***Beyond Guardianship: Toward Alternatives That Promote
Greater Self-Determination for People with Disabilities***

**Literature Review**

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***Beyond Guardianship: Toward Alternatives That Promote
Greater Self-Determination for People with Disabilities***

**Literature Review**

This literature review is an examination of relevant scholarship available in English addressing a series of research questions, pertaining to guardianship and alternatives – namely:

(1)    How does guardianship impact people with disabilities and their families? Does it help improve outcomes of health, safety, and protection for people?

(2)    Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?

(3)    How does the current use of guardianship align or conflict with other U.S. national disability policy goals and initiatives, including the goals of the Americans with Disabilities Act and its community integration mandate and principles of due process under the law?

(4)    Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?

(5)    What other alternatives are either recognized by states, currently being used to avoid guardianship or emerging as alternatives?

(6)    Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?

The review focuses on the most recent work competed, with a preference for studies concluded in the past decade, where possible. A detailed bibliography is included at the end of this report.

**Research Question 1: How does guardianship impact people with disabilities
and their families? Does it help improve outcomes of health, safety, and protection for people?**

1. **Guardianship: A Brief Introduction of Terms**

In the U.S., adult guardianship or conservatorship is a legal process governed by state law that varies across the nation. In general, it is a process whereby a court (a judge or jury) appoints a person or organization (“guardian”) to make some or all of the decisions on behalf of another person, after making a legal finding that that person is unable to make some or all decisions him or herself.[[1]](#endnote-1) While specific terminology varies from state to state, guardianships tend to be distinguished between guardianships of the person and guardianships of the estate (conservatorships).[[2]](#endnote-2) For the purpose of this literature review, we will be using the term “guardianship” to broadly cover both categories.

1. Lack of Nationwide Data Prevents a National Assessment of Guardianship Outcomes in the United States

“What actually happens to people under guardianship?” “How well does the current guardianship process protect people?” “What are the roadblocks families and others face in navigating guardianship systems?” Answers to these questions are unclear, because of the paucity of robust and reliable data on guardianship across the United States. Even identifying the number of active cases or their status is not possible in many states.[[3]](#endnote-3) Record keeping is frequently inconsistent or dated, and most states do not have centralized data collection or tracking systems. Studies have found that guardians have poor compliance with reporting requirements,[[4]](#endnote-4) which further limits the available data sets. As a result, “it is hard to determine whether people under guardianship are actually safer than others.”[[5]](#endnote-5)

Such data collection must improve in all U.S. states, so that more research can be conducted on what impact guardianship status has on a person’s self-determination, life satisfaction, community living, and participation in society.[[6]](#endnote-6) Currently, few states are able to report complete statewide adult-guardianship caseload data, because these cases are counted in a generic probate case type or otherwise blended into civil caseload statistics. Court filing tracking systems should be standardized within and across states, as should court training on the consistent use of such systems.[[7]](#endnote-7) The results will help demystify how guardianship proceedings start, are carried out, and then monitored, so that researchers and scholars can make more thorough recommendations for improving current practices and public policies.[[8]](#endnote-8)

As discussed further below, Congress, national advocacy organizations, and the media have increasingly highlighted the abuse of guardianships and conservatorships as a means to exploit people with disabilities and older Americans. The absence of accurate national information regarding the numbers of people affected by guardianships, the conditions under which a guardianship is imposed, the services and alternatives being offered, the frequency and nature of misfeasance by guardians, and the possible warning signs of abuse hampers the ability of the courts, service agencies, policy makers, advocates, and others to address the issues.[[9]](#endnote-9)

1. What We Know Now: Impact of Guardianship on People
with Disabilities
2. **Scope of Guardianships, Size of Population, and Demographics**

Generally speaking, guardianships have two basic forms: (1) limited or partial guardianship; and (2) plenary, full, or general guardianship. In limited guardianship, the court finds that the person does not lack capacity or competence to make some decisions (e.g., about finances or other matters), and so allows the person to retain those rights. In plenary guardianship, the court finds the person does not have the capacity to make legal decisions broadly and takes away virtually all legal rights.[[10]](#endnote-10)

Since 1995, the rough estimates on the number of adults under partial or plenary guardianship in the U.S. has tripled from .05 to 1.5 million.[[11]](#endnote-11) In addition, estimates approximate that the population over 65 years of age will increase from 40 million in 2010 to 72.1 million in 2030,[[12]](#endnote-12) which will likely mean an increase in the number of older adults with age-related cognitive deficits that may be at risk of guardianship.

Studies have shown that plenary guardianships are vastly more common than limited guardianships,[[13]](#endnote-13) although, once again, there is a lack of reliable data across the nation. One study found that plenary guardianship was ordered in 87% of the cases reviewed.[[14]](#endnote-14) A second found people with intellectual disabilities in Michigan were appointed full guardians in more than 54% of the cases.[[15]](#endnote-15) A third study found courts appointed limited guardianship in only 10% of the public guardianship cases examined.[[16]](#endnote-16) And a fourth study found that full guardianship was the default option for students with intellectual and developmental disabilities that were part of the research group.[[17]](#endnote-17) According to data collected by the National Core Indicators Project, 42% of adults with developmental disabilities living in participating states are under full guardianship, and another 7% are under limited guardianship.[[18]](#endnote-18) While, in practice, scholars have found that the distinction between plenary and limited guardianship is minimal in terms of the scope of authority exercised by a guardian,[[19]](#endnote-19) additional empirical research is needed to determine what factors prevent courts from implementing limited guardianships and whether limited guardianships result in better long-term outcomes for people with disabilities.[[20]](#endnote-20)

Demographic information pertaining to guardianships is not available consistently nationwide. However, looking at some available studies provides initial insight as to the population affected. One New York study involved a review of 2,414 guardianship case files between January 1, 2002, and December 21, 2012. It found that the majority of the people subject to guardianship were at least 65 years old (almost 60%), with annual incomes less than $20,000 (almost 55%).[[21]](#endnote-21) The most common reasons for appointing guardianship were property management (85% of cases) and health care decision-making (75%). Dementia was the reason given for guardianship in 41% of the cases and mental illness the reason in 20% of the cases.[[22]](#endnote-22)

By contrast, a 2005 national study found different trends in demographics, compared to both the New York study and a prior 1981 study. Based on the 2005 data results, the demographics of people under public guardianship shifted from the older adult population (people 65 years or older) to a younger population (people between 18 to 64 years old). Primary diagnoses were typically developmental and/or intellectual disabilities and mental illness, rather than dementia, unlike prior studies. People affected were fairly evenly split between men and women, representing another shift from the results of the 1981 study, which found the majority of people subject to guardianship were older White women. A surprising number continued to be White, with the most populations of people with color in any state being 33% (in Los Angeles, California).[[23]](#endnote-23)

**B.**  **Theories, Studies, and Findings Indicating Negative
Guardianship Outcomes**

1. **General Outcomes**

Guardianship has been referred to as a “double-edged sword” – an instrument designed to protect vulnerable people in society from abuse or neglect, while simultaneously removing fundamental rights that may increase opportunities for such abuse.[[24]](#endnote-24) “At best, guardianship will provide personal care and property management that an individual with a disability alone cannot handle. At worst, it will deprive that individual of decision-making authority that he or she does have the capacity to handle, and will, at the same time, create the opportunity for personal or financial abuse.”[[25]](#endnote-25)

Guardianship affects a person’s legal right to make some or all of the decisions in their lives, including those about finances, health care, voting, marriage, socializing, and working, among others.[[26]](#endnote-26) As one scholar noted: “One of the dangers of guardianship is that it can easily go beyond protecting rights and seriously interfere with self-determination if guardians exercise control in areas where persons could make their own decisions or engage in collaborative decision-making with support from significant others.”[[27]](#endnote-27) Another legal scholar expressed concerns that “the total power which the law gives to guardians creates the possibilities for isolation and vulnerability that leads to, or at least permits, abuse”[[28]](#endnote-28)

Guardianship is predicated on the idea of protection of the vulnerable and the state’s *parens patrie* power.[[29]](#endnote-29) However, when A. Frank Johns, an elder law scholar, surveyed 22 American projects, studies, and conferences on guardianship from 1961 to 1996, he cited no findings clearly indicating that guardianship leads to positive life outcomes for people who are subject to it.[[30]](#endnote-30) Rather, in his grim words, those prior investigative efforts:

 uncovered evils in guardianship: removing all individual rights; denying access, connection, and voice to those lost in guardianship’s gulag; and still continuing a process rooted in systemic perversities.[[31]](#endnote-31)

It was during the period that Johns reviewed – 1987 to be exact – that U.S. House Representative Claude Pepper famously and dramatically summarized his Congressional committee’s findings regarding abusive guardianship practices:

The typical [person subject to guardianship] has fewer rights than the typical convicted felon . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty.[[32]](#endnote-32)

In 2012, as a follow up to his 1997 article, Johns wrote that the more recent studies of guardianship monitoring and public guardians “acknowledge that guardianship still limits the autonomy, individuality, self-esteem, and self-determination” of those subject to guardianship,[[33]](#endnote-33) and he expressed continued concerns that the legal system surrounding guardianship focused more on the interest in protecting a person’s property than the person him/herself.[[34]](#endnote-34)

Many legal scholars similarly highlight the way in which guardianship orders impact the very decisions that define people as human beings,[[35]](#endnote-35) and thus have significant impact on the daily lives of people subject to them.[[36]](#endnote-36) Studies have found that, when a person loses the right to make his or her own decisions, there will likely be a negative impact on the person’s functional abilities, physical and mental health, and general well-being.[[37]](#endnote-37) One scholar talks about the “constructive isolation of guardianship” and its impact on people.[[38]](#endnote-38) People under guardianship can “feel helpless, hopeless, and self-critical”[[39]](#endnote-39) and experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,”[[40]](#endnote-40) as well as significantly decreased “physical and mental health, longevity, ability to function, and reports of subjective well-being.”[[41]](#endnote-41) Some scholars also argue that, because guardianship is too often sought based on an assumption that a person’s lacks capacity, it can be demeaning and socially stigmatizing.[[42]](#endnote-42)

**2. More Outcomes for Specific Populations**

Guardianship also may have disparate impact on different populations subject to it. For example:

 People with Intellectual and Developmental Disabilities (IDD)

* Guardianship is often implemented, because service providers, family, judges, and others assume people with disabilities cannot make decisions for themselves.[[43]](#endnote-43) But research shows that this is not true, and that it is possible for people with IDD to engage in decision-making, with appropriate supports.[[44]](#endnote-44) Research demonstrates that increased opportunities to make decisions is associated with self-determination and decision-making capacity, such as in financial decision-making.[[45]](#endnote-45)
* For young adults with IDD, guardianship may be an obstacle to the development of self-determination skills necessary for life after high school.[[46]](#endnote-46) Studies found that the appointment of a guardian for a young adult with IDD did not necessarily resolve the areas of concern prompting the parent taking that step and that, in some cases, the young adult under guardianship would have done just as well, if not better, without a guardian.[[47]](#endnote-47) The guardianship often appeared to have benefited the guardian, rather than the person under guardianship.[[48]](#endnote-48) Moreover, promoting self-determination of students with disabilities is a special education “best practice” leading to better life outcomes. [**Cross-Reference:** Part II.A of Research Question 3 below.]
* In states surveyed as part of the National Core Indicator project, data indicated that people with IDD who do not have a guardian are more likely to have a paid job, live independently, have friends other than staff or family, go on dates and socialize in the community, and practice the religion of their choice.[[49]](#endnote-49)
* People with IDD who are placed under guardianship may be predisposed or disproportionately subject to institutionalization.[[50]](#endnote-50) One study reviewed 15 state public guardianship programs and found that the program that used institutionalization the least still placed 37% of the people it served in institutions, while the program that most frequently institutionalized people placed 97% of them in institutions. Eleven of the 15 programs indicated that between 60% and 97% of the people they served lived in institutions.[[51]](#endnote-51)
* But See: Some scholars disagree, citing other studies indicating that guardianship may delay institutionalization, although ultimately not prevent it. They argue that, while anecdotes and press stories may highlight the alleged link between guardianship and institutionalization, it is a charge that cannot be substantiated or denied.[[52]](#endnote-52)

People who are Older

* Congressional hearings and federal reports from the Government Accountability Office continue to document cases of financial exploitation, neglect, and abuse of seniors in the guardianship system. For example, a 2010 report looking at the impact on older Americans found that in the guardianship abuse cases under review, courts had inadequately screened potential guardians and failed to monitor the guardians after appointment.[[53]](#endnote-53)

 People with Psychosocial Disabilities

* Research indicates people with severe psychosocial disabilities retain the capacity to make important personal decisions.[[54]](#endnote-54) Yet, society and judges are still making assumptions about their general incapacity and underestimate their abilities.[[55]](#endnote-55)
* Guardianship may be anti-therapeutic for people with psychosocial disabilities, because the incapacity label creates a sense of helplessness and loss of control, which, in turn, negatively impacts psychological wellbeing and diminishes their motivation to act and maintain or build competencies. In addition, guardianship may remove people with psychosocial disabilities from the therapeutically beneficial process of medical decision-making. Evidence indicates that direct dialogues between clinicians and people with psychosocial disabilities enables valuable assessment of treatment plans, increases compliance with those plans, and minimizes or improves the management of psychiatric crises.[[56]](#endnote-56)
* But See: A 2015 review of reported case law on cases involving restoring the rights of people subject to guardianship made a counterbalancing finding – i.e., that some of the people, including people with psychosocial disabilities, were attempting to access the restoration process, because they had “improved due to regimented medical treatment” while under the guardian’s care.”[[57]](#endnote-57)

**3. Theories, Studies, and Findings Indicating Positive
Guardianship Outcomes**

Some scholars assert that, even though guardianship removes aspects of a person’s self-autonomy, “the balance between autonomy and protection sometimes requires a guardian,”[[58]](#endnote-58) such as when a person does not have a family to assist them, cannot advocate and express a decision, or has family who are abusive or exploiting. In that way, they argue: “Public guardianship is necessary to serve those who are the most vulnerable.”[[59]](#endnote-59)

There are also theorists who consider guardianship as a way of “facilitating and supporting the enactment of autonomous choices of individuals with cognitive disabilities,” particularly “those with severe degrees of impairment.”[[60]](#endnote-60) They argue that guardianship can enable “full citizenship,”[[61]](#endnote-61) depending on the type of relationship and approach the guardian establishes with the person. A guardian can support a person with cognitive disabilities in leading a full life by simultaneously taking on a role of “care” and a role of “enablement.”[[62]](#endnote-62)

In 2012, A. Frank Johns took a similar take on the potential of guardianship to serve person-centered planning, after he concluded it was unlikely that American jurisdictions would consider abolishing their guardianship models. Johns saw “hope” in “tinkering with the existing guardianship system” to provide guardians with education training on implementing person-centered decision making, enhance monitoring and accountability to ensure that goal, and assure care and life planning for older people and people with disabilities.[[63]](#endnote-63) In this way, Johns appears to see a role for Supported Decision-Making principles to be incorporated into how guardians act with and on behalf of those they serve, similar to the National Guardianship Association “Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making.”[[64]](#endnote-64)

The 2002-2012 New York study referenced above found that the people it surveyed under guardianship received many supporting services, as a result of the guardian’s intervention. Such services included, for example, financial management, home care, Meals on Wheels, Medicaid, and supplemental nutrition and home energy assistance.[[65]](#endnote-65) Such a finding suggests – but does not definitively prove – that some of the guardianships reviewed may have resulted in some improved outcomes for people.

[**Cross-Reference:** Research Question 1, Part III. A, Above, “But See” bullet points of Research Question 1 above.]

**IV. What We Know Now: Impact of Guardianship on Families**

From what data is available, family members are usually the petitioners in guardianship proceedings. Moreover, some studies indicate that they, along with the person’s friends, are part of the largest group serving as the guardian for the person under guardianship.[[66]](#endnote-66) A growing number of states have expressed a preference among family members as guardians, prioritizing family members who may serve.[[67]](#endnote-67) “The law assumes the wisdom of relying on family members as guardians.”[[68]](#endnote-68)

In cases where the person has declining capacity as a result of age, family members are confronted with questions as to when and how to pursue decision-making options to support the person and his or her decision-making. Questions faced include: “When do I intervene? Who will serve as a guardian if my siblings live out of state? Where will my mother live? Who will manage her finances? Who will make medical decisions?”[[69]](#endnote-69) In cases involving children with disabilities reaching adulthood, parents may not understand that they do not automatically remain the guardian of their adult son or daughter, and that only a court can appoint a guardian over an adult. They may face school special education systems biased towards guardianship as the only option for them to continue to advocate for their child, and so they also likely need education on the less-restrictive decision-making support options that are available.[[70]](#endnote-70)

[**Cross- Reference:** Research Question 3, Part II below.]

Families may not know the consequences of seeking to become the guardian of their family member, including, for example, how to navigate the court process involved and what their ongoing responsibilities to the court will be, such as periodically reporting on the guardianship and returning to the court for additional hearing as required.[[71]](#endnote-71) The 2002-2012 New York study found that there were limited services available to assist families with such navigation.[[72]](#endnote-72) Also, guardianship changes relationships: A family guardian may not know how to respond when family relationships become complicated by disagreements about decisions made or when there is resistance from the person under guardianship.[[73]](#endnote-73) In acting on behalf of the person, the family guardian may default to decision-making standards that are familial in nature – such as well-meaning paternalism[[74]](#endnote-74) – rather than engaging the person in the decision-making process or making decisions based on the wishes of the person. Families may need education to understand that, if they were to be appointed as a legal guardian, they will have to “wear two hats” going forward – one as a family member (a familial relationship, e.g., father and son) and one as a fiduciary with legal responsibilities under the law and to the court (a guardianship relationship).[[75]](#endnote-75)

Family members also may not know that, when there is a petition for guardianship, the court may appoint a professional, non-familial guardian, depending on the specific circumstances and state law. An estimated one-fourth of guardians for adults in America are corporate employees or other professionals or practitioners.[[76]](#endnote-76) Such appointments bring with them their own impact to families and the person subject to guardianship. Depending on the state, professional guardians may be appointed if a court determines there has been a “failure of family and informal supports,”[[77]](#endnote-77) resulting in, e.g., neglect or abuse of the person. Professional guardians also may be appointed for people determined incapacitated if family members do not live near the person or have a financial conflict of interest, or if the person has assets that would benefit from professional management and/or greater oversight.[[78]](#endnote-78)

There are pros and cons to either families or professional guardians serving in that capacity. If a professional guardian is appointed, he or she is likely a “stranger” to the person, may know little about the person’s values, and may be seen as an unwelcome outsider when family disagrees with his or her actions – but also may be more familiar with how to navigate the social service system for the person under guardianship.[[79]](#endnote-79) Family guardians, on the other hand, may know more about what the person wants or would have wanted, but may be unfamiliar with the complex social service system and its various funding streams, experience guilt about certain decisions, or be involved in conflicts with other family members about what to do.[[80]](#endnote-80)

In short, families are impacted by guardianship, too, both in the deliberations that may lead up to it and in the aftermath, if a guardian is appointed. As such, they should be provided with sufficient information about guardianship processes and possible alternatives to make informed and appropriate decisions.

[**Cross-Reference:** Research Question 6.**]**

 **Research Question 2: Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?**

In the 1980s, serious guardianship abuses came to light in the popular press in the United States. For example, a 1987 Associated Press investigation described guardianship as: “a dangerously burdened and troubled system that regularly puts seniors’ lives in the hands of others with little or no evidence of necessity.”[[81]](#endnote-81) Proponents of guardianship reform called attention to limited due process protections for people in or facing guardianship, including inadequate notification of, legal representation for, and attendance at the hearing(s) on the guardianship petition.[[82]](#endnote-82) In response to media, federal, and local scrutiny, state legislatures took steps to reform guardianship laws to increase procedural safeguards for people subject to such proceedings. As a result, modern guardianship statutes generally provide more due process protections than their predecessors.[[83]](#endnote-83)

However, some commentators and advocates agree that these reforms have largely failed to prevent needless guardianships or to promote services and supports for persons who need some help in making decisions.[[84]](#endnote-84) Disparities exists in many jurisdictions between the letter of the law and how it is practically implemented,[[85]](#endnote-85) as well as in the way in which guardianship processes work across states and local jurisdictions.[[86]](#endnote-86) Over the last 10 years, researchers and commentators have raised serious concerns regarding the treatment of people within guardianship’s legal systems.

**I. Illustrative Example – A “Traffic Ticket” Process for Guardianship**

Back in 1994, the Center for Social Gerontology conducted a national study that examined the guardianship process in ten states. The study found that only about one-third of respondents were represented by an attorney during the guardianship hearing(s). While medical evidence was in the court file in most cases, medical testimony was rarely presented at the hearing. The majority of hearings lasted no more than 15 minutes and 25% of hearings lasted less than 5 minutes, thus raising questions as to whether there was opportunity for meaningful due process. 94% of guardianship petitions were granted; and only 13% of the orders placed limits on the guardian’s authority.[[87]](#endnote-87)

Fifteen years later, a Utah ad hoc court committee made similar findings, concluding:

The appointment of a guardian or a conservator removes from a person a large part of what it means to be an adult: the ability to make decisions for oneself . . . We terminate this fundamental and basic right with all the procedural rigor of processing a traffic ticket.[[88]](#endnote-88)

Near the time of this report, a local a news agency had reported on its impressions from witnessing Utah’s court guardianship proceedings in action: “[I]t was startling how quickly someone could be stripped of all decision-making rights. Once the paperwork is in order, ‘hearings’ average seconds, not minutes.”[[89]](#endnote-89)

In its report, the court committee went on list findings that directly impacted the procedural and substantive due process rights of people at risk of or facing guardianship in the state:

* + The person subject to the guardianship proceeding was sometimes either not represented or represented by a lawyer recruited by the petitioner's lawyer.
	+ The lawyer for the person subject to the guardianship proceeding sometimes acted as a guardian ad litem, acting in the perceived best interest rather than as an advocate for the person.
	+ There was no-to-minimal procedure for the person subject to the guardianship petition to elicit and challenge evidence, and the evidence of incapacity itself was cursory.
	+ Once appointed, guardians were often given the broader authority of a conservator regardless of whether that authority was warranted by the respondent's circumstances.
	+ While statutes claimed to prefer limited authority for guardians and conservators, they failed to describe less restrictive alternatives.
	+ Plenary appointments were common with little evidence to support the need.
	+ There was no planning to help the person live life as independently as possible.
	+ There was no regulation of professional guardians.
	+ There was little education or assistance for family guardians.
	+ There was little training for judges and clerks.[[90]](#endnote-90)

Based on reports in other jurisdictions[[91]](#endnote-91) and recent scholarship, Utah’s court committee is not alone in making these kinds of findings. Guardianship hearings are often brief, relying on incomplete or illegible information, and result in plenary appointments.[[92]](#endnote-92) When courts do limit the guardian’s authority, the community may nevertheless treat the person as globally incapacitated. Moreover, the person under guardianship may not be seen as having an “enforceable right” to participate in decision-making in his or her own life; the court proceeding itself can be stigmatizing; and courts frequently do not actively orat its own provocation consider alternatives to guardianship prior to appointment.[[93]](#endnote-93) In this way, the Utah report serves as a worthwhile introduction to the last decade of scholarship in this area.

**II. Guardianship and Barriers to Fair Treatment**

Based on this review, people at risk of or subject to guardianship face many barriers to fair treatment by the legal system. These barriers include problems accessing zealous representation; the overuse of plenary guardianship; disability-specific guardianship processes that raise due process concerns; the inadequacy of capacity assessments used to remove rights; the lack of court oversight of guardians; caseloads spiraling upward; and poor data collection and management.[[94]](#endnote-94)

1. **Right and Role of Counsel**

As in the Utah analysis, some commentators have raised concerns that people facing or under guardianship cannot access independent counsel. In analyzing this potential barrier, it is useful to compare the factors involved in a person having meaningful access to an attorney during the initial guardianship process, as compared to a guardianship hearing post-appointment.

* + 1. **Pre-Appointment of Guardian**

Based on an American Bar Association Commission on Law and Aging review,[[95]](#endnote-95) states generally recognize some form of a right to counsel for alleged incapacitated people in pre-appointment guardianship proceedings. However, depending on the state, that right to counsel may be qualified – e.g., by requiring appointment only when the person requests or wants to contest the guardianship, allowing the court discretion to appoint an attorney at all, requiring the person to bear the burden of the legal and expert fees, limiting a person’s choice of attorney; and/or prescribing the role the attorney plays in the proceeding (i.e., advocate of best interest versus the expressed wishes of the person).[[96]](#endnote-96) This may mean, in practice, that the appointment of an attorney to advocate for the person’s wishes in pre-appointment proceedings may not always occur.[[97]](#endnote-97)

The question of the role of the lawyer representing the person in pre-appointment proceedings has been much debated, with most commentators appearing to argue that, without a competent and zealous advocate, the person may face unnecessary restrictions on liberty, due process, and autonomy without a competent and zealous advocate.[[98]](#endnote-98)

**2. Post-Appointment of Guardian**

Some legal scholars argue that, for due process to be met, it is essential that people under guardianship be able to secure counsel in restoration proceedings.[[99]](#endnote-99) Restoration proceedings are post-guardianship-appointment proceedings petitioned for by interested party seeking for the court to restore the rights of the person under guardianship restored. Yet only 12 jurisdictions, including the District of Columbia, statutorily require the court to appoint counsel for unrepresented people under guardianship in such proceedings.[[100]](#endnote-100)

People under guardianship also face barriers in retaining/hiring their own counsel in such contexts. Case law is mixed, with some courts concluding the person’s right to contract with an attorney was removed by the guardianship order and others concluding due process grounds dictate otherwise.[[101]](#endnote-101) A recent legal analysis came firmly down on the latter side and recommended changes to the Model Rules of Professional Conduct to clarify attorney’s duties in this context.[[102]](#endnote-102) However, without that rule clarification, attorneys may be unwilling to represent the person, due to ethical concerns about the client’s legal capacity, perceived barriers to communication, uncertainty for recovering fees and costs, and perceptions that there is a low likelihood of success.[[103]](#endnote-103) Regardless, since people facing guardianship may have no-to-low income, they may not be financially able to independently pursue a restoration case.[[104]](#endnote-104) The extent to which legal service organizations and state Protection and Advocacy Systems may provide legal assistance in such cases is not known.[[105]](#endnote-105)

1. **Plenary Guardianship**

Empirical studies indicate that courts do not take advantage of the limited guardianship option and rarely limit a guardian’s authority.[[106]](#endnote-106) Most guardianship orders are not time-limited and so last until the subject’s death or a court modification or termination of the order – even though people’s capacity can change over time. For example, psychosocial conditions are often temporary or episodic, and people may experience improvement or fully recover their decision-making capabilities within a reasonably short time period. These kinds of condition fluctuations are not generally appropriately accounted for in either the initial decision to appoint a guardian or in the duration of the guardianship order.[[107]](#endnote-107)

“As long as the law permits plenary guardianship, courts will prefer to use it,” even though such guardianships are only appropriate in a sub-set of cases.[[108]](#endnote-108) Courts may make more global assessments of incapacity than are actually justified, based on stereotypes that lead them to undervalue the competencies and/or credibility of people with certain conditions, such as psychosocial conditions or intellectual and developmental disabilities.[[109]](#endnote-109) Courts may also not make the proper distinction between what they perceive as the rationality of a person’s decision and what that person’s actual ability to make a decision is. Additional factors may be a court wanting to err on the side of protection, experiencing difficulties in determining the exact areas of decision-making in need of assistance, desiring to avoid confusion about the scope of the guardian’s authority, and wishing to promote judicial economy by avoiding future proceedings to expand the scope.[[110]](#endnote-110)

1. **Capacity Assessments**

Ordering guardianship requires a court determination that a person lacks the capacity to make some or all decisions, which – under the current state guardianship systems – is generally based on evidence in the form of a capacity assessment. Historically, the standard of competency for guardianship was an “all or nothing” test, and only recently has decisional capacity started to be viewed along a continuum.[[111]](#endnote-111)

However, there is extreme variability across in the nation as to the nature and quality of such assessments,[[112]](#endnote-112) vague standards for court determination of capacity,[[113]](#endnote-113) and wide discretion at the court level[[114]](#endnote-114) that may result in disparate or unfair treatment of people with disabilities. Researchers have found that some guardianship appears to be ordered without sufficient evidence of the person’s decision-making incapacity.[[115]](#endnote-115) Guardians are sometimes appointed on the sole basis of a person’s diagnosis or intelligence scale scores.[[116]](#endnote-116) The evidence supporting the determination of competency is known to be highly subjective, and, in some states, can involve a simple statement by one or two doctors that a person has a particular diagnosis.[[117]](#endnote-117) In many instances, disability status alone still is used to determine the need for guardianship, rather than a thorough analysis of the person’s individual characteristics, functional abilities, environmental demands, and supports available or necessary for decision-making.[[118]](#endnote-118) This comes despite the fact that reform efforts have sought to shift guardianship laws from a medical model of capacity to a model that assesses an person’s functional abilities.[[119]](#endnote-119) Moreover, clinical evaluations in this context are often conducted by medical professionals who lack specialized training on how to conduct nuanced assessments of capacity and who do not recognize that doing so is different than evaluating a person’s ability to provide informed consent to medical care.[[120]](#endnote-120) In addition, such assessments frequently do not consider supports available and alternatives to guardianship.[[121]](#endnote-121)

Medical professionals have been urged to shift away from global declarations of competency based on diagnoses to a more complex and functional definition that can be used by courts as evidence warranting more limited guardianship orders. The National College of Probate Judges, the American Bar Association, and the American Psychological Association have set out core elements for clinicians to address in providing capacity evaluations to courts in guardianship proceedings. These six elements are: (1) the specific medical condition causing diminished capacity; (2) its effect on cognition; (3) its effect on the person’s everyday functioning; (4) the person’s values and preferences; (5) past or imminent risks; and (6) means to enhance capacity, such as assistive technology or medication.[[122]](#endnote-122) For implementation of such an approach, training and collaboration between legal and health communities is warranted, as is consultations between physicians and behaviorist or psychologists.[[123]](#endnote-123) Fair assessments must also include consideration of available alternatives to guardianships in a way that “balances personal autonomy with protection.”[[124]](#endnote-124)

1. **Disability Specific Guardianship Processes**

Most states have a single guardianship law that covers people with all kinds of disabilities, such as older people with progressive cognitive decline, people with psychosocial disabilities, and people with intellectual and developmental disabilities. Scholars have identified five states, including California, Connecticut, Idaho, Michigan, and New York, which have separate guardianship statutes specifically covering people with IDD.[[125]](#endnote-125) Some states have adopted streamlined procedures for appointing plenary guardians for individuals with disabilities.[[126]](#endnote-126) All may raise due process concerns.

There are additional states that have certain alternatives to standard guardianship that, in effect, amount to the same result as guardianship in many ways. As such, they may be seen as circumventing the due process rights of people with certain kinds of diagnoses, as compared to others. For example, Florida has a legal process for guardian advocacy that is only available to people with particular developmental disabilities. Rather than requiring Florida’s standard determination of incapacity by an “examining committee” of experts, the judge may use educational evaluations, Individualized Education Plans, and other support plans to determine whether the person “needs” a guardian advocate appointed to exercise certain rights. If so, that guardian advocate will essentially have the duties and responsibilities as a guardian under Florida law.[[127]](#endnote-127)

[**Cross-Reference:** Research Question 3, Part III.]

1. **Standard for Guardian’s Decisions**

Many U.S. guardianship laws, policies, and practices lack clear guidelines for how a guardian should make decisions for the ward. Some state’s laws require the guardian to consult with the ward in making decisions; some do not. Some require the guardian to make decisions according to the expressed or implied wishes of the person, while others may require the so-called “best interest standard”[[128]](#endnote-128) to be used. Encouraging states to adopt consistent standards that promote the person’s exercise of decision-making would further the goals of promoting self-determination and better life outcomes.

[**Cross-Reference**: Research Question 4, Part III.A.]

1. **Post-Appointment Monitoring**

After a guardian is appointed, the court should hold the guardian accountable for the duration of the guardianship.[[129]](#endnote-129) The National Probate Court Standards indicate that courts have an ongoing responsibility to ensure that the guardianship terms remain consistent with the needs of the person under guardianship.[[130]](#endnote-130) Periodic reports by the guardian to the court are important to facilitate judicial review.[[131]](#endnote-131)

Yet, active monitoring of guardianship is one of the most significant challenges facing courts today. When the guardian is appointed, many courts do not follow up with him or her, which makes it difficult to assess whether the guardian is meeting the needs of the person or whether the person is at risk of neglect or abuse.[[132]](#endnote-132) In addition, research has found that not all courts consistently enforce their jurisdiction’s mandates, and not all status reports are required to include evidence of the person’s continued incapacity or the continued need for guardianship. Few states require the guardian to report on efforts to restore the person’s capacity.[[133]](#endnote-133)

Also, a 2005 survey found that a significant portion of guardian reports are not independently verified.[[134]](#endnote-134) While a growing number of courts have staff or volunteers perform check-ins on guardianship, such visitors may not report to the court on capacity changes and judges may not act on their reports.[[135]](#endnote-135) Where there is inadequate oversight and no one petitions the court for restoration, courts may not be aware of improvements in a person’s capacity or the need for review of the scope of the guardianship order.[[136]](#endnote-136) Thus, there is likely an unknown population of people under guardianship who would not be, if more active monitoring and court tracking existed within the guardianship systems.[[137]](#endnote-137)

**G. Other Issues with Rights Restoration Proceedings**

While there has been a survey of statutory restoration provisions across U.S. states,[[138]](#endnote-138) actual implementation of those procedures is “unclear, ambiguous, and appears to vary significantly by state, court, and judge.[[139]](#endnote-139) Most states’ laws allow any interested person to petition for the restoration of rights of a person under guardianship. In addition, most state laws provide for written notice to interested parties of such petitions and the holding of a court hearing.[[140]](#endnote-140) However, restoration of rights “is surprisingly underutilized and, at least with regard to reported decisions, under-litigated.”[[141]](#endnote-141)

Once a guardianship is ordered, it can be difficult to modify or terminate it, even when it is no longer necessary for the person[[142]](#endnote-142) because there was only a temporary loss of capacity or there are less restrictive alternative decision-making supports available. Admittedly, in a 2015 survey of case law on guardianship restoration, legal scholars noted an evolution in terminology and attitudes over the last century, with court decisions law moving from “an overtly paternalistic and protective approach to a more person-centered focus on the [person’s] ability to make and communicate decisions.”[[143]](#endnote-143) However, the actual decisions reached varied in terms of outcome – with some courts or judges promoting the person’s “dignity of risk” and others denying restoration, despite evidence of capacity, because of concern the person would make harmful decisions.[[144]](#endnote-144) Overcoming paternalism and negative societal attitudes about mental disability or age can be a strong barrier to restoration efforts.[[145]](#endnote-145)

For the vast majority of people under guardianship, “there will not be a return to liberty.”[[146]](#endnote-146) Guardianship orders rarely have a limited duration and often continue until the death of the person under guardianship or subsequent order of the court.[[147]](#endnote-147) While the right to petition for restoration is generally part of the due process protection for people under guardianship, petitions for restoration are uncommon.[[148]](#endnote-148) One study also indicated that the right to petition for restoration was not exercised evenly across disability populations, with 51% of the collected cases identifying disability involving older people, 19% involving people with traumatic brain injuries, 16% involving people with mental illness, and 14% involving people with intellectual or developmental disabilities.[[149]](#endnote-149) This may point to disability-specific barriers to court access, which should be explored and addressed if substantiated.

While many state legislatures have taken efforts to expand access to the court system by, e.g., permitting informal requests for restoration or allowing any interested party to petition for restoration on the person’s behalf, questions remain whether that access is adequate in practical terms.[[150]](#endnote-150) Based on the 2015 restoration case review, there appeared to be “at least some reasonable access to the judicial process;” however, the study concluded that there may be an “unknown number of [people subject to guardianship] who have regained capacity, but have not pursued restoration.”[[151]](#endnote-151)

Other identified legal and procedural barriers in restoration cases have to do with who bears the burden of proof and what does that burden look like, given the person has already been adjudicated incompetent. Based on the 2015 case review, the answer to both of these questions varies depending on the jurisdiction, court, and case.[[152]](#endnote-152) In addition, guardian opposition to petitions for restoration can create barriers for people under guardianship, particularly if the court finds them liable for the fees the guardian generated in challenging the petition.[[153]](#endnote-153)

Due process protections require meaningful access to pursue restoration, including clear rules and a streamlined procedural process, as well as the opportunity and ability to make restoration requests and the assurance that they are required to be promptly responded to by the court system.[[154]](#endnote-154) The 2015 review included other recommendations for improving the treatment of people under guardianship in the restoration context, including improving judicial databases (e.g., by including data points specific to restoration, so the numbers of petitions and their outcomes are known) and raising awareness of the right to pursue restoration (e.g., by including that right in the initial order of guardian appointment,[[155]](#endnote-155) as well as educational material with that order, through court staff, and on court websites. In addition, the 2015 review recommended that state efforts be made to avoid overbroad or undue guardianship in the first place, by requiring, during initial guardianship proceedings, mandated and nuanced assessments of cognitive and functional abilities, consideration of less restrictive alternatives, and limitations on the scope of guardianship orders.

The ABA Commission on Law and Aging is completing its 2015-2016 Court File Research on Restoration, and its report and recommendations is pending finalization and publication.

[**Cross-Reference:** Research Question 3, Part III]

**Research Question 3: How does the current use of guardianship align or conflict with other U.S. national disability policy goals and initiatives, including the goals of the Americans with Disabilities Act and its community integration mandate and principles of due process under the law?**

With respect to whether guardianship aligns or conflicts with other U.S. national disability policy goals and initiatives, arguments have been made on both sides, with reference to the Americans with Disabilities Act; the school-to-adult transition process required by the Individuals with Disabilities in Education Improvement Act and Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunities Act of 2014; and due process and equal protection rights under the U.S. Constitution. We describe this debate further below. Discussion of the way in which guardianship may align or conflict with person-centered planning and choice requirements under the Center for Medicare and Medicaid Services (CMS) home-and-community-based settings rules and policy is discussed elsewhere and cross-referenced below.

1. **Americans with Disabilities Act & U.S. Supreme Court Olmstead Decision**

There is debate in scholarship as to whether the U.S. guardianship system, as it currently functions, conflicts with the Americans with Disabilities Act of 1990 (“ADA”), 42 U.S.C. §§ 12101-12213 (2013) (amended 2008) and unlawfully discriminates against people with disabilities.

**A. Guardianship as Conflicting with the Americans with Disabilities Act**

**1. Argument**

Some legal scholars argue that the current use of guardianship laws in the United States may violate the integration mandate of Title II of the Americans with Disabilities Act of 1990 (“ADA”), 42 U.S.C. §§ 12101-12213 (2013) (amended 2008).[[156]](#endnote-156) According to their legal analysis, by limiting a person’sright to make his or her own decisions, guardianship marginalizes and often imposes a form of segregation or “constructive isolation” that runs contrary to the ADA’s mandate to provide services in the most integrated and least restrictive manner, as interpreted by the U.S. Supreme Court in *Olmstead v. L.C. ex rel. Zimring,* 527 U.S. 581 (1999).[[157]](#endnote-157) In addition, when the *Olmstead* Court linked unjustified isolation to disability-related discrimination, it expressed concern that segregation would perpetuate disparaging stereotypes of the abilities and value of people with disabilities and decrease their opportunities to enjoy the benefits of participating in community life – which has been said to be the consequence of guardianship, as well.[[158]](#endnote-158) The U.S. Department of Justice has taken the position that the integration mandate applies not only to institutionalization, but to any and all activities of a public entity.[[159]](#endnote-159) Guardianship can involve multiple “instrumentalities of state and local government,” including local government agencies, organizational guardians contracted with those agencies to provide guardianship services, and the state courts themselves.[[160]](#endnote-160) Moreover, although some scholars disagree,[[161]](#endnote-161) studies have found that people under public guardianship may be at particular risk of institutional isolation[[162]](#endnote-162) – which raises additional concerns under the ADA and *Olmstead.*

**2. Recommendations**

Legal scholars who assert guardianship may violate the ADA have a number of recommendations for consideration. Some recommend that, under *Olmstead*, U.S. states be requiredto modify their current guardianship systems to specifically provide Supported Decision-Making as a less restrictive form of assistance than guardianship or substituted decision-making.[[163]](#endnote-163) In addition, some argue, the ADA integration mandate may require, before guardianship is imposed, for other less restrictive alternatives – such as advance directives, powers of attorney, joint accounts, representative payees, and trusts, to name a few – be considered and shown ineffective.[[164]](#endnote-164)

[**Cross-References**: Research Question 4 (Supported Decision-Making and Research Question 5 (Other Alternatives to Guardianship).]

Another recommendation includes state and/or federal investment in services and supports, such as person-centered planners and self-advocate mentors, to teach people and their family, friends, and how to promote their supported decision-making and community integration.[[165]](#endnote-165) One avenue of such funding may be through the Center for Medicare and Medicaid Services federal Home and Community Based Waiver Programs, given recent regulatory changes that advance personal choice and person-centered planning requirements.[[166]](#endnote-166)

Finally, some advocates have recommended a targeted “*Olmstead* advocacy” strategy to ensure that people in or at risk of organizational or public guardianship have access to community-based living and employment support and services. That strategy would include advocates reviewing available policies, procedures, and data at the guardian, state, and local government agency levels, and engaging in activism and representation at the individual and systemic level.[[167]](#endnote-167)

**B. Guardianship as Aligning with the Americans with Disabilities Act**

**1. Argument**

In contrast, another scholar, Eleanor Cashmore, asserts that, with proper oversight, public guardianship can help a state fulfill its ADA integration mandates. Under this argument, guardians can help the person with a disability navigate the housing system to obtain or maintain community living and avoid moving to or remaining in institutions such as nursing homes.[[168]](#endnote-168)

**2. Recommendations**

Cashmore recommends a social service agency model of public guardianship to meet *Olmstead* mandates, given employees at agencies providing direct services know people’s situations, are trained in advocacy and the needs of the populations they serve, and are familiar with guardianship procedures.[[169]](#endnote-169) However, she argues, states must also ensure proper oversight of the public guardians, including establishing written policies, developing uniform reporting forms and requirements. Public guardianships statutes should also emphasize that temporary or partial guardianship should be granted whenever possible, to respect a person’s autonomy while providing him or her with the assistance needed to remain in the community.[[170]](#endnote-170)

1. **Individuals with Disabilities in Education Improvement Act (IDEA)
and Related U.S. Law on Transition Planning for Students with Disabilities**

Scholars have identified an internal conflict within the provisions of the IDEA when it comes to guardianship. On the one hand, it mandates robust transition planning that would support student self-determination. On the other hand, it arguably promotes the creation and availability of additional, extra-judicial surrogate or substitute decision-making regimes that remove the right of the adult student to make decisions about his or her educational programming. That tension in federal policy as it relates to guardianship in the educational and transition context is explored in depth below.

**A. Guardianship as Conflicting with IDEA and Related Law**

Some scholars have opined that guardianship for young adults with disabilities runs contrary to the language and purpose of the Individuals with Disabilities in Education Improvement Act (“IDEIA” or “IDEA”), 20 U.S.C §§1400 et seq. (2013) (amended 2004).[[171]](#endnote-171) The IDEA mandates individualized transition planning for qualified students with disabilities to increase the likelihood of post-school employment and/or education.[[172]](#endnote-172) Transition planning outcomes should be tailored to students and their individual preferences, needs, and strengths, so they should contribute actively to the decision-making and planning process.[[173]](#endnote-173) With that in mind, “[t]he goals of transition planning, which focus on autonomy and independence, appear to be in direct conflict with the goal of guardianship, which is to facilitate the individual’s dependence on another person’s authority to make all or some of their decisions.”[[174]](#endnote-174)

As one team of researchers went on to observe, guardianship “can work against the goals of transition planning,” because it has broad implications regarding the loss of fundamental rights and personal liberty.[[175]](#endnote-175) Studies have found that students who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes.[[176]](#endnote-176) Moreover, promoting self-determination is a “best practice” in special education.[[177]](#endnote-177) Schools should focus on improving students’ ability to set goals, solve problems, make decisions and advocate for themselves and, just as importantly, give students the opportunity to exercise these skills,[[178]](#endnote-178) rather than refer the students’ parents to guardianship when the students reach transition age and are approaching adulthood. Yet, troubling enough, based on another study, schools are the most frequent source of such referrals.[[179]](#endnote-179)

**B. Guardianship as Aligning with IDEA and Related Law**

Paradoxically, some of those same scholars note that there are “traces of guardianship” built into the IDEA, and that those provisions may set into motion the appointment of guardians during the transition planning process.[[180]](#endnote-180)

The IDEA generally requires, once a student with a disability reaches the age of majority, for the school to transfer all of his or her parent’s educational rights to the student as part of the transition planning process.[[181]](#endnote-181) When that occurs, the student has the right to make all educational decisions on his own, or with the assistance of a parent or other adult, if he or she chooses.[[182]](#endnote-182) However, under the IDEA, the transfer of rights will not occur if the adult child is subject to guardianship or if the school uses a separately established extra-judicial process to determine that the student cannot provide informed consent to educational decisions and to appoint, e.g., a family member, as the adult student’s educational representative.[[183]](#endnote-183) It is at the transfer-of-rights “juncture” that we see parents and school personnel questioning the competence of students, and we see parents seeking to become the legal guardian of their young adult children.[[184]](#endnote-184)

At this point in the IDEA transition process, guardianship can be set in motion by a variety of factors. First, intentionally or unintentionally, school professionals may be biasing parents towards pursuing guardianship because of the way in which they notify them of the transfer-of-rights process. For example, they may start the conversation by asking parents if they have guardianship or are planning to obtain guardianship, rather than discussing the students strengths and abilities and the less restrictive options of decision-making support. Such conversations may pressure parents to pursue guardianship over their child, when they might not otherwise do so,[[185]](#endnote-185) so that they are assured they can continue to be involved in the educational process and to advocate for the special education services their child needs.

Second, while IDEA does not require appointment of a guardian for adult students in special education, it does allow – and arguably mandate – that states establish alternative procedures – short of guardianship and consistent with state law – for the appointment of the parent or other person to represent the educational interests of an adult student, if the school district determines that the student is unable to provide informed consent to his or her education program.[[186]](#endnote-186) Such extra-judicial processes raise due process concerns, in that rights are being taken away from the student without court adjudication. They also promote substitute or surrogate decision-making – rather than supported decision-making (see Part V below) – in the educational context. Parents may feel compelled to pursue that route because they are not aware of alternatives and want to ensure they remain involved.[[187]](#endnote-187)

**C. Related Recommendations**

Given this tension within the IDEA, scholars and advocates recommend people with disabilities, their families, and educators be informed of alternative decision-making support options – such as person-centered planning, supported decision-making, and other options – that do not result in the appointment of guardians. Schools must shift the decision-making paradigm to one that “presumes competence” of young adults with disabilities, so that the focus is on what the student can do and what supports are necessary to meet his or her individualized goals and needs through transition planning.[[188]](#endnote-188)

Moreover, when it comes to transition services that promote self-determination, independent living skills, and decision-making, special education teams and vocational rehabilitation programming should work in tandem, pursuant to requirements of the Rehabilitation Act of 1973, as amended by the Workforce Innovation and Opportunities Act of 2014.[[189]](#endnote-189)

Schools should provide information and training to teachers, parents, and students on the pros and cons of guardianship and alternatives early in the educational process; delete all reference to guardianship in their school materials to eliminate undue influence; offer support to families to explore and use alternatives to guardianship that focus on supporting decision-making abilities of the student; and collaboratively develop a plan to prevent the perceived needs for a guardian, including Individualized Education Program (“IEP”) goals and objectives designed promote decision-making skill building to avoid guardianship.[[190]](#endnote-190)

[**Cross-References:** Research Question 4 (Supported Decision-Making), Research Question 5 (Other Alternatives), and Research Question 6 (Education of Parents and People with Disabilities on Guardianship and Alternatives)]

1. **Procedural and Substantive Due Process Concerns**

This review has described ways in which people with disabilities are not receiving fair treatment within and across legal systems pertaining to guardianship. Some scholars have expressly described these issues as ones that violate people’s rights under the U.S. Constitution,[[191]](#endnote-191) while others have disagreed.[[192]](#endnote-192) [**Cross-Reference**: see Research Question 2, Part II above.]

This review has also noted that some U.S. states have separate guardianship statutes for people with developmental disabilities that permit them fewer due process rights than other people (see Research Question 2, Part II.D),[[193]](#endnote-193) and that scholars have challenged some of the laws on constitutional grounds [**Cross-Reference:** see Research Question 2, Part II.D]

For example, New York’s guardianship law has been under intense scrutiny in this regard. New York maintains two separate systems of guardianship for people with disabilities – i.e., Article 17-A of the Surrogate Court’s Procedure Act for people with developmental disabilities and Article 18 of the Mental Health Hygiene Law for all other people. Under the former, the basis for appointing a guardian is driven by diagnosis, rather than functionality. It also has less rigorous procedural requirements than Article 18 of the Mental Health Hygiene Law – e.g., a hearing on the guardianship petition is not required; the person with a disability does not have to be present; the guardianship cannot be limited; and guardians’ decisions are based on a “best interest,” rather than a substituted judgement, standard. As a result, one committee found that, the New York SCP 17-A 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.”[[194]](#endnote-194)

The Committee went on to find that the statutes of other states that deal separately with guardianship for this IDD population, including California, Connecticut, Idaho, and Michigan, provided more protections than Article 17-A. [[195]](#endnote-195) The Committee notes that, unlike New York, the other states ensured that the least restrictive means for the protection and wellbeing of the person under guardianship are met, through mandatory periodic review or time-limited guardianship.[[196]](#endnote-196)

The New York Olmstead Cabinet made similar conclusions to this Committee, and recommended reform on the basis of the ADA, finding that “[c]ommunity integration includes the ability of people with disabilities to make their own choices to the maximum extent possible,” and that guardianship “should, consistent with *Olmstead* only be imposed if necessary and in the least restrictive matter.”[[197]](#endnote-197) [**Cross-Reference:** Research Question 3, Part I.A.]

1. **Federal Medicaid Law & Person-Centered Planning**

**[Cross-Reference]** For a discussion of the way in which guardianship may align or conflict with person-centered planning and choice requirements under the CMS Home and Community Based Settings rules, please see: (1) Research Question 1, Part III.C, ¶¶ 2-3; (2) Research Question 3, Part I.A.2, ¶ 2; and (3) Research Question 4, Part III.A. ¶ 2.

**Research Question 4: Is supported decision-making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?**

Supported Decision-Making (“SDM”) is an emerging, national and internationally recognized alternative to guardianship that is currently in use, both in U.S. states and abroad. It has been recognized by scholars as having the strong potential for resulting in favorable outcomes in the lives of people with disabilities, and studies are underway to verify that that is the case.

1. **Definition of SDM and Its Connection to the Convention on the Rights
of People with Disabilities**

SDM is receiving national and international attention, because of concerns raised by advocates and legal scholars about the limitations of substituted decision-making arrangements (such as guardianship or conservatorship) place on the ability of people with disabilities to exercise autonomy and self-determination,[[198]](#endnote-198) and the need to shift systems towards a strength-based model of disability.[[199]](#endnote-199)

The United Nations Convention on the Rights of Persons with Disabilities (“CRPD”) brought SDM to the fore of internationally. Its Article 12 requires its State Parties to “recognize that persons with disabilities enjoy legal capacity on an equal basis to others in all aspects of life” and “take appropriate measure to provide access by a person with disabilities to the support they require in exercising their legal capacity.”[[200]](#endnote-200) The CRPD Committee clarified that: “[s]upported decision-making can take many forms;” supporters may help the person understand the choices at hand, communicate that person’s decisions to others, or even “help others realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.”[[201]](#endnote-201) Under SDM, it is the person with a disability who is the decision-maker; the supporter(s) explains the issues and may interpret the signs and preferences of the person to others. “Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to [his/her] wishes.”[[202]](#endnote-202) SDM offers a conceptual and practical alternative to substitute decision-making and it is designed to protect the right to autonomy with support, principles of equality, and non-discrimination based on disability.[[203]](#endnote-203)

While there is no singular definition or model of SDM,[[204]](#endnote-204) it generally occurs when people with disabilities use friends, family members, and professionals to help them understand the everyday situations and choices they face, so they may make their own decisions without the “need” for a substitute decision-maker, such as a guardian.[[205]](#endnote-205) One size does not fit all – i.e., SDM can look very different for different people and involve a number of formal or informal SDM tools. It can mean a person informally chooses another person or group of people that he or she trusts to provide assistance in making and communicating his or her own decisions to others. It may not be documented in a formal written agreement, although some SDM arrangements are to encourage third parties to rely on the decision made.[[206]](#endnote-206) Proponents argue that most adults with disabilities, are able to enter into an SDM Agreement, even if the law would not otherwise recognize them as having the “capacity” to enter into a contract, because an SDM agreement is not so much a contract, but rather an authorization; the adult with a disability authorizes another person(s) to advise and consult in that adult’s decision-making.[[207]](#endnote-207)

1. **Recognition and Implementation of SDM**

**A. International**

The CRPD entered into force on May 3, 2009, and has been ratified by at least 162 countries, with its results ranging from development of new laws, to including disability rights in national constitutions, to implementation on the ground.[[208]](#endnote-208) SDM has gained visible momentum in international academic journal articles, case law, regional courts and bodies, legislative reform, the creation of centers and institutes, non-peer reviewed publications, conferences and symposia, and UN activity.[[209]](#endnote-209) Countries have begun to conceptualize and, in some cases, implement SDM as a legal alternative to guardianship.[[210]](#endnote-210) Among others, the governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring adopting SDM.[[211]](#endnote-211)

**B. In the United States of America**

In recent years, guardianship in the U.S. has been the subject of significant reforms; however, unlike SDM, “they still accept the predominance of a legal regime that locates decision-making in the surrogate or guardian, and not in the individual being assisted.”[[212]](#endnote-212) In contrast to guardianship, SDM “retains the individual [with a disability] as the primary decision maker, while recognizing [he or she] may need assistance – and perhaps a great deal of it – in making and communicating a decision.”[[213]](#endnote-213) The move from substitute decision-making to SDM is a paradigm shift in how society thinks about the decision-making abilities of people with disabilities,[[214]](#endnote-214) and the U.S. has lagged behind the international community in moving that direction.[[215]](#endnote-215)

However, while the United States of America has not yet ratified the CRPD, SDM is being recognized, recommended, and, in certain cases, implemented by advocates, legislatures, policymakers, and courts in some U.S. states.

* **Case law –** Recent state or local case law, including cases out of New York and Virginia, have received attention by scholars, in that they either terminate or time limit guardianship in favor of SDM for people with intellectual disabilities.[[216]](#endnote-216) Additional relevant cases have been found in other states, including Pennsylvania and Massachusetts.[[217]](#endnote-217)
* **Statutes –** State legislatures have recognized SDM,[[218]](#endnote-218) including those that have codified SDM agreements as less restrictive alternatives to guardianship (Texas[[219]](#endnote-219) and Delaware[[220]](#endnote-220)), identified it as an option in special education (District of Columbia[[221]](#endnote-221)) and certain medical decisions (Maryland[[222]](#endnote-222)), or ordered studies and recommendations on it (Virginia[[223]](#endnote-223) and Maine[[224]](#endnote-224)).
* **Pilot Programs –** There have been or are SDM pilot programs in Texas, Massachusetts, and New York.[[225]](#endnote-225) Reported outcomes from these pilots are reported below.
* **Federally Sponsored National Resource Center –** In 2014, the Administration for Community Living (“ACL”) in the U.S. Department of Health and Human Services made funding available to create "a national training and technical assistance center on . . . supported decision-making." In doing so, ACL stated: "all people regardless of their disability or cognitive abilities have the right to make decisions and have those decisions implemented” and those concepts “inform and frame the conversation around developing the supported decision-making process.”[[226]](#endnote-226) In partnership with older adults, people with disabilities, attorneys, judges, professionals, and providers, the NRC-SDM goal is to conduct cutting-edge research, create educational programming, and gather and develop multidisciplinary best practices and tools, with the goal of advancing policy and practice to further establish SDM as a recognized and viable alternative to guardianship in the U.S.[[227]](#endnote-227) This effort has included offering small SDM grants to state coalitions, which have so far included ones in Delaware, Maine, Indiana, North Carolina, and Wisconsin.[[228]](#endnote-228)
* **Endorsements & SDM Summits** **–** SDM has been endorsed by the American Bar Association Commission on Law and Aging,[[229]](#endnote-229) the National Guardianship Association,[[230]](#endnote-230) as well as a number of federal advisory bodies.[[231]](#endnote-231) In 2012, the American Bar Association ("ABA") convened a stakeholder summit entitled "Beyond Guardianship: Supported Decision-Making by Persons with Intellectual Disabilities," with the goal "to explore concrete ways to move from a model of supported decision-making, consistent with the human right of legal capacity."[[232]](#endnote-232) In 2013, Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, and the Council on Quality and Leadership convened a group of 65 national and international thought leaders for an Invitational Symposium to discuss principles of education, research, and advocacy to guide future actions to advance SDM, which resulted in a report.[[233]](#endnote-233)
* **Practice Guides & Forms –** NRC-SDM has compiled SDM tools and guides on its web portal, [www.SupportedDecisionMaking.org](http://www.SupportedDecisionMaking.org), and highlighted them in the over 60 presentations completed across the nation in the last six months. Some are already being used in cases in D.C. and California.[[234]](#endnote-234) The Maine and North Carolina NRC-SDM grantees have developed and used SDM forms in their states.[[235]](#endnote-235)
1. **SDM & Outcomes**
2. **Benefits of Self-Determination & Research Recommendations**

According to numerous scholars and advocates, SDM has the potential to provide people with disabilities the support needed to understand the choices they have, while ensuring that they still retain ultimate legal decision-making authority,[[236]](#endnote-236) unlike guardianship. In discussing potential outcomes of that approach, they point to studies that have found that people with intellectual and developmental disabilities who exercise greater self-determination – who are “causal agents” with more control over their lives[[237]](#endnote-237) – have better life outcomes and quality of life,[[238]](#endnote-238) including being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse. They also point to research showing older adults with more self-determination have improved psychological health, including better adjustment to increased care needs,[[239]](#endnote-239) and that self-determination is linked to better life outcomes for youth in foster care[[240]](#endnote-240) and students with disabilities.[[241]](#endnote-241) The component elements of self-determined behavior include self-advocacy, goal setting and attainment, self-awareness, problem-solving skills, and decision-making skills.[[242]](#endnote-242)

Some scholars and advocates conclude that SDM “not only furthers the goal of CRPD and international law, but it also advances the overarching aims of US law,”[[243]](#endnote-243)

furthers federal policy goals, including those under: (1) the Americans with Disabilities, because of the link between self-determination and community integration;[[244]](#endnote-244) (2) the Individuals with Disabilities Education Act, because of the link between self-determination and successful school-to-adult transition;[[245]](#endnote-245) (3) the Rehabilitation Act, because of the link between self-determination and improved employment outcomes;[[246]](#endnote-246) and (4) to Medicaid and Home and Community Based Services regulations, because of the link to person-centered planning.[[247]](#endnote-247)

Research has shown that people with intellectual and developmental disabilities learn through the process of making decisions,[[248]](#endnote-248) and that self-determination, if taught, also can be learned,[[249]](#endnote-249) and older adults with progressive dementia are more likely to retain cognitive function when they use their cognitive skills.[[250]](#endnote-250) While one scholar concluded SDM appears to have less momentum in the context of senior care and elder services than people with intellectual and developmental disabilities,[[251]](#endnote-251) another legal practitioner sought to promote SDM in elder law practice, by maximizing older people’s capacity through accommodation of sensory loss and cognitive impairment, as required by the ADA and engaging in “gradual counseling” and helping a person build and use a trusted network of support to help clarify goals, values, and lifetime commitments.[[252]](#endnote-252) Another scholar concluded a formal program of decision-making supports significantly limits “the deleterious and segregating effect of guardianship on [people] with psychosocial conditions.”[[253]](#endnote-253)

According to some scholars, the greatest barrier to full implementation of SDM is the lack of reliable data specifically tying it – and not only the concept of self-determination, which has been highly studied – to improved life outcomes.[[254]](#endnote-254) This research should include people with severe intellectual disabilities.[[255]](#endnote-255) To better guide SDM models,[[256]](#endnote-256) validated empirical evidence is needed regarding best practices in SDM, including effective and support structures and methods, and whether people who engage in SDM are more self-determined, autonomous, experience better life satisfaction, and achieve meaningful community living and participation.[[257]](#endnote-257) There is also little evidence on how SDM is utilized in jurisdictions in which is being used, including the number of SDM arrangements and lack of demographic data for who is using SDM, who is acting as supporters,[[258]](#endnote-258) and how SDM can work for people with severe intellectual disabilities.[[259]](#endnote-259) Regardless, SDM should be explored as an alternative to guardianship, given the identified problems with guardianships impact on people’s lives.[[260]](#endnote-260)

To help fill this research gap, the NRC-SDM is conducting various qualitative and quantitative studies to document the nature, use, barriers to, and outcomes of SDM by older adults and people with intellectual and developmental disabilities.[[261]](#endnote-261) One has been completed. NRC-SDM published a final report on an online survey it collected on stories of SDM successes and challenges relating to people with IDD. Responders included individuals, family members, advocates, and providers from across the country. The results suggested that the majority of participants with IDD, with or without guardianship, reported that SDM brought greater confidence, the ability to do more things, and greater happiness. Those participants with IDD who did not have a guardian identified friends and parents most often as those that help with decisions. Fifty-eight percent of non-guardian supporters reported have the person’s competency challenged, including by service providers, school systems, family members, neighbors, doctors and medical professionals and employees. Most of the non-guardian supporters did not negotiate a formal SDM agreement with the person. The survey also supported the need to educate others on SDM, especially people with disabilities, family members, teachers, school administrators, service and health providers, lawyers, and judges; the need for more research on SDM in practice; and the need to educate parents about the SDM option before their child with IDD reaches the age of 18.[[262]](#endnote-262)

**B. International Outcomes & Recommendations**

Preliminary reviews of SDM implementation across Canada indicate that communities often use less-formal SDM methods at first and use formal representation agreements or other mechanisms as needed to obtain third-party recognition. Despite the process and use of SDM evolving over twenty years,[[263]](#endnote-263) researchers have found that there is still a need for education and greater awareness of SDM and how it can be used more effectively – i.e., just having an SDM regime in law is not enough.[[264]](#endnote-264) Individuals and third party institutions need practical training to help people use SDM.[[265]](#endnote-265) Canada’s implementation also concluded that there is a need for more research examining the nature of SDM models in practice and their outcomes.[[266]](#endnote-266) Canada’s experience also suggested that SDM was not being used across all disabilities in the country, but rather focused on younger adults with “mild to moderate” intellectual disabilities and actively engaged circles of support, and not older adults with cognitive impairments or people with psycho-social disabilities.[[267]](#endnote-267)

In Australia, the government has conducted small trials of SDM in various jurisdictions and commissioned evaluations of them. While the research is not able to be widely generalized because of the limited nature of the trials, evaluators found that SDM led to positive outcomes for participants, e.g., participants experienced greater community inclusion, improved decision-making skills, increased social and support networks, and increased self-confidence. The Australian consensus is that models of SDM are diverse and there is a need for more empirical research of SDM models and their outcomes.[[268]](#endnote-268) Recommendations include training family members and other supporters on understanding what the fundamental philosophy behind SDM is; how to use strategies of communication and conflict resolution; how to manage power differentials and the risk of undue influence; how to balance enabling rights and managing risk; and how to collaborate with other supporters. Training was also needed for third-party practitioners on understanding SDM and the differing roles of supporters.[[269]](#endnote-269)

Scholars point to Inclusion Europe for guidance on implementing SDM.[[270]](#endnote-270) Inclusion Europe is an organization that advocates for the human rights of people with intellectual disabilities. In 2008, it issued a position paper identifying eight key elements of a system of SDM:

1. Promoting and supporting self-advocacy – States Parties must ensure that self-advocacy skills are included in school curricula and that they support and promote self-advocacy organizations.
2. Using “mainstream mechanisms” for the protection of the best interests of the person – These mechanisms include, e.g., consumer protection and information, legal protection for tenants, and rights of medical patients, transport users, and employees. They should be made accessible, accommodating, and inclusive to people with intellectual disabilities and are preferable to using “special procedures” developed to protect people with disabilities.
3. Replacing traditional guardianship by a system of SDM – This will include a transition period from guardianship to support
4. Using SDM – Look to a formal system of support with registered supporters only for “essential and important decisions of legal relevance.” For many every day decisions, informal support networks are sufficient and should be used whenever possible.
5. Selecting and registering support people – Supporters are selected by the person and may be numerous. Jurisdictions need a registration system to allow supporters to be officially recognized and provide third parties with assurance that they are authorized to assist the person with a disability. It also will ensure supporters receive mandatory and regular training.
6. Overcoming communication barriers – When necessary, augmentative and alternative means of communication must be used. States must recognize that all forms of communication are valid and not a reason to question a person’s decision-making ability.
7. Preventing and resolving conflicts between supporter and supported person – This requires supporters to be able to demonstrate that they have informed the person “by all possible appropriate means” about the consequences of any important decision. States must also create a mechanism to prevent abuses, e.g., nullifying contracts where abuse has occurred, as well as easily accessible out-of-court procedures to resolve conflicts between the person and the supporter.
8. Implementing safeguards – These safeguards must ensure that there is a level of proportionality in the support provided – i.e., the safeguards are higher when a person has a higher degree of disability, higher support needs, or the decision will have a higher impact on the person’s life.[[271]](#endnote-271)

Along these same lines, Michael Bach has identified Canada’s three common SDM elements, which:

1. Are based on guiding principles of autonomy, presumption of capacity, and the right to make decisions on an equal basis with others.
2. Recognize that the basis of a decision-making process can be formed by a person’s intent without removal of the person’s decision-making rights.
3. Acknowledge that people with disabilities will often need assistance in decision-making through, for example, interrupter assistance, facilitated communication, assistive technologies, and plain language.[[272]](#endnote-272)

**C. U.S. State Outcomes & Recommendations**

As referenced above, there have been and continue to be pilot projects for SDM in the United States, in addition to the work done by the NRC-SDM state grantees. For example:

* **Texas Volunteer SDM Advocate Pilot (2011–2012) –** This pilot resulted from H.B. 1454, 81st Texas Legislation (2009) and started before the Texas SDM statute was passed. It focused on people with IDD and other cognitive impairments who lived in the community. The Texas Council of Developmental Disabilities funded the pilot, which was run by the Arc of San Angelo, beginning in March 2011. A report was issued in December 2012 that described successes and challenges at the mid-point of the pilot’s three-year term. In addition to training initiatives and community outreach, the pilot prevented two unnecessary guardianships, ended another, and established one ongoing relationship between a volunteer and a person with a disability. Identified challenges included assessing volunteer liability, facing resistance from physicians and attorneys regarding medical powers of attorneys executed by people with cognitive disabilities and resistance from state-funded service providers regarding recruitment of people with disabilities for the pilot; and performing the targeted outreach necessary for successful volunteer recruitment, followed by extensive training of volunteers. The project also learned that people at imminent risk of guardianship are not well served by volunteer SDM in the short term, and it needed to change community expectations for people with disabilities and decision-making.[[273]](#endnote-273)
* **Massachusetts SDM Pilot (2014-2016) –** This pilot is a partnership between Nanotuck Resource Associates, a shared living provider, and the Center for Public Representation (CPR), a disability legal advocacy organization. The plan was to assist approximately 10 people with IDD and their families in Western Massachusetts to design and implement SDM as an alternative to guardianship, with CPR providing legal representation as needed. The pilot is for two years, with an outside evaluation by Human Services Research Institute (HSRI) each year. CPR and Nonotuck staff engaged in SDM conversations with nine adults with intellectual and developmental disabilities, who were 24 to 80 years old, and executed SDM arrangements for seven of them. The SDM adopters elected for SDM broadly, opting for decision assistance across all the types of decisions (e.g., financial, medical, etc.). The SDM networks involved ranged from 2 to 10 supporters, who included parents, siblings, grandparents, aunts, and past and current providers. The pilot designed each SDM arrangement to meet each person’s individual needs and developed an SDM Pilot Toolkit, including SDM representation agreements, durable powers of attorney, and health care proxies. So far, one participant has been discharged from court-ordered guardianship in favor of SDM as a result of the project. The HRSI’s first-year evaluation was released in December 2015, and provides recommendations for establishing SDM pilots in the U.S., including suggestions for partnerships, choosing participants, creating plain language SDM agreements, ensuring needed resources and training, and structuring safeguards. The second-year evaluation will focus on the outcomes of people using SDM.[[274]](#endnote-274)
* **Texas SDM Law Clinic Pilot at the University of Texas at Austin (2014-2015)** This pilot, called “INCLUDE,” was a project of the Richard and Ginni Mithoff Pro Bono Program, in partnership with the William Wayne Justice Center for Public Interest Law. It targeted parents and adult students with disabilities in special education transition programs for counseling about SDM and alternatives to guardianship. This project resulted in 102 families receiving one-to-one counseling with supervised law students. 10 families adopted SDM during the first year, and the project continues.[[275]](#endnote-275)
* **New York Pilot Project (April 1, 2016 – March 31, 2015) –** This pilot project is funded by New York’s Developmental Disabilities Planning Council and is a collaboration of Hunter College, the Council on Quality and Leadership, and Disability Rights New York. The project is currently in its planning phase, but expected outcomes include developing an evaluation an SDM educational campaign, identifying culturally and geographically diverse participants with IDD, developing a specialized model for SDM mediation, formalizing decision-making plans and agreements between people and support systems, collecting relevant data on individual outcomes and process to inform changes in New York law, and identifying funding methodologies to ensure long-term sustainability of the project.[[276]](#endnote-276)

**D. Potential Unintended Consequences & Recommendations**

Scholars have identified the potential for number of potential unintended consequences associated with SDM models and implementation and proposed related safeguards for consideration.

* Supporters may misunderstand their role and substitute their decisions for the person with a disability[[277]](#endnote-277) or unintentionally lead the person to a pre-determined outcome “through issue-framing, inaccurate assessment of [the person’s] preferences, or simple conversations” in which the person gives deference to supporters.[[278]](#endnote-278) “Indeed, without more empirical evidence as to how [SDM] functions in practice, it is too early to rule out the possibility it may actually disempower individuals with disabilities by facilitating undue influence by their alleged supporters.”[[279]](#endnote-279)
* SDM programs are not without their vulnerabilities. For instance, it is difficult to meaningfully assess whether a person understands the risks and can foresee the consequences of a potentially risky decision. It also can be difficult to assist another person with decision making without inappropriately influencing his or her final decision. Therefore, SDM must adopt adequate safeguards to ensure the individual’s decision-making abilities are respected.[[280]](#endnote-280)
* If an SDM model adopted requires agency or court oversight, it may turn out to be no different from the predecessor approach to guardianship – e.g., people may be subjected to continuous monitoring.[[281]](#endnote-281)
* The risk of promoting SDM may conflict with a person’s right to make their own decisions by enforcing the model when people do not want that kind of assistance at all.[[282]](#endnote-282)

An Australian scholar identified four principles for safeguarding the relationship of SDM, including ensuring that both parties are respected as moral agents with full personhood; the inequality of power or dependence does not turn into domination; the product of the relationship is an expression of the person’s, and not the supporter’s will and preference; and the system of SDM does not over-regulate the life of the person with a cognitive disability. She asserts that this paradigm will require dedicated resources from the state, including those that ensure adequate access to resources to provide assistance or advice when needed and information about what a SDM relationship should look like. There also must be a mechanism for the person with a disability to meaningfully challenge their supporter and secure a different one, either through a government or non-governmental office. Best practice would be for the person with a disability to be present and participating in all decision-making processes and interactions with third parties. She cautions that the state must be very careful to provide safeguards without over-regulation of the lives of people with disabilities.[[283]](#endnote-283)

Another solution offered in British Columbia is to use “monitors,” who are chosen by the person with a disability for all or some decisions, or to place limitations in representation agreements on how/if supporters can act for certain kinds of important decisions.[[284]](#endnote-284)

Other possible SDM-related safeguards proposed include:

* Using “monitors,” chosen by the person with a disability for all or some decisions[[285]](#endnote-285) or “mentors” which can serve as the person’s “constant and trusted advisor [and] a relationship with [her or her] that coincides with the progressive decline of neurodegenerative conditions.[[286]](#endnote-286)
* Placing limitations in SDM or representation agreements on how/if supporters can act with regard to certain kinds of important decisions[[287]](#endnote-287) and create legal prohibitions that would disallow supporters form acting in transactions in which they have a conflict.[[288]](#endnote-288)
* Establishing a state or official office that has the power to investigate allegations that a supporter acted improperly and to resolve conflicts that may arise.[[289]](#endnote-289)
* Authorizing courts to have similar power over SDM Agreements as they do over powers of attorney – for example, the power to revoke them.[[290]](#endnote-290)
* Ensuring the involvement of more than one supporter in an arrangement.[[291]](#endnote-291)
* Providing sufficient resources for wide-spread education on SDM to the general public, people with disabilities, and third-parties working with people with disabilities and supporters and for training supporters on what it means to be support someone with decision-making, to minimize unintended undue influence and to make them understand, where necessary, “the total lack of any decisional power” being a supporter conveys.[[292]](#endnote-292)
* Providing funding for the government to directly provide supports for people who have no one suitable to act as a supporter or contract for those services through a non-governmental organization.[[293]](#endnote-293)
* Writing laws and policies that facilitate access to formal and informal supports for large number of people requiring assistance with day-to-day issues, while avoiding representative payee schemes or “nominee” arrangements that are considered not compatible with the CRPD.[[294]](#endnote-294)
* Funding more projects that specifically test SDM models and use SDM and the court systems to restore people’s rights as a matter of law.[[295]](#endnote-295)

Finally, some advocates for Article 12 of the CRPD have concluded that “there is a small group of persons – perhaps 5% – for whom none of the current models of [SDM] will be effective.” In those situations, “facilitated communication,” based on what the support person “believes to be the individual’s true wishes,” rather than best interests, should be used, for the shortest time possible and subject to independent and impartial review.[[296]](#endnote-296)

**Research Question 5: What other alternatives are either recognized by U.S. states, currently being used to avoid guardianship, or emerging as alternatives?**

**I. Established Alternatives to Guardianship**

Scholarship indicates that there are alternatives to guardianship, other than SDM, that have been recognized by in the U.S. These include, for example:

* **Advance Directive or Living Will –** A written document that a person can sign to provide instructions about his or her medical treatment, including, e.g., life prolonging medical treatments or psychiatric treatment during a crisis, in the event he or she becomes unable to communicate such decisions.[[297]](#endnote-297) Advance Directives usually combines a health care power of attorney and living will into one document.[[298]](#endnote-298) These documents are prepared easily, using state-specific forms, readily available, e.g., on the Internet or in most hospitals.[[299]](#endnote-299)
* **General or Financial Powers of Attorney –** Written documents, executed under state law, for a person(s) to represent or act on another person’s behalf in personal or business affairs or other legal matters,[[300]](#endnote-300) including education.[[301]](#endnote-301) A power of attorney is “durable” when the document indicates that the agent’s authority does not end if the person becomes incapacitated. These documents should be drafted by a lawyer to conform with relevant state law requirements, including, where required, notarization and witnessing.[[302]](#endnote-302)

* **Health Care Proxy or Durable Power of Attorney for Health Care –** A legal instrument, executed under state law, that allows a person to appoint an agent to make his or her health care decisions in the event he or she is incapable of making such decisions.[[303]](#endnote-303) It generally covers a broader array of medical procedures than Advance Directives or Living Wills.[[304]](#endnote-304)
* **Representative Payees –** A person appointed by a government agency, e.g*.,* the Social Security Administration (SSA), to receive, manage, and spend govern benefits for a beneficiary. A beneficiary may request a representative payee, but the agency usually requires one if it determines the beneficiary is physically or mentally unable to manage his or her own funds. The representative payee’s authority is limited to the government funds for which he or she is the payee.[[305]](#endnote-305) This is a substitute decision-making arrangement.
* **Trust or Special Needs Trust –** A financial arrangement that enables a person to transfer ownership of property into a trust that is managed by a trustee for the benefit of designated people. Special needs trusts, for example, are used to provide supplemental funds for a person with a disability without jeopardizing access to government programs because of being over resource or assets limits.[[306]](#endnote-306)
* **Joint Ownership –** Allows a co-owner of land or bank accounts to manage an incapacitated co-owner’s property.[[307]](#endnote-307)
* **Voluntary Guardianship Over Property –** Enables a person who is concerned about losing capacity to plan for property management with court oversight, but is allowed by only a few states.[[308]](#endnote-308)
* **Daily Money Management –** Provides services that help people with their financial affairs such as check depositing and writing, bill paying, budgeting and checkbook balancing, and tax preparation. They are voluntary, so the person must be able to ask for or accept them.[[309]](#endnote-309)
* **State-Specific Health Care Surrogate or Family Consent Law –** Provides legal authority for certain groups of people, such as spouses, adult children, or parents, to make health care decisions for an adult who cannot make or community such decisions and who has not executed a power of attorney.[[310]](#endnote-310) These laws are dependent on the particulars of state statutes. For example, New York state authorizes panels of four volunteers, which must include both a health care professional and an attorney, to make medical treatment decisions in state-operated or licensed facilities.[[311]](#endnote-311)
* **Case Management Services –** Provides coordinating services through community and government agencies, the extent of which depends on the specific state.[[312]](#endnote-312)

If alternatives to guardianship are thought of broadly – i.e., as services or supports that allow a person’s needs to be met without a court-appointed guardian – many other options may be included within the continuum of decision-making support, including, e.g., in-home care services, food and prescription delivery, daily call services, direct deposit or bill pay, medical or educational release forms to allow the sharing of confidential information with supporters, other credit union and banking services, technology,[[313]](#endnote-313) person-centered planning,[[314]](#endnote-314) vocational services, supported living services, and person-centered planning.[[315]](#endnote-315) Mediation before or after the filing of a guardianship petition may promote these alternatives and resolve disputes in a way that will not involve the appointment of a guardian – provided the rights of the adult at risk of guardianship remain the focal point during the entirety of the mediation to avoid undue influence on the person with the alleged disability.[[316]](#endnote-316)

Certain existing informal alternatives are considered “particularly appropriate” for students transitioning to adulthood, including counseling, direct bill pay, community services, self-advocacy, daily money management training, appointment of personal representatives, and establishing personal support networks and “circles of support.” The goal of using these supports would be to help a young person make decisions and manage transactions, while also fostering the development of their independence and self-determina

tion skills.[[317]](#endnote-317)

**II. Emerging Alternatives to Guardianship in the U.S.**

In terms of emerging trends for alternatives to guardianship in the U.S., while variability across the states remain, scholars have seen a gradual paradigm shift in advance planning from a “legal transactional approach” – which emphasizes standardized legal forms with mandatory formality, restrictions, and procedural requirements – to a “communications approach” – which is a more ongoing, flexible, and accessible process. For example, at least 15 states now recognize oral advance directives; there is more of an emphasis on self-help tools that focus on the process, personal values, and goals associated with planning; and there has been the emergence of Physician Orders for Life-Sustaining Treatment (“POLST”). The POLST process requires a discussion between the treating health care practitioner and the person about key end-of-life care treatment options, so that the person’s wishes can be identified and incorporated into doctor’s orders kept in the medical record or with the person. Those orders are reviewed periodically and must travel with the patient whenever he or she moves from one setting to another, thereby promoting continuity of care.[[318]](#endnote-318)

Another emerging alternative to guardianship is the availability of asset building accounts under the Achieving a Better Life Experience Act of 2014 (the “ABLE” Act). Those eligible for such accounts are people with significant disabilities that manifested before they turned 26 and who meet SSA’s definition of disability. Any individual may contribute to an ABLE account for the benefit of the beneficiary, and the funds can be used for a wide range of qualified disability expenses. The current total contribution is limited each year to $14,000. The first $100,000 in ABLE accounts are exempted from the individual’s resource limit under SSI and ABLE accounts are disregarded for the purpose of determining if a person meets the asset limit for Medicaid. An ABLE account arguably provides more choice and control of the beneficiary and family than other types of trusts and the cost to establish such an account is likely less expensive. Examples of state ABLE programs accepting enrollment nationwide include Ohio, Nebraska, and Tennessee.[[319]](#endnote-319)

**III. Advantages and Disadvantages of the Most Common Alternatives and Recommendations**

**A. Planning Tools**

The primary advantage of planning tools, such as powers of attorney and living wills, is that they are low cost and easy to create and revoke.[[320]](#endnote-320) The ability of many older adults, including those with diminishing capacity, has been widely recognized and discussed.[[321]](#endnote-321) Moreover, despite misconceptions to the contrary, many people with cognitive and intellectual disabilities also can execute powers of attorney and advance directives for health care.[[322]](#endnote-322) However, disadvantages include concerns that appointed agents or property co-owners have unfettered power without oversight.[[323]](#endnote-323) Will they follow the wishes of the person and act ethically and diligently? Will the lack of court supervision put the person’s safety or financial well-being at risk?

The concerns regarding the need for safeguards when using powers of attorney are not unjustified. Legal scholars cite examples of physical, emotional, and financial abuse by agents, including family members,[[324]](#endnote-324) even going so far as to warn that a durable power of attorney for property is “a license to steal.”[[325]](#endnote-325) Powers of attorney are only as protective as the agent is trustworthy, only as effective as the willingness of third parties to accept it, and – like guardianship – do not prevent family power struggles over the person or his or her assets.[[326]](#endnote-326)

Scholars debate what statutory reforms are needed to add safeguards to the use of powers of attorneys. Recent suggestions have included requiring all durable powers to follow a standard statutory form with protective language, e.g., like that in the Uniform Power of Attorney Act; all durable powers to be registered with an oversight agency to be effective; notice to be given to family members of such registration; and increased court or governmental oversight (short of guardianship) that allows inquiries or investigations if suspected abuse is reported.[[327]](#endnote-327)

**B. Representative Payees**

Concerns also have been recently raised with Social Security Administration (“SSA”) representative payee system, which has designated more than 6 million payees – organizations, groups, or individuals – to manage the Social Security benefits of over eight million beneficiaries. Concerns included past cases of physical, emotion, and financial abuse; the selection of payees; the monitoring of payees; and identifying and addressing payee misuse of funds.[[328]](#endnote-328) The SSA Advisory Board has only begun to examine the problems raised and plans to continue its work to develop recommendations for solutions.

**Research Question 6: Are people with disabilities who may need decision-making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?**

Guardianship is a complex legal concept, further complicated by variances from state to state. Studies have shown that few professionals explain the long-term consequences of guardianship to families and people with disabilities.[[329]](#endnote-329) – such as the facts that undoing a guardianship is unlikely and very difficult, and that guardianship outlives parents and can lead to strangers being appointed as guardians in the future. In addition, guardianship changes the nature of the relationship parents have with their adult children and invites the court into the family’s life on a continuing basis.[[330]](#endnote-330)

As mentioned in prior sections of this review, studies indicate that people with disabilities who may need decision-making assistance and their families are not always being provided with sufficient information about the guardianship process and possible alternatives, including skill building and SDM, among others. This appears to be particularly the case for parents of young adults with disabilities, who often seek to become their guardian, because they feel that they have no other choice.[[331]](#endnote-331) Studies indicate that parents do not always understand that young adults with disabilities have the ability to further develop life skills, regardless of their diagnoses.[[332]](#endnote-332) Another study highlighted that young adults with disabilities also have a limited understanding of guardianship and its relation to self-determination, and only some reported consideration of alternatives to guardianship.[[333]](#endnote-333)

The results of a recent study, issued in 2015, highlight these gaps. The study was conducted with the support of the TASH Human Rights Committee and the Alliance to Prevent Restraint, Aversive Interventions, and Seclusion (“APRAIS”).[[334]](#endnote-334) Target participants for the study were people with disabilities and their guardians. The web-based survey, among other things, sought to know “what information was presented to respondents on the range of adult support option for people with disabilities”[[335]](#endnote-335) – including guardianship and alternatives.

* The survey had respondents from 48 states, the District of Columbia, and several respondents who were not in the United States.[[336]](#endnote-336)
* Of the 1,255 people who completed a survey, more than half (58%) reported that they did not receive training related to guardianship.[[337]](#endnote-337)
* Of those that identified that received information on guardianship, less than 4% indicated that it was from the school – even though school personnel were most frequently as being the first to have suggested guardianship or conservatorship.[[338]](#endnote-338)

Recommendations from this study included:

* Professionals should be required to train people with disabilities and families on the full range of options, including SDM, and to promote a perspective of supporting rather than removing rights.[[339]](#endnote-339)
* This education and training must begin before the person with disability turns 18, so that the full impact of the ways in which guardianship can affect young people is understood.[[340]](#endnote-340)
* SDM models should be incorporated in school curricula for all students, including education on financial management, medical decisions, career decisions, living arrangements, and entering into contracts.[[341]](#endnote-341)

In short, schools should be key sources of information on alternatives to guardianship for students with disabilities and their families. Fewer studies appear to have been done for other populations, such as people who are aging – although this review has identified large gaps in terms of courts and others being informed of the range of decision-making supports available.

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