VOR
A Voice Of Reason
Speaking out for people with Intellectual & Developmental Disabilities

VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
https//:www.vor.net

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Joanne St. Amand
20 Sutton Place
Cranford, NJ 07016
(908) 272-0399
jrst.amand@verizon.net

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National Council on Disability (NCD)
1331 F Street, NW, Suite 850
Washington, DC 20004

Re: NCD Report, March 22, 2018, "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities"

To: Neil Romano, Chairman, Lisa Grubb, Executive Director

For 35 years, VOR has advocated for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). Our membership is mostly comprised of families of individuals with severe or profound intellectual disabilities, often complicated by significant medical, psychological, or behavioral conditions. Many of our loved ones are non-verbal or non-ambulatory. Many engage in self-injuring behaviors. They often require 24/7 care, provided by well-trained and caring direct support professionals. ***Our family members constitute a minority within a minority. They represent about 5% of the entire population of individuals with I/DD.*** The home and community-based settings that work for many people with I/DD often fail to meet the needs of these severely disabled, vulnerable individuals.

VOR has reviewed the March 22, 2018 report "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination". [1] The consideration of current guardianship law is an important issue upon which to focus. Any recommendations for changes in guardianship policy, however, should recognize that alternatives to court appointed guardianships, even with maximum assistance, are not feasible for everyone. This applies especially to the individuals and their families and friends who we represent.

As stated in the report, 75% of guardians are family members or personal friends. They are the most motivated and in the best position to advocate for the optimum outcome from the decision making process to promote the overall welfare and dignity of the person.

As guardianship alternatives are explored, it is imperative that court appointed guardianship remain an option for those who want or need it. Recognition of the varying needs of different populations who may be subject to guardianship, including people with profound and severe intellectual disabilities, will help ensure that any proposed change to guardianship law gives the appropriate assistance to each person based on individual need.

We welcome your response to our comments and urge you to take them into consideration in NCD deliberations on this important issue.

Sincerely,

Hugo Dwyer
Executive Director, VOR

[1] https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf

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VOR Comments on the Seven Findings of "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities"

Finding 1: There is a lack of data on existing guardianships and newly filed guardianship.

VOR agrees with this finding and the recommendation to "develop initiatives to produce effective and comprehensive data on guardianship". We recommend that data should also be collected on the welfare of persons who have been removed from the protections of court-ordered guardianship.

This finding supports a conclusion that without more reliable and complete data on guardianship, it is not possible to determine whether systemic reforms are needed. Evidence is also lacking that would support the limiting of guardianship or the wholesale replacement of guardianship with Supported Decision-Making or similar alternatives.

Finding 2: People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions…

VOR disagrees with the above statement, especially the word, "erroneously". It may be true that some people with disabilities are incorrectly assumed to be unable to make autonomous decisions. Others, especially those with profound and severe intellectual disabilities and other complex medical and behavioral conditions, are indeed incapable of making decisions for themselves in some or all aspects of their lives. When necessary, they should be afforded the due process protections of guardianship to assure that their interests and rights are protected.

In recommending that the DOJ should issue guidance to states on their legal obligations under the ADA in regards to guardianship, it is not clear what the NCD has in mind or how much control the federal DOJ has over state court-appointed guardianships. Unfortunately, the ADA and the 1999 Supreme Court *Olmstead* decision interpreting the federal anti-discrimination law have been widely misinterpreted to require that services be provided in the "community". They have been incorrectly used to limit the choices and range of services available to people with I/DD.

Guardianship may be inappropriate for some people with disabilities, but a finding that an individual lacks the capacity to make informed decisions and needs the protection of guardianship is not in itself discrimination.

Olmstead does not address guardianship or other forms of surrogate decision-making. The 2014 Home and Community-Based Settings Rule, however, confirms the authority of state courts to appoint guardians to represent people with disabilities: "**We note that where a legal guardian, conservator, or other person has the sole authority under state law to make decisions related to the individual's care, the state must comply with the decisions of the legal surrogate.**" *[p. 2995 of the Federal Register of 1/16/2014; Definition of Individual's Representative] [emphasis added].*

The recommendation that DD Councils, Universities of Excellence in Developmental Disabilities, and Protection and Advocacy organizations should work to avoid guardianship ignores the recognition of individual needs, including the possible need for court appointed guardianship.

Finding 3: People with disabilities are often denied due process in guardianship proceedings.

VOR believes that the vast majority of Probate Courts and state guardianship laws assure due process when properly enforced. We would appreciate any information on courts that do not adhere to this standard.

Finding 4: Capacity determinations often lack a sufficient scientific or evidentiary basis.

*VOR believes that this finding is a broad generalization and is not accurate***.** Requests for guardianship usually include statements from qualified physicians along with other information on the functioning abilities of the individual and recommendations on the need for guardianship. Recommendations and observations by parents and other family caregivers as to the functioning abilities of the individual should be included in assessments for guardianship.

Finding 5: Guardianship is considered protective, but courts often fail to protect individuals.

VOR believes this statement is overly broad and subjective. Most states require reports from guardians on the condition of the person under guardianship, and many require additional oversight of guardianship cases.

We agree with the recommendation for appropriate levels of oversight and regulation of professional and public guardians.

Finding 6: Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often do little to enforce this requirement.

VOR believes that for people who can make decisions for themselves, less restrictive alternatives to guardianship should be available, based on the needs and desires of the individual. The recommendation to "use SDM and the court systems to restore people's rights", even for people with severe intellectual disabilities, is questionable. Restoration of rights must consider the capacity of the individual to make decisions in some or all aspects of the person's life and whether guardianship is needed to ensure a person's safety, health, and general well-being. SDM has not been proven to be an effective method to replace guardianship and could instead place the person in harm's ways.

Finding 7: Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.

VOR believes that this finding may or may not be true, given that, "Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship…". **There must be recognition that ending guardianship for some people may be fraught with unintended and harmful consequences.** For an individual who has undergone rigorous assessments on his/her ability to make decisions, and has been found unable to do so, assessments would either have to show that the initial assessment was incorrect or that changes in the person's decision-making abilities no longer support a need for guardianship.

For the most part, the federal Protection and Advocacy system opposes guardianship on an ideological basis rather than following its mandate to consider and protect the rights of individuals with developmental disabilities. We believe that to encourage P&A organizations to continue on this path with extra funding to remove individuals from guardianship would be a poor use of federal funds.

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Issues to Consider Regarding Guardianship and Supported Decision-Making

Individuals with intellectual and developmental disabilities (I/DD) and their parents, family members and guardians may have heard about Supported Decision-Making (SDM), an initiative that could affect their decision-making rights. Some see SDM as an alternative to guardianship, while others view it as an attempt to remove the legal instrument that provides a safety net for vulnerable individuals.

VOR is a national organization that advocates for high quality care and human rights for individuals with I/DD. We understand the valuable role that guardians play in the emotional and physical well-being of their wards. As advocates who appreciate the diversity of the I/DD community and the need for a wide array of supports, we want to ensure that guardians and family members are aware of the issues connected to Supported Decision-Making so that they can make informed decisions about the care of their loved one with disabilities.

What is Guardianship?

Guardianship is the legal process whereby a state court appoints a person or organization to have the care and custody of an adult or child who has been determined to be legally incapacitated. Parents are the assumed legal guardians of their minor children, but a guardian may be appointed for a child if the parents are not able to fulfill that role. An incapacitated adult is one who has been determined by a court to lack capacity to make some or all personal and/or financial decisions and for whom a guardian has been appointed.

Guardianships are awarded to protect the "ward," the individual with a disability, from abuse, neglect, and exploitation. Guardians are expected to act in the best interests of the individual and to make decisions over medical, psychiatric, behavioral, and all other aspects of the person's care that are authorized by the court based on the degree to which the individual is incapacitated. Legal guardianship is both a responsibility and a privilege.

What is Supported Decision-Making?

The Supported Decision-Making movement is a new initiative that promotes the idea that, with almost no exceptions, all people with I/DD can make their own decisions with support from an informal network of advisors. Supporters of SDM claim that empowering individuals to make their own decisions would make most guardianships unnecessary. The advisors do not need to be court-appointed and do not bear any responsibility for ensuring the success of outcomes. Supported Decision-Making proponents view the "Right to Fail" as an important freedom, regardless of the individual's ability or vulnerability.

Issues to Consider

Supported Decision-Making might help those who need guardianship the least, if at all. In the process of attempting to change guardianship laws, it could weaken protections for those who are the most vulnerable. Those protected by guardianship include people with severe intellectual disabilities, people with I/DD who are susceptible to manipulation and coercion, and people with I/DD who lack awareness of the consequences of their actions and may cause harm to themselves or to others.

The primary goal of SDM is to move away from "substituted decision-making", where the guardian makes decisions for the incapacitated ward. Proponents of SDM make the assumption that all people with disabilities are capable of making all decisions for themselves with help from a support team. This approach would then, in fact, be doing what SDM proponents criticize: substituting the judgment of the incapacitated ward with the judgment of a "support team".

Guardians of people with I/DD usually have an existing network of informed persons to assist them in making decisions for their wards, including other family members, direct care providers, and medical personnel. This is what SDM promotes, but without the protection of court-ordered guardianship. The more individuals are able to express their wishes and play an informed, responsible role in their own decision-making, the more their participation should be included. But, it is irresponsible to remove an individual who lacks the capacity to make his or her own decisions from the protection of the court and ongoing evaluation. Most individuals with intellectual disabilities change over time, their needs change accordingly, and their ability to make their own decisions in a responsible manner should be examined at regular intervals.

VOR maintains that problems with guardianship can be avoided through strong enforcement and monitoring and better access to information on guardianship. To eliminate guardianship or make it more difficult for family members and friends to become guardians will leave people with I/DD more vulnerable to the abuse, exploitation, and neglect that guardianship is designed to prevent.

When people with I/DD and their families are presented with Supported Decision-Making, they should consider the following:

- The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) states: *"individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families."*
  - *DD Act, 42 U.S.C. 15001(c)(3)(2000)*
- Is the individual prepared to take on the responsibility of Supported Decision-Making?
- Is the individual's support group prepared to address the changing needs of the individual over the course of their lifetime? How will you maintain and ensure a consistent team of advisors?
- How do you reconcile the "Right to Fail" with the safety and comfort of the individual?
- How do you determine if SDM is not working and legal guardianship would be appropriate?
- You and your loved-ones with I/DD have the right to decide what is best for your unique situation, based on individual need. Take your time in making any major decisions regarding guardianship.

VOR does not oppose the use of SDM for all who voluntarily wish to use methods promoted by advocates of SDM. All decisions rest with the individual or the legal guardian as authorized by a state court and it must be understood that guardianship procedures are available to those who need them, regardless of their participation in SDM activities. As such, there is no reason to give up guardianship in order to use Supported Decision-Making.

Changes to guardianship laws in many states have already been proposed. Families should keep abreast of these changes and advocate for their loved-one with state officials if the changes could weaken the protections upon which he or she relies. VOR will do its best to keep you informed. Our vulnerable family members deserve nothing less than the protections that family guardians can provide.

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. VOR advocates for a full range of options to address the full range of needs of people with intellectual and developmental disabilities and their families. http://www.vor.net