

Alternative Options to Guardianship

November 18, 2016

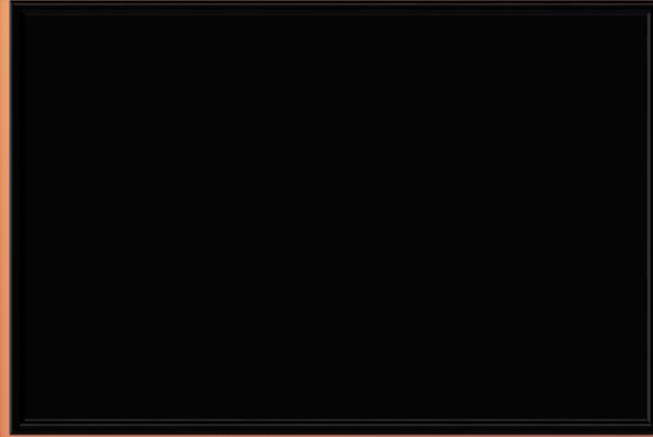
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Evolving Context

- 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.

Credo for Support



How does our view of guardianship for individuals with disabilities fit within this CURRENT evolving context?

What is a guardian?

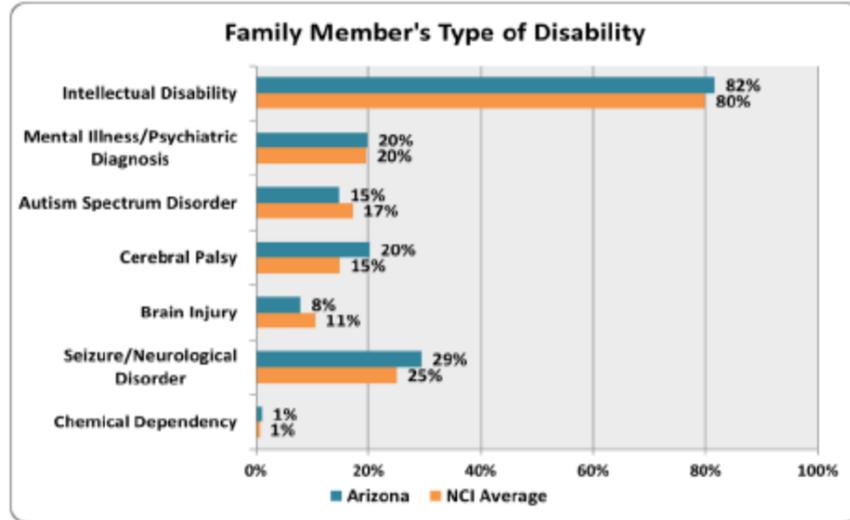
Definition (<https://www.law.cornell.edu/wex/guardian>)

- 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."

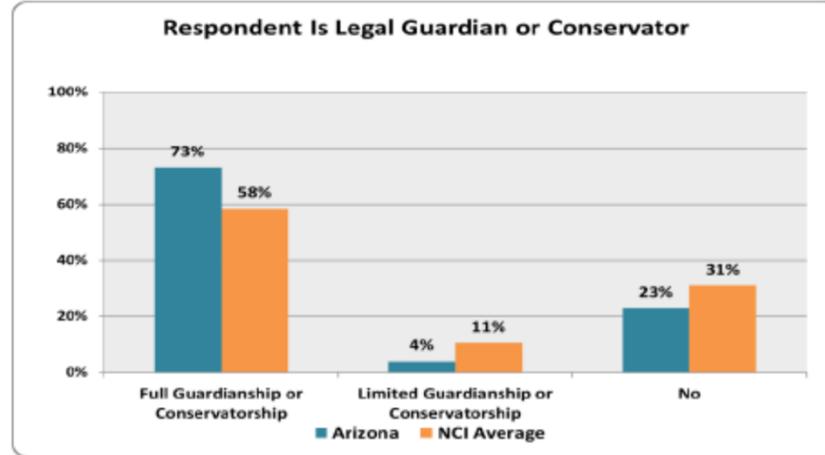
Guardianship: Before and Now

- Why has the number of guardianships for individuals with disabilities increased over the past decade?

GRAPH 5. TYPE OF DISABILITIES (NOT MUTUALLY EXCLUSIVE)



GRAPH 17. LEGAL GUARDIAN OR CONSERVATOR



Position Statements

- American Association on Intellectual and Developmental Disabilities (AAIDD) & The Arc
 - <http://aaidd.org/news-policy/policy/position-statements/guardianship>
- TASH
 - <http://tash.org/about/resolutions/tash-resolution-alternatives-guardianship/>
- CRPD, Article 12:
 - <http://www.un.org/disabilities/default.asp?id=272>
 - <http://www.un.org/disabilities/default.asp?id=242>

Why haven't our practices reflected this aspirational view?

- School personnel lack of knowledge
- Societal views (including court system) of Disability
 - "Disability Spread"



- Emma Van der Klift & Norman Kunc, "Hell-Bent on Helping"

Some of the Issues

- Guardianship as a blanket decision during post-school transition planning
 - Routinely granted when person has intellectual disability
 - “All or nothing” thinking
- “Limited guardianship” is not so “limited”
- Payment/Expenses for guardianship services
- Disconnect between goals of schooling and post-school environments
- Bureaucracy, loss of autonomy

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?

- 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 or address areas of need
- Encourage use of Alternatives to Guardianship

More Considerations

- Mental Capacity \neq Legal Capacity (only minimal capacity required)
- Role of Monitors & Advocates
- Shifting from what others believe is "in the best interest" of the individual to actual wishes of the individual
- 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.

How do I know what option is best?

- At the Center, we support the least restrictive options, with the goal of preserving individual independence
- What is in the best interest of the individual with a disability?
- More than one option may be appropriate

Legal Options: Who, What, How

- Representative Payee
- Designated Representative in Vocational Rehabilitation
- Designated Representative in Mental Health Care
- Delegation of Rights to Make Educational Decisions
- Advanced Directives and Living Wills
- Power of Attorney
- Guardianship
- Conservatorship



Representative Payee

- **WHO:** Only source of income is SSI or SSDI
- **WHAT:** Rep Payee accepts this income on behalf of the person with a disability to manage the \$\$ for him or her
- **HOW:** Fill out a form in person at your local Social Security Administration office



Designated Representative in Vocational Rehabilitation

- **WHO:** Needs help navigating the VR process
- **WHAT:** Designated Rep assists the individual in protecting his or her rights in the Individual Plan for Employment
- **HOW:** Notify VR Counselor in writing

Designated Representative in Mental Health Care

- **WHO:** Regional Behavioral Health Authority member requires help asserting needs in treatment & other related processes
- **WHAT:** Designated rep act as that member's advocate in staffings, planning meetings, & during the grievance and appeal process
- **HOW:** Notify RBHA in writing

Delegation of Rights to Make Educational Decisions- 1 year

- **WHO:** Students 18-22 receiving assistance through the Individualized Education Plan process
- **WHAT:** Designee is authorized to make educational decisions on behalf of the student
- **HOW:** Notify school personnel on student's IEP in writing with student's notarized signature

Advanced Directives & Living Wills

- **WHO:** Wants to direct health care decisions, now or in the future



- **WHAT:** Delegates certain types of decisions to someone else, or instructs what future healthcare is to be provided
- **HOW:** Attorney General's office, physician, etc.

Types of Directives and Wills

- Health Care Advanced Directive/Durable Health Care Power of Attorney
- Mental Health Care Advanced Directive/Durable Mental Health Care Power of Attorney
- Living Will

Power of Attorney

- **WHO:** Needs help with certain financial matters
- **WHAT:** Delegates specified financial responsibilities to an "agent"
- **HOW:** Contact any financial institutions where accounts are held for forms, prepare a POA form

Conservatorship

- **WHO:** Person with significant assets that need to be protected due to the person's inability to manage
- **WHAT:** Conservator acts as a financial manager, overseeing all financial matters
- **HOW:** Requires court intervention, accounting



Guardianship

- **WHO:** Lacks the ability to make/communicate responsible decisions concerning life's most basic needs
- **WHAT:** Someone is chosen to make certain decisions in the best interest of the individual
- **HOW:** Requires court intervention, accounting- some counties provide extensive assistance

Trusts

- **WHO:** Person who wants to maintain financial eligibility for government programs such as Social Security and who also has funds available from some other source
- **WHAT:** Trust sets aside money that can only be used for certain purposes that allows a person to stay eligible
- **HOW:** Requires expertise of specialized attorney

What happens if my legal representative becomes unavailable?

- It depends
- If a person gave away his or her right to make certain decision, then he or she can freely designate someone else to make those decisions
- If the court took away a person's right to make decisions, then the court will be involved in choosing someone new

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

National Resource Center for Supported Decision-Making

<http://www.supporteddecisionmaking.org>

In Your State

Want to know how the system works in your state?
Select the state to view guardianship laws by state



Compiled in Summer 2012 by Morgan K. Whitlatch, Senior Attorney at Quality Trust, with invaluable assistance from legal interns Matthew Casale, Julie Case, Morgan Given, Evan Greenberger, Lara Kasten, Susanna Chrock, and Amanda Nagorsky.

Alaska
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Arkansas
California
Colorado
Connecticut
Delaware
District of Columbia
Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Massachusetts
Michigan
Minnesota
Mississippi
Missouri
Montana
Nebraska
Nevada
New Hampshire
New Jersey
New Mexico
New York

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?

Jenny Hatch



"Fifty years from now, the disability community will be talking about the Jenny Hatch case"

[The Washington Post \(quoting Denille Francis\)](#)

"[Jenny] struck a powerful blow for autonomy and independence . . . Her case sends a message and sets a precedent for other situations involving guardianship disputes."

[Care 2 Make a Difference](#)

"Supported decision making and providing powers of attorney are the options we should look to first – rather than reflexively choosing guardianship and stripping a person of every civil liberty."

[American Civil Liberties Union](#)

"Any attorney worth their salt . . . can now point to Jenny Hatch's case and say that . . . there's at least a responsibility to take the time to find out before jumping to conclusions about the client's level of understanding"

[Girl with the Cane Blog](#)

"Jenny.

Take a seat, on the bus, right next to Rosa - I think you'd have a lot to talk about."

[Doing Damns the Darkness Blog](#)

"Jenny Hatch's victory is more than affording one young woman the right to live in the community and make her own choices. It is a case to remind all of us that one among us being weaker by virtue of age or disability is not an invitation for someone else to step in and claim ownership."

[The Columbus Dispatch](#)

What does this mean for our
work?

COMMENTS?
QUESTIONS?
STORIES TO SHARE?