CONSIDERATIONS FOR SUPPORTED DECISION-MAKING

Elizabeth Hecht
Specialist for Public Policy
Waisman Center UCEDD
CYSCHCN
Regional Centers

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

Need some help?

Call us!
Making Decisions is a Learned Skill

- Families do the best they can to raise & support their children.
- 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 to develop these skills.
- Families and youth vary in their tolerance for risk.
What Happens at Age 18?

■ Any person in Wisconsin over the age of 18 is legally an adult:
  - is presumed to be able to manage his or her own affairs,
  - choose where to live, consent to medical treatment, vote, make contracts, marry, manage finances
  - 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.
Families Need Information

- Start a conversation well in advance
- Ask if the family has thought about the need for decision making supports
- Share information
- Connect families and youth to learning opportunities
- Explore decision-making skills and skill-building opportunities
- Ask about:
  - Access to typical experiences
  - Impact of growth & development
  - Learning self-advocacy skills
Information on Supported Decision-Making

- Other
- Judge/Court
- Special Needs Trust
- Friend/Family Member
- Medical Professional
- Attorney
- Adult or Social Service Personnel
- School Personnel

Percentage

Supported Decision Making
Power of Attorney
Limited or Partial
Full guardianship
Alternatives to guardianship

Jameson et al. Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities. 2015
Research and Practice for Persons with Severe Disabilities.
What is Supported Decision-Making?

- **Supported Decision-Making**, a series of relationships, practices, arrangements and agreements designed to assist an individual with a disability to make and communicate to others decisions about their life.

- “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
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?

Person-Centered Planning
Tools for Decision-Making Support

- Release of information/consent
- Power of Attorney for healthcare, finances or education
- Representative Payee
- Trustee
- Restricted Bank Accounts
- Limited or Full Guardianship of the person and/or estate
- Supported Decision-Making Agreements
Supported Decision-Making Agreements

- WI formalized the concept of Supported Decision-Making into law in April 2018
- WI now has a statute which formalizes the option to complete a supported decision-making agreement
- Individual with functional impairment completes
- Names a Supporter
- Supporter can assist them in obtaining information, communicating their decisions, and in understanding the information and options
- Agreements are flexible and can be updated easily
Supported Decision-Making—both the concept and formal SDM agreements—can be used in combination with other legal arrangements such as a powers of attorney for health care or finances or limited or full guardianships.

These options are not mutually exclusive and can be used to complement each other.
Guardianship

The rights to liberty, to the pursuit of happiness, 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 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
"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."

“Guardianship and Incompetence

“We have to reject the very idea of incompetence. We need to replace it with the idea of ‘assisted competence’. This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights…” Thomas Nerney, Director of Center for Self Determination for Persons with Developmental Disabilities
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
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.
- 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.
Resources

- Family Voices of WI - FACT SHEET: Supported Decision Making for Transition Age Youth
- National Resource Center for Supported Decision Making
- Got Transition-Guardianship and Alternatives for Decision Making Support
- Wisconsin Guardianship Support Center
- WI DHS Advance Directives and POA Forms
- WI DHS Supported Decision-Making Agreements Form