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VOR Comments to Proposed Guardianship, Conservatorship, and Other Protective Arrangements Act

Supported Decision making (SDM), Guardianship, and the Least Restrictive Standard The Prefatory Note and Section 314 speak in favor of the “least restrictive means” of serving the ward with a bias toward Supported Decision-making. [We refer you to VOR’s Position Paper on SDM.] SDM does not offer a “least restrictive” means of providing support to an individual. For individuals who are incapable of participating in the decision-making process due to their intellectual disabilities, the SDM team would be engaging in the substitute decision-making that SDM allegedly prevents. How is the substitute decision-making of the SDM team “less restrictive” than the decision-making of a guardian, especially when that guardian is a family member with intimate knowledge of the ward and motivated by unconditional love?

The term “least restrictive” should be defined in the Act. The “least restrictive means” should be defined in terms of what is actually least restrictive for the individual based on that person’s needs and preferences to the extent that the preferences are actually known or reasonably ascertainable by the guardian and the court.

Residential Choice The “least restrictive means” also entails a bias against congregate residential facilities. The Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision which interpreted the ADA, recognize the unique needs of the individual with disabilities and their right of choice in accessing public accommodations for disabilities, such as residential services. In *Olmstead*, the justices affirmed the “States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities,” *Olmstead v. LC 527 US 581, 597* and stated,

“We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”
Olmstead at 601-602

Furthermore, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 supports individual choice among residential options and recognizes families as the primary decision-makers,

“Individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision-making 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).

Section 314 (c)(4) and Section 317 (a)(7) of the draft act requires guardians to take additional steps and to provide increased reporting should they choose an “institution,” “nursing home,” or “facility” as a residential placement for a ward. The language in these sections instills a bias against such settings. As these settings serve individuals requiring higher levels of care, the language works against the most severely and profoundly disabled individuals needing guardianship. Additionally, this language infringes on the right of choice of individuals and their guardians and flies in the face of the second prong of *Olmstead* which confirms the individual’s right “to oppose” placement in the community. Parents and guardians are the most knowledgeable about a ward’s overall needs, and therefore, their decision-making with respect to residential choice should be respected..

Sensitivity to certain terms (e.g., “ward”) The Prefatory Note speaks about the drafts’ updated terminology. The draft does not use the terms “ward,” “incapacitated,” and “incompetent”. These terms define why guardianship is needed, and as such, serve as protections for the individuals affected. The descriptive nature of the terms alert others to the fact that the affected individuals need additional assistance, and thus, stimulates compassion in others. “Person subject to guardianship” is non-descriptive and could actually cause confusion as

to the degree of disability at hand.

Excessive Reporting VOR believes that responsible and caring individuals wanting to serve as guardian for an incompetent person should be encouraged, especially when those individuals are family members and close life-long friends of the individual. We are concerned that the Guardian Plan required in Section 316 could discourage guardianship by adding unnecessary burdens. Given that a Guardianship Report is already required, a Plan in addition seems excessive and could be intimidating for some caring and loving people who would make excellent guardians, but are not comfortable with bureaucratic and legalistic-sounding paperwork. The Guardian Plan is likely to be redundant for individuals with I/DD who are receiving services. Most states require service plans that guardians and other family members participate in. These could easily be included as part of the evaluation of an individual for guardianship.

Visitor In Section 304, the addition of the visitor into the guardianship process adds a third party between the petitioner, the respondent, and the court. The visitor is given the responsibility to investigate, look into medical history, and make a recommendation to the court as to the appropriateness of guardianship. It raises many concerns including, what qualifications does the visitor have and how are they chosen? Do they have expertise in the myriad co-morbidities which may exist? The visitor's feedback is purely substitute feedback, and as such, infringes upon the decision-making authority of the court and the vital and caring role the petitioner plays in the life of the respondent, especially when the petitioner is a family member and close friend.

Appointment of an Attorney Section 305, Alternative A and Alternative B, require the appointment of an attorney for the respondent, in some or all proceedings, whom the respondent must compensate. If the respondent is incapacitated, he or she is not in a position to provide direction to an attorney. The attorney would be engaging in substitute decision-making and could manipulate the respondent and work against a well-meaning and knowledgeable family guardian or close friend. Additionally, paying an attorney is a significant financial responsibility, especially for an incompetent person with limited income which in many cases may consist only of Social Security income.

Who Should Be Guardian Section 309 of the draft prioritizes the parties that can be guardian, placing family members last. A family member should be given the highest priority given their intimate knowledge of the individual and their having the greatest motivation to act in the best interest of the individual. Indeed, this is no different than the way most Americans lead their lives. When competent adults prepare their wills and estates or engage in personal and financial planning, most look to family members for advice and to help them protect their interests. Why should an incapacitated person not enjoy this same privilege? How can a law that is to protect vulnerable people be credible if it severs these individuals from their most loyal support systems? Section 310 compounds this insult by placing the "least restrictive means" to meet a respondents' needs ahead of family members, putting technology and supported decision-making teams ahead of familial bonds. It should be noted, an incapacitated individual often requires assistance with technology, and therefore, the technology itself is subject to manipulation, and as such, so is the incapacitated individual.

When public or professional guardians are needed to protect vulnerable individuals, they must act with independence when they make decisions on behalf of their ward. For public guardians financed by the government, conflicts of interest arise. These guardians must not be pressured to make decisions that fulfill the agendas of government agencies rather than protect the interests of their wards, nor should they be pressured to adhere to an ideology that does not accept that there are individuals who cannot make decisions. VOR members have seen the adverse affects of conflicts of interests with public guardians. Model law and state courts should protect the right of all people with intellectual disabilities to be treated as individuals and not make presumptions based on their status as part of a class; nor should model law or state courts which address guardianship be unduly swayed by an ideology that does not respect the inability of some in their charge to engage in decision-making.

Termination or Modification of Guardianship Section 311 and Section 319 allows for the "adult subject to guardianship" to petition to have guardianship removed and an attorney provided. How is the incapacitated adult able to make such a determination? Such a provision potentially undermines the ability of the guardian to act in the ward's best interest when the ward does not understand or accept the reasons for the guardians' decisions.

Restrictions on Ability of Guardian to Protect the Ward Section 311 requires court authorization in order for a guardian to restrict communications and visitors with the ward. As the responsible party who could be held accountable if the ward is harmed, such a requirement unduly inhibits the guardian from carrying out his or her duty to protect the ward. To require the guardian to petition the court to exclude certain individuals from interacting with or visiting the ward fails to allow the guardian to use his or her best judgment in subsequent instances where contact may harm the ward. Delays caused by having to petition the court could place the ward in serious jeopardy.

In conclusion, Supported Decision-making as an alternative to guardianship does not live up to the standards for accountability and monitoring that is required in guardianship procedures. Discouraging families and close friends from taking on the responsibility of guardianship does a disservice to people with profound and severe cognitive disabilities who are not capable of speaking on their own behalf, or to individuals with mild or moderate cognitive disabilities who are easily manipulated. Without the ability to give informed consent, these persons are unable to provide advance directives for their care or to designate a person with the authority to act on their behalf. When there is no guardian, service providers are left to make decisions that are most convenient for themselves without the oversight and protection of a caring third party without a conflict of interest.

VOR is deeply concerned about any effort to weaken the protections of guardianship. Attempts to replace guardianship with technology or Supported Decision-making affect not only those with severe intellectual disabilities but also people with I/DD who are vulnerable to manipulation and coercion by others as well as individuals who lack awareness of the consequences of their own actions which may cause harm to themselves or others.