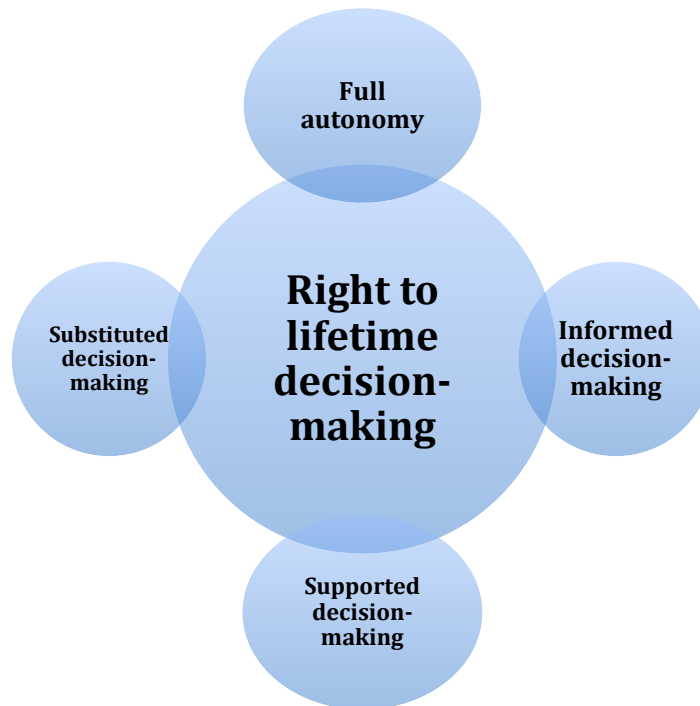


How Do We Support People in Making Choices?

Core Concepts and Basic Principles

A range of decision-making options exists for individuals with disabilities - from complete autonomy to supported decision-making, and as a last resort, substituted decision-making (i.e., guardianship).

Before exploring these approaches, it is critical that we are grounded in core concepts and basic principles established through the United States Constitution and recognized through the American with Disabilities Act (ADA) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD). These core concepts and basic principles clarify that the law for individuals with disabilities is equal to that of persons without disabilities.



They include the:

- right to autonomy, liberty, freedom and dignity,
- presumption of competence; and,
- right to lifetime decision-making support.

Decision-making Approaches: Definitions

Let's start with definitions of existing decision-making approaches that currently exist in our state and in intellectual and/or developmental disability (I/DD) specific literature:

Autonomy refers to the psychological instinct of a person to have control over his/her life; the legal right to do; and the duty of family, friends,



and providers to support the person to have autonomy

Informed Decision-Making results in a decision that is based on knowledge of a subject or situation. Good information is essential if people are to make informed choices about services.

Supported Decision-Making consists of building a support team to advise a person who wants and needs help making decisions. This model empowers the individual to make decisions with support from an individual or network of people. Support may include friends, family, community members or other trusted individuals.

Guardianship is a legal relationship in which an individual is given the authority by the court to make decisions on behalf of another individual who is unable to make and/or communicate decisions on their own.

Substituted Decision-Making is a standard under guardianship that considers what the person would most likely choose in given situations as opposed to the “best interest” standard that relies on what the guardian would choose in the best interest of the person.

Dignity of Experience and Informed Decision-Making

Supporting people with I/DD to have typical life experiences hinges on a person with I/DD having the information and guidance needed to make informed choices (“informed decision-making”) or otherwise receiving support to jointly make choices with “others who care and respect” the person’s choices.

Making Informed Decisions---the Key Elements/Questions

How do we support people to make informed decisions? It depends on the decision and on the person! The bigger the decision, the more critical the information.

Making Informed Decisions: The Real-World Models	You likely....
If you were deciding where to live...	Visited different places, talked to other people who had experience; researched online
If you wanted to learn something....	Sought out someone who had done it; practiced it; researched it; went to school
If you wanted to get married....	Dated; learned from past relationships

Dignity of Experience and Supported Decision-Making

Supported Decision-Making consists of intentionally building a support team to assist in making choices. This model empowers the individual to make decisions with support from an individual or network of people whom he or she trusts. Support may include friends, family, community members or other trusted individuals.

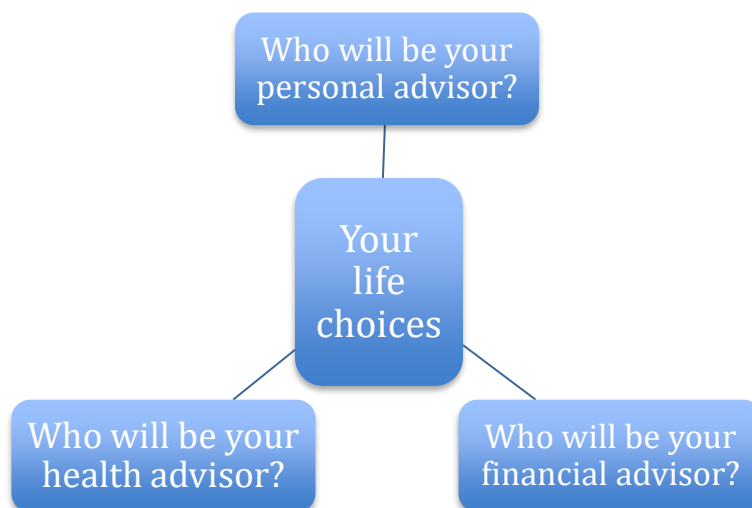


How to Make Supported Decision-Making Work

- Think about the type of decisions that need support and the type of help that is needed. Often, these are related to finances, health and other life choices.
- Talk to people who can help and discuss what type of help is needed and when.
- Then, when a decision is needed, an individual can contact a chosen advisor.
- It is possible but not essential to create a written plan naming the people who will provide support, when they will provide it, and how. The plan may be shared with others.
- As an example, imagine that you want your sister to support you in making medical decisions. You'd write up a plan between you and your sister saying she'll help you do that and how. Then you can share the plan with your doctor so that your doctor knows that your sister is a part of your health care "team."

Reflection Activity:

Take a moment to consider a supported decision-making agreement for yourself. Who would YOU ask to be your 1) financial/business advisor; 2) health/medical advisor; 3) daily living or personal advisor?



A Story... Janie and Suvya*

Janie Desmond and Suvya Carroll share an apartment in a regular neighborhood in Durham, NC. While each had lived away from family during college, neither had lived on her own as an adult. The myriad regular responsibilities, the minor and more serious emergencies that come up, and the longer-term questions about life and direction have all provided a ripe context for using supported and/or informed decision-making.

Luckily, both Janie and Suvya have bountiful networks of friends and family to whom they tap for advice as needed, so they have not needed to identify one single advisor for this or that type of decision. Living on one's own for two years together, they have figured out who can help most effectively with what. They have also figured out (most of the time) when something is an emergency, and if it is, who to contact: a neighbor? Family who is further away? 911?

Only through practice in real life experiences can individuals learn these nuances. And real community settings also provide access to more people who are unpaid, be they neighbors, storekeepers, family, or friends.

Sometimes the concerns around which they ask help are related to Janie's staff. It occasionally gets complex, as both women are compassionate. If



someone doesn't show up, whom to complain to and what might be the consequence? Is it okay to talk to that person directly? What might be the consequence? Other concerns are security, or health, or finance related. And they come up almost daily.

It is incumbent on people supporting these women to push them to make their own decisions when it is clearly in their power. In their power does not mean they will always get it right, but without stretching the muscles, there is no growth. This has clearly led to less asking, more acting, and greater self-determination.

*Story told by Janie's mother Betsy MacMichael, Executive Director, First in Families of NC.

Dignity of Experience and Guardianship

Defined as a legal relationship in which an individual is given the authority by the court to make decisions on behalf of another individual, guardianship is the most restrictive of decision-making options and is understood to be the option of last resort.

The information provided below is directed at individuals who have not yet petitioned for guardianship (see “Why are you thinking about guardianship?”) and individuals who are already serving as guardians (see “If you ARE a guardian...”).

Why are you thinking about guardianship?

Someone may be telling you that you or someone you love needs to have a guardian. It might be school staff (schools routinely send out a letter about guardianship when a child who has an individualized education plan (IEP) turns 17), a medical professional, a service coordinator, or even another parent.

There are a lot of reasons why individuals with developmental disabilities, their families, and key supporters might be considering their guardianship options and alternatives for decision-making support and/or protection. For example:

- You have a child with a developmental disability close to the age of 18.
- An educator or service provider has told you that you need guardianship to maintain your rights to provide support and/or protection for someone you care about.
- Someone is pressuring you to file for guardianship.
- You or someone you know is, or is at risk for being, taken advantage of by others.
- You have fears and concerns in relation to your current guardianship status.
- You currently have a guardian, but don't think you need one, or you don't agree with the decisions they are making for you.
- The individual you are concerned about currently needs protection or assistance.
- You are seeking information about guardianship because someone you care for or someone you work with is experiencing a difficult time.

Before pursuing guardianship, it is important that you consider whether guardianship will achieve the outcome you desire. Guardianship is not a quick fix, it is a legal action that limits or denies a person the right to make his or her own decisions. It is important to consider the individual's needs for support and/or protection and then ask, “How will having a guardian address each specific need?”¹

Terri Hancharick, a mother of an adult child with a developmental disability suggests²,

“Instead of empowering people we take everything away from them. How are they going to recognize danger when they see it? Do we think that guardianship is going to keep them safe? The more power someone has over someone else and the more segregated that person is, the higher the chance is for abuse.”

If you ARE a guardian...

As previously noted, guardianship is a legal relationship under which a person or agency (the guardian) is appointed by a court to make decisions and act on behalf of an adult deemed incapacitated with respect to his or her personal affairs, financial affairs, or both.

Yet, it is important to point out that guardianship in no way precludes an individual from residing in his or her own home, as is possible through the Supported Living Program.

While clearly the most restrictive of all decision-making approaches, it is still possible to include and honor any individual's choices about his or her life while in a guardianship arrangement.

Through the emerging “gold standard” of substituted decision-making (as opposed to best interest decision-making), a guardian attempts to learn as much as possible about the lifestyle, behaviors, preferences, and decisions made by the individual under guardianship. Taking these factors into careful consideration, the guardian makes a decision that would as closely as possible reflect what the incapacitated person would have decided if he or she had the capacity to make the decision.

Think about your role and ways that you are incorporating the following *Ethical Principles*, established by the National Guardianship Association based on Standards of Practice. How are these consistent with what you've learned about Supported Decision-Making?

1. A guardian treats the person with dignity
2. A guardian involves the person to the greatest extent possible in all decision-making
3. A guardian selects the option that places the least restrictions on the person's freedom and rights.
4. A guardian identifies and advocates for the person's goals, needs and preferences.
5. A guardian maximizes the self-reliance and independence of the person.
6. A guardian keeps confidential the affairs of the person.
7. A guardian avoids conflicts of interest and self-dealing.
8. A guardian complies with all laws and court orders.
9. A guardian manages all financial matters carefully.
10. A guardian respects that the money and property being managed belong to the person.

Resources

Rethinking Guardianship – <http://rethinkingguardianshipnc.org/>

Rethinking Guardianship Frequently Asked Questions -
<http://rethinkingguardianshipnc.org/sites/default/files/resources/FAQs/Rethinking%20Guardianship%20FAQS.pdf>

Rethinking Guardianship – “An Introduction to Options” brochure:
<http://rethinkingguardianshipnc.org/sites/default/files/general%20documents/Rethinking%20Guardianship%20Brochure%20Final%20May%202018.pdf>

National Resource Center for Supported Decision-Making -
<http://supporteddecisionmaking.org/>

Sample Supported Decision-Making Agreements -
<http://www.supporteddecisionmaking.org/sites/default/files/sample-supported-decision-making-model-agreements.pdf>

National Guardianship Association Standards of Practice
<https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf>

¹ The author acknowledges that the section entitled “Why are you thinking about guardianship?” comes from The Alternatives to Guardianship Project, collaboration between the UMKC-Institute for Human Development, UCEDD; the Missouri Developmental Disabilities Council, Missouri Protection & Advocacy Services, and the Missouri Department of Mental Health and is funded in part by the MODDC under provisions of PL 106-402, the DDA and Bill of Rights Act. The reader can access more information through <http://moguardianship.com>

² Terri Hancharick’s full article on her daughter’s experience with guardianship is available upon request.