# **Guardianship: Synthesizing the Data**

Kristin Hamre, PhD and Derek Nord, PhD

## What is Guardianship

A legal process to protect people who are determined by a court be "incapacitated" and unable to make decisions about their own care, property, and/or unable to understand and enter into a legal contract. A legal guardian is appointed by a court. Wide variability in procedures, rights retained, and/or terminology exists from state-to-state. A guardian could be an individual or an entity. Guardians may serve as a "full" or "partial" guardian, indicating they have decisional authority over all life decisions or specific areas (e.g., finances). People most affected by guardianship are elders, and people with intellectual and developmental disabilities (IDD), mental health conditions, and physical disabilities.

## Systemic Challenges related to Guardianship

<u>Due Process is often not afforded</u>. In Indiana, it was found that the guardianship petition failed to provide evidence of incapacitation. The protected people were typically not present and only 2% were represented by counsel at the guardianship hearings (Indiana Adult Guardianship State Taskforce, 2012). Restoration of rights rarely occurs, despite each having a process to regain ones autonomy (National Council on Disability, 2018).

<u>Guardianship occurs early for many</u>. Nearly 60% of young adults with IDD, age 18-22 that receive funded supports are under guardianship (Bradley et al., 2019).

<u>There is a lack of centralized national and state data</u>. Limited data makes it impossible to confidently know who and what types of disabilities people under guardianship have. Active guardianship cases or their status in not even possible to determine in many states (National Council on Disability, 2018).

<u>National standards of practice are not required</u>. The National Guardianship Association has developed standards of practice, but these are not binding on state or federal courts (Kirtland, 2020). No national bill of rights exists to ensure people under guardianship have basic protections.

### Self-Determination and Guardianship

<u>Guardianship relates to lower quality of life</u>. People with IDD under guardianship experienced lower quality of life and greater feelings of hopelessness and helplessness. They were also found to receive lower levels of preventive health care and have fewer social relationships (Bradley et al., 2019).



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*Lower Levels of Employment*. People with IDD under guardianship were significantly less likely to have a goal to work in the community (Nord et al., 2018) and experienced lower levels of employment (Bradley et al., 2019).

<u>Guardians limit involvement in decision making</u>. Despite the National Guardianship Association standards of practice that articulate supporting self-determination, family and professional guardians of elderly and adults with disabilities continue to limit the involvement of people in informing and/or making decisions affecting their own lives (Hamre & Nord, under review).

<u>Guardianship does not guarantee safety</u>. While a guardianship is enacted to protect a person deemed incapacitated and vulnerable, there is no guarantee of safety under any agreement. Many cases of abuse and exploitation occur within guardianship, and often, though not exclusively, by family members serving as guardians. Several states have begun to address the issue of unnecessary guardianships and to promote less restrictive alternatives. (Schmidt et al., 2022).

#### **Guardianship Practices**

<u>Training is inconsistent and often lacking</u>. Nationally, guardianship as a field has been inconsistent in its training and expectations from state-to-state. Training requirements for new guardians range from no training required for new guardians (e.g., Indiana) to completion of a defined training program (e.g., Illinois) (Guardianship and Advocacy Act, 2018).

<u>Training needs vary by quardian type</u>. Large training gaps exist between family and professional guardians of elderly and adults with disabilities, suggesting a need for a differing approach for these two groups (Hamre & Nord, under review).

### Less Restrictive Alternatives to Guardianship

<u>Alternatives to quardianship exist</u>. Less restrictive alternatives may include but are not limited to Power of Attorney, Healthcare Representative, and Support Decision Making Agreements. Partial guardianship may also be a less restrictive alternative to full guardianship.

<u>Limited knowledge of alternatives</u>. Alternatives are not well known nor are they being presented to people so they can seek them (National Council on Disability, 2019).

<u>Minimal state legislation advancing alternatives</u>. Only a few states have legislation advancing less restrictive alternatives. Systems are not in place to monitor and enforce the implementation and takeup of such approaches.



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