More on National Council on Disability Reports

“Beyond Guardianship” and “Turning Rights Into Reality”

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What is the National Council on Disability?

- NCD is an independent federal agency that provides guidance, counsel, and recommendations to the President, Congress, and other federal agencies on national disability policy and other matters affecting the lives of an estimated 57 million Americans with disabilities.
- NCD is made up of five presidential appointees, four congressional appointees, an Executive Director appointed by the Chairperson, and a full-time career staff.

NCD: A Brief History

- First established as a small advisory Council within the Department of Education in 1978, NCD became an independent agency in 1984.
- In 1986, NCD recommended enactment of a civil rights law for people with disabilities, and then drafted the first version of the Americans with Disabilities Act (ADA) introduced in the House and Senate in 1988.
- Since the ADA was passed in 1990, NCD has continued to play a leading role in analyzing the needs of people with disabilities and proposing policy solutions.

How NCD Achieves Its Mission

To ensure equal opportunity for Americans with disabilities, NCD:

- Convenes stakeholders to acquire timely and relevant information
- Researches, gathers, and analyzes data
- Engages advocates and decision-makers to help shape and inform current debates and agendas
- Recommends actions regarding emerging and long-standing issues, policies and concerns
- Provides tools to facilitate effective implementation

Recent Projects

- National Disability Employment Policy, From the New Deal to the Real Deal: Joining the Industries of the Future
- Individuals with Disabilities Education Act Report Series (5 Report Briefs)
- Has the Promise Been Kept? Federal Enforcement of Disability Rights Laws
- Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination
- Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities

Guardianship and Disability Rights

Although it is a state law construct, guardianship potentially conflicts with national disability policy goals

- Guardianship is often viewed as an issue for older individuals, but the idea of “lacking capacity” cannot be separated from disability

Guardianship also impacts people with:

- Intellectual and Developmental Disabilities
- Mental Health
- Brain Injury
- Sensory/ Communication

Goals of 2018 “Beyond Guardianship” Report

- First NCD report on guardianship
- Provide contextualized analysis of guardianship to federal policy makers
- Align NCD position on guardianship with existing NCD positions and national policy
- Make recommendations regarding guardianship and other decision making alternatives that promote self-determination and better outcomes

“Beyond Guardianship” Project Methodology

- Advisory Board
- Literature Review
- Qualitative Study
  - 46 total interviews, cross-disability and aging representation
- Findings and recommendations

“Beyond Guardianship” Finding 1 & Recommendations

There is a lack of data on existing guardianships and newly filed guardianships.

- Federal agencies should collect data on whether or not individuals they serve are subject to guardianship.
- States should be offered incentives and technical assistance to develop electronic filing & reporting systems
- My Minnesota Conservator

Finding 2 & Recommendations

People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions

- The Department of Justice & Department of Health and Human Services should issue guidance regarding legal obligations under the Americans with Disabilities Act.
- Office of Special Education and Rehabilitation Services should implement transition-related guidance recognizing alternatives to guardianship
- ACL Funded Projects

Finding 3 & Recommendations

People with disabilities are often denied due process in guardianship proceedings.

- Model legislation developed under the Elder Abuse Prevention and Prosecution Act incorporates the UGCOPAA
- Federal grant money should be made available to promote the availability of legal representation for people subject to guardianship proceedings
- Court Improvement Program on adult guardianship should be funded
- The DOJ should find that making the degree of due process contingent on the type of disability is discriminatory

Finding 4 & Recommendations

Capacity determinations often lack a sufficient scientific or evidentiary basis.

- National agencies that fund scientific research should provide grants to researchers on how people make decisions and the impact of disability.
- Resources should be focused on functional approaches to capacity assessments.

Finding 5 & Recommendations

Guardianship is considered protective, but courts often fail to protect individuals

- The Court Improvement Program should enhance the ability of courts to monitor guardianships
- States should be provided with incentives to establish statewide boards that can provide for the accreditation and oversight of professional guardians.
- States should require family guardians to undergo training.

Finding 6 & Recommendations

Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often pay lip service to this requirement

- Fund more geographically and demographically diverse projects and pilots that specifically test SDM models and use of SDM to restore rights.
- DOJ should fund training to judges on availability of alternatives to guardianship
- DOJ should develop guidance promoting use of alternatives to guardianship, as recognized in the UGCOPAA

Finding 7 & Recommendations

Every state has a process for restoration, but it is rarely used and can be complex, confusing, and cost-prohibitive

- Electronic filing and auditing systems should include data on restoration.
- The state guardianship Court Improvement Program should include improvements to the restoration process
- DOJ should publish guidance on the right to restoration and best practices.
- Protection and Advocacy Systems should be funded to provide legal assistance to individuals in rights restoration cases

Goals of 2019 “Turning Rights Into Reality” Report

- Build on first NCD report on guardianship and alternatives by focusing on people with ID/DD.
- Discuss U.S. policy implications under U.S. federal laws, including the Individuals with Disabilities Education Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act, the Rehabilitation Act, and the Workforce Innovation and Opportunities. Act
- Make recommendations regarding guardianship and other decision making alternatives that promote self-determination and better outcomes for people with ID/DD

Project Methodology

- Advisory Board
- Updated literature review
- Personal story collection and key informant interviews
- Data collection and analysis
  - National Core Indicator (NCI) data
  - DC guardianship data
- Findings and recommendations

Story Collection & Interviews

- Developed on-line and in-person story collection templates
- Conducted outreach through The Arc, QT, ASAN, NRC-SDM networks, among others
- Collected over 70 substantive responses through the on-line tool and conducted dozens of interviews

Debunking Myths of “Intelligence Testing” of People with ID/DD

- Parent: I am guardian because “[o]ur daughter functions as a 5 year old to 16 year old, depending on the context.”

- Person with ID/DD: “People are shocked [I don’t have a guardian] because I have so many disabilities and I have been told from people who did tests on me that I am like a 2 year old.”

NCI Data

- The percentage of people with ID/DD in guardianship varies widely between states.
- Of the 17 states that have NCI data available from both the 2008-09 and 2017-18 reporting periods, most had guardianship percentage increases.
- When a person is in guardianship, most are full guardianship
- In 2015-16, 18 to 21-year-olds with ID/DD were the most likely of all of the age groups to be in guardianship (58%)
- NASDDS, HSRI, and UMKC: “What Do NCI Data Reveal about the Guardianship Status of People with IDD?” (April 2019)

DC: A Story from the Nation's Capital

- Data analysis
  - DC Probate Court public computerized system
  - DC Department of Disability Services annual reports

- DC's promising legislative and policy reform
  - Legislative reforms for adult guardianship proceedings
  - DC WINGS complaint process and trainings on alternatives to guardianship
  - Special education reforms to promote alternatives to guardianship
  - Reforms recognizing Supported Decision-Making across the lifespan

Some of the Lessons Learned from DC

- Supported Decision-Making can and should be recognized as an alternative to guardianship for transition-age youth, including those with ID/DD in special education. State law change is not required.
- While state law, regulation, and policy changes to advance alternatives to guardianship are needed, more is required to ensure full implementation for people with ID/DD on the ground.
- DC's law promoting limited guardianship is not significantly impacting the scope of an appointed guardian's authority over people with ID/DD, which has tended to be general or plenary in nature.
- Educational oversight agencies must develop tracking mechanisms, so that they can trend the way in which IDEA decision-making rights are exercised by and/or for adult students with disabilities.

Finding 1 & Recommendations

The lack of data on existing guardianships and newly filed guardianships means there is a lack fo information regarding the specific disabilities of those involved.

- The Social Security Administration should collect data on guardianship and trend it against type of disability.
- The Federal government should offer incentives and technical assistance with developing electronic filing and reporting systems.
- The NCI website should specify, on a state-by-state basis, precisely to what population of people with ID/DD the state is administering its survey.

Importance of Data

“In short, we collect data on issues that are important to us. Guardianship should be one of those issues, given its impact on the civil rights of people with disabilities and the potential impact on their ability to live, work, and participate in the community.”

Finding 2 & Recommendations

People with ID/DD currently are at higher risk for guardianship because of the “School-to-Guardianship Pipeline.”

- U.S. Department of Education should require State Educational Agencies to:
  - Ensure trainings for educational professionals at the agency and school level on options for supported decision-making of adult students with ID/DD
  - Create a modified FERPA form that documents SDM arrangements.
  - Develop tracking mechanism to determine how decision-making are exercised by and/or for adult students in special education.
- Require teacher educational programs and vocational rehabilitation agencies to cover the full range of decision-making options in their transition programming.

Comments on School-to-Guardianship Pipeline

- “Too often schools have told family members that a student with ID/DD must have guardianship if they want a family member or friend to assist with one’s IEP when the student turns 18.”
- “Students are not informed, parents are uninformed, and educators are uninformed. . . It’s a triple whammy.”
- “It makes me cringe now . . . I didn’t experience from my [school] mentors that this was a human rights issue, that you were [contributing to] taking someone’s rights away by recommending guardianship [as an educator].”

Finding 3 & Recommendations

A minority of U.S. states have guardianship provisions that are applicable solely to people with ID/DD, as opposed to other alleged disabilities. These statutes raise ADA concerns, in that they discriminate amongst people with different disabilities.

- The U.S. Department of Justice should take the position that, under the ADA, the degree of due process in a guardianship matter under state law or practice should not be different for people with ID/DD
- A Court Improvement Program for adult guardianship should be funded and require guardianship be utilized as a matter of last resort and the person's functional abilities should be assessed on an individual basis, consistent with the Uniform Guardianship, Conservatorship, and Other Protective Proceedings Act (UGCOPAA)

Comments on Different ID/DD Guardianship Statutes

- NY City Bar Assoc. Mental Health Law & Disability Law Committees: New York guardianship law "discriminates against persons with intellectual and developmental disabilities, denies procedural and substantive due process to those for whom guardianship is sought, and over whom guardianship is imposed, fails to honor or promote autonomy, self-determination and dignity, and fails to protect persons under guardianship from abuse, neglect and exploitation."
- Parents (Michigan)
  - Separate ID/DD law was a "good thing," because of "the problems with guardianship . . . vary[] a great deal for people who are elderly and people with ID/DD."
  - Michigan preference for partial guardianships that terminate after five years not effective; guardianships are often not partial in practice or not ordered

Finding 4 & Recommendations

While more states should advance alternatives to guardianship in their state laws, regulations, and policies, more is required to ensure that these changes are fully implemented on the ground.

- DOJ should issue guidance to states on their legal obligations pursuant to the ADA to ensure guardianship is a last resort.
- The Court Improvement Program should require states, among other things, to ensure an unconditional right to counsel for people in initial and post-appointment guardianship proceedings and provide judicial and attorney trainings on less-restrictive options.

Finding 4 & Recommendations (cont.)

The U.S. Department of Health and Human Services should promote the availability of

- Health Advocate programs
- Financial case management services
- Educational advocate services

Link to Supported Decision-Making

Comments on Reform vs. Practice

“For these promising reforms to have an impact, a culture shift still needs to happen – at the family level, at the school level, at the judicial level, at the governmental agency level – that recognizes guardianship is not the only game in town for [people] with ID/DD.”

Finding 5 & Recommendations

Despite the existence of restoration-of-rights procedures in many state laws, many people with ID/DD and their families are unaware of those options, let alone less-restrictive alternatives. People with ID/DD may, therefore, remain in guardianships that are overbroad or undue for most of their lives.

- The Court Improvement Program should provide regular notice of restoration of rights, periodically review guardianships, and train family and professional guardians and people in guardianship.

Finding 6 & Recommendations

There is a lack of reliable data on the number of adult abuse, neglect, or exploitation cases in which the perpetrator is the court-appointed guardian or other substitute decision-maker.

- States should continue to be encouraged through the National Adult Maltreatment Reporting System and other mechanisms to collect, track, and report the number of cases with such perpetrators.
- The Court Improvement Program should require state courts review reports of guardians for signs of unusual or deficient account and abuse and neglect.

Comments on Guardianship

- “They talk to me, not him – it’s like he is not there beside me.”
- “We feel we can be proactive rather than reacting [to] a problem. Having guardianship makes it easier to speak and make [decisions] with professional[s] (medical and governmental) about our son.”
- “Guardianship is not going to be a bubble around you that protects you completely. . . . The problem with guardianship, in general, is the extent of authority that people do have over other people and the potential for exploitation and abuse.”

Where to Find the Reports

www.ncd.gov

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