

# What About Guardianship?

**Important Considerations  
Related to Choosing  
Decision-Making Supports  
for Adults with Disabilities**

# Topics We Will Cover

- ▶ What is adult guardianship?
- ▶ Why should families think about other options first?
- ▶ What information is important to consider?
- ▶ What considerations are most important in choosing a strategy for decision-making support?

# What is “Guardianship” for Adults?

- ▶ Guardianship is:
  - A formal legal step that removes some or all decision-making from an adult and assigns it to an agent of the court who is called a “**guardian.**”
- ▶ To be a guardian over an adult, a person has to go through a **court process** and get a **court order**.
- ▶ It can vary in **scope** -- time-limited vs. permanent; general vs. limited.

# Guardianship Facts

- ▶ Guardianship laws vary by state.
- ▶ Uniform Guardianship and Protection Proceeding Act:

Guardianship is ordered when:

- 1) An adult **lacks “capacity”** to make decisions for him or herself; AND
- 2) The person’s identified needs **cannot be met by less restrictive means**

# Why do families think about getting guardianship?

Parents or family members may:

- ▶ Have been told by their child's school or other advisors to do so.
- ▶ Be worried about access to their child's doctor.
- ▶ Want to help their child handle money, health concerns or other important issues.
- ▶ Be concerned that they will not be able to connect their child with adult services without it.

# Why should you think about other options first?

- ▶ Guardianship takes away some or all of a person's rights to make important decisions about his or her life.
- ▶ The court will become part of both the guardian's and the person's life going forward.
- ▶ Guardianship can change relationships.
- ▶ Guardianship can take time and cost money.
- ▶ Decision-making is a learned skill – people need the opportunity to practice!

# And it also makes sense!

## ▶ **Self-Determination**

- ▶ Life control — People’s ability and opportunity to be “causal agents . . . Actors in their lives instead of being acted upon” (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)

## ▶ **People with greater self-determination are:**

- ▶ More independent
- ▶ More integrated into their communities
- ▶ Healthier
- ▶ Better able to recognize and resist abuse

# And Yet....

- ▶ Guardianship is the default option for students with intellectual disabilities (Payne-Christiansen & Sitlington, 2008).
- ▶ School personnel are the most frequent source of recommendations that parents seek guardianship (Jameson, et al, 2015).
- ▶ QT gets a lot of calls from about guardianship!



# & Explore Alternatives First

- ▶ Finding the Right Support: Considerations
  - What kind of decision needs to be made?
  - How much risk is involved?
  - How hard would it be to undo the decision?
  - Has the person made a decision like this before?
  - Is the decision likely to be challenged?
- ▶ Ask: What is the least restrictive support that might work?

# Consider this Real Life Scenario

Mom is considering entering pursuing guardianship when her son turns 18 to make him stay in school.

Person is: 16

Has Autism and Mental Health Issues

Has a tested IQ of 76

What issues need to be discussed?

# Critical Questions

- ▶ How do you determine if guardianship will help?
- ▶ How do you assess capacity for decision-making?
- ▶ What do you review?
- ▶ What practical steps do you take to help?

# Remember:

- ▶ Capacity and competence are not “black and white”
- ▶ A person may be able to make some decisions and not others
- ▶ Or they can make decisions at some times, but not others

# Another Real Life Scenario

Parents say they've been recommended to seek guardianship – but want their young adult son to develop independent living skills.

Person:

Is 19 years old

Has Intellectual Disabilities

Has limited verbal abilities

# Questions

- ▶ How do you determine capacity?
- ▶ What else is important to consider?
- ▶ What do you recommend if you believe the person lacks capacity?

# One more scenario...

Person is:

- 25 and has intellectual disabilities
- does not have a job and does not want to work
- is living on her own and does not follow her budget

Parents are concerned about her ability to manage daily living and finances. They have been recommended to seek guardianship....what should they do?

# What about Guardianship?: A Family Perspective

»» Susie King from  
Washington, DC

# Ryan King



# Our story

- ▶ How it started
- ▶ Our families experience
- ▶ What we tried
- ▶ Where we are today
- ▶ Our vision for the future

# Some additional thoughts

»» Principles for Practice

# Some Rights of Individuals under Guardianship

- ▶ Be treated with dignity and respect
- ▶ Have preferences and personal choice supported to the greatest extent possible
- ▶ Have notice and explanation of decisions and actions that concern their lives
- ▶ Have a guardian that is available and focused on meeting their needs
- ▶ Regular review of the need for continued guardianship

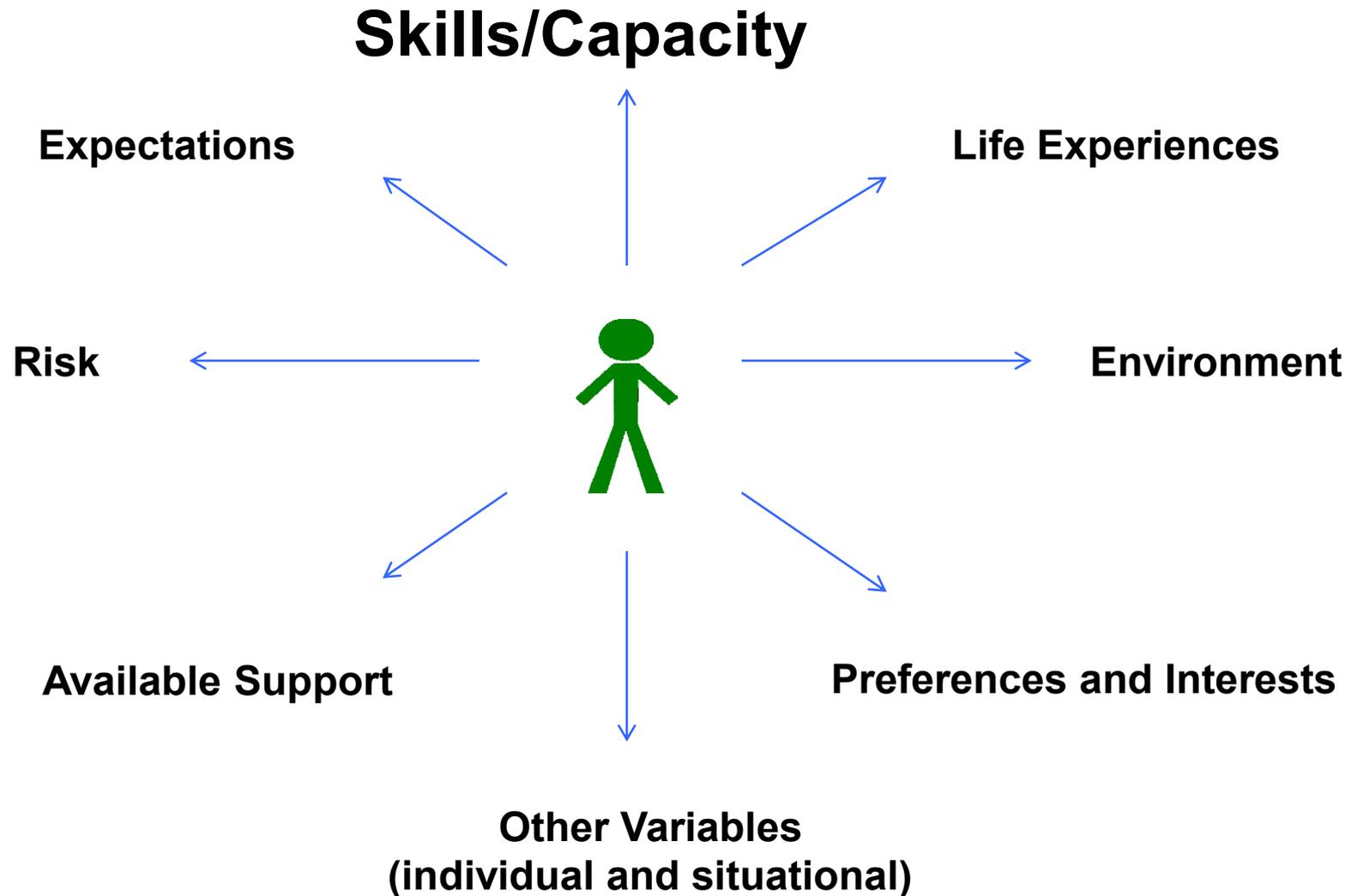
# Being a “good” Guardian

- ▶ Get to know the person you are appointed to support
- ▶ Listen to what is important to him or her
- ▶ Use preferences to guide decision-making whenever possible
- ▶ Only make decisions in areas where the person needs help and the guardians has specific authority

# Issue #1: Human Decision Making

- ▶ Many decisions made every day
- ▶ Some big, some small
- ▶ No standard process or measure of “goodness”
- ▶ “Good” decision making seems part science and part art?
- ▶ Who decides if our decisions are “good”?

# Issue #2: Assessment



# Issue # 3: Tools

- ▶ Effective Communication
- ▶ Peer Support
- ▶ Written Documents
- ▶ Agreements
- ▶ Practical Experiences
- ▶ Role Play and Practice
- ▶ Life Coaching
- ▶ Mediation



# “Substituted Judgment”

- ▶ Requires surrogate to learn as much as possible about the lifestyle and preferences of the person
- ▶ Uses the person’s values and beliefs as a guiding element
- ▶ Guardian makes decisions that reflect what the person would have decided if he/she were capable of making the decision

# Best Interest

- ▶ Used only when it's not possible to determine what the person would have done in a given situation
- ▶ Based on what a reasonable person would do
- ▶ Recommended for use only as an option when Substituted Judgment can't be made to work

# Finding a path forward....

- ▶ Be proactive
- ▶ Assess each person's situation
- ▶ Identify opportunities for
  - Learning more about options
  - Getting experience with decision-making
  - Respecting the person as the primary decision-maker
  - Involving family and others as supporters

# Ask Questions – Now or Later

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National Resource Center for Supported Decision-Making

[www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org)

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