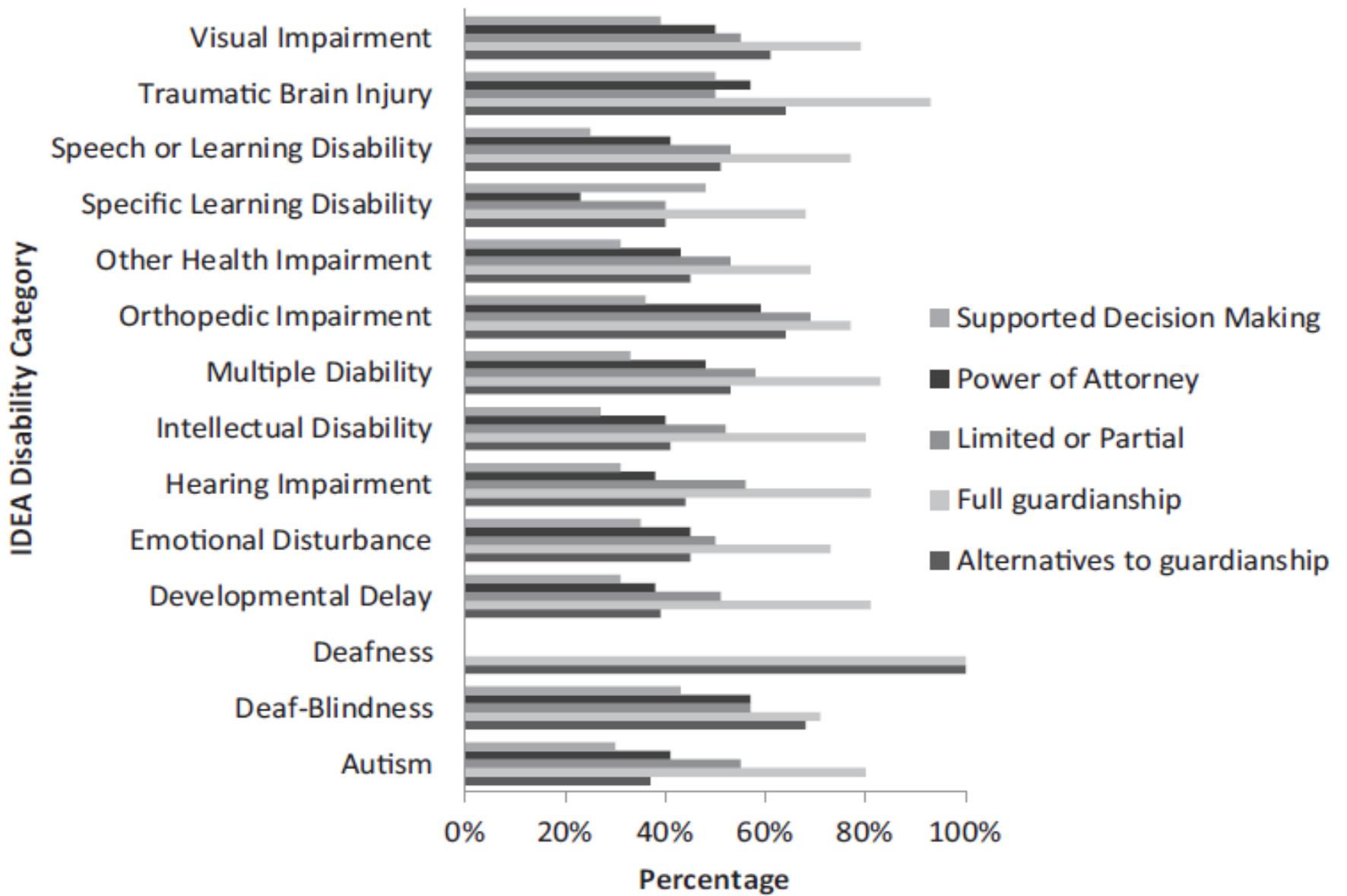
Supported Decision-Making

- * “An emerging approach to providing decision-making assistance ... without imposing any long-term legal limitations on rights or personal liberties” (Campanella, 2015)
- * “an alternative to guardianship through which people use friends, family members and professionals to help them understand situations and choices they face, so they may make their own decisions without the “need” for guardianship.” (Blanck & Martinis, 2015)
- * The number of adults under guardianship has tripled since 1995 with ~ 90% being full guardianship



I. Guardianship recommendations by who first recommended guardianship.

Jameson et al. "[Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities.](#)" *Research and Practice for Persons with Severe Disabilities*, 2015, online ahead of print



Guardianship recommendations based on IDEA disability category.

Citizenship and Guardianship

- * The rights to liberty (freedom to control our own lives), to the pursuit of happiness (choosing and seeking to reach our own goals in life), and to control our own property are central to our idea of what it means to be an adult citizen of the United States.
- * Guardianship restricts those rights, and labels the person as someone who does not have the full rights of other adults.

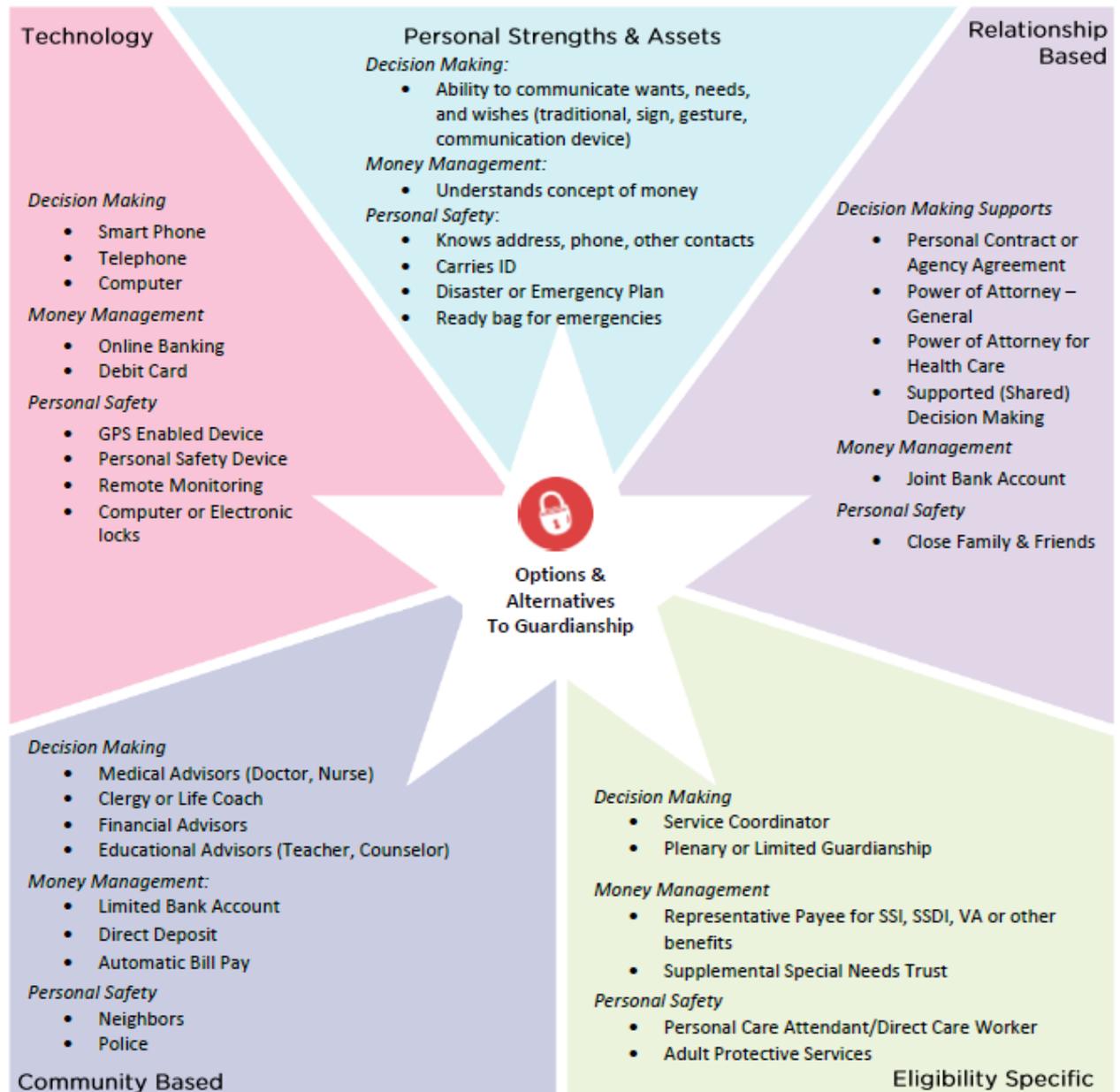
We All Make Decisions

How do you make decisions?

Who do you go to for help?

Have you ever made a bad decision?

What did you learn?



Guardianship

Guardianship is a legal process where a court decides if:

- * A person lacks “capacity” to make decisions for themselves AND
- * There are no less-restrictive alternatives than guardianship
- * It may be temporary or permanent
- * Guardian of the person: when the guardian has custody and control of decisions made for the “ward”
- * Guardian of the estate: when the guardian is responsible for managing the “wards” money and property

Guardianship and Standard for Incompetence

- * Risk of harm
 - * Guardianship of the person - unable to meet the essential requirements for his or her physical health and safety
 - * Guardianship of the estate - the person has property that will be lost; is unable to provide for his or her support; or is unable to protect himself or herself from financial exploitation.
- * No less restrictive alternative - it is not possible to meet the person's need for assistance in decision-making or communication in a less restrictive way

Guardianship-Role of the Physician or Psychologist

“the Court’s decisions about what rights and powers the person will keep are largely based on the opinions of the physician or psychologist who prepared the report in support of guardianship”

Guardianship-Physician or Psychologist Report

- * An opinion about what rights and powers the person has capacity to exercise
- * Information about the person's functional ability to make and communicate decisions (evaluative capacity)
 - * Must see the person personally
 - * Can be based on past treatment
 - * Use information from others who know the person
 - * Examination if needed
- * Submit to the petitioner, the court, the guardian ad litem and the person (if applicable).

Guardianship-Additional Considerations

“A central issue for the court is the impact of the impairment on the person’s **functional ability** to make decisions that are important to his or her health and safety. Guardianship is based not on the quality of the decisions the person makes, but on the process by which he or she makes and communicates the decision.”

- * Need for typical experiences
- * Growth and development
- * Self-advocacy skills

Positive Consequences Of Guardianship

- * • Making decisions the person is unable to make for himself or herself, and giving consent the person is not able to give
- * • Exercising rights on behalf of the adult that the adult is unable to exercise for himself or herself
- * • Acting as an advocate for the adult's best interests
- * • Taking action to protect the adult from abuse, neglect, self-neglect, financial exploitation and violation of rights

Negative Consequences Of Guardianship

- * Determination of “incompetent” can be a painful process, emphasizing the person’s incapacity, rather than strengths.
- * The person may feel labeled as a second-class citizen and a loss of dignity and respect
- * Other people may assume that the person is incapable or incapacitated
- * The right to take risks is an opportunity to learn and grow.

Negative Consequences Of Guardianship

- * A person who is unaware of his or her basic rights and of how to assert them, is at greater risk of abuse and exploitation by others.
- * If we want the person to be able to say “no” to others, we must accept the inconvenient fact that they will sometimes say “no” to us.
- * A person who is used to having decisions made by someone else can lose self-confidence and see themselves as incapable of developing decision-making skills.

Jackie is a young women (17 ½) with a mild intellectual disability. As she gets older and spends more time away from school and family, her parents are concerned for her safety. They are not confident that her choices are thoughtful and she is easily influenced by others. They have been encouraged by her physician to consider guardianship before she turns 18. They have asked you for additional information.

- What information might this family find helpful?
- How would guardianship address this family's concerns?



Resources

- * [**Resource Sheet: Supported Decision-Making and Health Care: Basics for Pediatric Physicians**](#)
- * [**Family Voices of WI FACT SHEET: Assisted Decision Making What Parents of Transition Age Youth Need to Know**](#)
- * [**Got Transition: Guardianship and Alternatives for Decision-Making Support**](#)