Guardianship for Individuals with Intellectual Disability: Trends and Issues

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Goals of Presentation

• To recognize that the evolving view of guardianship for individuals with I/DD must be viewed within the context of promoting greater self-determination.

• To recognize that the rights and privileges that everyone values is the same for those with I/DD.
Evolving Context

• Movement away from institutionalization (i.e., Olmstead).
• Expanding views of inclusion and least restrictive environments in schools and in communities (i.e., LRE and HCBS).
• Increasing focus on civil rights for individuals with disabilities (i.e., ADA).
• Increasing focus on self-advocacy and self-determination.
HOW DOES OUR VIEW OF GUARDIANSHIP FOR INDIVIDUALS WITH I/DD FIT WITHIN THIS CURRENT EVOLVING CONTEXT?
What is a guardian?

Definition

• Courts appoint guardians to care for people who cannot take care of themselves. The person a guardian protects is called that guardian's ward. Wards may be either minor children or incapacitated adults. In some other jurisdictions, "custodial" or "conservator" is used instead of "guardian," and some jurisdictions use different terms to refer to different types of guardianships, for example calling the protector of elderly wards a "conservator" while calling the protector of minor children wards a "guardian."

– https://www.law.cornell.edu/wex/guardian
Types of Guardianships

• Plenary vs. “Limited”
• Guardianship of the Estate
• Guardianship of the Person
Procedures for Establishing Guardianship

• Formal Petition
• Court procedures:
  – Guardian ad litem (GAL)
  – Court-appointed attorney
  – Court investigator
  – Evaluation to determine incapacity/incompetence
  – Hearing
• Post-guardianship requirements
Guardianship: Before and Now

• Why has the number of guardianships for individuals with I/DD increased over the past decade?
Position Statements

• American Association on Intellectual and Developmental Disabilities (AAIDD)

• TASH
  – http://tash.org/about/resolutions/tash-resolution-alternatives-guardianship/
  – CRPD, Article 12:
Current aspirational view of rights of individuals with disabilities

• Everyone deserves to self-direct their lives, to live self-determined lives.
Why haven’t our practices reflected this aspirational view?

- School personnel lack of knowledge
- Societal views (including court system) of Intellectual Disability
  – “Disability Spread”

- Emma Van der Klift & Norman Kunc, “Hell-Bent on Helping”
Some of the Issues

- Routinely granted when person has ID
- "All or nothing" thinking
- "Limited guardianship" is not so "limited"
- Payment/Expenses for guardianship services
- Disconnect between goals of schooling and post-school environments
- Guardianship as a blanket decision during post-school transition planning
- Bureaucracy
Unintended consequences of guardianship

- Loss of basic civil rights and civil liberties
- Perpetuation of disabling view by society
- Feelings of disempowerment and loss of control
- Failure to recognize changing needs
- Potential for abuse/exploitation
- Difficulty with changing guardianship status
What needs to happen?

• Supported Decision-Making—Facilitated Decision-Making
• Stronger connection between school and adulthood goals
• Guardianship within the context of transition planning: strengths, needs, preferences, interests
  – Strengths-based Model: Focus on what skills individual has and then what supports will better enhance those skills
More Considerations

• Mental Capacity ≠ Legal Capacity (only minimal capacity required)
• Role of Monitors & Advocates
• Shifting from what others believe is “in the best interest” of the individual to individual’s actual wishes
• Distinguish between “making decisions for” and “making decisions with” (“sliding scale of abilities”)
How to Get There

• Start early! Teach skills to make decisions.
• Start with Person-Centered Planning
• Explore alternatives, and make choices that are the least intrusive while meeting the identified need (focus on areas of need).
• Build in advocacy supports
• Work to change policies that allow for greater flexibility to create individualized supports and services.
Alternatives

- Panels of Volunteers; Microboards or “Circle of Support” (NY: must include health care professional and an attorney)
- Power of Attorney
- Educational Power of Attorney
- Advance Directives for Health Care
- Representative Payee (SSA) or Special Bank Accounts
- Representation Agreement (Canada)
- Special Needs Trust
- Case Management Services
- Supported Decision-Making (shared decision making)
Supported Decision Making

• Four primary characteristics (Salzman):
  1. Individual retains legal decision-making authority
  2. Relationship can be freely entered into and freely terminated
  3. Individual actively participates in decision-making
  4. Decisions are legally enforceable
Next Steps

• Work towards state policies to support least restrictive alternatives

• Create a mechanism for advocates and self-advocates to protect rights of those with court-appointed guardianships (i.e., NJ’s Guardianship Monitoring Program)

• Promote self-determination, self-advocacy, empowerment as life-long skills

• Engage in public awareness

• Connect with projects and organizations (i.e., National Resource Center for Supported Decision-Making)
INSTEAD OF ASKING *IF* THE PERSON NEEDS A GUARDIAN, ASK *HOW CAN WE SUPPORT THE INDIVIDUAL TO BE SELF-DETERMINED AND PRESERVE HIS/HER CIVIL RIGHTS TO THE MAXIMUM EXTENT POSSIBLE?*
References

- https://www.law.cornell.edu/wex/guardian
- American Bar Association Round Table
  - http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf