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## The Current State of Guardianship Law Furthering a Need for Supported Decision-Making in Connecticut

JULIA R. VASSALLO

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# CONNECTICUT LAW REVIEW

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#### **Note**

### The Current State of Guardianship Law Furthering a Need for Supported Decision-Making in Connecticut

#### JULIA R. VASSALLO

Despite living in a society that values autonomy and individual thought, people with disabilities in the United States are continually subjected to oppression and discrimination, often in the name of a "well-intentioned" paternalistic desire to protect such individuals. Legally recognized protective orders, including guardianships and conservatorships, are often used to restrict the autonomy of people with disabilities, including individuals with intellectual and/or developmental disabilities, individuals with mental health disorders, and aging individuals experiencing Alzheimer's or other degenerative diseases that have the ability to impact an individual's cognitive functioning. While guardianships and conservatorships may be appropriate in a number of circumstances, for the majority of the disability community, such mechanisms are overbroad, stripping people with disabilities of the ability to make decisions regarding their own legal, health, financial, and personal affairs.

In an attempt to promote substantial reform in guardianship law, this Note discusses a more appropriate, and less restrictive, tool: Supported Decision-Making, which enables people with disabilities to practice self-determination skills and maintain their own autonomy while being supported by trusted individuals of their choosing, who can provide them with relevant information to make an informed choice. This Note identifies the current state of guardianship law in the state of Connecticut, the value of Supported Decision-Making as exemplified by real users, and the potential avenues Connecticut can take to formally recognize Supported Decision-Making and increase its use, with or without a statute.

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### The Current State of Guardianship Law Furthering a Need for Supported Decision-Making in Connecticut

JULIA R. VASSALLO\*

#### INTRODUCTION

Caroline<sup>1</sup> is an energetic eighteen-year-old with Down syndrome who is preparing to graduate high school. She loves to spend time with her friends after school. Together, they discuss their plans upon graduation, including where they are going to go to college, work, and live. Many of Caroline's friends are excited to move away from home, wishing to experience greater independence from their family members. After doing well in her home economics class, Caroline expresses an interest in moving out of the family home so that she has more privacy and opportunities to practice her self-determination skills. Despite Caroline's expressed interest and her ability to live elsewhere, her parents refuse to allow her to do so.

Similarly, Matthew<sup>2</sup> is a seventy-five-year-old who was recently diagnosed with Alzheimer's. He lives on his own and has been experiencing some difficulties remembering to eat; he recently got lost on his way home from his doctor's office. His children are concerned that Matthew should not be living alone anymore, but they do not reside nearby, and they have busy schedules that make it difficult for them to check in on him. Matthew has shared that he would like to remain in his home, and that he wants to have an aide help him for a few hours a day and accompany him on errands and at medical appointments. Worrying that he will need increasing care, Matthew's children begin the process of relocating Matthew to an assisted living facility against his wishes.

What do these individuals have in common? They both have diagnoses that have the potential to limit their abilities to care for themselves and make informed decisions that are in their best interests. This assumption of incapacity has allowed their families to obtain guardianships over them,

<sup>\*</sup> J.D. Candidate, University of Connecticut School of Law, May 2024; Certificate of Interdisciplinary Disability Studies in Public Health, University of Connecticut Center for Excellence in Developmental Disabilities Education, Research and Service, May 2024. I would like to extend my sincerest thanks to Professor Susan Schmeiser for her guidance in the development and mentorship of this Note. Thank you to the members of Volume 56 of the *Connecticut Law Review*, especially those involved with the Online Edition for their hard work. I also wish to extend my thanks to my family and friends for their support throughout this endeavor.

<sup>&</sup>lt;sup>1</sup> This is an imaginary hypothetical person and scenario intended to demonstrate the experiences of young adults with intellectual disabilities who may need additional supports to make personal decisions.

<sup>&</sup>lt;sup>2</sup> This is an imaginary hypothetical person and scenario intended to demonstrate the experiences of elderly individuals who may need additional supports to make personal decisions.

which have essentially revoked their rights to personal autonomy and opportunities to practice self-determination. One of the most influential, real-world cases involving similar facts in the United States, aside from the recent legal battles to terminate the conservatorships of Britney Spears<sup>3</sup> and Michael Oher, 4 is that of Ross v. Hatch, in which Margaret "Jenny" Hatch was faced with an unwanted Petition for Guardianship, which she successfully contested in favor of Supported Decision-Making ("SDM").<sup>5</sup> Jenny is a woman with Down syndrome who was faced with a Petition for Guardianship in 2012 when she was twenty-nine years old.<sup>6</sup> In the early stages of this process, Jenny was forced to move into a group home, was placed under a temporary guardianship, was removed from her job, and was isolated from her friends and community. While under guardianship, Jenny was deprived of her autonomy in multiple ways. Reflecting on her experiences in the group home she was moved into, Jenny reported that she "felt like a prisoner," recalling "I was told I had rights at the group homes. But that wasn't true. JFS [Jewish Family Services] took them away. It was like I didn't matter. Like I didn't exist. JFS took away my rights, my choices,

<sup>&</sup>lt;sup>3</sup> In 2008, Britney Spears was placed under two conservatorships over her person and her estate, after a finding by the Superior Court of California for the County of Los Angeles, Central District, that Britney was "subject to undue influence and unable to properly provide for her personal needs relating to physical health, food, clothing, or shelter." George J. Tzimorangas, "Gimme More" Freedom, Your Honor: How Guardianship and Conservatorship Laws Can Be Reformed Amid Britney Spears' Controversial Conservatorship Coming to an End, 36 QUINNIPIAC PROB. L.J. 54, 55–56 (2022). Throughout the case, Britney was vocal about her desire for the conservatorship to end and publicly shared examples of the manipulation and abuse she was subjected to during her conservatorship, including being forced to perform and take various medications against her will. Id. at 57. After nearly fourteen years, Britney's conservatorship was finally terminated when her petition was granted on November 12, 2021. Id.

<sup>&</sup>lt;sup>4</sup> In 2004, Michael Oher was placed under a conservatorship after he, as a ward of the state, began living with Sean and Leigh Anne Tuohy in his final year of high school. Ayana Archie, *A Judge Orders the End of the Conservatorship Between Michael Oher and the Tuohys*, NPR (Sept. 29, 2023, 7:41 PM), https://www.npr.org/2023/09/29/1202776970/michael-oher-tuohys-conservatorship. Purportedly, the Tuohys expressed a desire to adopt him; however, because he was over eighteen years of age, the Tuohys presented him with a conservatorship, which Oher alleges the Tuohys "gave him the impression that by signing it, he would be considered adopted by the Tuohys." *Id.* The conservatorship prohibited Oher from signing contracts or making his own medical decisions. *Id.* It was not until February of 2023 that Oher discovered he had no legal, familial relation to Tuohys. *Id.* Subsequently, in August of 2023, Oher filed a petition requesting that the conservatorship be dissolved. *Id.* 

<sup>&</sup>lt;sup>5</sup> Final Order, JENNY HATCH JUST. PROJECT, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://jennyhatchjusticeproject.org/wp-content/uploads/2022/10/jhjp\_trial\_final\_order.pdf [hereinafter Final Order] (last visited Oct. 30, 2023).

<sup>&</sup>lt;sup>6</sup> Jenny Hatch Justice Project, JENNY HATCH JUST. PROJECT, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://jennyhatchjusticeproject.org/ [hereinafter Hatch Justice Project] (last visited Oct. 30, 2023).

<sup>&</sup>lt;sup>7</sup> *Id.* The Petition for Guardianship was prompted after Jenny's mother and stepfather were informed by attorney Patrick B. McDermott that their "powers as attorneys in fact for [Jenny would] not overcome [Jenny's] 'free will even if her physicians [felt] she [was] not competent to make her own medical decisions," and McDermott advised Jenny's family to seek a Court ordered guardianship. *Petition for Appointment of Guardians*, JENNY HATCH JUST. PROJECT, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://jennyhatchjusticeproject.org/wp-content/uploads/2022/10/jhjp\_trial\_petition\_for\_guardianship.pdf (last visited Oct. 30, 2023).

my independence.... I lost a year of my life." Jenny's experiences help to explain how restrictive and isolating guardianship can be, especially for individuals who had previously been meaningfully engaged with their community.

Although none of the above examples or cases arose in Connecticut, Connecticut is not immune from the impacts of guardianship. In 2021, Senator Richard Blumenthal scheduled a hearing to examine the troublesome guardianship and conservatorship arrangements across the country, which the American Bar Association ("ABA") commended as a step toward potential reform in guardianship law. In a 2018 hearing, Senator Blumenthal voiced his concerns that in Connecticut, elected probate judges, who need not be attorneys, are in charge of making guardianship and conservatorship decisions. Such judges "are essentially beyond any oversight," having "their own fiefdoms," while the decisions they make have enormous impacts on the lives of others. Senator Blumenthal further expressed a "need to figure out a way to assure greater accountability" in the guardianship system in Connecticut and beyond, unless, of course, "Connecticut is an outlier . . . [and] the rest of the system is perfect."

Jenny's experience is just one example of the situations in which probate court judges have enormous authority to control individual lives. It also shows us that, with the right supports, a diagnosis does not automatically mean that a person cannot make important decisions or that their desires should be ignored because of what their families think is best. Guardianship is not a one-size-fits-all tool to be used for people with disabilities, mental health concerns, or memory loss. Instead, it must be used sparingly and as a last resort rather than a first choice and should be granted only after a careful evaluation of the abilities and circumstances of the individual at issue.

In the United States, Americans value autonomy and the ability to make individualized decisions on our own behalf. These choices, ranging from

<sup>&</sup>lt;sup>8</sup> Jenny in Her Own Words, JENNY HATCH JUST. PROJECT, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://jennyhatchjusticeproject.org/justice-project/about-the-jenny-hatch-justice-project/jenny-in-her-own-words/ (last visited Oct. 30, 2023).

<sup>&</sup>lt;sup>9</sup> Letter from Reginald M. Turner, President, Am. Bar Ass'n, to Richard Blumenthal, Chair, Subcomm. on the Const. & Ted Cruz, Ranking Member, Subcomm. on the Const. (Sept. 27, 2021), https://www.americanbar.org/content/dam/aba/administrative/government\_affairs\_office/guardianship-letter-senate-judiciary.pdf. The ABA wrote to Senator Blumenthal to additionally request that the ABA's policy resolution be raised in the hearing. The policy advocates for Congress to create and fund a Guardianship Court Improvement Program to "support state court efforts to improve the legal process in the adult guardianship system, improve outcomes for adults subject to or potentially subject to guardianship, increase the use of less restrictive options than guardianship, and enhance collaboration among courts, the legal system, and the aging and disability networks." Am. Bar Ass'n, Report to the House of Delegates, Annual Resolution 105 (2020), https://www.americanbar.org/content/dam/aba/directories/policy/annual-2020/105-annual-2020.pdf.

<sup>&</sup>lt;sup>10</sup> Ensuring Trust: Strengthening State Efforts to Overhaul the Guardianship Process and Protect Older Americans: Hearing Before the S. Spec. Comm. on Aging, 115th Cong. 15–16 (2018) (statement of Sen. Richard Blumenthal), available at <a href="https://www.govinfo.gov/content/pkg/CHRG-115shrg37591/pdf/CHRG-115shrg37591.pdf">https://www.govinfo.gov/content/pkg/CHRG-115shrg37591.pdf</a>.

<sup>&</sup>lt;sup>11</sup> *Id*.

small to substantial, include determining where to live, where to work, whom to associate with, how to manage personal finances, when and how to seek medical care, whether to pursue higher education, and whether and whom to marry. Even individuals with the legal capacity to make independent decisions often prefer to discuss options, weighing the pros and cons, with trusted family members or friends before arriving at a final determination. However, in the experiences of people with disabilities, including elderly individuals with dementia or Alzheimer's, there may be a need for more structured decision-making processes and supports. To accomplish this, every state within the United States needs to adopt an SDM statute as a preferred alternative to guardianship or conservatorship for people with disabilities, mental health concerns, and memory loss. More specifically, the State of Connecticut needs to reduce the use of guardianship and conservatorship in favor of less restrictive alternatives that are more likely to benefit people with disabilities.

SDM should be understood as a viable alternative to an allencompassing full, or total, guardianship. In its simplest form, SDM is a tool that enables people with disabilities to retain their decision-making abilities by selecting trusted individuals to support them and help them to make choices.<sup>13</sup> Although definitions vary, SDM can be understood to mean "a

<sup>13</sup> Supported Decision-Making: Frequently Asked Questions, AM. C.L. UNION, https://www.aclu.org/sites/default/files/field\_document/faq\_about\_supported\_decision\_making.pdf (last visited Oct. 30, 2023).

<sup>&</sup>lt;sup>12</sup> For the purpose of this Note, any reference to people with disabilities or individuals under guardianship will encompass individuals with intellectual disabilities, mental health disorders, and conditions that negatively impact or impair an individual's capacity to make reasoned decisions that are in their best interest, regardless of whether this inability is temporary (as may be the case with mental health disorders) or long lasting. A note on the differences in guardianship for the elderly: the Connecticut Department of Developmental Services' ("DDS") general guidance fails to mention the use of guardianship or its alternatives for elderly individuals, as the focus is more on transition-age individuals. The current application for guardianship bases the petition for the appointment of a guardian on the definition of "intellectual disability," as defined in the Connecticut General Statutes.

Petition/Guardianship of Person with Intellectual Disability, PC-700, CONN. PROB. CTS., http://www.ctprobate.gov/Forms/PC-700.pdf (last visited Oct. 30, 2023) (internal quotations omitted). The statutory definition means "a significant limitation in intellectual functioning existing concurrently with deficits in adaptive behavior that originated during the developmental period before eighteen years of age." CONN. GEN. STAT. § 1-1g(a) (2020). While this could be interpreted to mean that Connecticut does not support the use of guardianship for elderly individuals or individuals with mental health disabilities, that is likely not the case, as older individuals who did not have an intellectual or developmental disability as minors find themselves under full guardianship after receiving an Alzheimer's diagnosis, for example. Michael T. Nedder, Guardianships in Connecticut: An Overview, NEDDER & ASSOCS., LLC, (Sept. 28, 2020), https://nedderlaw.com/blog/guardianships-in-connecticut. For older individuals, the debate becomes one of whether bodily and personal autonomy should be preserved to the greatest extent possible or if the focus should be on acting within the best interests of the individual on their behalf. Megan S. Wright, Dementia, Healthcare Decision Making, and Disability Law, 47 J.L. MED. & ETHICS 25, 25 (2019). Conditions such as dementia and Alzheimer's, which cause memory loss, can create changes in an individual's communication, personality, and interests (current and former) which can make it difficult to help them maintain their autonomy and also preserve their quality of life. Id. Although the ways in which elderly individuals communicate may be impacted by memory loss, their wishes should not be discredited, and they should be included to the furthest degree possible in making decisions about their care and the services they require.

process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult." <sup>14</sup> In this process, a supporter can be a family member, friend, or respected professional or advocate whom the individual trusts to advise them. In serving as a support, that person agrees to help the individual with a disability to "understand, consider, and communicate decisions, giving the person with a disability the tools to make [their] own, informed decisions." <sup>15</sup>

This Note explains the traditional practices of guardianship and conservatorship within the United States at large while also focusing on their specific uses in the state of Connecticut that impact individuals with intellectual disabilities, transition-age individuals subjected to guardianship or conservatorship at the age of eighteen, aging individuals experiencing memory loss, and individuals experiencing mental health disorders. Part I of this Note proceeds to discuss the Least Restrictive Alternative Doctrine and the support it provides for shifting away from guardianship and conservatorship in favor of less restrictive legal systems and supports including SDM. Part II also evaluates the current efforts in guardianship reform, both in Connecticut and across the nation, as highlighted by the enactment of SDM statutes in states like Texas and Washington. To conclude, Part III of this Note recommends that Connecticut adopt a tailored SDM statute of its own, continue to raise awareness for the use and value of agreements, create stronger methods to monitor existing guardianships, and advocate for the use of least restrictive alternatives to minimize the burdens placed on individuals' legal autonomy going forward.

#### I. OVERVIEW OF GUARDIANSHIP AND CALLS FOR CHANGE

#### A. A General Overview of Guardianship in the United States

Traditionally, United States law has permitted guardianships and conservatorships for people with intellectual, developmental, and mental health disabilities. Guardianship is a mechanism by which a probate court transfers the duty and power to make decisions for another individual to the guardian or conservator who will have the legal authority to make decisions on behalf of the individual going forward. Although each jurisdiction defines "guardianship" and "conservatorship" differently, often limiting the latter to financial matters, in general, persons appointed as guardians manage the legal, financial, health, and personal affairs of adults under guardianship—

<sup>&</sup>lt;sup>14</sup> Tex. Est. Code Ann. § 1357.002(3) (2015).

 $<sup>^{15}</sup>$  Am. C.L. UNION, supra note 13.

even to the exclusion of the individual's input. <sup>16</sup> This process essentially entails removing fundamental rights from adults under guardianships, which is often a permanent transfer rather than a temporary one. <sup>17</sup>

While it is difficult to identify the precise number of individuals under guardianship in the United States, a recent estimate suggests that there are 1.3 million active adult guardianship cases across the nation. According to data from 2012, there were approximately 1,300 guardianship cases in Washoe County, Nevada alone. Upon further analysis, Judge Frances Doherty of Nevada discovered that almost one-third of guardianship petitions were brought for individuals between the ages of 18 and 29, and another third were brought for individuals aged 60 and older. The breakdown of the ages of individuals under guardianship and conservatorship may be similar, although it is difficult to discern without the availability of precise data.

While guardianship and conservatorship are governed by state law, there are a number of national standards, guidelines, and model laws that are offered to states for further review and implementation. The National Guardianship Association recently approved the fifth edition of their Standards of Practice in October of 2022.<sup>21</sup> The current edition of the Standards of Practice was influenced by the recommendations of the Fourth National Guardianship Summit of 2021.<sup>22</sup> These standards are

<sup>&</sup>lt;sup>16</sup> While the topics discussed in this Note apply practically to both guardianship and conservatorship, there are times when the focus will be largely on guardianship law because of the closer connection SDM currently has to guardianship law as a whole, accounting for differences in terminology by state. Furthermore, this Note may refer to guardianship rather than both guardianship and conservatorship at times simply for brevity.

<sup>&</sup>lt;sup>17</sup> Jenica Cassidy, *Restoration of Rights in the Termination of Adult Guardianship*, 23 ELDER L.J. 83, 84 (2015); Section C.R. & Soc. Just., Comm'n on Disability Rts. & Section Real Prop., Tr. & Est. L., Comm'n on L. & Aging, Am. Bar Ass'n, *Report to the House of Delegates, Resolution 113* (2017), https://supportmydecision.org/assets/tools/ABA-Resolution-113.pdf [hereinafter ABA Resolution 113]. ("Although virtually all statutes include a strong preference for limited guardianships, what empirical data exists suggests that the vast majority of guardians appointed are given total, or plenary power, to substitute their decisions for those of the persons under guardianship, often referred to as 'wards' or 'incapacitated persons.'").

<sup>&</sup>lt;sup>18</sup> Kristen Booth Glen, What Judges Need to Know About Supported Decision-Making, and Why, 58 JUDGES' J. 26 (2019).

<sup>19</sup> Id. at 29.

<sup>&</sup>lt;sup>20</sup> *Id*.

<sup>&</sup>lt;sup>21</sup> NAT'L GUARDIANSHIP ASS'N, STANDARDS OF PRACTICE 1–2 (5th ed. 2022), available at https://www.guardianship.org/standards/.

<sup>&</sup>lt;sup>22</sup> NAT'L GUARDIANSHIP ASS'N, STANDARDS OF PRACTICE 3 (4th ed. 2013), available at https://www.guardianship.org/standards/. The First National Guardian Symposium, sponsored by the American Bar Association, was held in 1988. David English, *The Fourth National Guardianship Symposium: An Introduction*, 72 SYRACUSE L. REV. 1, 2 (2022). The Second National Guardianship Conference of 2001, held at Stetson Law School, continued this effort, identifying "sixty-eight steps in education, training, practice, data collection, funding and research to improve the adult guardianship process." Sally Hume & Erica Wood, *Symposium Third National Guardianship Summit: Standards of Excellence*, 2012 UTAH L. REV. 1157, 1159-60 (2012). This contributed to the creation of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act in 2007, which has since been enacted in forty-six states, including Connecticut. Hume & Wood, *supra*, at 1160, fn. 17; English, *supra*, at 3;

recommended to states as best practices, much like the Model Rules of Professional Conduct<sup>23</sup> are to the Connecticut Rules of Professional Conduct that appear in the Connecticut Practice Book.<sup>24</sup> Regardless of whether states opt to incorporate the Standards of Practice into their legislative frameworks, the standards can be used by practitioners, guardians, legislatures, courts, guardianship programs, agencies, and other professional organizations to improve the quality of guardianship law, policies, and practices in their respective states.

#### B. The Goals of Guardianship and Present Obstacles

The goal of guardianship is to assist and protect individuals who are deemed unable to make decisions for themselves. <sup>25</sup> Yet this is a largely paternalistic approach that is overbroad and inappropriate in most circumstances. Although people with disabilities and aging individuals may have a diminished capacity to make reasoned decisions for themselves, there should not be an automatic assumption that they require the services of another to make the decisions on their behalf. Rather, there should be a greater effort to promote autonomy and utilize the least restrictive means possible to assist the individual in managing their own legal, health, financial, and personal affairs.

The American Bar Association (ABA) recognizes that guardianship is an all-consuming measure that deprives the individual of "virtually all legal rights to make decisions and choices." Noting that courts often appoint guardians for individuals who could likely continue to make their own decisions when provided with the right supports and services, the ABA advocates for the use of less restrictive alternatives to guardianship. As one of the most promising of these alternatives, SDM was formally endorsed by the ABA in a 2017 Supported Decision-Making Resolution. SDM is also recognized and endorsed by the U.S. Department of Health and Human

UNIFORM ADULT GUARDIANSHIP & PROTECTIVE PROCEEDINGS JURISDICTION ACT (UNIF. L. COMM'N 2007). As a result of the cumulative efforts of the first three National Guardianship symposia and summits, the National Guardianship Association Standards and the Probate Court Standards were both revised in 2013. See Nat'l Guardianship Ass'n, Standards of Practice, supra; English, supra, at 4; Nat'l Coll. of Prob. Ct. Judges, National Probate Court Standards (2013), https://ncsc.contentdm.oclc.org/digital/collection/spcts/id/240 (explaining this collectively). The Uniform Law Commission further incorporated the results of the Third Symposium into the 2017 revision of the UGCOPAA. Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (Nat'l Conf. Comm'rs on Unif. State. L. 2017) [hereinafter UGCOPAA]; English, supra, at 4.

<sup>&</sup>lt;sup>23</sup> MODEL RULES OF PRO. CONDUCT (AM. BAR ASS'N 1983).

<sup>&</sup>lt;sup>24</sup> Jud. Branch, State of Conn., Rules of Professional Conduct, in CONNECTICUT PRACTICE BOOK 1, 1–65 (2023), https://www.jud.ct.gov/publications/PracticeBook/PB.pdf (last visited Oct. 30, 2023).

<sup>&</sup>lt;sup>25</sup> ABA Resolution 113, *supra* note 17.

<sup>&</sup>lt;sup>26</sup> Comm'n on L. & Aging, Am. Bar Ass'n, *Supported Decision Making*, AM. Bar Ass'n (July 27, 2023), https://www.americanbar.org/groups/law\_aging/resources/guardianship\_law\_practice/supported-decision-making/ [hereinafter COLA SDM].

<sup>&</sup>lt;sup>27</sup> Id.

<sup>&</sup>lt;sup>28</sup> ABA Resolution 113, *supra* note 17.

Services Administration for Community Living.<sup>29</sup> Pursuant to Resolution 113, the ABA "urges state, territorial, and tribal legislatures to amend their guardianship statutes to require that supported decision-making be identified and fully considered as a less restrictive alternative before guardianship is imposed."<sup>30</sup> The ABA also calls for courts to consider SDM as a less restrictive alternative (LRA)<sup>31</sup> to guardianship, both in petitions to appoint a guardian and petitions to terminate a guardianship and restore individual rights.<sup>32</sup> Despite increasing support and advocacy for recognizing SDM as an LRA, however, the number of states implementing SDM into their relevant guardianship statutes remains minimal.

## C. The Least Restrictive Alternative Doctrine in the Context of Guardianship

Personal autonomy and self-determination are incredibly important components of daily life that must be protected and exercised freely to the furthest extent possible. For people with disabilities, it is easy for these rights to be overlooked or restricted when well-intentioned, but misinformed, individuals seek to assist them through the appointment of a guardian. While petitioning for guardianship may sound (and often is) extreme, some individuals seek guardianship for a loved one simply because they do not know of other less restrictive alternatives.<sup>33</sup>

Generally, the principle of the LRA is discussed in the context of health care services. In particular, the doctrine arises in determinations of treatment plans for individuals with mental health diagnoses and similarly situated individuals who may require a higher level of daily support than others. One of the most famous discussions of the LRA mandate occurred in the case of *Olmstead v. L.C. ex rel. Zimring*, a 1999 U.S. Supreme Court decision which evaluated the validity of segregated confinement for people with mental health and intellectual disabilities.<sup>34</sup> The Court held that community-based placements must be considered as an alternative to confinement in segregated facilities for people with disabilities, and offered to individuals

<sup>&</sup>lt;sup>29</sup> COLA SDM, supra note 26.

<sup>&</sup>lt;sup>30</sup> ABA Resolution 113, *supra* note 17.

<sup>&</sup>lt;sup>31</sup> In the context of this Note, "LRA" will be used to refer to both the Least Restrictive Alternative Doctrine and to the concept of less restrictive alternatives to guardianship and conservatorship.

<sup>&</sup>lt;sup>32</sup> ABA Resolution 113, *supra* note 17.

<sup>&</sup>lt;sup>33</sup> See discussion infra Section II.B.

<sup>&</sup>lt;sup>34</sup> Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 587 (1999). The principle of the "least restrictive alternative" originated in the case *Shelton v. Tucker*; however, *Olmstead* is the case that is most often cited. Shelton v. Tucker, 364 U.S. 479, 493–94 (1960) ("Where state assertions of authority are attacked as impermissibly restrictive upon thought, expression, or association, the existence vel non of other possible less restrictive means of achieving the object which the State seeks is, of course, a constitutionally relevant consideration."); ABA Resolution 113, *supra* note 17 ("The 'least restrictive alternative' principle was first recognized by the U.S. Supreme Court in *Shelton v. Tucker*. . . .").

when such placement is appropriate, as to avoid unjustified institutionalization and discrimination.<sup>35</sup>

The Court went on to recognize that unjustified institutional placement and isolation of people with disabilities itself is a form of discrimination for at least two reasons: (1) "institutional placement[s]" perpetuate stereotypes and misconceptions that individuals are "incapable or unworthy of participating in community life;" and (2) "confinement . . . severely diminishes the everyday life activities of individuals," which includes economic independence, social contacts, and cultural enrichment. The latter remark not only applies to confinement, but also sheds light on the harmful effects of guardianship and conservatorship on the individual. Much like institutionalized individuals are restricted in their abilities to interact with members of the community—more specifically people without disabilities—limiting their access and opportunities to build social relationships, individuals under guardianship face difficulties in maintaining their connections to the community because of a lack of control over their personal affairs and opportunities for meaningful choice.

#### D. Connecticut's Current Practices in Guardianship Law

#### 1. Definitions of Guardianship and Conservatorship

The types and definitions of guardianship vary by jurisdiction. In Connecticut, guardianship is defined by statute to mean "guardianship of the person of a minor," which "includes: (A) [t]he obligation of care and control . . . [and] (B) the authority to make major decisions affecting the minor's education and welfare, including, but not limited to, consent determinations regarding marriage, enlistment in the armed forces and major medical, psychiatric or surgical treatment. . . ."<sup>37</sup> While this definition centers around the guardianship of minors, guardianships can extend to individuals beyond the age of majority when a petition to the court is made; additional definitions specify the types of guardianship applicable to individuals with intellectual disabilities.<sup>38</sup>

Connecticut utilizes two primary forms of guardianship: plenary and limited. A plenary, or full, guardianship is created when an individual, serving as a plenary guardian, is appointed by the Probate Court "to

<sup>&</sup>lt;sup>35</sup> Olmstead, 527 U.S. at 607 ("[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with [intellectual or developmental] disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with [intellectual or developmental] disabilities.").

<sup>&</sup>lt;sup>36</sup> *Id.* at 600–01.

<sup>&</sup>lt;sup>37</sup> CONN. GEN. STAT. § 45a-604(5) (2024).

<sup>&</sup>lt;sup>38</sup> *Id.* §§ 45a-669–670. Connecticut is one of a handful of states that has a separate statutory provision pertaining to individuals with intellectual disabilities; a majority of states use a single guardianship statute for all incapacitated adults regardless of the origin or type of disability they possess. ABA Resolution 113, *supra* note 17.

supervise all aspects of the care of an adult person" that benefit the person under guardianship after the court determines that the person is "totally unable to meet essential requirements for [their] physical health or safety and totally unable to make informed decisions about matters related to [their] care." A limited, or partial, guardianship serves a similar purpose, although a limited guardian is appointed to supervise a series of specified aspects of care for the person rather than all aspects of their care.

In this context, being "unable to make informed decisions" is understood to mean that the person, as a result of a disability or condition, is unable to obtain a basic understanding (even when efforts to explain are provided) of the information necessary to make decisions related to their physical and mental health needs, diet, hygiene, property, belongings, care, and protection from abuse. These definitions imply that the ability of the person to make informed choices and act in their own best interests is a substantial factor in the court's evaluation of whether to grant a petition for guardianship. But how exactly is this determination made?

According to the Connecticut General Statutes, Section 45a-676, the court must first find, "by clear and convincing evidence," that the person, by reason of disability, is "totally unable to meet essential requirements for [their] physical health or safety and totally unable to make informed decisions about matters related to [their] care" before the court can appoint a plenary guardian.<sup>42</sup> Along the same lines, if the court finds that the person can accomplish some of the necessary tasks and make some informed decisions, but not all, the court may appoint a limited guardian.<sup>43</sup> These determinations require clear and convincing proof of the person's recent behaviors that would cause a risk of harm or actual harm. 44 Preferably, the risky behaviors offered as proof will have occurred within the last six months prior to the hearing; however, a court can grant a guardianship based on older behaviors if the court provides additional reasons for doing so.<sup>45</sup> The Department of Developmental Services ("DDS") provides another possible source of evidence through the submission of a written assessment of the person for whom the guardianship is being sought, which includes a determination of whether they have an intellectual disability, the severity of the condition, and specific areas in which the person needs additional

 $<sup>^{39}</sup>$  CONN. GEN. STAT. § 45a-669(1) (2024) (defining the role and responsibilities of a plenary guardian).

<sup>&</sup>lt;sup>40</sup> Id. § 45a-669(3) (defining the role and responsibilities of a limited guardian).

<sup>&</sup>lt;sup>41</sup> *Id.* § 45a-669(7).

<sup>&</sup>lt;sup>42</sup> *Id.* § 45a-676(a).

<sup>1</sup>*a*. § 45a-676(a). 43 *Id*. § 45a-676(b).

<sup>&</sup>lt;sup>44</sup> *Id.* § 45a-676(c).

<sup>&</sup>lt;sup>45</sup> The court is also required by statute to provide written findings that support the granting of the plenary or limited guardianship. *Id.* § 45a-676(e).

supervision and protection by a guardian.<sup>46</sup> When a guardian is appointed, the court recommends that guardians encourage the protected person to take an active role in the decision-making process, voicing their preferences in a way that helps the guardian promote their wishes.<sup>47</sup>

Conservatorships can be used to attain similar effects, as the Probate Court can assign a conservator of the estate or a conservator of the person. A conservator, much like a guardian, can be appointed when a person is determined incapable of caring for themselves or managing their affairs due to the person having "a mental, emotional or physical condition that results in such person being unable to receive and evaluate information or make or communicate decisions" so that they are unable "to meet essential requirements for personal needs" or perform inherent functions of managing their affairs, with or without assistance from others. 49

Even when a conservatorship is granted, it is intended to be used as the least restrictive means of intervention, meaning that it should only operate to the extent necessary to provide for the personal needs or property management of the conserved person. As such, the guidance of the Connecticut legislature is to preserve the "independence and self-determination" of conserved persons to the greatest extent possible, and not to interfere with exercises of autonomy beyond what is required to meet the specific needs for which the conservatorship was granted. This legislation falls in line with the Least Restrictive Alternative Doctrine, which further serves to protect the interests and autonomy of people with disabilities. However, in practice, conservatorships can jeopardize the security of persons when, for example, a conservator uses the protective measure as an opportunity to take financial advantage of the conserved person. Going forward, it is important for Connecticut to provide greater information about the common LRAs that are available in place of a more

<sup>&</sup>lt;sup>46</sup> OFF. OF THE PROB. CT. ADM'R STATE OF CONN., PROBATE COURT USER GUIDE PERSONS WITH INTELLECTUAL DISABILITY 2 (2020), http://www.ctprobate.gov/Documents/User% 20Guide% 20Persons% 20with% 20Intellectual% 20Disability.pdf [hereinafter Intellectual Disability Probate Court User Guide] (note that this only applies to petitions for people with intellectual disabilities, although guardianships can be granted for other disabilities and conditions, such as mental health diagnoses, memory loss, and traumatic or acquired brain injuries). DDS professionals responsible for the assessment in the report may also testify at the guardianship hearing. *Id.* 

<sup>&</sup>lt;sup>47</sup> *Id.* at 5.

<sup>&</sup>lt;sup>48</sup> § 45a-644(a)–(b) (defining the responsibilities of appointed conservators of the estate or the person).

<sup>&</sup>lt;sup>49</sup> *Id.* § 45a-644(c)–(d).

 $<sup>^{50}</sup>$  Id. § 45a-644(k).

<sup>&</sup>lt;sup>51</sup> *Id*.

<sup>&</sup>lt;sup>52</sup> See, e.g., Peter Yankowski, Stamford Couple Stole Nearly \$500K from Norwalk Resident's Estate, Police Say, The Hour (May 12, 2023), https://www.thehour.com/news/article/stamford-couple-stole-500k-norwalk-estate-18096393.php (reporting that, according to Norwalk, CT police, a Stamford couple is facing charges for larceny and conspiracy after it was reported that the couple was "illegally taking money from an elderly person." It was subsequently determined that one of the accused served as the conservator of the victim and that the couple purportedly took approximately \$460,000 from the victim for their personal use).

restrictive measure, such as a plenary or limited guardianship. By statute in Connecticut, there is language implying that conservatorship should be viewed as one of the primary LRAs to guardianship.<sup>53</sup> However, the mere existence of conservatorships as an alternative to full guardianships does not go far enough in preserving individuals' autonomy interests or providing guidance to probate judges about the options available. In either a new piece of SDM-specific legislation, or a revision of current conservatorship and guardianship statutes employed by the state, it is necessary for Connecticut to include language identifying additional LRAs. These would include the use of an SDM agreement, power of attorney, health care directive, trust, or financial agent, depending on the specific needs of the individual, as well as explicit language that requires LRAs to be considered before initiating a guardianship or conservatorship action.<sup>54</sup> Since this language is currently absent from the relevant statutes, Connecticut can also promote the use of LRAs retroactively and enhance reporting and monitoring processes to ensure that guardianships are not improperly maintained.

#### 2. Guardianship Trends and Challenges to SDM

Based on the recent 2020-2021 Biennial Report of the Connecticut Probate Courts,<sup>55</sup> published by the Office of the Probate Court Administrator, data collected estimates that of the individuals conserved in Connecticut, approximately forty-six percent are under the age of 65, with twenty-two percent 45 years old or younger.<sup>56</sup> While the intention of many

<sup>&</sup>lt;sup>53</sup> The statute specifies that "[i]f the court finds by clear and convincing evidence that the respondent is incapable of" managing their affairs or caring for themselves, and that these matters cannot be resolved adequately without appointing a conservator, "and that the appointment of a conservator is the least restrictive means of intervention available to assist the respondent" in managing their affairs or caring for themselves, the court has the discretion to appoint a conservator of the person and/or the estate. CONN. GEN. STAT. § 45a-650(f)(1)-(2) (2019). Another statutory provision defines the "[1]east restrictive means of intervention" as "intervention for a conserved person that is sufficient to provide, within the resources available to the conserved person either from the conserved person's own estate or from private or public assistance, for a conserved person's personal needs or property management while affording the conserved person the greatest amount of independence and self-determination." CONN. GEN. STAT. § 45a-644(k) (2019). See also Am. BAR ASS'N, COMM'N ON L. & AGING, SUPPORTED DECISION-MAKING LESS-RESTRICTIVE ALTERNATIVES: STATUTORY Α https://www.americanbar.org/content/dam/aba/administrative/law\_aging/2022-sdm-lst-rstctdaltntvs.pdf. The original source has since updated its data to reflect new metrics in 2023 pertaining to SDM statutes only and, thus, excludes Connecticut data on LRAs. The version used to support this statement is available at https://perma.cc/JX6X-P9K4.

<sup>54</sup> ELIZABETH A. MORAN & ERICA C. R. COSTELLO, NAT'L CTR ON L. & ELDER RTS., ALTERNATIVES TO GUARDIANSHIP IN CIVIL LEGAL AID PRACTICE (2022), https://ncler.acl.gov/getattachment/Legal-Training/upcoming\_event/Alternatives-to-Guardianship-Ch-Summary-(1).pdf.aspx?lang=en-US#:~:text=Such% 20alternatives% 20to% 20guardianship% 20include, ability% 20to% 20make% 20informed% 20choices. This source is now available at https://perma.cc/FGL2-A94X.

<sup>&</sup>lt;sup>55</sup> OFF. PROB. CT. ADM'R, THE CONNECTICUT PROBATE COURTS 2020-2021 BIENNIAL REPORT (2022).

<sup>&</sup>lt;sup>56</sup> *Id.* at 20.

is to have such conservatorships be short-lived, the reality is that many conservatorships continue for decades.<sup>57</sup>

In the State of Connecticut, guardianships and conservatorships also exist in part to save the state money—especially because older persons could require greater assistance through Medicaid without an appointed guardian or conservator.<sup>58</sup> This economic motive is one of the largest factors working against individuals who are at risk of being placed under guardianship or conservatorship. The numbers of conservatorships and guardianships granted by the Probate Courts of Connecticut have continually grown, with a *nine percent* increase in conservatorships between the end of the fiscal year for 2019 and that of 2021.<sup>59</sup> For adults with intellectual disabilities, the Connecticut Probate Courts report receiving approximately 600–800 new petitions for guardianship a year.<sup>60</sup> There are considerably more involuntary conservators of the person, and the person and estate, than voluntary appointments;<sup>61</sup> this ratio further illustrates the coercive dynamics at work in such decisions.

These trends in the number of guardianships and conservatorships and the populations that are most commonly subjected to guardianship appear to run counter to the efforts of SDM advocates. They also frustrate the goal of seeking the least restrictive alternative to guardianship whenever possible to promote greater autonomy and self-determination among people with disabilities. The Uniform Guardianship, Conservatorship and Other Protective Arrangements Act ("UGCOPAA") specifically works to address this discrepancy, focusing on "the need to limit the use of guardianship and create alternatives that maximize the self-determination of those who may need decision-making assistance." Part of the difficulty in promoting self-determination among people with disabilities is the "lack of concrete information" pertaining to the number of guardianships granted and the

<sup>57</sup> I.d

<sup>&</sup>lt;sup>58</sup> Reportedly, \$95,000 a year is saved "for every case where a Probate Court keeps a senior aging in place at home with the support of a conservator instead of in a nursing home under Medicaid." *Id.* at 4.

<sup>&</sup>lt;sup>59</sup> *Id*. at 19.

<sup>&</sup>lt;sup>60</sup> *Id.* at 21. Records from recent fiscal years indicate that 552 guardians were appointed for people with intellectual disabilities in 2021, 602 in 2020, 575 in 2019, and 602 in 2018. *Id.* at 24, 28.

<sup>&</sup>lt;sup>61</sup> The ratio of involuntary to voluntary appointments seems to exceed 3:1 in most years. A comparison of the number of voluntary and involuntary appointments of conservators of the person and estate in 2021 shows that there were 1,969 involuntary and 539 voluntary appointments, 1,932 involuntary and 638 voluntary appointments in 2020, 2,020 involuntary and 718 voluntary appointments in 2019, and 1,961 involuntary and 660 voluntary appointments made in 2018. *Id.* at 23, 27. In terms of voluntary and involuntary appointments of conservators of the person only, 258 involuntary and 92 voluntary appointments were made in 2021, 201 involuntary and 95 voluntary appointments in 2020, 278 involuntary and 120 voluntary appointments in 2019, and 276 involuntary and 127 voluntary appointments in 2018. *Id.* at 23, 27.

<sup>&</sup>lt;sup>62</sup> Kristen Booth Glen, *What Judges Need to Know About Supported Decision-Making, and Why*, 58 JUDGES' J. 26, 27 (2019); NAT'L COUNCIL ON DISABILITY, BEYOND GUARDIANSHIP: TOWARD ALTERNATIVES THAT PROMOTE GREATER SELF-DETERMINATION 63 (2018), *available at* https://ncd.gov/sites/default/files/NCD\_Guardianship\_Report\_Accessible.pdf.

circumstances of the cases in which guardianships are routinely granted.<sup>63</sup> Yet, data shows that, where enacted, SDM legislation has been successful in decreasing the number of adult guardianships; in Texas, there has been a sixpercent decrease in adult guardianships since the statute's enactment, according to an estimate from 2019.<sup>64</sup>

Based on such studies, it is clear that a key component of amending a guardianship statute entails addressing how to evaluate the least restrictive alternative to guardianship within guardianship proceedings. Doing so would not only help to limit the granting of inappropriate guardianships but also serve to educate individuals bringing guardianship requests about the alternatives that they may not have been aware of prior to commencing the proceeding. In this way, greater education about the impacts of guardianship and viable alternatives has the potential to promote a closer evaluation of the LRAs to guardianship, which can benefit and empower people with disabilities to exercise self-determination.

#### E. Connecticut Guardianship and Probate Court Monitoring

Currently, Connecticut requires the court to review each granted guardianship at least once every three years in order "to determine the of continuing. appropriateness modifying or terminating guardianship."65 However, mandatory guardian reporting is the primary source of monitoring. Connecticut requires that plenary and limited guardians submit a report to the court in five scenarios: (1) annually; (2) when the court requires additional reports; (3) when there are significant changes in the capacity of the protected person regarding their ability to meet the essential requirements of maintaining their health and safety; (4) when the guardian resigns or is removed; and (5) when the guardianship is terminated by the court.<sup>66</sup> The report form is issued by the Office of the Probate Court Administrator. <sup>67</sup> The types of information to include are "(1) [slignificant changes in the capacity of the protected person . . . ; (2) the services being provided to the protected person . . . ; (3) the significant actions taken by the . . . guardian . . . ; (4) any significant problems relating to the guardianship . . . ; and (5) whether [the] guardianship, [according to] the guardian, should continue, be modified, or be terminated."68 One of the main issues with this current approach is that guardians have too much

<sup>65</sup> Intellectual Disability Probate Court User Guide, *supra* note 46, at 5.

<sup>63</sup> Glen, supra note 62, at 29.

<sup>&</sup>lt;sup>64</sup> *Id*.

<sup>&</sup>lt;sup>66</sup> CONN. GEN. STAT. § 45a-677(f) (2019). Guardians with authority over the protected person's finances are also required to submit a financial report at the end of the first year of guardianship and every three years. Intellectual Disability Probate Court User Guide, *supra* note 46, at 6.

<sup>&</sup>lt;sup>67</sup> Intellectual Disability Probate Court User Guide, *supra* note 46, at 5. The form is called *Guardian's Report/Guardianship of Person with Intellectual Disability, PC-771* and can be found on the Probate Court website. *Id.* 

<sup>68</sup> CONN. GEN. STAT. § 45a-677(g) (2019).

discretion in deciding how to fill out the report. Yes, guardians are supposed to report any problems that have arisen during the guardianship and to evaluate whether the guardianship is still necessary, but this does not mean that guardians, practically speaking, are always honest about the circumstances or ongoing need for a guardianship. Under the current requirements, guardians may fail to provide full disclosure for a number of reasons, ranging from a guardian's abuse of the protected individual to a lack of effort to reevaluate the guardianship, leaving the guardian to copy and paste the same information into each report; both scenarios are entirely plausible.

Courts must also consider a practice of issuing letters on a yearly basis to remind guardians of the requirement to reevaluate the guardianship as part of the reporting process and to recommend that those under guardianship themselves reconsider whether a current guardianship is appropriate. Such reminders might lessen the burden on probate courts to reevaluate all guardianships unless these individuals wish to bring a petition to the court. This approach may further prompt a discussion of when guardianship is appropriate and draw attention to the opportunities for remedying an inappropriate guardianship if there is an explanation of the termination process. Sending out letters would also serve to help the court better track the number of guardianships and record the top reasons for continued guardianship and termination. In this way, stronger records would likely help to align the practice of guardianship with the intentions and goals of guardianship.

#### II. THE CONCEPT AND PRACTICE OF SDM

#### A. The Current Status of SDM in the United States

Improving guardianship law in Connecticut is imperative to better serve the interests of people with disabilities, as it would further minimize the possibility of abuse and create greater accountability among appointed persons. However, it is also crucial that Connecticut promote the use of SDM in order to more fully preserve the autonomy of people with disabilities. Presently, SDM is not widely recognized within the United States. Despite the international popularity of similar ideas, as represented by the Montreal Declaration on Intellectual Disabilities<sup>69</sup> and Article 12 of the UN Convention on the Rights of Persons with Disabilities ("CRPD"),<sup>70</sup> the United States has only recently begun to entertain the idea of promoting

<sup>&</sup>lt;sup>69</sup> The Montreal Declaration on Intellectual Disabilities was published in 2004 as a result of the Montreal Pan-American Health Organization (PAHO) and the World Health Organization (WHO) Conference on Intellectual Disability. *See generally* Jocelin Lecompt & Céline Mercier, *The* Montreal Declaration on Intellectual Disabilities of 2004: An Important First Step, 4 J. POL'Y & PRAC. INTELL. DISABILITIES 66 (2007).

<sup>&</sup>lt;sup>70</sup> The CRPD was adopted by the UN General Assembly in 2006. G.A. Res. 61/106, Convention on the Rights of Persons with Disabilities (Dec. 13, 2006).

and supporting the autonomy of people with disabilities. This is in part due to the fact that "[l]egal capacity is governed primarily by State-level law."<sup>71</sup> In 2015, Texas became the first U.S. state to enact legislation that would formally recognize SDM agreements as a viable alternative to guardianship.<sup>72</sup> Since then, a number of states have adopted their own SDM statutes, including Alabama, Alaska, Arizona, California, Colorado, Delaware, the District of Columbia, Illinois, Indiana, Louisiana, Maryland, Nevada, New Hampshire, New York, North Dakota, Rhode Island, Washington, and Wisconsin, among others.<sup>73</sup> While it helps to have supportive legislation, SDM agreements are valid regardless of an absence of such legislation.<sup>74</sup> Using the SDM Agreement Statute of Texas as an example, the process by which the statute recognizes SDM is through the use of SDM agreements, which are defined as "an agreement between an adult with a disability and a supporter."75 In this way, SDM agreements are similar to contracts and other legal agreements that individuals commonly use to convey their desires in the event of incapacity such as a power of attorney, advance health care directive, and living will.

Unlike guardianship, which is often a permanent transfer of rights, SDM agreements can be terminated as specified by the statute. For example, the Texas statute conditions termination of an SDM agreement on three circumstances: "(1) the Department of Family and Protective Services finds that the adult with a disability has been abused, neglected, or exploited by the supporter; (2) the supporter is found criminally liable for conduct . . .; or (3) a temporary or permanent guardian of the person or estate appointed for the adult with a disability qualifies." The flexibility allowed by this language helps to ensure that the interests of the person with a disability can be maintained more readily.

A lack of knowledge and education efforts to inform individuals about less restrictive alternatives to guardianship, such as SDM, is a primary contributor to the number of guardianships that are requested by family members and granted by judges. State judicial branches and individual judges have the ability to serve a critical role in the expansion and public knowledge of SDM.<sup>77</sup> In Texas, Justice Nathan Hecht led the effort to enact

<sup>&</sup>lt;sup>71</sup> JOHN R. VAUGHN, NAT'L COUNCIL ON DISABILITY, FINDING THE GAPS: A COMPARATIVE ANALYSIS OF DISABILITY LAWS IN THE UNITED STATES TO THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD) 4 (2008), available at http://www.ncd.gov/publications/2008/May122008#a12.

<sup>&</sup>lt;sup>72</sup> Eliana J. Theodorou, *Supported Decision-Making in the Lone-Star State*, 93 N.Y.U. L. REV. 973, 974 (2018).

<sup>&</sup>lt;sup>73</sup> *U.S. Supported Decision-Making Agreement Laws*, CTR. FOR PUB. REPRESENTATION, https://supporteddecisions.org/resources-on-sdm/state-supported-decision-making-laws-and-court-decisions/ (last visited Oct. 28, 2023).

<sup>&</sup>lt;sup>74</sup> See discussion infra Sections III.B-C.

<sup>&</sup>lt;sup>75</sup> TEX. EST. CODE ANN. § 1357.002(4) (2015).

<sup>&</sup>lt;sup>76</sup> TEX. EST. CODE ANN. § 1357.053(b) (2015).

<sup>&</sup>lt;sup>77</sup> Glen, supra note 62, at 28.

the first U.S. SDM statute.<sup>78</sup> The Texas statute was successful, in part, because of the efforts of the Texas Judicial Council, which formed a committee to investigate and monitor guardianships in a variety of Texas counties.<sup>79</sup> With the results of the investigation and the subsequent unanimous passage of the legislation, there was also an educational reform that directed Texas attorneys practicing in the guardianship system to complete continuing legal education requirements and to consider SDM before guardianship can be imposed.<sup>80</sup>

#### B. The Value of SDM: Real-World Examples

SDM agreements can empower people with disabilities to practice self-determination with the support of others, meeting their personal needs and retaining the freedom to explore their life choices. One of the most prominent examples comes from the experiences of Jenny Hatch. In contesting her guardianship, Jenny was briefly placed under a limited guardianship of limited powers and duration for one year after the Order was issued, with the ultimate goal that she would transition to the SDM model. As per the Order, Jenny's wishes were observed; she moved into a private residence and received SDM assistance throughout the remainder of her guardianship in order to make for a smooth transition to SDM.

In the wake of this prominent case, <sup>84</sup> the Jenny Hatch Justice Project was created as an extension of Quality Trust, which is now part of the National Resource Center for Supported Decision-Making ("NRC-SDM"). <sup>85</sup> The project's mission is to "inspire and support strength and justice through advocacy, information, research and education" by providing tools to promote and protect the rights of people with disabilities so that they can make independent choices and set their own life paths and goals. <sup>86</sup> Similar projects and organizations have increased in number, all serving to raise awareness, provide support and education, and work towards a greater sense of inclusion for people with disabilities in the context of legal and health

<sup>&</sup>lt;sup>78</sup> *Id*.

<sup>&</sup>lt;sup>79</sup> *Id*.

<sup>80</sup> Id

<sup>81</sup> For additional information, see discussion supra Introduction.

<sup>82</sup> Final Order, supra note 5.

<sup>&</sup>lt;sup>83</sup> *Id*.

<sup>&</sup>lt;sup>84</sup> Jenny's case was covered by the media as Jenny became known as a "symbol of strength among a population used to being assessed by its weaknesses." Theresa Vargas, *Virginia Woman with Down Syndrome Becomes Hero to the Disabled*, WASH. POST (Aug. 17, 2013, 7:41 PM), https://www.washingtonpost.com/local/virginia-woman-with-down-syndrome-becomes-hero-to-the-disabled/2013/08/17/0da21766-062e-11e3-a07f-49ddc7417125\_story.html.

<sup>&</sup>lt;sup>85</sup> About Us, NAT'L RES. CTR. FOR SUPPORTED DECISION MAKING, https://supporteddecisionmaking.org/about/ (last visited Oct. 29, 2023) (mentioning that NRC-SDM builds on and extends the work of Quality Trust's Jenny Hatch Justice Project).

<sup>&</sup>lt;sup>86</sup> About the Jenny Hatch Justice Project, JENNY HATCH JUST. PROJECT, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://jennyhatchjusticeproject.org/justice-project/about-the-jennyhatch-justice-project/ (last visited Oct. 29, 2023).

care decisions. As a result, individuals such as Ryan King, who were initially inspired by Jenny Hatch's success in terminating her guardianship, were eventually able to reach the same result.<sup>87</sup> For Ryan, it took two attempts for his guardianship to be terminated; after a failed attempt in 2007, despite having the support of his parents, Ryan petitioned again in 2016 and won.<sup>88</sup>

For a number of individuals with SDM agreements, the process of creating and exercising an SDM agreement is enjoyable and helps them to obtain a greater sense of independence, regardless of whether they live with family members, or in a group setting. Consider, for example, the experience of Christian, a young man with Down Syndrome who participated in the SDM pilot program sponsored by Nonotuck and the Center for Public Representation ("CPR") in Massachusetts after his family was approached by DDS to discuss guardianship as part of Christian's future planning. <sup>89</sup> For Christian, SDM is a good fit because he enjoys being "his own boss" and seeking assistance from trusted family members and friends when making big decisions. <sup>90</sup> Since creating his SDM agreement, Christian now makes decisions about who his caregiver is, which day program to participate in, and when to change the dosage of his medications, among others. <sup>91</sup>

Another participant in the pilot program, Craig, expresses his appreciation for SDM agreements because of their ability to validate his decision-making abilities and independence; "SDM gives me and my family a paper to show other people that I can make my own decisions and that people shouldn't decide things for me but help me decide for myself." Like many people, Craig prefers to be given choices rather than being told what to do; 93 while an SDM agreement is not necessarily required for this to occur, having such an agreement helps to provide structure and a framework for approaching decisions, both large and small, that individuals like Craig can learn to make for themselves.

In addition to the benefits SDM provides for people with disabilities, there are also noted benefits for friends and family members who may be selected to serve as supporters. For example, SDM is a good fit for parents seeking to support their adult children with disabilities upon reaching the age of majority. This is the case for Cory's parents, who, prior to Cory's participation in the CPR pilot program, placed Cory under a guardianship because they did not know of any other options that would allow them to

<sup>&</sup>lt;sup>87</sup> Guardianship Bill of Rights Act: Hearing on S. 1148 Before the S. Special Comm. on Aging, 118th Cong. (2023) (statement of Ryan H. King, Guardianship Reform Advocate).

<sup>&</sup>lt;sup>88</sup> *Id*.

<sup>&</sup>lt;sup>89</sup> Christian's Story, Pub. Representation, https://supporteddecisions.org/stories-of-supporteddecision-making/christians-story/ (last visited Feb. 16, 2024).

<sup>&</sup>lt;sup>90</sup> Id.

<sup>91</sup> Id

<sup>&</sup>lt;sup>92</sup> Craig's Story, CTR. FOR PUB. REPRESENTATION, https://supporteddecisions.org/stories-of-supported-decision-making/craigs-story/ (last visited Feb. 16, 2024).

<sup>93</sup> Id

help Corv make decisions about his health and finances. 94 Subsequently. Cory was able to successfully petition to terminate his guardianship, which was replaced with an SDM agreement, Power of Attorney, and Health Care Directive. 95 Cory's case represents the first time that a resident of Massachusetts succeeded in terminating a guardianship in favor of SDM.<sup>96</sup> In exercising his SDM agreement, Cory feels empowered to make his own decisions. When considering a move into an independent living apartment, Cory used his supports to fully understand the risk he was taking and was confident that the move was something he wanted to experience.<sup>97</sup>

Serving as an appointed guardian or conservator is a time-consuming position, largely because such individuals need to be actively involved in making decisions on behalf of the protected person. In addition to the risks these systems create for abuse and neglect, 98 they also strain the relationships of family members and friends.<sup>99</sup> While serving as a supporter in the context of an SDM agreement is also an important responsibility, the burden on family members and friends is minimal in comparison to that imposed on guardians and conservators because the individual being supported retains their capacity to make their own decisions instead of depending on their guardian or conservator for even small choices. For these reasons, instead of serving as an appointed guardian or conservator, family members and friends may be better suited to serve as supports to the individual, which may also help them to become better advocates since the burden of care they are required to provide is significantly reduced. SDM also lessens the strain on probate courts because such agreements tend to require a lower level of reporting and long-term monitoring, if any at all, given the contractual nature

<sup>94</sup> Cory's Story, CTR. FOR PUB. REPRESENTATION, https://supporteddecisions.org/stories-ofsupported-decision-making/corys-story/ (last visited Feb. 16, 2024).

<sup>&</sup>lt;sup>96</sup> *Id*.

<sup>98</sup> There has been increasing attention to the instances of abuse and neglect in guardianships recently. The most common types of abuse are physical, sexual, psychological, financial exploitation, neglect, and abandonment. U.S. GOV'T ACCOUNTABILITY OFF., GAO-17-33, ELDER ABUSE: THE EXTENT OF ABUSE BY GUARDIANS IS UNKNOWN, BUT SOME MEASURES EXIST TO HELP PROTECT OLDER ADULTS 5, 5 tbl. 1 (2016). One of the most prevalent areas of guardian abuse can be found within cases of elder abuse. While the extent of abuse by guardians is unknown, the matter becomes particularly difficult to track in the case of elders. Id. at 6. This is in part due to a lack of available data to track and appropriately monitor elder guardianships. As part of a study, the Government Accountability Office interviewed court officials of six states, none of whom could provide specific statistics as to the numbers of guardians for the elderly, and none of the states appear to have a reliable system for tracking cases that are related to elder abuse at the hands of appointed guardians. Id.

<sup>&</sup>lt;sup>99</sup> This is in part because of caretaker burnout, which is a well-documented concern given the high levels of stress guardians and conservators are under when they are tasked with making financial and legal decisions on behalf of another. The stress and confusion of trying to navigate the system of disability benefits and related reporting requirements for guardians and conservators can further stress the relationship between family members, even resulting in feelings of resentment and guilt among siblings serving as guardians or conservators for their adult sibling with disabilities, Meghan R. Lurtz, Andrew Komarow & Elizabeth Yoder, Siblings, Family Systems Theory, Guardianship, and Restoring the Triad, 14 J. FIN. THERAPY 85, 89-90 (2023).

of the agreement that can be readily modified or terminated without extensive court intervention. 100

#### C. Sample SDM Agreements

In the absence of an SDM statute, it may be difficult to understand what an SDM agreement should include, which can make it challenging for individuals seeking an SDM agreement to know what to ask for and for practitioners to know what to draft. The NRC-SDM is one resource that provides model SDM agreement forms that can be used as a guide in crafting an SDM agreement. A majority of the examples are derived from sample forms of states that have formally recognized SDM as a viable alternative to guardianship. <sup>101</sup> Some states, including Texas <sup>102</sup> and Washington, <sup>103</sup> even include a sample form within the statutes.

The common elements of such an agreement include the name and information of the individual to be supported (including address, phone number, and E-mail address), the date of the agreement, the purpose of the agreement, information about the supporter(s) (including name, address, phone number, and E-mail address), the areas of support assigned to the supporter(s), restrictions on what the supporter(s) can do (e.g., my supporters are not allowed to make choices on my behalf. To help me make my choices, my supporters may help me find out more about the choices, understand the choices, and tell other people about my decision), and the signatures of all parties as well as those of witnesses and/or a notary public. <sup>104</sup> Depending on the structure of the agreement used, individuals may opt to have multiple SDM agreements that specify different types of support (e.g., medical, financial, and social) and different supporters. While SDM agreements can be modified and personalized, if a given state has a sample format offered either by an agency of the state or within the statutes of the state, it would be advisable to closely model the sample form. For individuals interested in creating SDM agreements in states without such samples, such as Connecticut, any format can be used.

<sup>100</sup> UGCOPAA (2017), Prefatory Note, 2.

The SDM model agreements highlighted by the NRC-SDM include forms from the District of Columbia, Texas, and Delaware, as well as that of the Nonotuck Research Associates, Center for Public Representation form which is based in Massachusetts. *Supported Decision-Making Model Agreements*, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://supporteddecisionmaking.org/resource\_library/sdm-model-agreements/ (last visited Oct. 29, 2023).

<sup>&</sup>lt;sup>102</sup> TEX. EST. CODE ANN. § 1357.056 (explaining that an SDM agreement will only be valid if it is substantially similar to the sample form included in the statutory provision).

<sup>&</sup>lt;sup>103</sup> WASH. REV. CODE § 11.130.745 (2022) (explaining that an SDM agreement will only be valid if it is substantially similar to the sample form included in the statutory provision).

<sup>104</sup> See Sample Supported Decision-Making Agreements, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, https://supporteddecisionmaking.org/wp-content/uploads/2022/10/sample-supported-decision-making-model-agreements.pdf (last visited Oct. 29, 2023) (containing model SDM agreement forms).

#### D. The History of SDM in Connecticut

Thus far, Connecticut has not passed legislation to legally recognize SDM. Onnecticut's current lack of SDM legislation leaves only the vague suggestion that guardianship should not be treated lightly or used overbroadly, as the Connecticut DDS has recommended. According to the DDS's brief statement, "[n]ot every person with an intellectual disability needs a legal guardian," and "[t]he legal guardian's role," when one is appointed, "is to help a person make the best decision for himself/herself, not to dictate how he or she should live their life." Notwithstanding this sentiment that personal autonomy should be maintained to the utmost when possible, there is a concerning lack of restoration of rights for individuals who may no longer require a guardianship. Although legislation was introduced in 2019 that would have recognized SDM, the Bill failed, and similar bills have not been subsequently raised. The proposed Bill sought to amend the Connecticut General Statutes to

permit an adult with a disability to voluntarily enter into one or more supported decision-making agreements under which the adult with a disability authorizes a supporter to do any of the following: (1) Provide supported decision-making; (2) be present during the supported decision-making process, when requested by the supported person; or (3) in the presence of the supported person, assist the supported person in: (A) Obtaining information that is relevant to a given life decision from any person, provided the supporter shall keep such information confidential; or (B) communicating the supported person's decisions to others. <sup>108</sup>

One concern with the 2019 Bill was raised by an attorney on behalf of the Connecticut Bar Association ("CBA"). According to the testimony that the CBA submitted to the Judiciary Committee, the Bill was "vague, overly broad, confusing and create[d] opportunities for the abuse of persons with disabilities, especially the elderly." This testimony suggests that in reintroducing similar legislation Connecticut should look to the Texas SDM

<sup>&</sup>lt;sup>105</sup> Connecticut, NAT'L RES. CTR. FOR SUPPORTED DECISION-MAKING, http://www.supporteddecisionmaking.org/state-review/connecticut (June 6, 2023).

<sup>&</sup>lt;sup>106</sup> State of Connecticut: Department of Developmental Services: Guardianship, CT PORTAL, https://portal.ct.gov/DDS/Family/Family-Individuals-and-Families/Guardianship#:~:text=In%20Connecticut%20legal%20guardianship%20has,disability%20nee

ds% 20a% 20legal% 20guardian (last visited Oct. 29, 2023).

<sup>&</sup>lt;sup>107</sup> S.B. 63, Gen. Assemb., Jan. Sess. (Conn. 2019); Connecticut, supra note 105.

<sup>&</sup>lt;sup>108</sup> S.B. 63, Gen. Assemb., Jan. Sess. (Conn. 2019).

<sup>109</sup> An Act Concerning the Use of a Supported Decision-Making Agreement by a Person with a Disability: Hearing on S.B. 63 Before the Comm. on Judiciary, 2019 Leg., Jan. Sess. (Conn. 2019) (statement of Att'y Christine M. Tenore, Executive Comm. Conn. Bar Ass'n Elder L. Section), available at https://www.cga.ct.gov/2019/juddata/TMY/2019SB-00063-R000401-Connecticut%20Bar%20 Association-TMY.PDF.

statute, which provides "specific, targeted assistance with specific tasks or identified goals" rather than permitting broad, sweeping authority. The CBA testimony also calls for providing more information on who could serve as a supporter and what protections will exist to prevent abuse or to terminate the agreement if necessary. If another SDM agreement bill were introduced and addressed these concerns by clearly identifying the scope of the agreement, there would be a greater possibility of the legislation being enacted. In fact, the CBA concluded its testimony by explaining that it does support the intentions of the proposed Bill, but that it would need to be reworked into a more comprehensive bill to meet the needs of people with disabilities. The question then becomes, why was another bill not introduced in subsequent legislative sessions, as was encouraged?

There may be a variety of reasons why another bill has not been presented to the state legislature. This hesitation is likely related to a lack of knowledge about SDM and the dynamic nature of guardianship law, which varies greatly by jurisdiction. Insufficient knowledge and awareness are part of the reason why there are National Guardianship symposia and summits to discuss possible solutions to challenges in guardianship law, and why the National Guardianship Association produces Standards of Practice for national and state consideration.

#### III. STATUTORY AND POLICY RECOMMENDATIONS

#### A. The Introduction of a Federal Bill

On a systemic level, federal legislative reform may be an influential and expedient way to prompt extensive reform of guardianship and conservatorship law in every state so that the rights of people with disabilities receive universal minimal protection that states are obligated to comply with, if not build upon. A recent step towards this goal was the introduction of a new bill to the United States Senate on March 30, 2023. The Bill, which aimed "[t]o establish rights for people being considered for and in protective arrangements, including guardianships and conservatorships, or other arrangements, to provide decision supports," can be referred to as the Guardianship Bill of Rights Act. The Guardianship Bill of Rights Act sets forth a process that will establish a bill of rights for

<sup>&</sup>lt;sup>110</sup> *Id*.

<sup>&</sup>lt;sup>111</sup> Id.

<sup>&</sup>lt;sup>112</sup> *Id*.

<sup>&</sup>lt;sup>113</sup> The Bill is cosponsored by Senators Bob Casey, John Fetterman, Elizabeth Warren, and Bernie Sanders. Guardianship Bill of Rights Act, S. 1148, 118th Cong. (2023); Casey Holds Hearing on Guardianships, Introduces Bill to Promote Alternative Options for Seniors, People with Disabilities, and their Families, BOB CASEY (Mar. 30, 2023), https://www.casey.senate.gov/news/releases/casey-holds-hearing-on-guardianships-introduces-bill-to-promote-alternative-options-for-seniors-people-with-disabilities-and-their-families.

<sup>&</sup>lt;sup>114</sup> S. 1148, 118th Cong. (2023).

individuals who are under, or being considered for, guardianship, conservatorship, SDM, or other arrangements, to ensure that individuals' civil rights are protected and that they have substantial involvement and significant opportunities to engage in the consideration and practice of such arrangements.<sup>115</sup>

If it passes, the Guardianship Bill of Rights Act would establish a council on guardianship and other protective arrangements as well as supported decision-making, which would help to advise the Secretary of Health and Human Services and the Attorney General on beneficial standards and requirements to consider expounding. 116 The Guardianship Bill of Rights Act would also establish standards enumerating the inherent civil rights of individuals who may be subjected to guardianship or conservatorship.<sup>117</sup> There would be a series of standards created for establishing, modifying, reviewing, and terminating guardianships and conservatorships as well as standards for establishing SDM arrangements. 118 Such provisions cumulatively work to ensure that the uses of guardianships and conservatorships are limited to only those instances in which LRAs are inadequate, that such proceedings are conducted fairly, that regular and impartial review occurs, and that the rights of people with disabilities are protected regardless of the type of protective arrangement they are a party to. The Guardianship Bill of Rights Act also seeks to establish a standardized process by which individuals under guardianship or conservatorship can be transitioned to SDM. 119 This provision would help to raise awareness for the methods by which an individual can request review of their guardianship or conservatorship and petition for the termination of such arrangement in favor of SDM.

While the Bill appears quite robust, an additional provision that would provide further benefits and protections would focus on education and applicable training and continuing education for the general public, health care providers, judges, attorneys, and other individuals who are involved in guardianship proceedings or as supports for individuals who may be subject to a protective agreement. Such a provision would help to ensure that the legislation, along with the products and guidance of the council, remain accessible and adaptable as additional flaws in the guardianship systems of the United States are identified. Enacting the Bill would have substantial implications for the future of guardianship and conservatorship law and would reasonably initiate a chain reaction of state amendments to relevant

<sup>&</sup>lt;sup>115</sup> *Id.* at § 2(b).

<sup>&</sup>lt;sup>116</sup> *Id.* at § 4(a)(1), (3), (4).

<sup>&</sup>lt;sup>117</sup> The standards created would apply to inherent civil rights; due process protections for said civil rights; fundamental rights listed under section 2(a)(5) of the Act; and rights related to voting, decision-making (marriage and other relationships, finances, education, and health care, among others). *Id.* at § 5(a)-(b).

<sup>&</sup>lt;sup>118</sup> *Id.* at § 6(a)-(b).

<sup>&</sup>lt;sup>119</sup> *Id.* at § 6(c).

statutes, as well as the enactment of SDM-specific legislation and the strengthening of oversight measures to identify issues in existing guardianship and conservatorship arrangements. If the Bill were to pass, Connecticut must carefully reform its guardianship and conservatorship legislation to, at a minimum, align with the federal standards, and, ideally, enact SDM-specific legislation. In the meantime, however, while the Guardianship Bill of Rights Act is still pending, there are a variety of actions Connecticut can take to promote the use of LRAs over guardianship and conservatorship and to better advocate for and protect the rights of people with disabilities.

#### B. Adopting an SDM Statute in Connecticut

A new SDM bill that heeds the advice of opponents to Connecticut's 2019 Bill and is modeled after successful SDM statutes, such as those of Texas<sup>120</sup> and Washington, 121 must be introduced to the state legislature for the next legislative session. The new bill must include provisions defining SDM and SDM agreements, identifying who can use SDM, who can serve as supporters, what SDM can be used for, what other agreements can be used with SDM, and how to terminate SDM agreements. It would also be beneficial if the bill could direct individuals to the process for terminating a guardianship or conservatorship as well as educational resources that can be consulted to learn more about alternatives to guardianship.

The Texas and Washington statutes serve as good models for states interested in adopting an SDM statute because of the level of detail they have included in attempting to make a clear and effective law that can be readily understood by practitioners, probate court judges, advocates, and individuals requiring some heightened level of support alike. Texas did an especially thorough job drafting its statute, and there is an extra value attached to being the first state to adopt an SDM statute. A provision of particular interest in each statute is the scope, which is expansive, enumerating a variety of areas in which supporters may help the individual, at the discretion of the individual. Yet this list is not all-encompassing, providing some flexibility in practice without being too vague to the point of confusion.

Both statutes provide express language mandating that individuals receiving a copy of the agreement, or who have knowledge of the agreement, must report suspected abuse, neglect, abandonment, or personal or financial

<sup>&</sup>lt;sup>120</sup> TEX. EST. CODE ANN. § 1357 (2015).

<sup>121</sup> WASH. REV. CODE § 11.130.700-755 (2022).

<sup>&</sup>lt;sup>122</sup> Special Needs Alliance, Supported Decision-Making in the US: History and Legal Background, THE VOICE, (Aug. 11, 2022, 10:01 AM), https://www.specialneedsalliance.org/the-voice/supported-decision-making-in-the-us-history-and-legal-background/ (explaining that the Texas statute addresses SDM in great detail, even including an example agreement, and that many states have followed the example of Texas by adopting their own detailed statutes or regulations that include sample forms as well).

<sup>&</sup>lt;sup>123</sup> Tex. Est. Code Ann. § 1357.051 (2015); Wash. Rev. Code § 11.130.715 (2022).

exploitation by a supporter,<sup>124</sup> a requirement also included prominently on the sample form provided by the statutes. The apparent intent of the warning provisions and language is to provide greater oversight and protection built into the governing statute and the SDM agreement itself in a way that likely reduces the risk of supporter misconduct and increases the chances that such misconduct would be identified and corrected readily. Interestingly, the Washington statute also includes a provision that expressly disqualifies select individuals who might present a conflict of interest from serving as a supporter, which is another way to limit the risk of supporter misconduct.<sup>125</sup> The Washington statute further includes a presumption of capacity, which provides individuals with the flexibility to act independently of the agreement rather than being dependent on their designated supporter for all decisions; this presumption fosters the goal of helping people with disabilities practice self-determination in ways that work for them.<sup>126</sup>

The two statutes also provide express methods by which SDM agreements can be terminated. Both statutes specify that an agreement can be terminated if there is a finding by the designated agency of abuse, neglect, or exploitation on the part of the supporter or if the supporter is found criminally liable for such misconduct, however, the statutes have additional provisions that diverge. 127 The Texas statute permits termination of an SDM agreement if a temporary or permanent guardian is appointed; inclusion of this provision anticipates situations when SDM is not working to effectively meet the needs of the individual. 128 If Connecticut were to add a similar provision to a newly created SDM statute; however, it should specify that an evaluation of other LRAs must be conducted prior to an assessment of whether a guardianship or conservatorship should be granted. Such a provision would help ensure that the rights of the individual are not unnecessarily restricted when supplementing an SDM agreement with an additional LRA would have been sufficient. Relatedly, the Washington statute includes two additional methods by which an SDM agreement can be terminated: if the individual with disabilities or the supporter provide notice to the other party of their intention, respectively, to terminate the agreement or resign from the position. 129 While it may seem obvious that one party's expressed desire to exit would terminate an SDM agreement, expressly stating all methods by which termination of SDM agreements may occur is a good practice. It adds to the clarity of the statute and furthers the purpose

 $<sup>^{124}</sup>$  Tex. Est. Code Ann. §§ 1357.102, 1357.056 (2015); Wash. Rev. Code §§ 11.130.755, 11.130.745 (2022).

Employers or employees of the individual or a person who directly provides paid support services to the individual, who are not immediately family members of the individual, and persons whom the individual has a protective order against, or who is the subject of a criminal or civil order prohibiting contact with the individual, cannot serve as supporters. WASH. REV. CODE § 11.130.730 (2022).

<sup>&</sup>lt;sup>126</sup> WASH. REV. CODE § 11.130.710 (2022).

<sup>&</sup>lt;sup>127</sup> TEX. EST. CODE ANN. § 1357.053 (2015); WASH. REV. CODE § 11.130.725 (2022).

 $<sup>^{128}</sup>$  Tex. Est. Code Ann.  $\S~1357.053.$ 

<sup>&</sup>lt;sup>129</sup> Wash. Rev. Code § 11.130.725 (2022).

of the statute to support people with disabilities using an adaptable and personalized agreement that is specifically tailored to the individual and their available support network. Ideally, Connecticut will closely study existing SDM statutes and guidelines in an attempt to introduce a new bill within the near future.

#### C. What Connecticut Can Do in the Absence of an SDM Statute

While enacting an SDM statute is one of the best ways to implement SDM, through legal recognition, greater education, and emphasis on personalized planning for people with disabilities, SDM agreements can still be created and enforced without a formal statute. Because of the nature of the SDM agreement, which is a contractual agreement, it can be thought of much like a power of attorney, advance health care directive, or living will. On a similar note, SDM agreements can also be used in conjunction with other documents, like a power of attorney or advance health care directive, to further express the desires of the individual in terms of their legal, financial, and health care decisions. To legally recognize SDM, short of enacting an SDM-specific statute, Connecticut can adopt the UGCOPAA to reform current guardianship and conservatorship law and recognize SDM as one of the LRAs to guardianship and conservatorship.

Connecticut can also provide transparency about the methods of restoring rights in Connecticut after a guardian or conservator has already been appointed.<sup>132</sup> It is necessary for Connecticut to increase the monitoring and reporting requirements in the state to confirm that guardianships and conservatorships do not persist when inappropriate or when there are signs of misconduct on the part of the guardian or conservator; this could be accomplished by requiring annual review, substantially shortening the three-year mandatory reporting period that was previously discussed.<sup>133</sup>

#### D. Restoration of Rights

Some individuals under guardianship would also benefit from having their rights restored through the termination of a guardianship in favor of an

<sup>&</sup>lt;sup>130</sup> Public Act No. 23-137, An Act Concerning Resources and Support Services for Persons with an Intellectual or Developmental Disability, which was recently enacted in the State of Connecticut, supports this sentiment by asserting that the Department of Education, in consultation with local disability rights advocacy groups, needs to develop an online resource for students and parents, among others, that includes information about "alternatives to guardianship and conservatorship, including supported decision-making, powers of attorney, advance directives, and other decision-making alternatives." 2023 Conn. Pub. Acts § 41.

<sup>&</sup>lt;sup>131</sup> UGCOPAA, *supra* note 22 ("[T]he act recognizes the role of, and encourages the use of, less restrictive alternatives, including supported decision-making and single-issue court orders instead of guardianship and conservatorship. To this end, the act provides that neither guardianship nor conservatorship is appropriate where an adult's needs can be met with technological assistance or supported decision-making.").

<sup>&</sup>lt;sup>132</sup> See discussion infra Section III.D.

<sup>&</sup>lt;sup>133</sup> See discussion supra Section I.E.

LRA, such as an SDM agreement, even if Connecticut does not opt to formally adopt an SDM statute. The ABA Commission on Law and Aging ("COLA") conducted a 2013-2014 study on adult guardianship restoration law and practice. 134 The study sought to obtain a better understanding of the current state of restoration in the United States, employing statutory review, case law analysis, online questionnaires for judges and attorneys, and stakeholder interviews. 135 Results of this study demonstrate that petitions for restoration of rights are uncommon; however, those that are brought do have a moderate rate of success. 136 Exercise of the right to petition for restoration does not appear to be widely used among all disability communities, as 51% of cases in the study involved actions to restore the rights of an older individual.<sup>137</sup> Part of the reason for this discrepancy may be a lack of knowledge regarding the existence of the right to pursue restoration. 138 Another key barrier may be a lack of proof that the guardianship is no longer necessary because the protected individual may not have had prior opportunities to exercise self-determination or independent decisionmaking. <sup>139</sup> This lack of opportunities for self-determination, paired with the wide discretion of judges in this area and evidence presented, may explain why petitions for restoration are underutilized and only moderately successful. 140

Beyond the ABA COLA's study, additional research into guardianship termination and restoration of rights highlighted the processes used in Washington, Minnesota, Kentucky, and Illinois. 141 Data over a three-year period identified 275 cases for restoration in the four states; 142 however, without available data on the total number of guardianships (plenary or limited), it is difficult to discern how common it is to restore or attempt to restore one's rights. The data that was available indicated that in most cases, the protected individual does not have legal representation. These cases tend

<sup>134</sup> Jenica Cassidy, Restoration of Rights for Adults Under Guardianship, 36 BIFOCAL 63, 63–64 (2015).

135 *Id.* at 63.

<sup>136</sup> Id. (explaining that "[f]orty-seven percent of the 412 attorney questionnaire respondents have filed at least one petition for restoration within the last 10 years [and that] [o]f those, 96% reported having success with at least some of the petitions").

<sup>138</sup> Id. at 64 (explaining that there is no requirement that individuals be informed of the right to request restoration and that individuals may wish to petition for restoration but lack the resources to do so).

<sup>140</sup> When evaluating a petition for restoration, courts tend to rely on two types of evidence when determining whether to grant the petition to restore rights: (1) a medical examination of the capacity of the individual under guardianship; and (2) an in-court observation of the individual under guardianship. Id. (indicating that when an individual has not had the opportunity to exercise self-determination, the court's observations of their capacity are partly based on "the results of a psychological evaluation based on factors that may have little to do with life skills and the ability to self-determine," and thus, that the analysis is largely circumstantial and discretionary).

<sup>&</sup>lt;sup>141</sup> Erica Wood, Some Guardianships Last Longer than Necessary, but They are Rarely Overturned, 38 BIFOCAL 87, 87-88 (2017).

<sup>&</sup>lt;sup>142</sup> Id. at 87.

to involve younger individuals, a greater number of whom have mental health disabilities, and most of the petitions for termination were raised after an average of nearly five years under guardianship. <sup>143</sup> Of these petitions, approximately 75% were granted with either full or partial rights being restored. <sup>144</sup>

Taken together, the findings of both the ABA COLA study and the data collected from four states indicate that there may be a substantial number of cases wherein guardianships remain despite no longer being needed. Part of the problem lies in the lack of knowledge about alternatives to guardianship in the first place and the right to petition for restoration of rights. Given this lack of knowledge, guardianship reform efforts must focus on greater education about guardianship law and support for individuals involved in a guardianship. A potential avenue to achieve this education is to implement stronger probate court monitoring. State statutes should consider incorporating a regular review/reassessment requirement into their legislative framework in order to ensure that previously granted guardianships do not endure without a clear need. Because guardianship law is state-specific, it is necessary for states to reform their relevant statutes to clearly emphasize a priority for LRAs to guardianship or conservatorship, mentioning SDM, among others, and directing individuals to detailed SDM resources, such as those offered by the NRC-SM. States that have not already done so, including Connecticut, should also adopt the 2017 UGCOPAA, which advocates for greater awareness of the legitimacy and use of SDM as one of the leading LRAs to guardianship and conservatorship. 145

#### E. Educational Organizations, Tools, and Opportunities

While awaiting the adoption of an SDM statute, a great deal can be done at the grassroots level—especially in terms of education. As mentioned previously, <sup>146</sup> one of the primary reasons why guardianship is still used more commonly than SDM is a lack of knowledge among individuals, family members, practitioners, and probate judges. In addition to the resources provided by national advocates for SDM, including the NRC-SDM, a variety of resources exist at the state and local levels. One such resource is the protection and advocacy ("P&A") network, which has an agency in every state. <sup>147</sup> In Connecticut, an organization called Disability Rights Connecticut

<sup>&</sup>lt;sup>143</sup> *Id.* at 87–88.

<sup>&</sup>lt;sup>144</sup> *Id.* at 88.

<sup>&</sup>lt;sup>145</sup> UGCOPAA, *supra* note 22, at 2.

<sup>&</sup>lt;sup>146</sup> See discussion *supra* Section II.A.

<sup>&</sup>lt;sup>147</sup> The P&A network operates under the Developmental Disabilities Assistance and Bill of Rights Act, or the DD Act, which is codified at 42 U.S.C. § 15041 *et seq.* With the purpose of protecting and advocating for the rights of individuals with developmental disabilities, P&A systems have the authority to pursue administrative, legal, and other remedies for protected individuals, investigate incidents of

("DRCT") serves as the P&A system. One of DRCT's current initiatives is self-determination, which includes SDM. As such, DRCT works with individuals across the state through a series of webinars, workshops, and publications to educate others on SDM and help individuals learn about the process of drafting SDM agreements.

Additional agencies and organizations may be a source of information and support, including the Arc of Connecticut.<sup>149</sup> To identify and publicize available resources, it would be advisable to create a Working Interdisciplinary Network of Guardianship Stakeholders ("WINGS") task force in Connecticut that would be solely dedicated to issues in guardianship and conservatorship law and to evaluating the use of SDM and other LRAs.

#### F. Creating a WINGS Network

WINGS task forces are designed to "evaluate guardianship practice in individual states and develop action plans to advance reform and promote less restrictive options." In 2013 and 2015, the National Guardianship Network coordinated with the ABA Commission on Law and Aging to obtain start-up funds and support from the State Justice Institute and the Borchard Foundation Center on Law and Aging, among others, to pilot a program called WINGS in a few states. Is According to the ABA, WINGS is "a project to support court-led partnerships in states to drive changes in guardianship policy and practice[,]" with state WINGS serving to produce a "collective impact" on guardianship law through their efforts to coordinate actions to achieve desirable goals. Is

abuse and neglect, regularly monitor a variety of service providers within their jurisdiction, and obtain relevant records to carry out such activities. 42 U.S.C. § 15043. For Connecticut-specific authorization, see 2016 CONN. GEN. STAT. § 46a-10b.

148 DRCT's 2024 Priorities and Objectives, DISABILITY RTS. CONN., https://static1.squarespace.com/static/5952983059cc68ff83ce3153/t/65294fb5958f231b738c2907/1697 206197326/DRCT+FY2024+priorities+and+objectives+for+FY24%29%28Final%29.pdf (last visited Oct 30, 2023)

<sup>149</sup> The Arc of Connecticut is an advocacy organization that is committed to "protecting the rights of individuals with intellectual and developmental disabilities . . . and promoting opportunities for their full inclusion in their communities." *Mission & Values*, ARC CONN., https://thearcct.org/mission-values (last visited Oct. 30, 2023). One of the Arc's core goals is to promote self-determination and self-advocacy among individuals with intellectual and developmental disabilities, providing them with necessary resources and support to make decisions for themselves and to be heard as advocates on matters that impact their well-being. *Id.* 

<sup>150</sup> English, *supra* note 22, at 4–5; *see* COMM'N ON L. & AGING, A.B.A., WINGS BRIEFING PAPER: ADVANCING GUARDIANSHIP REFORM & PROMOTING LESS RESTRICTIVE OPTIONS 10 (2020) (describing how the ABA Commission promoted the establishment and expansion of WINGS programs in seven states).

151 Guardianship Reform/WINGS Background, AM. BAR ASS'N (Jan. 23, 2023), https://www.americanbar.org/groups/law\_aging/resources/wings-court-stakeholder-partnerships0/guardianship-reform-wings-background/.

152 WINGS Court-Stakeholder Partnerships, AM. BAR ASS'N, https://www.americanbar.org/groups/law\_aging/resources/wings-court-stakeholder-partnerships0/ (last visited Oct. 30, 2023).

<sup>153</sup> *Id*.

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Despite the growing number of states establishing WINGS or similar networks, Connecticut still does not have such a program. 154 If Connecticut wants to better serve and support people with disabilities, the State could utilize the WINGS State Replication Guide to establish its own WINGS. 155 A WINGS network can be established officially through legislation, a court order, a publicized community launch of the program, or other means of public recognition. 156 To ensure a sustainable Connecticut WINGS. legislative action would be ideal. Moreover, such legislation may have the potential to be combined with SDM provisions, closely aligning the goals of the programs, and accelerating the use of SDM agreements. It may also be possible for the Connecticut Supreme Court to create a "permanent, multidisciplinary court committee on guardianship," as was done in Ohio, Nebraska, and Nevada. 157 This may further help to support the initiatives of a WINGS program and serve as a tool within the courts to educate judges about the value of SDM agreements as an alternative to guardianship. Even if guardianship is deemed to be appropriate for a given individual, having a court guardianship committee would help to ensure that the granted guardianship is not overbroad, and that the guardianship is tailored to meet the specific needs of the individual. Such a committee would also be aptly situated to monitor, support, and implement guardianship reforms, which may help to reduce the burden on the probate courts responsible for overseeing guardianship and conservatorship petitions and related proceedings.

#### **CONCLUSION**

In its current state, guardianship law faces many challenges in effectively serving the interests of people with disabilities, mental health diagnoses, and memory loss because of its tendency to restrict both the practice of self-determination and the use of trusted supports to help these

<sup>154</sup> See State WINGS, AM. BAR ASS'N, https://www.americanbar.org/groups/law\_aging/resources/wings-court-stakeholder-partnerships0/state-wings/ (last visited Oct. 30, 2023) (listing states that have WINGS programs and Connecticut is not listed)

listed).

155 See generally COMM'N ON LAW & AGING, AM. BAR ASS'N, WORKING INTERDISCIPLINARY NETWORKS OF GUARDIANSHIP STAKEHOLDERS: WINGS STATE REPLICATION GUIDE 2019 (2019), https://www.americanbar.org/content/dam/aba/administrative/law\_aging/2019-wings-replication-guide.pdf. The guide outlines ten essential steps for creating a new WINGS network: (1) seeking support from the highest level of court leadership; (2) establishing or initiating the WINGS network; (3) designating a coordinator, chair, and steering committee; (4) identifying and cultivating stakeholders; (5) convening an initial WINGS meeting; (6) conducting priority setting and strategic planning initiatives; (7) developing focused working groups; (8) promoting stakeholder engagement and synergy; (9) continuing to evaluate measures of success; and (10) identifying funding sources for sustaining WINGS. *Id.* at 12–38.

<sup>156</sup> Id. at 15.

<sup>&</sup>lt;sup>157</sup> Id. (Ohio's Supreme Court created a permanent Advisory Committee on Children and Families that has a Subcommittee on Adult Guardianship; Nebraska's Supreme Court created a Commission on Guardianship and Conservatorship; and Nevada's Supreme Court established a Guardianship Commission.).

individuals make a variety of decisions independently. While guardianship and conservatorship may be necessary in certain circumstances, the best approach in making this determination is to first give the person multiple opportunities to participate in the decision-making process before petitioning for a guardianship. Such opportunities require assessing the availability of LRAs like SDM. An SDM agreement is one of the most effective ways to ensure that people with disabilities are provided with the necessary support and tools they need to feel comfortable making decisions pertaining to their own health and well-being.