

The National Guardianship Network hosted the Third World Congress on Adult Guardianship on May 28–30, 2014 in Washington, D.C. Each World Congress on Adult Guardianship facilitates learning and collaboration with participants from around the world who are involved in adult guardianship, aging, disability, and elder law. The theme of the Third World Congress was “Promising Practices to Ensure Excellence in Guardianship Around the World” with focus on the individual, guardians, the courts, and decision-making.

The convention included 120 presenters representing 21 countries over six continents. Most of the following articles are materials adapted from speeches of the Third World Congress on Adult Guardianship presenters. Therefore, the submissions included in this volume do not reflect a standard article publication.



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# **GUARDIANSHIP FOR YOUNG ADULTS WITH DISABILITIES AS A VIOLATION OF THE PURPOSE OF THE INDIVIDUALS WITH DISABILITIES EDUCATION IMPROVEMENT ACT**

*Arlene S. Kanter\**

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#### I. INTRODUCTION

In 1975, Congress enacted the Education for All Handicapped Children's Act (EAHCA).<sup>1</sup> The purpose of this law was to ensure that "all handicapped children have available to them . . . a free appropriate public education which emphasizes special education and related services designed to meet their unique needs."<sup>2</sup> Since 1975, the law has been amended, and renamed, in 2004, the Individuals with Disabilities Education Improvement Act (IDEIA).<sup>3</sup> The current IDEIA guarantees children with disabilities a "free appropriate public education," and requires that the education they receive is consistent with "our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency."<sup>4</sup>

In order to ensure that all students with disabilities have the necessary skills for life after high school, the IDEIA requires transition planning for students as they reach the age of majority.<sup>5</sup> Transition planning must address the student's plans for "post-

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<sup>1</sup> Pub. L. No. 94-142, 89 Stat. 773 (codified as 20 U.S.C. §§ 1400-1482 (1975)).

<sup>2</sup> *Id.* § 3, 89 Stat. at 775.

<sup>3</sup> Pub. L. No. 108-446, § 1, 118 Stat. 2647 (codified as 20 U.S.C. § 1400 (2004)).

<sup>4</sup> 20 U.S.C. § 1400(c)(1), (3) (2012).

<sup>5</sup> 20 U.S.C. § 1470 (2012).

secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation.”<sup>6</sup> However, rather than prepare some students with disabilities for life after high school by helping them to develop their decision-making skills and abilities, many schools encourage parents to become legal guardians for their young adult children. Since guardians typically make decisions for another person, guardianship, as a legal procedure, appears to run counter to the IDEIA’s goal of ensuring “equality of opportunity, full participation, independent living, and economic self-sufficiency.”<sup>7</sup> Once guardians are appointed, these young adults are deprived of opportunities to practice decision-making skills, just at the time in their lives when they should be supported in developing and practicing self-determination. Further, once a court authorizes a guardianship for a young adult with a disability, he or she is labeled “incompetent” or “incapacitated.”<sup>8</sup> Such a finding is generally based on the individual’s label of disability or misguided assumptions about the young person’s abilities, and without the application of any clear legal standards or adequate legal protections.<sup>9</sup>

This Article critically examines the practice of appointing guardians for young adults with intellectual or developmental disabilities as a result of the IDEIA transition planning process. The Article adopts a social model of disability that views “disability as a social, cultural, and political phenomenon.”<sup>10</sup> Viewing disability in this way runs counter to the view of

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<sup>6</sup> 20 U.S.C. § 1401(34)(A) (2012).

<sup>7</sup> 20 U.S.C. § 1400(c)(1).

<sup>8</sup> See Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157, 164 (2010).

<sup>9</sup> *Id.*

<sup>10</sup> Arlene S. Kanter, *The Law: What’s Disability Studies Got to Do with It or an Introduction to Disability Legal Studies*, 42 COLUM. HUM. RTS. L. REV. 403, 407 (2011) [hereinafter Kanter, *Law: What’s Disability Studies Got to Do*]; see also Arlene S. Kanter, *The Relationship Between Disability Studies and Law*, in RIGHTING EDUCATIONAL WRONGS: DISABILITY STUDIES IN LAW AND EDUCATION 1, 1 (Arlene S. Kanter & Beth Ferri eds., 2013) [hereinafter Kanter, *Relationship Between Disability Studies and Law*].

disability as an inherent and immutable trait or medical “problem” located in the person that must be fixed or cured by the medical intervention.<sup>11</sup> According to the social model, disability is seen “as the result of socio-cultural dynamics that occur in [one’s] interactions [with] society.”<sup>12</sup> Under this social model of disability, society becomes responsible for removing the physical, attitudinal, social, and legal barriers that prevent people with disabilities from exercising their right to full inclusion in society.<sup>13</sup> Consistent with the social model of disability, the goal of the IDEIA is to enable the young person with a disability to gain the skills he or she needs to overcome the many barriers to inclusion that exist in school and, later, in society.<sup>14</sup> Indeed, one of the overarching purposes of the IDEIA is to promote self-determination skills so that upon leaving high school, students with disabilities are capable of living on their own or with support, as needed.<sup>15</sup> The appointment of guardians for students in the context of transition planning therefore violates the goal of the IDEIA.<sup>16</sup>

This Article begins with an overview of the IDEIA’s transition planning process, particularly as it relates to young adults with intellectual and developmental disabilities. The IDEIA requires that once a student with a disability reaches the age of majority, the school must transfer all educational rights of the parents to the student as part of the transition planning process.<sup>17</sup> Once this “transfer of rights” is completed, the student is responsible for making all educational decisions on his or her own, or with the assistance of a parent or other adult.<sup>18</sup> If a court finds the student incompetent and appoints a guardian, or if the school

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<sup>11</sup> Kanter, *Law: What’s Disability Studies Got to Do*, *supra* note 10, at 419–20; *see also* Kanter, *Relationship Between Disability Studies and Law*, *supra* note 10, at 2.

<sup>12</sup> Kanter, *Law: What’s Disability Studies Got to Do*, *supra* note 10, at 407; *see also* Kanter, *Relationship Between Disability Studies and Law*, *supra* note 10, at 1–2.

<sup>13</sup> Kanter, *Law: What’s Disability Studies Got to Do*, *supra* note 10, at 420–21, 427; *see also* Kanter, *Relationship Between Disability Studies and Law*, *supra* note 10, at 10–11.

<sup>14</sup> *See* 20 U.S.C. § 1400(c)(1).

<sup>15</sup> *See id.*

<sup>16</sup> *See id.*

<sup>17</sup> 20 U.S.C. § 1415(m)(1) (2012); 34 C.F.R. § 300.520(a) (2015).

<sup>18</sup> *See id.*

considers the student unable to give informed consent but not incompetent, as a legal matter, the transfer of rights will not occur.<sup>19</sup> In such cases, the parents or other designated adult will retain the student's rights under the IDEIA. It is therefore at this juncture in the student's educational life when parents, in consultation with school personnel, question the student's overall competence, and when many parents seek to become the legal guardians of their young adult children.

The second section of the Article discusses guardianship as a legal procedure that authorizes one person (or entity) to make decisions for another person.<sup>20</sup> This section begins with a general overview of state guardianship laws, and then discusses various efforts to reform guardianship laws that have been undertaken in response to the many problems inherent in most, if not all, guardianship laws. This section also addresses the continuing problems of guardianship, even after such reform efforts.

The third section of the Article identifies the specific problems of guardianship, as applied to young adults with disabilities. This section discusses the conflict between the purpose of the IDEIA, which is to equip students for life after high school, and guardianship laws, which limit the ability of an individual to live and think independently by authorizing one person to make all or some decisions for another person. In the context of young adults with disabilities, guardianship necessarily deprives them of the opportunity not only to make their own decisions, but also to learn how to make decisions, which is a key element of self-determination. This section of the Article, therefore, discusses the damaging presumption of incompetence upon which guardianship laws are based, as well as the false sense of protection that guardianship orders may offer to parents of adult children with intellectual or developmental disabilities.

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<sup>19</sup> *Id.*

<sup>20</sup> Dorothy Squatrito Millar, "I Never Put it Together": The Disconnect Between Self-Determination and Guardianship—Implications for Practice, 42 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 119, 120 (2007).

The fourth section of the Article discusses recent legal challenges to the appointment of guardians for young adults with disabilities, followed by the fifth section of the Article, which provides an overview of the research that has been conducted to date on the appointment of guardians for young adults with intellectual or developmental disabilities. This research supports the conclusion that the appointment of guardians may interfere with the development of important self-determination skills of young adults with disabilities.

The next and sixth section of the Article discusses various alternatives to guardianship, including changes in school policies and practices that could be implemented immediately, as well as supported decision-making as an alternative to guardianship for young adults with disabilities. Supported decision-making has gained prominence recently in the context of the 2006 adoption of the Convention on the Rights of People with Disabilities (CRPD), by the United Nations (UN). Article 12 of the CRPD, which specifically affirms the right of all persons with disabilities to legal capacity and requires State Parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”<sup>21</sup> Supported decision-making is considered a vehicle to ensure compliance with Article 12 of the CRPD, and has been successfully implemented as a formal procedure in various countries, and, informally, in the United States for some time.<sup>22</sup> Supported decision-making allows the person with a disability to identify another trusted person (or group of people) to assist him or her in making decisions. As discussed in this section, supported decision-making differs from

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<sup>21</sup> U.N. Convention on the Rights of Persons with Disabilities, G.A. Res. 106, U.N. Doc. A/RES/61/106, Art. 12, (Dec. 13, 2006), <http://www.un-documents.net/a61r106.htm> [hereinafter CRPD]; see Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities*, 34 SYRACUSE J. INT'L L. & COM. 287 (2007).

<sup>22</sup> See Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8 (2011–2012); Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93 (2012); Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111 (2013).

traditional guardianship because it requires one person (or group) to assist a person with a disability in making decisions as opposed traditional guardianship where the guardian makes decisions on behalf of the person with a disability. In this way, supported decision-making offers a young adult with a disability the opportunity to exercise his or her right to autonomous decision-making, without being declared incompetent, as is required in most guardianship laws.

The Article concludes with recommendations for the development and use of supported decision-making alternatives to guardianship as part of the transition planning process for young adults with disabilities leaving high school. Such alternatives protect the dignity of young adults with disabilities, while at the same time address their right to safety and well being, but without the overreaching parentalism that is inherent in guardianship laws.

It is the hope that this Article will contribute to the conversation among federal and state lawmakers, educators, families, and young people with disabilities themselves about the conflict between guardianship and the purpose of the IDEIA. Supported decision-making offers a practical solution for those people who need help in making decisions by creating circles of support and other informal supportive mechanisms that are designed specifically to support young people with disabilities as they learn the skills necessary to live the independent and self-determined life. As such, the goals of supported decision-making are consistent with, rather than at odds with, the goals of the IDEIA.

## II. AN OVERVIEW OF THE IDEIA'S TRANSITION PLANNING PROCESS FOR STUDENTS APPROACHING THE AGE OF MAJORITY

Before 1975, children with disabilities were generally not allowed to attend public schools.<sup>23</sup> The courts' decisions in *Pennsylvania Association for Retarded Children*<sup>24</sup> and *Mills v. Board of Education*<sup>25</sup> changed that, leading in 1975 to the enactment of the EAHCA, the precursor to the IDEIA. The EAHCA sought to protect the right of all children with disabilities to receive a "free, appropriate public education."<sup>26</sup>

Education is the primary vehicle through which one may gain the skills necessary to advance in society.<sup>27</sup> The overarching purpose of the IDEIA is to "ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."<sup>28</sup> For students with disabilities, the IDEIA has meant that they have an equal right

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<sup>23</sup> See 20 U.S.C. § 1400(c)(2)(B); see also *Mills v. Board of Educ. of D.C.*, 348 F. Supp. 866 (D.D.C. 1972); *Pa. Ass'n for Retarded Children v. Pennsylvania (PARC)*, 334 F. Supp. 1257 (E.D. Pa. 1971).

<sup>24</sup> *PARC*, 334 F. Supp. 1257. In *PARC*, the parties entered into a consent decree, in which the state agreed to provide children with mental retardation up to the age of 21 with access to a free public education. *Id.* This case also established the right of all children to an education appropriate to his or her learning capacities and that children of all ages should be educated in the least restrictive placement. *Id.*

<sup>25</sup> *Mills*, 348 F. Supp. 866. In *Mills*, the U.S. District Court ruled that school districts were constitutionally prohibited from deciding that they had inadequate resources to serve children with disabilities because the equal protection clause of the Fourteenth Amendment would not allow the burden of insufficient funding to fall more heavily on children with disabilities than on other children. *Id.*

<sup>26</sup> See Pub. L. No. 94-142, § 3(c), 89 Stat. at 775.

<sup>27</sup> See e.g., *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954). In *Brown*, the United States Supreme Court wrote

Compulsory school attendance laws and the great expenditures for education both demonstrate our recognition of the importance of education to our democratic society. . . . Today it is a principal instrument in awakening the child to cultural values, in preparing him for later professional training, and in helping him to adjust normally to his environment. In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education.

*Id.* at 493.

<sup>28</sup> 20 U.S.C. § 1400(d)(1)(A).



to education and the corresponding chance for a successful life after high school.<sup>29</sup>

In order to provide the “free appropriate public education,” to which all qualified children with disabilities are entitled, the IDEIA contemplates an individualized planning process. This process includes an annual Individualized Education Program (IEP), developed by the school with participation of the child’s parents, and which results in a “written statement for each child with a disability that is developed, reviewed, and revised.”<sup>30</sup> The IEP has been described by the Supreme Court as “the centerpiece of the statute’s education delivery system for disabled children.”<sup>31</sup> The IEP includes information about the student’s strengths and limitations as well as an educational program designed to meet the student’s unique needs.<sup>32</sup> The IEP also includes the student’s current performance, annual goals, special education and related services, accommodations, participation in state and district-wide tests, measured progress, and needed transition services.<sup>33</sup> As students approach their final years in school, transition planning is an important element of the IEP process.

Since 1997, the IDEIA has required transition planning for students with disabilities throughout their education.<sup>34</sup> By the age of 16, the child’s IEP must include “appropriate measurable postsecondary goals [and] transition services (including courses of study) needed to assist the child in reaching those goals.”<sup>35</sup> The scope and extent of transition services may vary from state to state, but under federal law, transition services are defined as “a coordinated set of activities for a child with a disability” that:

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<sup>29</sup> See 20 U.S.C. § 1400(c).

<sup>30</sup> 20 U.S.C. § 1414(d)(1) (2012).

<sup>31</sup> *Honig v. Doe*, 484 U.S. 305, 311 (1988).

<sup>32</sup> 20 U.S.C. § 1414(d)(1)(A).

<sup>33</sup> *Id.*; *Honig*, 484 U.S. at 311.

<sup>34</sup> 20 U.S.C. § 1401(34).

<sup>35</sup> 34 C.F.R. § 300.320(b) (2015).

[are] designed to be within a results-oriented process, that [are] focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; [are] based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and [include] instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.<sup>36</sup>

Most important to the successful outcome of the transition planning process is the involvement of the student. The IDEIA requires all students with disabilities to receive notification of the IEP meetings, at which transition goals and services will be discussed.<sup>37</sup> The regulations implementing the IDEIA also specifically require schools to invite students to join their parents and school personnel in transition planning meetings where "postsecondary goals [of] the child and the transition services needed to assist the child in reaching those goals"<sup>38</sup> will be considered. If a student cannot attend an IEP meeting when transition planning for life after high school will be discussed, the

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<sup>36</sup> 20 U.S.C. § 1401(34); *accord* 34 C.F.R. § 300.43. Some families have gone to court to clarify which transition services are appropriate for individual students. For example, one court in South Dakota required driver's education, self-advocacy, and independent living skills such as cooking and cleaning as part of a student's transition services plan. *Yankton Sch. Dist. v. Schramm*, 93 F.3d 1369, 1370–71 (8th Cir. 1996).

<sup>37</sup> 20 U.S.C. § 1414(b)(1); 34 C.F.R. § 300.322 (2015).

<sup>38</sup> 34 C.F.R. § 300.321(b)(1).

school “must take other steps to ensure that the child’s preferences and interests are considered.”<sup>39</sup>

Student participation in the development of transition plans is considered necessary to ensure the student’s understanding of post-high school goals and to increase his or her potential for success after high school. As one team of researchers has observed, “[t]oo often secondary programs have not implemented ‘best practices’ such as involving the student in developing the [IEP].”<sup>40</sup> By not including the young adult student in developing the transition plan, the student is framed as an “object of care”<sup>41</sup> rather than an agent capable of making decisions about his or her own life. Without the student’s participation, even minimally, the transition planning process violates the IDEIA by becoming something that is done *to* the student, rather than *with* the student. Moreover, practices that limit full and active participation by a student in the transition planning process perpetuate the view of the student as incompetent and unable to exercise authority for his or her own life. On the other hand, a process that provides a student with the opportunity to fully participate in transition planning, to the best of his or her ability, allows the student to practice important decision-making skills.

In addition to the student, parents, and school personnel, representatives from government agencies that are “responsible for providing or paying for transition services” must also be invited to attend the transition planning meetings that take place toward the end of the student’s schooling.<sup>42</sup> It is the services provided by these local, state and federal agencies that will assist the student in life after high school. Implicit in the requirement of participation by these agencies is the recognition of the importance of the student’s role in expressing his or her views regarding what

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<sup>39</sup> *Id.* at (b)(2).

<sup>40</sup> Sharon Field et al., *Self-Determination: A Key to Success in Postsecondary Education for Students with Learning Disabilities*, 24 REMEDIAL & SPECIAL EDUC. 339, 340 (2003).

<sup>41</sup> Vivian M. May & Beth A. Ferri. “I’m a Wheelchair Girl Now”: *Abjection, Intersectionality, and Subjectivity in Atom Egoyan’s The Sweet Hereafter*, 30 WOMEN’S STUD. Q. 131, 143 (2002).

<sup>42</sup> 34 C.F.R. § 300.321(b)(3).

services he or she may need after high school. In fact, recent court decisions have held that a school district's failure to invite representatives of the agencies that would be responsible for providing services to the student after high school constituted a violation of the student's rights under the IDEIA.<sup>43</sup>

In addition to these requirements, the IDEIA mandates that within one year after the student reaches the age of majority under the applicable state law, or by the age of 16, whichever comes first,<sup>44</sup> the student and his or her parents shall be notified of the "transfer of rights."<sup>45</sup> Under the IDEIA, the parents of a child with a disability have exclusive rights under the IDEIA, but only until the student reaches the age of majority.<sup>46</sup> Once the student reaches the legal age of majority, the educational rights of the parents under the IDEIA are transferred to the student.<sup>47</sup> According to this "transfer of rights" provision, once the student reaches the age of majority, the student has the right to make all of his or her own educational decisions, with or without the help of his or her parents or others, depending on his or her preference.<sup>48</sup> Thus, once the transfer of rights provision is fully implemented, the student has the right to receive all notices about and to participate in all IEP meetings, as well as the right to provide or withhold consent to evaluations, to participate in placement decisions, request mediation, and, if the student disagrees with the recommendations in the IEP, to pursue a due process hearing, according to the procedures set out in the IDEIA.<sup>49</sup>

The IDEIA's transfer of rights provision applies to all students with disabilities upon reaching the age of majority, except for two categories of students: (1) students who are found by a

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<sup>43</sup> *Carrie I. ex rel. Greg I. v. Dep't of Educ.*, Hawaii, 869 F. Supp. 2d 1225, 1245–47 (D. Haw. 2012); see also *United States v. Arkansas*, 794 F. Supp. 2d 935, 983 (E.D. Ark. 2011).

<sup>44</sup> 34 C.F.R. § 300.320(c).

<sup>45</sup> 20 U.S.C. § 1415(m)(1)(C); 34 C.F.R. § 300.520.

<sup>46</sup> 34 C.F.R. § 300.520.

<sup>47</sup> 20 U.S.C. § 1415(m); 34 C.F.R. § 300.520.

<sup>48</sup> 20 U.S.C. § 1415(m); 34 C.F.R. § 300.520.

<sup>49</sup> See 20 U.S.C. § 1415.

court to be incompetent or incapacitated and for whom a guardian is appointed,<sup>50</sup> and (2) students who qualify for coverage under the “special rule” for students who have not been adjudicated by a court as incompetent or incapacitated but who are considered by the school or the parents as unable to provide informed consent to their educational programs.<sup>51</sup>

Once a court finds a student to be “incompetent” or “incapacitated” under state law, it will appoint a guardian, typically one of the student’s parents. After a court appoints the parent as the student’s guardian, the parent is authorized, as the guardian, to exercise all of the student’s rights under the IDEIA.<sup>52</sup> Thus, once the guardian is appointed, the transfer of rights never occurs and the student loses his or her right to make any and all educational decisions under the IDEIA.<sup>53</sup> Depending on the terms of the guardianship order, the student also may lose his or her right to make all other life decisions, regardless of the student’s interest in or ability to make decisions alone or with support.

Those young adults for whom a court has not ordered guardianship but who are nonetheless considered by the school or parents to lack the ability to provide informed consent are subject to a “special rule” under the IDEIA.<sup>54</sup> This special rule requires

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<sup>50</sup> 34 C.F.R. § 300.520(a). Although the definition of legal incompetence varies from state to state, most states define incompetence as incapacity to make responsible decisions. See Sally Hurme & ABA Comm’n on L. & Aging, *Capacity Definition & Initiation of Guardianship Proceedings*, ABA, [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_CHARTCapacityandInitiation.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_CHARTCapacityandInitiation.authcheckdam.pdf) (last updated July 2014) [hereinafter *ABA Capacity Definition*]. See generally ABA Comm’n on L. & Aging, *State Adult Guardianship Legislation: Directions of Reform—2013*, ABA, [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2013\\_final\\_guardianship\\_legislative\\_update\\_12-18-13.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2013_final_guardianship_legislative_update_12-18-13.authcheckdam.pdf) (2013) [hereinafter *ABA State Adult Guardianship Legislation*].

<sup>51</sup> This Special Rule provides that “A State must establish procedures for appointing the parent of a child with a disability, or, if the parent is not available, another appropriate individual, to represent the educational interests of the child throughout the period of the child’s eligibility under part B of the Act if, under State law, a child who has reached the age of majority, but has not been determined to be incompetent, can be determined not to have the ability to provide informed consent with respect to the child’s educational program.” 34 C.F.R. § 300.520(b).

<sup>52</sup> See 34 C.F.R. § 300.520.

<sup>53</sup> See *id.*

<sup>54</sup> 34 C.F.R. § 300.520(b).

“the State [to] establish procedures for appointing the parent of the child, or if the parent is not available, another appropriate individual, to represent the educational interests of the child throughout the period of eligibility of the child under this [part].”<sup>55</sup> Some states require courts to make the determination of whether or not the student is unable to give informed consent and then appoint a limited guardian or conservator in such cases, while other states simply allow a hearing examiner or IEP team to make the determination.<sup>56</sup> However, regardless of which procedure is followed, the student is prevented from exercising his or her ability to make decisions, even with assistance. Such practices also place these students at risk of being “denied opportunities to communicate and make personal decisions because decision-making is taken out of their hands and assigned to other individuals who, ostensibly, make choices on their behalf.”<sup>57</sup> Once the decision-making process is taken out of their hands, these students are denied the opportunity to practice their decision-making and self-determination skills. Without such ongoing practice, the students’ ability to foster and develop such skills may be limited. Therefore, the exception to the transfer of rights requirement for students who are either considered unable to give consent or found by a court to be “incompetent” or “incapacitated,” undermines one of the core purposes of the IDEA: to prepare students with disabilities “to lead productive and independent adult lives, to the maximum extent possible.”<sup>58</sup> In addition, the transfer of rights exception also supports a presumption of the incompetence of certain students, thereby

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<sup>55</sup> 20 U.S.C. § 1415(m)(2).

<sup>56</sup> In Idaho, for example, a court or a student’s IEP team may determine whether a student is capable of providing informed consent to his or her educational program. Deborah Rebores & Perry Zirkel, *Transfer of Rights Under the Individuals with Disabilities Act: Adulthood with Ability or Disability?*, 33 BYU EDUC. & L.J. 33, 44–45 (2000) (citing IDAHO CODE § 33-2002(4) (1998)).

<sup>57</sup> *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities* 1 (2012) (Briefing Paper for Roundtable Discussion Guardianship UN Convention of Human Rights), available at [http://www.nlrc.aoa.gov/legal\\_issues/guardianship/docs/kris\\_glen\\_paper\\_final\\_10-12.pdf](http://www.nlrc.aoa.gov/legal_issues/guardianship/docs/kris_glen_paper_final_10-12.pdf).

<sup>58</sup> 20 U.S.C. § 1400(c)(5)(A)(ii).

perpetuating the stigma of disability that the IDEIA was enacted to eradicate.<sup>59</sup>

While state educational agencies are responsible for implementing the transfer of rights provision, it is often at this stage in the student's educational career when parents are first asked about the necessity of guardianship for their child.<sup>60</sup> In many states, if not most, parents may view guardianship as the only available option to ensure the continuation of services for their child after high school, especially for children with intellectual or developmental disabilities. Thus, it appears that the IDEIA's transfer of rights provision, itself, may be the reason that many parents seek to become guardians.

For example, in one study on the transfer of rights process used in a school district in Michigan, the researcher found that parents choose to file guardianship petitions only after teachers asked the parents, "Do you have a guardian?"<sup>61</sup> A position statement of the Council of Exceptional Children's Division of Mental Retardation and Development Disabilities echoed this practice, finding that "parents and family members will feel compelled to obtain guardianship or other legal decision-making status over their son or daughter when they might not otherwise do so."<sup>62</sup> Yet, as discussed in the following sections of this Article, the appointment of a guardian may be detrimental to the student and contrary to the language and purpose of the IDEIA.

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<sup>59</sup> For a comprehensive discussion of the presumption of incompetence inherent in guardianship laws applied to young adults with disabilities see Carrie E. Rood et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*, 39 RESEARCH & PRACTICE FOR PERSONS WITH SEVERE DISABILITIES 319 (2015).

<sup>60</sup> 20 U.S.C. § 1415(m).

<sup>61</sup> Millar, *supra* note 20, at 125.

<sup>62</sup> Pam Lindsey et al., *Age of Majority and Mental Retardation: A Position Statement of the Division on Mental Retardation and Developmental Disabilities*, 36 EDUC. & TRAINING IN MENTAL RETARDATION DEVELOPMENTAL DISABILITIES 3, 13 (2001).

### III. GUARDIANSHIP: PAST AND PRESENT

#### A. An Overview of Guardianship Laws

Guardianship is a legal relationship created by state law in which a court gives one person, a group of people, or an entity (the guardian) the duty and power to make personal and/or property decisions for another adult person (the ward). Historically, guardianship laws were based on the principle of “*parens patriae*,” in which the state acts as a “parent” to intervene on behalf of those whom the State deems unable to care for themselves.<sup>63</sup> The intent of such guardianship laws was to protect those who are at risk of abuse or exploitation by others.<sup>64</sup> For decades, court-appointed guardians have been seen as part of the legitimate function of the State to protect young and old people, alike, whom a court adjudicates “incompetent” or lacking the capacity to make decisions in their own self-interest.<sup>65</sup>

Today, guardianship state laws vary widely. Most states provide for plenary guardians who have some or all of the authority to make decisions regarding a person’s personal health, welfare, and property. A plenary guardian is authorized by the court to make all decisions for the “ward,” without limitation. The word “ward” itself harkens back to an antiquated view of a person who is in custody and unable to exercise his or her free will.<sup>66</sup> The plenary guardian is thus seen as the decision maker for the incompetent or incapacitated “ward,” with the power to decide where the ward will live, what he or she will do, which friends he or she may or may not see, and what he or she can buy, wear, or eat each day.<sup>67</sup> A plenary guardian also has the right to engage in

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<sup>63</sup> Salzman, *supra* note 8, at 164.

<sup>64</sup> See *id.*; see Dorothy Squatrito Millar & Adelle Renzaglia, *Factors Affecting Guardianship Practices for Young Adults with Disabilities*, 68 EXCEPTIONAL CHILDREN 465, 480 (2002).

<sup>65</sup> *ABA Capacity Definition*, *supra* note 50; see *ABA State Adult Guardianship Legislation*, *supra* note 50 (outlining state guardianship laws).

<sup>66</sup> See A. Frank Johns, *Ten Years After: Where Is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?*, 7 ELDER L. J. 33, 40–51 (1999).

<sup>67</sup> Salzman, *supra* note 8, at 160; see Millar & Renzaglia, *supra* note 64, at 474–75, 480 (listing examples of powers granted to partial guardians).



all sorts of transactions on behalf of the ward, including selling and buying property, entering into contracts, and accepting or refusing medical treatment, health care or other services.<sup>68</sup>

A limited guardian, on the other hand, is authorized to make only those decisions specified in a court order. Typically, limited guardians have the authority to make decisions about the person's real and personal property and are referred to in some states as "conservators."<sup>69</sup> In such cases the court has discretion to decide the scope and powers of a limited guardian. Thus, the court is free to authorize even limited guardians to make many or all of a ward's decisions. One study of guardianship in Colorado found, for example, that while approximately one-third of the guardianship orders were technically limited guardianships,<sup>70</sup> they were actually "plenary orders with some specific limitations on the guardians' powers added in."<sup>71</sup>

In most states, the probate division of the state's court system handles guardianship cases, although, in some states guardianship cases are heard by courts of general jurisdiction. The procedures governing guardianships also vary from state to state. Typically, once a prospective guardian files a petition for guardianship, the court sends a notice to the prospective "ward," and an investigation takes place. Then, often, but not always, a judge may hold a hearing to determine the legal competency of the prospective ward. The court typically has total discretion regarding whom to appoint as a guardian as well as the scope of the guardian's authority over the ward's life. Once a guardian is appointed, the ward cannot even petition the court to review the guardianship order, since once a guardian is appointed, the person

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<sup>68</sup> Salzman, *supra* note 8, at 160; see Millar & Renzaglia, *supra* note 64, at 474–75, 480 (listing examples of powers granted to partial guardians).

<sup>69</sup> See Salzman, *supra* note 8 at 171–73.

<sup>70</sup> Leslie Salzman, *Guardianships for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS J. HEALTH L. & POL'Y 279, 295 n.73. (2011); Jennifer L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J.L. & PSYCHIATRY 350, 367 (2010).

<sup>71</sup> Salzman, *supra* note 70, at 295 n.73 (quoting Wright, *supra* note 70, at 367 n.144).

loses his or her right to petition a court, including the court that ordered the guardianship.

Another problem identified with guardianships is that the evidence supporting the determination of competency is known to be highly subjective.<sup>72</sup> For example, in some states, a statement by one or two doctors of a person's diagnosis of an intellectual, psychiatric or developmental disability, alone, is sufficient to justify the appointment of a guardian.<sup>73</sup> In other states, more may be required.<sup>74</sup>

In recent years, some states have adopted streamlined procedures for appointing plenary guardians for individuals with disabilities.<sup>75</sup> Other states, such as New York, California, Connecticut, Idaho, and Michigan, have enacted entirely separate guardianship statutes for people with intellectual disabilities and developmental disabilities.<sup>76</sup> New York, for example, has two guardianship statutes. One guardianship statute, Article 17-A of New York's Surrogate Procedure Act, applies specifically to people who are "mentally retarded," "developmentally disabled," or who have "traumatic head injuries."<sup>77</sup> The other New York

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<sup>72</sup> For example, the ABA Commission on Law and Aging's Report, titled, "Conduct and Findings of Guardianship Proceedings Chart" shows that 7 out of 50 states state that the standards of proof required in guardianship cases is "not stated." Sally Balch Hurme & ABA Comm'n on L. & Aging, *Conduct and Findings of Guardianship Proceedings Chart*, ABA, [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2014\\_CHARTConduct.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2014_CHARTConduct.authcheckdam.pdf) (last updated Dec. 31, 2013). The laws in Montana and Idaho state that guardians will be appointed "if court is satisfied," New Hampshire uses "beyond reasonable doubt" as the standard of proof, and the remaining states cite "clear and convincing" standard of proof with few of them providing any additional information. *Id.*

<sup>73</sup> N.Y. SURR. CT. PROC. ACT LAW § 1750 (McKinney 2015); N.Y. MENTAL HYG. LAW, art. 81 (McKinney 2015).

<sup>74</sup> In Florida, for example, examining committees consist of three members, and not every member of the committee must be a physician. Fla. Stat. § 744.331(3)(a) (2015).

<sup>75</sup> See, e.g., ALA. CODE § 26-2A-102 (2015) (addressing the appointment of guardians to people for an incapacitated person); N.Y. SURR. CT. PROC. ACT LAW § 1750. See also ALA. CODE § 12-13-21 (2015) (addressing the appointment of guardians to people with developmental disabilities).

<sup>76</sup> See CAL. PROB. CODE § 1850.5 (West 2015); CONN. GEN. STAT. ANN. § 45A, Ch. 802H, Pt. V (West 2015); IDAHO CODE ANN. § tit 66, ch. 4 (West 2015); MICH. COMP. LAWS ANN. § Ch. 330, Ch. 6 (West 2015); N.Y. SURR. CT. PROC. ACT LAW § 1750, 1750-a.

<sup>77</sup> This law covers those whose developmental disability is "attributable to cerebral palsy, epilepsy, neurological impairment, autism or traumatic head injury and . . . dyslexia resulting from a disability" that originates before age of 22. N.Y. SURR. CT. PROC. ACT LAW § 1750;

guardianship law, Article 81 of the New York Mental Hygiene Law, applies to people who are considered incapacitated for reasons other than having mental retardation, developmental disability, or a traumatic brain injury.<sup>78</sup> Article 17-A not only continues to use the outdated term “mentally retarded” but also denies people covered under this law the same procedural protections as those guaranteed in the state’s general guardianship law under Article 81.<sup>79</sup>

For example, under Article 17-A, New York Surrogate Courts have no option but to order plenary guardianships that are based on the certification of two healthcare professionals, including one medical doctor.<sup>80</sup> Such certification is required to state only that the person for whom guardianship is sought has been diagnosed with mental retardation or a developmental disability; that the condition is likely to continue indefinitely; and that the person has an “impaired ability to understand and appreciate the nature and consequences of decisions which result in such person being incapable of managing himself or herself and/or his affairs.”<sup>81</sup> No detailed report or supporting documentation is required; all that is required is the form on which the health professionals simply check “yes” or “no” as to whether the person meets the requirements for the appointment of a guardian. In addition, under Section 17-A, the person with a disability is not even required to attend the guardianship hearing.<sup>82</sup> Although some people subject to guardianship under 17-A may choose to be present in court, one former New York State Surrogate Court judge recently observed that, “as a practical matter [the person] never appears and so is unavailable for cross-examination.”<sup>83</sup> Moreover, if the petitioners are the parents, and

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see also ALA. CODE § 38-9A-1 (2015) (defining “developmentally disabled”).

<sup>78</sup> N.Y. MENTAL HYG. LAW, art. 81 (McKinney 2015).

<sup>79</sup> N.Y. SURR. CT. PROC. ACT LAW § 1750; N.Y. MENTAL HYG. LAW, art. 81.

<sup>80</sup> N.Y. SURR. CT. PROC. ACT LAW § Ch. 59-a, art. 17-A (McKinney 2015).

<sup>81</sup> N.Y. SURR. CT. PROC. ACT LAW § 1750, 1750-a.

<sup>82</sup> Id. at §§ 1750, 1754.

<sup>83</sup> Glen, *supra* note 22, at 120 n. 126.

they consent to waive the hearing, there will be no hearing at all.<sup>84</sup> Moreover, Section 17-A does not require the guardians to report periodically to the court nor does it include a process by which the court may inquire into the ward's situation after the guardian has been appointed.<sup>85</sup> Thus, once the guardian is appointed in New York under Section 17-A, the court will have no further contact with the guardian or the ward, unless the guardian dies or someone petitions to replace the current guardian.<sup>86</sup>

In a recent case involving a person whom the court described as a “disabled, vulnerable, institutionalized young man, wholly dependent on Medicaid, unvisited and virtually abandoned,”<sup>87</sup> a New York Surrogate Court ruled that Article 17-A was unconstitutional because it did not require the guardian to report periodically to the court.<sup>88</sup> What was at issue in this case was a multi-million dollar trust left for the young man’s care by his deceased mother.<sup>89</sup> The court stated that without periodic reporting, “the court [could not] ascertain whether the deprivation of liberty resulting from guardianship [was] still justified . . . or whether [the ward had] progressed to a level where [he could] live and function on [his] own” as a result of the services and educational opportunities provided to him during the preceding period of the guardianship.<sup>90</sup> The court also stated that without periodic reporting, the court could not fulfill its responsibility to effectively monitor the ward and ascertain if the guardian was fulfilling his fiduciary duty to the ward.<sup>91</sup> Accordingly, the court concluded that under Section 17-A, a guardian should submit yearly reports to the court and respond to a court questionnaire intended to substantiate the continuing need for the guardianship.<sup>92</sup>

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<sup>84</sup> *Id.* at 120.

<sup>85</sup> N.Y. SURR. CT. PROC. ACT LAW § 1750, 1750-a.

<sup>86</sup> *Id.*; see also Gloria R. Tressler, *Status of Liberty Rights for Persons with Mental Retardation*, 23 NYSBA ELDER & SPECIAL NEEDS L.J. 7, 12–14 (2013).

<sup>87</sup> *In re JP Morgan Chase Bank N.A.*, 956 N.Y.S.2d 856, 857 (Sur. Ct. 2012).

<sup>88</sup> *In re Mark C.H.*, 906 N.Y.S.2d 419, 435 (Sur. Ct. 2010).

<sup>89</sup> *JP Morgan Chase Bank*, 956 N.Y.S.2d at 857.

<sup>90</sup> *In re Mark C.H.*, 906 N.Y.S.2d at 428.

<sup>91</sup> *JP Morgan Chase Bank* 956 N.Y.S.2d at 866.

<sup>92</sup> *In re Mark C.H.*, 906 N.Y.S.2d at 431.

However, such requirements are not part of the law. Thus, in New York and other states in which streamlined procedures have been established for persons with intellectual or developmental disabilities, the lack of procedural protections continues to be a source of controversy.

## B. Guardianship Reform Efforts

Over the past three decades, two widespread reforms of guardianship laws have taken place throughout the US.<sup>93</sup> In 1987, an Associated Press (AP) report, which reviewed over 2,000 guardianship files of elderly people from all 50 States and the District of Columbia, found a broken system.<sup>94</sup> This report led to the first major guardianship reform. Following the AP report, the American Bar Association's Commission on Legal Problems of the Elderly and the Commission on Mental and Physical Disability organized a major conference, known as the Wingspread Conference,<sup>95</sup> held at the Wingspread Conference Center in Wisconsin.<sup>96</sup> This conference recommended changes to guardianship laws, including greater procedural protections and changes that would require a determination of capacity based on functional ability rather than medical diagnosis.<sup>97</sup> The result of this

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<sup>93</sup> Although many states have reformed their guardianship laws, neither the judicial nor social systems responsible for these "cases" have meaningful data regarding guardianship practices. See Sally Balch Hurme, *Monitoring of Guardianship*, in *GUARDIANSHIP OF THE ELDERLY: PSYCHIATRIC AND JUDICIAL ASPECTS* 115, 129–131 (George H. Zimny & George T. Grossberg eds., 1998); George H. Zimny, *Empirical Research on Guardianship*, in *GUARDIANSHIP OF THE ELDERLY*, *supra* note 89, at 135, 135–48.

<sup>94</sup> Fred Bayles & Scott McCartney, *Guardians of the Elderly: An Ailing System Part I: Declared "Legally Dead" by a Troubled System*, ASSOCIATED PRESS, Sept. 19, 1987, <http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally-Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f>.

<sup>95</sup> ABA Comm'n on Mentally Disabled & ABA Comm'n on Legal Problems of the Elderly, *Guardianship: An Agenda for Reform, Recommendations of the National Guardianship Symposium and Policy of the American Bar Association*, at iii, (1989), available at [http://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011/2011\\_aging\\_gship\\_agda\\_refrm.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_agda_refrm.authcheckdam.pdf) [hereinafter *ABA, An Agenda For Reform*].

<sup>96</sup> Glen, *supra* note 22, at 109.

<sup>97</sup> *ABA, An Agenda for Reform*, *supra* note 95. For a complete list of publications on guardianship by the American Bar Association, see ABA Comm'n on L. & Aging, *Guardianships and Alternatives to Guardianship Publications*, ABA, [http://www.americanbar.org/groups/law\\_aging/publications/gship\\_pubs.html](http://www.americanbar.org/groups/law_aging/publications/gship_pubs.html) (last visited July 28, 2015). See also ABA Comm'n on L. & Aging, *Guardianship Law & Practice*, ABA,

effort was the adoption of the Uniform Guardianship and Protective Proceedings Act of 1997 (UGPPA) and significant reforms of guardianship laws in at least 17 states.<sup>98</sup>

In the 1990s, another study by the Center for Social Gerontology, called for guardianship reform based on concerns about guardianship practices involving elderly people in 10 states.<sup>99</sup> Following this study, a second round of reforms resulted in amendments to the UGPPA.<sup>100</sup> These amendments changed the Act's overly paternalistic standards for determining capacity to what was considered more progressive language which directs the guardian to "consider the expressed desires and personal values of the ward to the extent known to the guardian . . . [who shall] at all times . . . act in the ward's best interest and exercise reasonable care, diligence and prudence."<sup>101</sup>

In 2002, the National Guardianship Association adopted a standard for guardian decision-making in its Standards of Practice. This standard requires the guardian to make decisions for people who lose their capacity based on what the "ward would have made when competent,"<sup>102</sup> so long as following the ward's wishes would not cause any substantial harm to the ward.<sup>103</sup> Most recently, in 2011, the Third National Guardianship Summit recommended additional changes to guardianship laws,<sup>104</sup> focusing particularly on the need to "maximize the incapacitated person's dignity and autonomy"<sup>105</sup> by permitting substitute decision-making "only 'to

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[http://www.americanbar.org/groups/law\\_aging/resources/guardianship\\_law\\_practice.html](http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html) (last visited July 28, 2015).

<sup>98</sup> Glen, *supra* note 22, at 109–10.

<sup>99</sup> Lauren Barritt Lisi et al., *National Study of Guardianship Systems: Summary of Findings and Recommendations*, 29 CLEARING HOUSE REV. 643, 643–44 (1995).

<sup>100</sup> Glen, *supra* note 22, at 115–16.

<sup>101</sup> Uniform Guardianship & Protective Proceedings Act (UGPPA) 1997 § 314(a) (West 2014) (guardianship order should remove only those rights that the "incapacitated" person can no longer exercise on her own); Glen, *supra* note 22, at 116.

<sup>102</sup> Glen, *supra* note 22, at 117 (quoting Nat'l Guardianship Ass'n Standards of Practice, Standard 7 (2007)).

<sup>103</sup> *Id.* at 117.

<sup>104</sup> *Id.* at 118; *Id.* at 118 n.120.

<sup>105</sup> *Id.* at 119.

the extent the person cannot currently direct the decision.”<sup>106</sup> In all other such cases, the person must be able to participate in the decision-making process.<sup>107</sup>

Throughout these successive guardianship reform efforts, the focus shifted “from a medical model that determines ‘incompetence’ or ‘incapacity’ based on an individual’s [medical] diagnosis, to a model that assesses an individual’s functional abilities.”<sup>108</sup> As a result, many state guardianship laws today require more narrowly tailored orders to meet the individual’s specific needs and greater monitoring and oversight of the guardians after their appointment. Many state laws also now require the consideration of less restrictive alternatives to guardianship.<sup>109</sup> However, to date, no state has determined that guardianships for young adults with disabilities constitute a violation of the IDEIA.

Despite these widespread reforms, scholars and activists alike are now calling for further reform or even the abolition of guardianship laws altogether.<sup>110</sup> As Professor Leslie Salzman

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<sup>106</sup> *Id.* at 118 (quoting Nat’l Guardianship Network, Third National Guardianship Summit Standards and Recommendations, Standard 5.3 (2011)).

<sup>107</sup> *See id.*

<sup>108</sup> Salzman, *supra* note 8, at 171 n.40 (implicitly citing the UGPPA § 102(5) (defining an “incapacitated person” as “an individual [who is] unable to receive and evaluate information or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance”); N.Y. MENTAL HYG. LAW § 81.02(b) (defining “incapacity” as the inability to “provide for personal needs and/or property management . . . and . . . the person cannot adequately understand and appreciate the nature and consequences of such inability”); and generally citing *ABA State Adult Guardianship Legislation*).

<sup>109</sup> *E.g.*, Salzman, *supra* note 8, at 171–72 (citing UGPPA §§ 311(a)(1)(B) (requiring determination that respondent’s identified needs cannot be met by any less restrictive means)); N.Y. MENTAL HYG. LAW § 81.02(a)(2) (providing that only necessary and appropriate powers can be granted to a guardian, and these powers must be granted in a way that least restricts the remaining powers of the incapacitated person).

<sup>110</sup> Salzman, *supra* note 8, at 173 (implicitly citing UGPPA § 317 (requiring guardian reports within thirty days of appointment and annually thereafter); UGPPA §§ 418(c), 419, 420 (requiring property guardian to file a plan and property inventory within sixty days of appointment and subsequent annual reports that include a recommendation as to whether guardianship or conservatorship should be continued or modified)). *See also* Dinerstein, *supra* note 22; Michael L. Perlin, “*Striking for the Guardians and Protectors of the Mind*”: *The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law*, 117 PENN. ST. L. REV. 1159 (2013); Glen, *supra* note 22, at 117.

documents in her research, “[d]espite the adoption of these critically important reforms, problems persist in guardianship both because of a continuing failure to fully implement the enacted reforms and because the reforms themselves are not sufficient to address the problems inherent in the guardianship paradigm.”<sup>111</sup> Such calls for further reform to guardianship laws have gained momentum, especially since the adoption of the United Nations Convention on the Rights of People with Disabilities (CRPD). Article 12 of the CRPD calls for replacing the substituted decision-making model inherent in most guardianship laws with a new supported decision-making model.<sup>112</sup> But before we consider supported decision-making as an alternative to guardianship, we will review the continuing problems of guardianship laws today, particularly as applied to young adults with disabilities.

### C. The Continuing Problems of Guardianship Laws

Today, many substantive and procedural deficiencies in state guardianship laws remain.<sup>113</sup> Substantively, guardianship laws are still criticized for undermining the rights of people who are labeled as incompetent or incapacitated, by stripping them of their basic civil rights and civil liberties, and without providing any clear standards defining competency and capacity. For this reason, guardianship laws have been criticized as violating the rights of people with disabilities as well as perpetuating discrimination against them.<sup>114</sup>

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<sup>111</sup> Salzman, *supra* note 8, at 174.

<sup>112</sup> See Comm. on the Rights of Persons with Disabilities, Rep. on its 1st Sess., Feb. 23–27, CRPD/C/1/2, 16 (Oct. 8, 2009), <http://www.unhcr.org/refworld/docid/4ae57ad32.html> (stating the need to “transition from the medical model to the human rights and social model of disability.”). See also Terry Carney & David Tait, *Caught Between Two Systems? Guardianship and Young People with a Disability*, 20 INT’L J. OF L. & PSYCHIATRY 141, 143 (1997); Dinerstein, *supra* note 22; Eilionóir Flynn & Anna Arstein-Kerslake, *Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity*, AUSTL. GUARDIANSHIP & ADMIN. COUNCIL 1 (2012), <http://agac.org.au/images/stories/2012mel/2012-mel-028.pdf> (presented at the Second World Congress on Adult Guardianship); Leslie Salzman, *supra* note 70; Wright, *supra* note 70.

<sup>113</sup> See, e.g., Dinerstein, *supra* note 22; Glen, *supra* note 22, at 117; Kohn et al., *supra* note 22; Salzman, *supra* note 8, at 170.

<sup>114</sup> See Salzman, *supra* note 8, at 169; see also Tressler, *supra* note 86.



Guardianship laws also have been criticized recently as violating the integration mandate of Title II of the Americans with Disabilities Act.<sup>115</sup> In the 1999 case *Olmstead v. L.C. ex rel. Zimring*, the Supreme Court held that states must not confine people with mental disabilities in institutions if they have been recommended for placement in the community,<sup>116</sup> and if such placement would not fundamentally alter the nature of the state's mental health system.<sup>117</sup> According to the Supreme Court in *Olmstead*, the ADA's Title II integration mandate requires states to provide services in the least restrictive or "most integrated" community-based setting so long as the person does not oppose community placement.<sup>118</sup> People under guardianship orders are often not even allowed to voice their preference for community placement since their guardians make such decisions for them. Thus, although guardianship may appear less restrictive than institutionalization, it may result in the literal confinement of people in institutions, violating the ADA.<sup>119</sup>

Further, guardianship itself is far more restrictive than other types of decision-making models. To the extent that the integration mandate of Title II of the ADA requires that services be provided in the most integrated setting, one could argue that even before guardianship is imposed, alternatives such as advance directives, living wills, representation agreements, powers of attorney, health care proxies, joint accounts and ownership, representative or substitute payees, and trusts must be considered and shown to be ineffective.<sup>120</sup>

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<sup>115</sup> See Salzman, *supra* note 8, at 161; Salzman, *supra* note 70, at 282–83.

<sup>116</sup> *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999).

<sup>117</sup> *Id.* at 603.

<sup>118</sup> *Id.* at 602.

<sup>119</sup> See Eleanor B. Cashmore, *Guarding the Golden Years: How Public Guardianship for Elders can Help States Meet the Mandates of Olmstead*, 55 B.C. L. REV 1217, 1229 (2014).

<sup>120</sup> For information on living wills (a legal document that a person uses to make known his or her wishes regarding life prolonging medical treatments), see Gregory G. Sarno, Annotation, *Living Wills: Validity, Construction, and Effect*, 49 A.L.R.4th 812 (1986). For information on representation agreements, see Representation Agreement Act, R.S.B.C., ch. 405, pt. 2.8 (1996) (Can.) (providing that an adult may enter into a standard representative agreement despite being "incapable of (a) making a contract, (b) managing his or her health care, personal care or legal matters, or (c) the routine management of his or her financial affairs."). For information on Powers

Guardianship laws and the courts that enforce them have been harshly criticized for the broad powers they afford guardians, particularly plenary guardians who are appointed for the ward's lifetime.<sup>121</sup> Such lifetime guardianships are apparently based on the assumption that people with intellectual and development disabilities will never improve their decision-making abilities over time. According to this view, there is no reason to review the need for a guardian once a guardian is appointed since the person will never regain competence, and will always be considered unable to make decisions about his or her own life. But this assumption is unfounded. The interests and abilities of people with intellectual or developmental disabilities, just like those of people without disabilities, do not remain static. When people, with or without disabilities, are exposed to new experiences, they can learn new skills.<sup>122</sup> In fact, research has shown that people with intellectual

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of Attorney (written authorization to represent or act on another's behalf in private affairs, business affairs, or other legal matters), see Kelly Greene & Jessica Silver-Greenberg, *Power Grab! Signing Over Power of Attorney to a Loved One Has Never Been Trickier. Here's What You Need to Know*, WALL ST. J. ONLINE, May 14, 2011, <http://online.wsj.com/news/articles/SB10001424052748704681904576315662838806984>. For information on health care proxies (an instrument that allows a patient to appoint an agent, usually a family member or trusted friend, to make his or her health care decisions in the event that the person is incapable of making such decisions), see Hannah E. Schindler, *Health Law—Health Care Proxies Can Make Medical Decisions on a Principal's Behalf Outside of a Hospital Setting—Stein v. County of Nassau*, 642 F. Supp. 2d 135 (E.D.N.Y. 2009), 6 J. HEALTH & BIOMEDICAL L. 377 (2010). See also UNITED STATES SENATE SPECIAL COMM. ON AGING, GUARDIANSHIP FOR THE ELDERLY: PROTECTING THE RIGHTS AND WELFARE OF SENIORS WITH REDUCED CAPACITY 1, 11 (2007), [http://www.guardianship.org/reports/Guardianship\\_Report.pdf](http://www.guardianship.org/reports/Guardianship_Report.pdf) [hereinafter GUARDIANSHIPS FOR THE ELDERLY]; Nidus Personal Planning Resource Centre & Registry, *Representation Agreement Overview*, NIDUS (2015), [http://www.nidus.ca/?page\\_id=501%3B](http://www.nidus.ca/?page_id=501%3B). See generally Nat'l Guardianship Ass'n, Inc., *What is Guardianship*, NAT'L GUARDIANSHIP ASS'N, INC., [http://www.guardianship.org/what\\_is\\_guardianship.htm](http://www.guardianship.org/what_is_guardianship.htm) (last visited July 28, 2015). For information on advance directives (a set of written instructions that specify what actions should be taken regarding a person's health if and when the person is no longer able to make decisions due to illness or incapacity), see generally GARY L. STEIN, *ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING FOR PEOPLE WITH INTELLECTUAL AND PHYSICAL DISABILITIES* (2007), available at <http://aspe.hhs.gov/daltcp/reports/2007/adacp.pdf>.

<sup>121</sup> Lawrence A. Frolik, *Guardianship Reform: When the Best is the Enemy of the Good*, 9 STAN. L. & POL'Y REV. 347, 354 (1998); see also Salzman, *supra* note 8, at 170.

<sup>122</sup> Vaso Totsika et al., *Active Support: Development, Evidence Base, and Future Directions*, 35 INT'L REV. OF RESEARCH IN MENTAL RETARDATION 205, 206 (2008) (describing life in Active Support model group homes include "a system for promoting the residents' personal development through goal setting and skill learning."); see Richard P. Hastings, *Support Staff Working in Intellectual Disability Services: The Importance of Relationships and Positive Experiences*, 35 J. OF INTELLECTUAL & DEVELOPMENTAL DISABILITY 207 (2010)

and developmental disabilities, in particular, are capable of acquiring new skills throughout their lifetimes.<sup>123</sup>

Guardianship laws also have been criticized for their procedural deficiencies. Many guardianship laws lack clear standards regarding how the guardian should make decisions for the ward. Some state laws now require the guardian to consult with the ward in making decisions, while others do not. Some state laws also may require the guardian to make decisions according to the expressed or implied wishes of the ward, while others may require a more objective “best interest” standard. But no state law requires guardians to assist the ward in making his or her own decision in a given case. Instead, due to the very nature of guardianship orders, these laws remove from the person the right to make his or her own decisions, as well as the right even to provide input into the guardian’s decision-making process. As a result, under most, if not all, state laws, the guardian retains sole authority to make all sorts of decisions for the ward.<sup>124</sup> Thus, to the extent that guardianships necessarily strip individuals of their right to make decisions about some or all aspects of their own lives,<sup>125</sup> guardianships have been described as “civil death.”<sup>126</sup>

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(describing how relationships can be important to people with intellectual disabilities); Wolf Wolfensberger, *A Brief Overview of Social Role Valorization*, 38 MENTAL RETARDATION 105, 105 (2000) (stating that “people’s welfare depends extensively on the social roles they occupy.”); Wolf Wolfensberger, *Social Role Valorization: A Proposed New Term for the Principle of Normalization*, 49 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 435, 437 (2011) (stating that people with a positively valued social image will be provided with experiences to increase their competencies, while people with negatively valued social images will not be offered those same opportunities).

<sup>123</sup> See Totsika, *supra* note 122, at 208.

<sup>124</sup> Millar & Renzaglia, *supra* note 64.

<sup>125</sup> Pamela B. Teaster et al., *Public Guardianship After 25 Years: In the Best Interest of Incapacitated People? National Study of Public Guardianship, Phase II Report*, 1, 14 (2007), available at

[http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/wards\\_state\\_full\\_re\\_p\\_11\\_15\\_07.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/wards_state_full_re_p_11_15_07.authcheckdam.pdf); Oliver Lewis, *New Project on Reforming Guardianship in Russia*, Executive Director’s Blog, MENTAL DISABILITY ADVOCACY CTR.,

<http://www.mdac.info/en/content/new-project-reforming-guardianship-russia> (Aug. 11, 2009); see also Salzman, *supra* note 8, at 164.

<sup>126</sup> Lewis, *supra* note 125; Perlin, *supra* note 110, at 1162; Matthew Brunwasser, *Memo From Pravda—In Eastern Europe, Lives Languish in Mental Facilities*, N.Y. TIMES, Jan. 5, 2009, at A7; see Glen, *supra* note 22, at 119; see also Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 SYRACUSE J. INT’L L. &

Although some state guardianship statutes now seek to ensure certain procedural protections such as the right to notice, counsel, and a hearing, many still do not. For example, when a petition is brought by a parent of an adult child with an intellectual or developmental disability, some state guardianship laws do not even allow or encourage the potential ward to appear in court, to be represented by counsel, or to call and cross-examine witnesses.<sup>127</sup> The justification for this denial of due process rights in such cases is that medical certifications alone are deemed sufficient to make out the *prima facie* case for guardianship.<sup>128</sup>

In those states that do provide the opportunity for hearings in guardianship cases, such hearings are more often than not perfunctory, without the court reviewing for the need of a guardian in the first place and without any consideration of less restrictive options for support. For example, a recent study found that the majority of guardianship hearings throughout the United States lasted less than 15 minutes.<sup>129</sup> Further, courts in most states continue to appoint plenary guardians even though state laws authorize less restrictive options.<sup>130</sup> As one legal scholar has observed,

[a]t best, guardianship will provide personal care and property management that an individual with a disability alone cannot handle. At worst, it will deprive that individual of decision-making

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COM. 429, 446 n.77 (2007) (discussing “legal death”).

<sup>127</sup> See N.Y. SURR. CT. PROC. ACT LAW § 1750, 1754; see also Kohn et al., *supra* note 22, at 1116–18.

<sup>128</sup> See Kohn et al., *supra* note 22, at 1117.

<sup>129</sup> Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship* (Mar. 31, 2005), available at <http://apps.americanbar.org/aging/publications/docs/wardofstatefinal.pdf> (discussing research and evidence on the misuse of guardianship, including a 1994 national study by the Center for Social Gerontology which found that the majority of guardianship hearings last less than 15 minutes); see also Kohn et al., *supra* note 22, at 1117 n.12.

<sup>130</sup> Frolik, *supra* note 121, at 354 (noting that “as long as the law permits plenary guardianship, courts will prefer to use it” even though plenary guardianship is only appropriate in a sub-set of cases, and urging those promoting guardianship reform to prioritize educating judges about limited guardianship). Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 233 (2007) (reporting, based on a national study, that “[c]ourts rarely appoint the public guardian as a limited guardian); see also Johns, *supra* note 66.

authority that he or she *does* have the capacity to handle, and will, at the same time, create the opportunity for personal or financial abuse.<sup>131</sup>

#### IV. *THE SPECIFIC PROBLEMS OF GUARDIANSHIP FOR YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES*

As the previous sections indicate, guardianship laws are fraught with substantive and procedural problems, even after widespread reforms. As applied to young adults with intellectual and developmental disabilities, guardianship is particularly problematic. Once a parent decides to petition a court to become the guardian for his or her adult child, and the court agrees, the young adult is denied the opportunity to develop and practice decision-making skills that will be necessary for life beyond school. The parent, as guardian, is authorized to make all of the young adult's decisions, sometimes for the rest of the person's life.<sup>132</sup> Even if a parent wanted to use his or her guardianship authority to help the young person learn and practice decision-making skills, the guardianship system itself undermines that process. In order to become a guardian, the parent must demonstrate to a court that his or her child is "incompetent," or "incapacitated" and unable to make decisions about his or her own life.<sup>133</sup> Although a claim of incompetence must be difficult for families of elderly people with dementia or Alzheimer's, for parents of young adult children with intellectual or developmental disabilities, such a claim of incompetency has been characterized as "devastating."<sup>134</sup> While parents would prefer not to resort to guardianships, many believe that they have no choice.<sup>135</sup> Once

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<sup>131</sup> Perlin, *supra* note 110, at 1171.

<sup>132</sup> JOHN PARRY & ERIC Y. DROGIN, MENTAL DISABILITY LAW, EVIDENCE AND TESTIMONY: A COMPREHENSIVE REFERENCE MANUAL FOR LAWYERS, JUDGES, AND MENTAL DISABILITY PROFESSIONALS 115, 138 (2007); Millar, *supra* note 20, at 123.

<sup>133</sup> Frolik, *supra* note 121, at 349–350.

<sup>134</sup> Dorothy Squatrito Millar, *Self-Determination in Relation to Having or Not Having a Legal Guardian: Case Studies of Two School-Aged Young Adults with Developmental Disabilities*, 43 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 279, 281 (2008).

<sup>135</sup> See *id.* (finding that parents pursued guardianship proceedings because they thought they were

parents become guardians, their child's label of incompetency or incapacitation can last throughout their child's lifetime.<sup>136</sup> Moreover, the label incompetency or incapacity may become a self-fulfilling prophecy.<sup>137</sup> Once a young person is found to be incompetent, he or she may experience self-doubt and begin to believe that the choices, circumstances, and events of his or her life are beyond his or her control. In fact, it is well documented that when students with disabilities are frequently assisted by adults, they experience loss of personal control and loss of identity; they begin to develop learned helplessness, interact less with their typical peers, and they fail to develop self-determination skills.<sup>138</sup>

The loss of the right to make one's own decisions, with or without help, also has a particularly negative impact on a young adult's functional abilities and general sense of well-being.<sup>139</sup> Just at the time in his or her life when a young adult is expected to begin to make his or her own decisions, a guardianship order indicates to the young adult that he or she lacks competence to do so.<sup>140</sup> In fact, "the label of 'incapacity' alone [can] have a[n especially] negative psychological effect on a[ young person and his or her] sense of competency to act in the world."<sup>141</sup> As a result of this label of "incompetence," the young person will have "few opportunities to test and develop"<sup>142</sup> life skills, resulting in further loss of control, self-esteem, and the young person's "withdrawal

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supposed to).

<sup>136</sup> See Rood et al., *supra* note 59, at 320.

<sup>137</sup> See Salzman, *supra* note 8, at 168–70. In this article, Professor Leslie Salzman, discusses a variety of problems with guardianship, generally. Although her focus is on older adults, similar criticisms may be made of guardianship on behalf of young adults with disabilities.

<sup>138</sup> See CANDACE S. BOS & SHARON VAUGHN, STRATEGIES FOR TEACHING STUDENTS WITH LEARNING AND BEHAVIORAL PROBLEMS 391–93 (6th ed. 2006); Michael F. Giangreco et al., *Helping, or Hovering? Effects of Instructional Assistant Proximity on Students with Disabilities*, 64 EXCEPTIONAL CHILDREN 7, 12–15 (1997). See also Salzman, *supra* note 8, at 168–70 (discussing that it is not just the legal status of having a guardian that is of concern, it is also the isolation that having one may bring).

<sup>139</sup> See Millar, *supra* note 134, at 290.

<sup>140</sup> See *id.* at 280.

<sup>141</sup> Salzman, *supra* note 8, at 169–70. As Professor Salzman has written, when an individual is deprived of the right to make decisions, "he or she experiences a loss of control and a feeling of helplessness that has critical implications for his or her psychological well-being." *Id.* at 169.

<sup>142</sup> *Id.* at 169.

from participation in life's activities.”<sup>143</sup> In short, once a young person is labeled as incompetent and determined to be in need of a legal guardian, a cycle may develop in which the determination of incapacity results in the inability of the young adult to make decisions, which then diminishes the young person's opportunities to test his or her abilities. The resulting “‘disuse of decision-making powers’ may lead to further decline in the [young person]’s capabilities and sense of competence to act in the world, leading to further isolation and loss of abilities.”<sup>144</sup>

Because plenary and limited guardianships require a finding of incompetency or incapacity, when a young person is appointed a guardian, it can be particularly damaging to that young person's sense of self-worth and self-respect.<sup>145</sup> Guardianship, therefore, jeopardizes the young person's ability to develop necessary life skills. As Professor Salzman has written about guardianship, generally, “[w]hen a guardianship order transfers an individual's right to make some or all of these decisions, the resulting guardianship can have a significant impact on an individual's daily life, and it may do so in ways that we may not fully consider when thinking about guardianship.”<sup>146</sup> For young adults with disabilities, one such impact is the risk to the young person's ability to develop the skills necessary to achieve an independent and self-determined life, which is exactly what the IDEIA requires.

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<sup>143</sup> *Id.* at 170.

<sup>144</sup> *Id.* at 170.

<sup>145</sup> See generally Tina Minkowitz, *Norms and Implementation of CRPD Article 12* (2012) (on file with Author) (describing which norms of Article 12 should be incorporated into law, the challenges to incorporation, and how the application of formal equality and the principles of inclusive design, accessibility, reasonable accommodations, and positive measures to ensure de facto equality can overcome some of those challenges to incorporation).

<sup>146</sup> Salzman, *supra* note 8, at 167.

A. Guardianship as an Obstacle to the Development of Self-Determination Skills Necessary for Life After High School

As discussed above, guardianship is typically triggered for students with intellectual or developmental disabilities as they approach the age of majority. Prior to that time, there is no need for students to have court-appointed guardians since their parents, like parents of children without disabilities, have the legal authority to make all decisions on their behalf. But as students proceed through high school, the IDEIA requires schools to develop transition plans for students that are specifically designed to “facilitate the child’s movement from school to post-school activities, including . . . independent living and community participation.”<sup>147</sup> As part of this transition planning process, the transfer of rights becomes necessary as the student begins to “assume [an] adult role[] and act in a self-determining way.”<sup>148</sup> However, the legal determination of incompetency necessary for the appointment of a guardian undermines the young adult’s potential for self-determination that is essential to the development of decision-making skills.

Self-determination is defined as “a combination of skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior.”<sup>149</sup> It is not dependent upon one’s IQ or academic credentials; instead, it is based on “a foundation of knowing and valuing oneself.”<sup>150</sup> In fact,

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<sup>147</sup> 20 U.S.C. § 1401(34)(A).

<sup>148</sup> Erin M. Payne-Christiansen & Patricia L. Sitlington, *Guardianship: Its Role in the Transition Process for Students with Developmental Disabilities*, 43 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 3, 9 (2008).

<sup>149</sup> Field et al., *supra* note 40, at 339.

<sup>150</sup> David W. Test et al., *Student Involvement in Individualized Education Program Meetings*, 70 EXCEPTIONAL CHILDREN 391, 391 (2004) (quoting Sharon Field & Alan Hoffman, *Development of a Model for Self-Determination*, 17 CAREER DEV. & TRANSITION FOR EXCEPTIONAL INDIVIDUALS 159, 164 (1994)); see MICHAEL L. WEHMEYER ET AL., PROMOTING SELF-DETERMINATION IN STUDENTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (2007); Michael L. Wehmeyer, *Self-Determination and Individuals with Severe Disabilities: Re-examining Meanings and Misinterpretations*, 30 RESEARCH & PRACTICE FOR PERSONS WITH SEVERE DISABILITIES 113 (2005).



research has shown that individuals with intellectual disabilities, like individuals without disabilities, benefit by responsible goal-setting and choice-making opportunities that enhance their ability to learn and practice self-determination skills.<sup>151</sup> Moreover, self-determination furthers the belief that “when acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society.”<sup>152</sup> Today, there are numerous resources for educators on how to facilitate the development of self-determination skills in their students and models to assist educators in measuring the development of those skills in their students.<sup>153</sup>

Despite these resources, many students with intellectual and developmental disabilities are not afforded opportunities to learn and practice self-determination skills. One explanation may be the mistaken belief among some teachers about their students’ intellectual capacity.<sup>154</sup> For example, a team of researchers found

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<sup>151</sup> Karrie A. Shogren & Ricky Broussard, *Exploring the Perceptions of Self-Determination of Individuals with Intellectual Disability*, 49 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 86, 95–96 (2011).

<sup>152</sup> SHARON FIELD ET AL., A PRACTICAL GUIDE FOR TEACHING SELF-DETERMINATION 10 (1998), available at <http://files.eric.ed.gov/fulltext/ED442207.pdf>.

<sup>153</sup> The Self-Determination scale of the ARC, which was developed by Dr. Michael L. Wehmeyer in 1995, is still widely used. MICHAEL WEHMEYER & KATHY KELCHNER, THE ARC’S SELF-DETERMINATION SCALE, ADOLESCENT VERSION (1995), available at <http://www.thearc.org/document.doc?id=3670>; see MICHAEL L. WEHMEYER, THE ARC’S SELF-DETERMINATION SCALE: PROCEDURAL GUIDELINES (1995), available at <http://www.thearc.org/document.doc?id=3671>. This scale consists of 72 items that assist educators in assessing the strengths and limitations of adolescents with intellectual or cognitive disabilities in terms of their Self-Determination. WEHMEYER & KELCHNER, *supra* note 153; WEHMEYER, *supra* note 153. The scale consists of four sections, which are considered essential characteristics of self-determination: autonomy, self-regulation, psychological empowerment, and self-realization. WEHMEYER & KELCHNER, *supra* note 153; WEHMEYER, *supra* note 153. This scale suggests that self-determination skills may be measured based on the successful accomplishment of such skills as choice making (appropriately choosing between a finite number of choices) and problem-solving (weigh pros & cons of potential actions, identify barriers to success). WEHMEYER & KELCHNER, *supra* note 153; WEHMEYER, *supra* note 153. According to this scale, decision-making involves choosing between unlimited options and goal setting and attainment, which is defined as the ability to set appropriate goals for oneself and to achieve these goals with actions. *Id.* Individuals who score higher on measures of Self-Determination have more positive adult outcomes such as better employment opportunities and better living situations. WEHMEYER & KELCHNER, *supra* note 153; WEHMEYER, *supra* note 153.

<sup>154</sup> Michael L. Wehmeyer & Susan B. Palmer, *Adult Outcomes for Students with Cognitive Disabilities Three Years After High School: The Impact of Self-Determination*, 38 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 131, 140 (2003).

that teachers with students identified as having severe cognitive disabilities were “significantly less likely to use student-directed learning strategies” than were teachers with students identified as having “mild” disabilities.<sup>155</sup> Such strategies provide students opportunities to practice self-regulated learning and behaviors. The reason for this difference, the researchers found, was that despite research to the contrary, the teachers did not believe students with labels of cognitive disability were “capable of becoming more self-determined.”<sup>156</sup>

Similarly, in another qualitative study that sought to assess the development of self-determination skills in students with intellectual disabilities, the researchers found that “there had been little support for self-determination in school, and [the students] had not learned to be self-determined until they were adults.”<sup>157</sup> The justification for not employing these “best practices” strategies with respect to the development of self-determination skills was the stigma associated with the imposition of the label of intellectual or developmental disability.

Teacher reluctance to develop strategies to nurture self-determination skills in students with intellectual or developmental disabilities is especially surprising since in life, as well as in school, self-determination is a “highly valued outcome.”<sup>158</sup> A strong relationship between self-determination skills and positive school outcomes, such as increased academic skills and access to the general education curriculum, has been well documented.<sup>159</sup> Numerous studies also have shown that students who leave school

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<sup>155</sup> *Id.*

<sup>156</sup> *Id.*; accord Wehmeyer, *supra* note 150, at 114.

<sup>157</sup> Shogren & Broussard, *supra* note 151, at 92.

<sup>158</sup> Dan Ezell et al., *Empowering Students with Mental Retardation Through Portfolio Assessment: A Tool for Fostering Self-Determination Skills*, 34 EDUC. & TRAINING IN MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES 453, 461 (1999); Millar & Renzaglia, *supra* note 64, at 479; accord Martin Agran et al., *Teacher Perceptions of Self-Determination: Benefits, Characteristics, Strategies*, 34 EDUC. & TRAINING IN MENTAL RETARDATION & DEVELOPMENTAL DISABILITIES 293, 294-95 (1999).

<sup>159</sup> Karrie A. Shogren et al., *Effect of Intervention with the Self-Determined Learning Model of Instruction on Access and Goal Attainment*, 33 REMEDIAL & SPECIAL EDUC. 320, 320 (2012).

self-determined achieve more positive adult outcomes and attain a better quality of life and higher lifestyle satisfaction.<sup>160</sup> These studies also show that achieving self-determination “requires not only that people with disabilities develop inner resources, but that society support and respond to [them].”<sup>161</sup>

To achieve self-determination skills, students must practice them. Therefore, students must be given opportunities to make choices, solve problems, and set goals. Indeed, as students with disabilities prepare to leave school, their progress in developing self-determination skills is perhaps one of the most important indicators of their future success in life. However, a student’s development of self-determination skills may be cut short by the appointment of a guardian. Instead of supporting a student with a disability to learn how to make choices and decisions, and when to ask for help or not, the guardian makes the decisions for the student. No matter how caring, considerate, effective or even deferential to the student’s preferences a guardian may be, the appointment of the guardian *per se* says to the student as well as to society that the student is unable to make his or her own decisions. Thus, the effect of guardianship on young adults as they reach the age of majority, is to undermine the development of the young adult’s self-determination skills as well as his or her own self-confidence in those skills. By so doing, guardianship undermines rather than furthers the IDEIA’s vision of students living independent and self-determined lives after high school.

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<sup>160</sup> Michael Wehmeyer & Michelle Schwartz, *Self-Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities*, 63 EXCEPTIONAL CHILDREN 245 (1997); Michael L. Wehmeyer, *Autodeterminación y la Tercera Generación de prácticas de inclusión [Self-Determination and the Third Generation of Inclusive Practices]*, 349 REVISTA DE EDUCACIÓN [J. OF EDUC.] 45 (2009).

<sup>161</sup> Millar & Renzaglia, *supra* note 64, at 483 (quoting Michael J. Ward, *The Many Facets of Self-Determination*, No. 5 TRANSITION SUMMARY (Nat’l Info. Ctr. for Children & Youth with Handicaps, Wash., D.C.), 1988, at 2, 2).

## B. Guardianship Offers a False Sense of Protection for Parents

Given the arguments against guardianships, one may ask why parents would want to become guardians for their children. The most common reason given by parents is their interest in protecting their young adult children.<sup>162</sup> Many parents also believe that becoming their adult child's guardian is simply the next step in the IEP process and necessary to ensure that their child will receive services after high school.<sup>163</sup> This latter reason is especially true for those parents whose schools encourage them to petition the court as part of the transition planning process. Yet guardianship for young adults with disabilities does not necessarily offer the protection and guarantee of services that some parents believe it does. Guardianship itself can neither protect the young adult person with a disability from harm and exploitation nor can it guarantee access to needed services.<sup>164</sup>

In fact, a recent study on the effect of guardianship appointments on young adults with developmental disabilities found that the appointment of a guardianship not only fails to protect the young adult with a disability but that it may, in fact, give the parent a false sense of protection or belief that the guardianship order itself can protect a young person from making bad personal decisions.<sup>165</sup> The study found that in some cases a young adult under guardianship would have done just as well, if not better, without a guardian.<sup>166</sup> Such research supports calls for further reform or even the abolition of guardianship laws.<sup>167</sup>

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<sup>162</sup> See, e.g., Kohn, *supra* note 22, at 1118.

<sup>163</sup> 20 U.S.C. § 1470.

<sup>164</sup> Dorothy Squatrito Millar, *Age of Majority, Transfer of Rights and Guardianship: Considerations for Families and Educators*, 38 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 378, 392 (2003).

<sup>165</sup> In this study, the researcher recounts an interview with a mother who explained that even though she had become her son's guardian, he moved out of her house and into an apartment with his pregnant girlfriend. *Id.* Although a DNA test confirmed that the son was not the baby's father, "[t]he point is, the mother had petitioned in order to protect her son, however, he still made decisions without her knowledge." *Id.*

<sup>166</sup> *Id.*

<sup>167</sup> See Herbert M. Kritzer et al., *Adult Guardianships in Wisconsin: How is the System Working?*, 76

C. Guardianship's Presumption of Incompetence is  
Contrary to the Purpose of the IDEIA

As stated above, state guardianship laws require the court to find the potential ward is incompetent or incapacitated (depending on the language of the state law) before ordering the appointment of a guardian. The determination of a young person's competence is, more often than not, based on a professional's view of what is considered "normal." These professionals use traditional IQ and other related tests, rather than on the actual strengths, competencies, or abilities of the person with a disability, to make their determinations. Researchers have determined, however, that individuals cannot be judged or found to be competent "simply from intelligence scale scores."<sup>168</sup> One such study found that the "evidence" used to determine competency was unclear and that the majority of determinations in guardianship cases involving young adults with disabilities were based on a doctor's certification of a diagnosis of developmental disability rather than on any evidence regarding the young adults' lack of ability to make sound decisions.<sup>169</sup>

Guardianship orders typically assume that people identified with intellectual or developmental disabilities do not have the capacity to exercise their rights as adults simply because of their intellectual or developmental disability label.<sup>170</sup> Thus, it seems that states exercise their authority to appoint guardians "with less concern about the needs of persons with disabilities, focusing instead on society's desire to protect itself from those deemed 'dangerous' or merely different."<sup>171</sup>

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MARQ. L. REV. 549 (1993); Kris Bulcroft et al., *Elderly Wards and Their Legal Guardians: Analysis of County Probate Courts in Ohio and Washington*, 31 THE GERONTOLOGIST 156 (1991); Lisi et al., *supra* note 99 (suggesting a need for further research to form better guardianship policies and practices).

<sup>168</sup> Lindsey et al., *supra* note 62, at 9.

<sup>169</sup> Millar, *supra* note 164, at 385–386.

<sup>170</sup> See Lisi et al., *supra* note 99; Millar, *supra* note 134, at 280.

<sup>171</sup> Salzman, *supra* note 8, at 164.

Unlike guardianship laws, which focus on the person's incompetence, the IDEIA is intended to focus on the student's competencies and abilities. The IDEIA specifically requires that students "be prepared to lead productive and independent adult lives, to the maximum extent possible."<sup>172</sup> Moreover, the regulations implementing the 1997 amendments highlight the law's particular focus on self-sufficiency:

[O]ne of the key purposes of the IDEA Amendments of 1997 was to "promote improved education results for children with disabilities through . . . educational experiences that prepare them for later educational challenges and employment." Thus, throughout their preschool, elementary, and secondary education, the IEPs for children with disabilities must . . . focus on providing instruction and experiences that enable the child to prepare himself or herself for later educational experiences and for post-school activities, including formal education, if appropriate, employment and independent living.<sup>173</sup>

In order to fully comply with the language and intent of the IDEIA and its implementing regulations, a new presumption of competence (rather than incompetence)<sup>174</sup> is necessary to protect the student's ability to make decisions about his or her life.<sup>175</sup> By focusing on the purpose and language of the IDEIA and its implementing regulations, schools can better develop positive constructions of disability that will help them to empower their

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<sup>172</sup> 20 U.S.C. § 1400(c)(5)(A)(ii).

<sup>173</sup> 34 C.F.R. pt. 300, app. A, at 106 (2000) (citing H. REP. NO. 105-95, at 82 (1997); S. REP. NO. 105-17, at 4 (1997) (citations omitted)).

<sup>174</sup> See generally Douglas Biklen & Jamie Burke, *Presuming Competence*, 39 EQUITY & EXCELLENCE IN EDUC. 166, 167-68 (2006).

<sup>175</sup> See, e.g., J. MICHAEL PETERSON & MISHAEL M. HITTIE, *INCLUSIVE TEACHING: THE JOURNEY TOWARDS EFFECTIVE SCHOOLS FOR ALL LEARNERS* (2d ed. 2009).

students to develop decision-making skills, including learning the important life-skill of knowing when to ask, or not ask, for help.

In sum, all of these issues dealing with the application of guardianship laws, especially to young adults with disabilities, should raise concerns for parents who seek to become guardians as part of their child's transition planning process. Not only is the determination of a young person's incompetence in a guardianship proceeding inconsistent with the IDEIA's goal of self-sufficiency and independent living, but also the appointment of a guardian itself will not protect the child. In fact, it may actually interfere with the adult child's development of self-determination skills, which is at the heart of the transition planning process. As one team of researchers has observed, "[g]uardianship . . . can work against the goals of transition planning," because it has broad implications regarding loss of fundamental rights and personal liberty.<sup>176</sup> Thus, instead of appointing guardians for young people who may need help in decision-making, schools and parents should consider alternatives to guardianship that support rather than undermine the young person's development of important life skills.

#### V. LEGAL CHALLENGES TO GUARDIANSHIP FOR YOUNG ADULTS WITH DISABILITIES

Only a few cases have been brought under the IDEIA to address transition planning, and none of those specifically discuss guardianship. However, the transition planning cases that have been decided to date support the argument in this Article that guardianships undermine the development of self-determination skills, which are an important part of the transition planning process. For example, in *Dracut School Committee v. Bureau of Special Education Appeals*, the court found that transition services should be "reasonably calculated to support[] independent living

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<sup>176</sup> Payne-Christiansen & Sitlington, *supra* note 148, at 10. See generally Scot Danforth, *Learning from Our Historical Evasions: Disability Studies and Schooling in a Liberal Democracy*, in VITAL QUESTIONS FACING DISABILITY STUDIES IN EDUCATION 77 (Scot Danforth & Susan L. Gabel eds., 2006).

outside of high school, such as maintaining self-hygiene, and learning transportation skills,”<sup>177</sup> and how to grocery shop. Anything less than the development of those skills would not, in the court’s view, meet the requirements of the “free appropriate public education,” that the IDEIA requires.<sup>178</sup>

In another case, and perhaps the most important recent case involving the appropriateness of guardians for young adults with disabilities (although outside of the IDEIA context), the court was asked to consider is the appropriateness of a guardian for Jenny Hatch, a 29 year old woman with Down Syndrome (and an IQ of around 50).<sup>179</sup> In this case, the parents of Jenny Hatch petitioned the court to become her legal guardians.<sup>180</sup> Prior to the petition, Ms. Hatch had a job, many friends, and was living with her employers, Kelly Morris and Jim Talbert, in their home.<sup>181</sup> The court initially appointed the Jewish Family Services (JFS) to be the temporary guardian of Ms. Hatch, but after JFS requested relief, the court appointed the mother and stepfather of Ms. Hatch to be her temporary guardians.<sup>182</sup> Once they were appointed temporary guardians, they required Jenny to move out of the Morris-Talbert home and into a group home with people she did not know.<sup>183</sup> Jenny was not allowed to work at her job, which she enjoyed, or to see her many friends.<sup>184</sup> Her parents also took away her cell phone

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<sup>177</sup> *Dracut Sch. Comm. v. Bureau of Special Educ.*, Appeals of the Mass. Dept. of Elementary and Secondary Educ., 737 F. Supp. 2d 35, 53 (D. Mass. 2010).

<sup>178</sup> *Id.* But see *M.C. ex rel. K.C. v. Mansfield Indep. Sch. Dist.*, 618 F. Supp. 2d 568 (N.D. Tex. 2009) (finding that despite their many obvious shortcomings, the transition planning services offered were insufficient to constitute a denial of the student’s right to a free appropriate public education).

<sup>179</sup> Theresa Vargas, *Woman with Down Syndrome Prevails over Parents in Guardianship Case*, WASH. POST, Aug. 2, 2013, available at [http://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751\\_story.html](http://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-in-guardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751_story.html). See generally *Jenny Hatch*, THE JENNY HATCH JUSTICE PROJECT, <http://jennyhatchjusticeproject.org/jenny> (2014).

<sup>180</sup> Vargas, *supra* note 179.

<sup>181</sup> *Id.*

<sup>182</sup> *Introduction to Order Appointing Temporary Guardians*, THE JENNY HATCH JUSTICE PROJECT 1 (n.d.), available at [http://jennyhatchjusticeproject.org/docs/justice\\_for\\_jenny\\_trial/jhjp\\_trial\\_order\\_appointing\\_temporary\\_guardians.pdf](http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_order_appointing_temporary_guardians.pdf).

<sup>183</sup> Vargas, *supra* note 179.

<sup>184</sup> *Id.*



and social media access.<sup>185</sup> In short, once her parents were appointed her temporary guardians, Ms. Hatch lost her right to live the life she had known or to make any and all decisions about her life.<sup>186</sup>

Following a six-day trial, the court terminated the parents' temporary guardianship and ordered Ms. Hatch to return to the Morris-Talbert home, as she had requested.<sup>187</sup> The Court further ordered that Ms. Morris and Mr. Talbert be designated as limited guardians for up to one year in order to help Jenny prepare for supported decision-making.<sup>188</sup> During that year, Ms. Morris and Mr. Talbert would continue to help Ms. Hatch to make her own decisions but would not make any decisions for her.<sup>189</sup> This is apparently the first such case in which a court ordered supported decision-making rather than substitute decision-making for a young adult with an intellectual disability.<sup>190</sup>

The Jenny Hatch case has spurred other individuals to fight for their rights to make their own decisions; among them is a young man named Ryan King.<sup>191</sup> When Mr. King turned 18, his parents became his guardians although Mr. King was able to make his own decisions.<sup>192</sup> He worked independently, managed his own finances, and volunteered in the community.<sup>193</sup> Mr. King also arranged his own services and supports.<sup>194</sup> In 2007, Mr. King's parents petitioned the court to remove them as their son's guardian,

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<sup>185</sup> *Trial Closing Argument*, THE JENNY HATCH JUSTICE PROJECT 35 (n.d.), available at [http://jennyhatchjusticeproject.org/docs/justice\\_for\\_jenny\\_trial/jhjp\\_trial\\_closing\\_argument.pdf](http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_closing_argument.pdf). The group home Jenny was placed in also took away her cell phone and her laptop. *The Justice for Jenny Trial*, THE JENNY HATCH JUSTICE PROJECT, <http://jennyhatchjusticeproject.org/trial> (2014).

<sup>186</sup> Vargas, *supra* note 179.

<sup>187</sup> *Id.*; *Trial Final Order*, THE JENNY HATCH JUSTICE PROJECT 2, 6 (n.d.), available at [http://jennyhatchjusticeproject.org/docs/justice\\_for\\_jenny\\_trial/jhjp\\_trial\\_final\\_order.pdf](http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf).

<sup>188</sup> Vargas, *supra* note 179; *Trial Final Order*, *supra* note 187, at 6.

<sup>189</sup> *Trial Final Order*, *supra* note 187, at 6.

<sup>190</sup> *Id.* at 1.

<sup>191</sup> *Impact Stories: Ryan King's Quest*, THE JENNY HATCH JUSTICE PROJECT, [http://jennyhatchjusticeproject.org/impact\\_story\\_1](http://jennyhatchjusticeproject.org/impact_story_1) (2014).

<sup>192</sup> *Id.*

<sup>193</sup> *Id.*

<sup>194</sup> *Id.*

but the court refused.<sup>195</sup> The same not-for-profit group that provided representation to Jenny Hatch is now representing Mr. King in his challenge to the court's guardianship order as well as many other clients in similar cases.<sup>196</sup>

In another recent case, a New York Surrogate Court Judge terminated the guardianship of a young adult woman on the grounds that she did not need other people to make decisions for her and that she had an adequate support network of family, friends and professionals to assist her in making her own decisions using "supported decision-making."<sup>197</sup> Although this case did not arise in the context of a student transitioning out of high school, the court's discussion of the need for supported decision-making rather than the substituted decision-making supports the argument that a persons with disabilities, of any age, can benefit by learning how to make decisions with support rather than having decisions made for them.<sup>198</sup>

## VI. RESEARCH SUPPORTS ARGUMENTS AGAINST THE USE OF GUARDIANSHIP FOR YOUNG ADULTS WITH DISABILITIES

Despite the many problems of guardianship, and its potential for violating the purpose and language of the IDEIA, only a handful of studies have been conducted on the appointment of guardians for young adults with developmental or intellectual disabilities. Of those studies, most were performed by the same researchers in Michigan.<sup>199</sup> The paucity of research on the topic is

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<sup>195</sup> *Id.*

<sup>196</sup> *Id.*; see also *Welcome Letter from Tina Campanella*, THE JENNY HATCH JUSTICE PROJECT 2 (n.d.), available at [http://jennyhatchjusticeproject.org/docs/other/jhjp\\_welcome\\_tcampanella.pdf](http://jennyhatchjusticeproject.org/docs/other/jhjp_welcome_tcampanella.pdf).

<sup>197</sup> *In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848 (Sur. Ct. 2012) (also citing Article 12 of the UN Convention on the Rights of Persons with Disabilities, as discussed *infra*, to support the court's position in favor of supported decision-making as an alternative to substituted decision-making).

<sup>198</sup> See *id.*

<sup>199</sup> See Dorothy Squatrito Millar, *Comparison of Transition-Related IEP Content for Young Adults with Disabilities Who Do or Do Not Have a Legal Guardian*, 44 EDUC. & TRAINING IN DEVELOPMENTAL DISABILITIES 151, 152–53 (2009); Millar, *supra* note 20; Millar, *supra* note 134 at 279–81; Millar, *supra* note 164; Millar & Renzaglia, *supra* note 64; Payne-Christiansen & Sitlington, *supra* note 148.

somewhat surprising given the “generally poor post school outcomes repeatedly found for individuals with disabilities as reported in the literature.”<sup>200</sup> One would expect that as a result of such poor outcomes, extensive research would be done to identify the reasons for these outcomes, including whether guardianship helps or hurts the development of skills necessary for students with disabilities to succeed in school, and in life after high school.<sup>201</sup>

Of those studies that have been conducted, they all support the view that guardianship is not only often unnecessary, but may also interfere with the development of self-determination skills in young adults with developmental and intellectual disabilities. For example, two Michigan researchers, Dorothy Millar and Adelle Renzaglia, conducted the first comprehensive study of guardianship and young adults with intellectual and developmental disabilities in 2002.<sup>202</sup> That study sought to examine guardianship as it affects young adults with disabilities by determining the factors that predict whether or not a young adult coming of age would be appointed a guardian in the context of the transfer of rights provision of the IDEIA.<sup>203</sup> The researchers reviewed a random sample of 221 court files in nine different jurisdictions in Michigan to determine the reasons why parents sought guardianship orders.<sup>204</sup> This review of the case files found that the average annual income of the young adults with guardians ranged from \$5,000 to \$5,999, and most of the young adults with guardians (60%) were male.<sup>205</sup> At the time the petitions were filed, most young adults (70%) lived with a relative and a vast majority (90.5%) had not completed high school and were students when

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<sup>200</sup> Millar & Renzaglia, *supra* note 64, at 466; see also Jose Blackorby & Mary Wagner, *Longitudinal Postschool Outcomes of Youth with Disabilities: Findings From the National Longitudinal Transition Study*, 62 EXCEPTIONAL CHILDREN 399 (1996); Richard S. Neel et al., *What Happens After Special Education?: A Statewide Follow-Up Study of Secondary Students Who Have Behavioral Disorders*, 13 BEHAVIORAL DISORDERS 209 (1988).

<sup>201</sup> Perhaps as a result of this Article, which seeks to raise awareness about the many concerns related to guardianship for young adults with intellectual and developmental disabilities, additional research will be done on this topic.

<sup>202</sup> Millar & Renzaglia, *supra* note 64, at 466.

<sup>203</sup> *Id.* at 466–67.

<sup>204</sup> *Id.*

<sup>205</sup> *Id.* at 472.

the petitions were filed.<sup>206</sup> The researchers reviewed all the forms that the petitioners were required to complete. These forms asked if “[t]he individual has a developmental disability described as a severe, chronic condition . . . and results in substantial limitations in [certain] life activities.”<sup>207</sup> The petitioner was then asked to check a minimum of three life activities that are so limited.<sup>208</sup> Of the 112 petitioners who answered this question, “32 (28.5%) marked all but mobility, and 29 (25.8%) marked all . . . choices.”<sup>209</sup> Each guardian was permitted to define these activities subjectively as no definition was provided on the form. Family members filed most of these petitions, and, in most cases, the mother filed the petition, completed the necessary forms, and was awarded guardianship by the court.<sup>210</sup>

In Michigan, courts may appoint a plenary or partial guardian over the person or over the person and the estate. Of the cases reviewed, most were plenary or partial guardianships over the person, followed in number by plenary guardianships over the person and the estate.<sup>211</sup> The court gave the guardians partial powers ranging from providing consent for medical treatment (including sterilization, abortion, organ transplant and experimental treatment) to control over financial matters (including limiting the amount the ward could spend each week, ranging from \$1 to \$44/week), and consent to living arrangements.<sup>212</sup> The court usually appointed partial guardians to wards with the most “mild disabilities,” whereas it appointed plenary guardians to those wards with “severe mental retardation.”<sup>213</sup> Although the law included a distinction between plenary and partial guardianships, the researchers found that upon

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<sup>206</sup> *Id.*

<sup>207</sup> *Id.* at 473.

<sup>208</sup> *Id.* The life activities that are listed are: “(a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living and (g) economic self-sufficiency.” *Id.*

<sup>209</sup> *Id.*

<sup>210</sup> *Id.*

<sup>211</sup> *Id.* at 474.

<sup>212</sup> *Id.* at 474–75.

<sup>213</sup> *Id.* at 477, 479.

“deeper investigation, the distinction between plenary and partial guardianships becomes blurred . . . [and that] disability may be equated with poor decision-making abilities and the need for continued protection.”<sup>214</sup>

Moreover, the court paid little attention to the young adult’s preferences<sup>215</sup> or specific decision-making abilities, the researchers found.<sup>216</sup> For example, the researchers pointed to one parent’s comments to illustrate the apparent presumption of incompetence inherent in the system. As the parent stated, “He is Downs syndrome. He will always be Downs syndrome. His condition will not change.”<sup>217</sup> The implication here, according to the researchers, “is that [the] parent does not see [the] adult child as having the ability to further develop his or her life skills.”<sup>218</sup> Based on these findings, the researchers concluded that “[c]learly the intent of the law is not being followed.”<sup>219</sup> Although young people “with disabilities should be afforded the opportunities to [become] self-determined, the findings [of] this study support [the] statement that we ‘must first shatter the pervasive stereotypes which imply that [young adults with developmental disabilities] cannot, or perhaps should not, practice self-determination,’ and the pervasive desire of society to protect individuals with disabilities, which when coupled with lowered expectations, have restricted choices available to people with disabilities.”<sup>220</sup>

Subsequent studies by Dorothy Millar and others have found little or no evidence to support the need for guardians for young adults with disabilities. In 2003, Millar used the same 221 case files from her 2002 study, discussed above, to determine why petitions for guardianship were filed in the first place. The

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<sup>214</sup> *Id.* at 479.

<sup>215</sup> *Id.* at 477.

<sup>216</sup> *Id.* at 479.

<sup>217</sup> *Id.*

<sup>218</sup> *Id.*

<sup>219</sup> *Id.* at 480.

<sup>220</sup> *Id.* (quoting Michael J. Ward, *The Many Facets of Self-Determination*, No. 5 TRANSITION SUMMARY (Nat’l Info. Ctr. for Children & Youth with Handicaps, Wash., D.C.), 1988, at 2, 2).

researcher found “that the disability label was often used to show just cause of a guardian appointment . . . [despite the fact that] disability alone does not equate with incapacity.”<sup>221</sup> Another common reason for parents to seek guardianship was the fact that their child turned 18 and was considered by the parent (without any required evaluations or other evidence) as “not capable of making informed decisions.”<sup>222</sup> One interesting finding of this 2003 study was that unlike past studies of guardianship proceedings, in which the subject of the proceeding (usually an elderly person) was not present at the guardianship hearings, most (86.8%) of the young people in this study did attend their guardianship hearings,<sup>223</sup> but 31 of them attended without legal representation.<sup>224</sup> This study also identified confusion about the respective rights of the ward and the guardian as well as cause for concern that many guardians were overstepping their authority under the law.<sup>225</sup> For example, the study found that guardians generally reported no change or improvement in the ward’s condition, even though the statute requires the guardian to “help the ward[] further develop [his or her] independent skills.”<sup>226</sup> This finding, in particular, led the researcher to recommend at least an annual review of all guardianship orders in order to determine their continued appropriateness.<sup>227</sup>

Millar published a subsequent study on the guardianship process in 2007. This study involved focus groups of the three key stakeholder groups in the guardianship process: young adults with developmental disabilities who either did or did not have a guardian; parents of young adults with developmental disabilities; and teachers.<sup>228</sup> The study found that transition to adulthood is a challenging time for these families and that parents wanted to

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<sup>221</sup> Millar, *supra* note 164, at 390.

<sup>222</sup> *Id.* at 385.

<sup>223</sup> *Id.* at 385, 391.

<sup>224</sup> *Id.* at 391.

<sup>225</sup> *Id.* at 392.

<sup>226</sup> *Id.*

<sup>227</sup> *Id.*

<sup>228</sup> Millar, *supra* note 20, at 126.

create opportunities for their children to develop independence. As one parent who served as a guardian stated, “[s]ome students get taken advantage of and a guardian may help, not sure.”<sup>229</sup> Another parent who became a guardian for her adult child added, “I thought I was supposed to do it.”<sup>230</sup> A third parent who had refused to become a guardian noted that “[w]e all make mistakes, and we all need help sometime — but that doesn’t mean we need guardians.”<sup>231</sup>

Of the teachers who were interviewed, two teachers said that although they wanted their students to learn to advocate for themselves, “students aren’t really allowed to make choices and are taught helplessness.”<sup>232</sup> One teacher shared the story of a former student who wanted to pursue her education after high school but was not given the opportunity to do so. Of this student, the teacher said, she “remain[s] at home with no tangible future in sight.”<sup>233</sup> The teacher added that from her perspective, knowing the student and her family as she did, “I truly believe that it is her mother that is unable to function independently of the student; not the other way around!”<sup>234</sup>

All of the students in the focus groups in this 2007 study indicated they had been involved in their IEP meetings and received self-determination skills training.<sup>235</sup> In order to confirm that the students understood what was meant by “self-determination skills training,” the researchers asked them to provide examples.<sup>236</sup> One student replied: “We talk about human rights and legal rights – I voted.”<sup>237</sup> Another student said, “They

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<sup>229</sup> *Id.* at 125.

<sup>230</sup> *Id.*

<sup>231</sup> *Id.*

<sup>232</sup> *Id.*

<sup>233</sup> *Id.* at 126.

<sup>234</sup> *Id.*

<sup>235</sup> *Id.* at 124.

<sup>236</sup> *Id.*

<sup>237</sup> *Id.* at 124–25.

teach us to say what we want – but they don’t always listen.”<sup>238</sup> Those students with guardians seemed to have a general idea about the role of the guardian in their lives, as one student observed, the guardian “[wi]ll help you with how to dress. Like that’s got a spot on it, or that’s wrinkled, go take it off.”<sup>239</sup> Another student described her experience with a guardian as follows: “You have to do this thing they say and sometimes you don’t feel like doing it. I always listen to her . . . — sometimes I don’t want to listen.”<sup>240</sup> Similarly, other students added, “‘We are adults. They need to accept that,’ ‘they need to listen.’”<sup>241</sup> Interestingly too, all three focus groups (of students, parents, and teachers) offered the same advice: that parents must encourage their children to advocate for themselves.<sup>242</sup> Based on these interviews, the researcher concluded that the participants had only a limited understanding of guardianship, and that most of the young adult participants failed to “recognize [the] disconnect between self-determination and guardianship.”<sup>243</sup> Further, only some of those interviewed reported consideration of alternatives to guardianships.<sup>244</sup>

In 2008, Millar conducted another study comparing self-determination competencies of adults with disabilities who had guardians to those who did not.<sup>245</sup> This study sought to explain why some young adults with disabilities have a guardian while others do not, and whether or not the young adults with guardians are more or less likely to be self-determined than those without guardians.<sup>246</sup> According to Millar, “it was hoped that through a case study approach, an in-depth view to guardianship and self-determination would lead to increased awareness as to what guardianship is really about, and the extent to which a guardian

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<sup>238</sup> *Id.* at 125.

<sup>239</sup> *Id.*

<sup>240</sup> *Id.*

<sup>241</sup> *Id.*

<sup>242</sup> *Id.*

<sup>243</sup> *Id.* at 126.

<sup>244</sup> *Id.* at 124.

<sup>245</sup> Millar, *supra* note 134.

<sup>246</sup> *Id.* at 281.



impacts a young adult's life."<sup>247</sup> Millar noted that adults without guardians could be perceived as having greater competencies and control over their lives than did their peers with guardians.<sup>248</sup> In particular, Millar noted another study that "provide[d] objective evidence that individuals with less restrictive substitute decision-making arrangements actually do exercise greater control over their lives."<sup>249</sup> Although this study includes little data that is generalizable, Millar concludes in it that if guardians are appointed for students as they reach the age of majority, the guardian appointments should be time limited, reviewed regularly, and eliminated as the young person gains more experiences.<sup>250</sup>

A final study that Millar conducted in 2009 also sought to understand the experiences of students and their families at the time the students reach the age of majority and guardianship is considered.<sup>251</sup> This is the first study comparing IEP transition-related content for young adults with developmental disabilities who have legal guardians with those who do not. Millar chose to review the students' IEPs because they included the students' educational program and served as "an evaluation device for determining the student's progress toward educational goals."<sup>252</sup> However, Millar acknowledges that IEPs may not always fully convey all the services provided to the student.<sup>253</sup> In fact, this study found some notable differences in the educational programs of the students with and without guardians.<sup>254</sup> Students without guardians were more likely to earn a high school diploma, whereas students with guardians were more likely to earn a certificate of

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<sup>247</sup> *Id.*

<sup>248</sup> *Id.* at 280 (citing Robert J. Stancliffe et al., *Substitute Decision-Making and Personal Control: Implications for Self-Determination*, 38 MENTAL RETARDATION 407, 417 (2002)).

<sup>249</sup> *Id.* Although the participants of Millar's study under guardianship exerted more decision-making than participants without guardians, the author postulates that the participants of the study are not representative of most students in similar guardianship situations. The author hopes that future studies will include much larger numbers of participants to give a more accurate representation of students in guardianship situations. *Id.* at 291.

<sup>250</sup> Millar, *supra* note 134.

<sup>251</sup> Millar, *supra* note 199.

<sup>252</sup> *Id.* at 154.

<sup>253</sup> *Id.* at 163.

<sup>254</sup> *Id.* at 157-63.

program completion at the end of high school.<sup>255</sup> However, a majority of the students in the study, regardless of whether they had a guardian or not, did not participate in state assessments.<sup>256</sup> They all had a specialized curriculum, which the researcher found “interesting given that provisions in both [the] No Child Left Behind Act (2001) and IDEIA (2004) mandate that students across all categories of disability have access to the general education curriculum.”<sup>257</sup> This study also found that students without guardians were more likely to choose to live on their own, while students with guardians continued to live at home.<sup>258</sup>

Although most of the students in both groups attended their IEP meetings, the young people with guardians might be less likely to lead or to demonstrate self-determination skills during educational planning decisions.<sup>259</sup> This study also reviewed the guardianship status of students who signed a statement attesting that the student had “been informed of all procedural safeguards and sources to obtain assistance, and understand: (a) [] the contents of the IEP and (b) agree with the IEP and its implementation.”<sup>260</sup> “[O]f the 125 students [(out of 156)] who signed this [statement], 62 had legal guardians and were legally declared incapable of making informed decisions.”<sup>261</sup> According to the study’s author, this finding, therefore,

raises the question as to whether the IEP team understands what a guardian appointment means, and if they do, how the knowledge impacts the team members’ interactions with the student. It has been suggested that knowing someone has a

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<sup>255</sup> *Id.* at 158, 163.

<sup>256</sup> *Id.* at 163.

<sup>257</sup> *Id.*

<sup>258</sup> *Id.* at 158.

<sup>259</sup> *Id.* at 165.

<sup>260</sup> *Id.*

<sup>261</sup> *Id.*

guardian may negatively impact how that person is treated.<sup>262</sup>

Based on her series of studies, Millar makes several recommendations. First, she recommends that the goal of the transition planning should be to help the students develop decision-making skills in order to avoid the need for a guardian.<sup>263</sup> As she writes, “[P]rior to the student reaching the age of majority, the school evaluation process can be proactive and specifically discuss the strengths and weaknesses of a student with regard to that individual becoming a self-sufficient adult.”<sup>264</sup> She goes on to acknowledge that:

There is an ever increasing research base that suggests that the more self-determined individuals are, the better their educational and post school outcomes are. Paying attention to the impact guardianship could have on an individual’s life is needed to avoid unintended consequences. Supporting youth as they assume adult roles may be challenging for all involved, however through information sharing, exploration, and collaboration, the challenges can be effectively addressed.<sup>265</sup>

Second, in those cases where a guardian has been appointed, Millar suggests that the “IEP goals and objectives [should] focus on [the] development of skills [that] may lead to modification or termination of a guardian appointment.”<sup>266</sup> Even after a student is appointed a guardian, the school should then evaluate which skills could be developed “with the aim of the

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<sup>262</sup> *Id.*

<sup>263</sup> *Id.* at 166.

<sup>264</sup> *Id.* at 165–66.

<sup>265</sup> *Id.* at 166.

<sup>266</sup> *Id.*

student becoming a self-sufficient adult.”<sup>267</sup> Finally, Millar suggests that schools should encourage parents to seek formal or informal least restrictive alternatives to guardianship and that such alternatives should be specific to the student’s post-high school goals.<sup>268</sup>

Thus, these studies by Millar and others contribute significantly to discussions about guardianship and the transition planning process for young people with disabilities. On the whole, they cast serious doubt on the benefits of guardianship for young adults with disabilities.

## VII. *ALTERNATIVES TO GUARDIANSHIP FOR YOUNG ADULTS WITH DISABILITIES*

Although the studies that have been conducted to date suggest that guardianships for young adults with disabilities should be avoided, they do not discuss the range of existing alternatives to guardianships. Many parents seek to become their young adult child’s guardian because they believe they have no other choice, but many choices do exist. The following is an overview of the many informal and formal alternatives to guardianship that currently exist and that may be implemented immediately, often without any expense to schools or families.<sup>269</sup> A chart explaining these alternatives in greater detail is included in an Appendix at the end of this Article.

First, a number of existing informal alternatives to guardianship exist that are particularly appropriate for students transitioning into adulthood. These informal alternatives include counseling, direct bill pay, and community services; self-advocacy, and daily money management training; appointments of personal representatives; and establishing personal support networks and

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<sup>267</sup> *Id.* at 165.

<sup>268</sup> *Id.* at 166.

<sup>269</sup> See Stanley S. Herr, *Self-Determination, Autonomy, and Alternatives for Guardianship*, in *THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL* 429, 447–48 (Stanley S. Herr et al. eds., 2003).

“circles of support.”<sup>270</sup> These informal supports may play an important role in helping a young person to make decisions and manage transactions while also fostering the development of a young person’s independence and self-determination skills.

Second, there are a variety of more formal legal procedures that may be used as alternatives to guardianship but do not require a court finding of incompetency. These alternatives include advanced health care directives, durable powers of attorney (for property and/or health care decisions), joint bank accounts and ownership, representative or substitute payees, trusts, living wills, and the appointment of executors of estates.<sup>271</sup> Such legal mechanisms support an individual’s right to self-expression and autonomy by allowing the individual to select a trusted person to help carry out his or her wishes without a judicial finding of the individual’s incapacity or incompetency.

A. Alternatives that May be Applied Immediately in the School Context

In the context of transition planning, in particular, several alternatives may be considered in place of guardianship. These examples may be implemented immediately, without the need for any formal action, and at no additional expense to schools or families.

First, schools could provide information and training to teachers, parents, and the students themselves about guardianship and the unintended risks that may be associated with guardianship orders. At the very least, the pros, cons, and consequences of seeking guardianship orders could be thoroughly explained to all parents and students as early in the educational process as possible.

Second, schools could delete all reference to guardianships in their school materials in order to rebut any presumption that the

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<sup>270</sup> See generally Nat’l Guardianship Ass’n, Inc., *supra* note 120.

<sup>271</sup> See generally *id.*; GUARDIANSHIPS FOR THE ELDERLY, *supra* note 120 (see the Appendix).

school favors guardianship for young adults with intellectual and developmental disabilities. It is inappropriate for a school to categorize a segment of its population as “incompetent” as it does when it includes the option of guardianship on IEPs and other school materials.

Third, in addition to informing schools, parents, and students with disabilities about the consequences of guardianship, schools could offer support to families to explore and use alternatives to guardianship. Such alternatives should focus on supporting the decision-making abilities of the student rather than on substituting a third party’s decision for the decision of the student. School personnel and other professionals also should be required to become knowledgeable about alternatives to guardianship that exist within their jurisdictions, and work with students and their families to develop the supports they need to maximize the students’ independence and self-determination skills through such alternatives.

In fact, a variety of quasi-legal alternatives to guardianships are available in most, if not all states. As discussed above, these alternatives include health care proxies, durable powers of attorney, representation agreements, trust funds, case management services, special needs trusts, and even special bank accounts.<sup>272</sup> In addition, if the type of assistance the student needs relates only to managing his or her social security payments, the Social Security Administration authorizes the appointment of a third party as a representative payee to manage an individual’s benefits without any court proceedings.<sup>273</sup> Some states also have laws authorizing third parties to make medical-related decisions without specific court authorization.<sup>274</sup> For example, the Mental Hygiene Law of New York empowers panels of four volunteers (which by law must include both a health care professional and an attorney) to make major medical treatment decisions for residents of state-operated or

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<sup>272</sup> See the Appendix to this Article.

<sup>273</sup> 42 U.S.C. § 1007 (2012).

<sup>274</sup> Kohn et al., *supra* note 22, at 1116.

state-licensed facilities, and other patients “receiving home and community-based services . . . individualized support services . . . [or] case management or service coordination funded, approve, or provided by the office for people with developmental disabilities.”<sup>275</sup> This model could be expanded to apply in other situations. Moreover, students with disabilities themselves have the right in certain states to appoint surrogate decision-makers by executing powers of attorney or advance directives for their own health care and medical treatment.<sup>276</sup> These procedures also could be recommended for implementation in other states. These are just a few of the many examples of quasi-legal alternatives to guardianship that support young adults but that do not require a judicial finding of the student’s incapacity or incompetence, as is required in guardianship laws.

Fourth, at the time of the IDEIA’s “transfer of rights,” parents, students, and school personnel could develop together “an advance plan of action [to] prevent the perceived needs for a guardian.”<sup>277</sup> This plan may include information about alternatives to guardianships as well as specific IEP goals and objectives designed to avoid guardianship.<sup>278</sup> In this way, schools would focus more on “[t]eaching self-determination, life, and employment skills,” as required by the IDEIA, than “on remediation of identified deficits” according to the now outmoded medical model of disability.<sup>279</sup> With these steps, the number of guardianships may be reduced while at the same time the parents’ interests in protecting their young adult children from harm will be addressed.

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<sup>275</sup> *Id.*; N.Y. MENTAL HYG. LAW, art. 80.

<sup>276</sup> See STEIN, *supra* note 120 (discussing ability of persons with intellectual disabilities to engage in advance care directives, quoted in Kohn et al., *supra* note 22, at 1117).

<sup>277</sup> Millar & Renzaglia, *supra* note 64, at 482; see Dorothy Squatrito Millar, *Guardianship Alternatives: Their Use Affirms Self-Determination of Individuals with Intellectual Disabilities*, 48 EDUC. & TRAINING IN AUTISM & DEVELOPMENTAL DISABILITIES 291, 298 (2013).

<sup>278</sup> Millar & Renzaglia, *supra* note 64, at 482. See generally Millar, *supra* note 277.

<sup>279</sup> *Id.*

## B. Supported Decision-Making as an Alternative to Guardianship for Young Adults with Disabilities

All of the formal and informal alternatives to guardianship mentioned above have been practiced for many years,<sup>280</sup> and could be considered examples of “supported decision-making.” However, supported decision-making as a model has only recently gained notoriety through the adoption of the United Nations Convention on the Rights of Persons with Disabilities.

The CRPD is the first binding international treaty dedicated to the protection of the rights of people with disabilities.<sup>281</sup> It was adopted by the UN in 2006 and, as of July 2015, has been signed by 159 countries and ratified by 157 countries.<sup>282</sup> On July 30, 2009, the US signed the CRPD,<sup>283</sup> but it has not yet ratified it.<sup>284</sup> The CRPD adopts the social model of disability and a human rights approach by recognizing the right of all people with disabilities to dignity, autonomy, and equality in all aspects of life.<sup>285</sup> Article 12 of the CRPD specifically prohibits laws and practices that deprive people with disabilities of their legal capacity and affirms the right of all persons with disabilities to legal capacity and to make decisions on their own behalf.<sup>286</sup> Article 12 also expects countries to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity,” but only if such

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<sup>280</sup> See Glen, *supra* note 22, at 140–53.

<sup>281</sup> Kanter, *supra* note 21, at 288.

<sup>282</sup> UNITED NATIONS ENABLE, <http://www.un.org/disabilities/> (2015).

<sup>283</sup> See Luisa Blanchfield & Cynthia Brown, *The United Nations Convention on the Rights of Persons with Disabilities: Issues in the U.S. Ratification Debate*, CONGRESSIONAL RESEARCH SERVICE 5 (Jan. 21, 2015).

<sup>284</sup> Convention and Optional Protocol Signatures and Ratifications, UNITED NATIONS ENABLE, <http://www.un.org/disabilities/countries.asp?navid=12&pid=166> (last visited July 28, 2015); see also *The Convention on the Rights of Persons with Disabilities*, U.S. INTERNATIONAL COUNCIL ON DISABILITIES, <http://www.usicd.org/index.cfm/crpd> (last visited July 28, 2015) (stating that on December 4, 2012, the U.S. Senate considered the ratification but it fell short by five votes). For a comprehensive discussion of the CRPD’s history in the U.S. Senate, see Arlene S. Kanter, *The Americans with Disabilities Act at 25 Years: Lessons to Learn from the Convention on the Rights of People with Disabilities*, 63 *DRAKE L. REV.* 819, 864–877 (2015).

<sup>285</sup> Kanter, *supra* note 284, at 845–48; see Kanter, *supra* note 21, at 290–91.

<sup>286</sup> CRPD, *supra* note 21.



assistance is requested by the person with a disability.<sup>287</sup> Article 12, therefore, recommends a new model of supported decision-making to replace the more traditional substituted decision-making model that has been enshrined within guardianship laws throughout the world for decades, if not longer.<sup>288</sup>

Supported decision-making is based on the view that every person has the right to make his or her own decisions, to the extent of his or her ability, and with whatever support he or she may need or chooses. Central to the supported decision-making model, therefore, is the view that individuals with disabilities should have the same opportunities as others without disabilities to rely on people whom they know and trust when making decisions. These “supporters” can include “one trusted person or a network of people; it might be necessary occasionally or all the time.”<sup>289</sup>

Although the CRPD does not specifically mention supported decision-making, the CRPD Committee charged with interpreting the CRPD has affirmed the need to replace substitute decision-making with the supported decision-making model.<sup>290</sup> In its General Comment on Article 12, the CRPD Committee specifically affirms the importance of supported decision-making when it states that Article 12 “implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.”<sup>291</sup> Thus, the CRPD Committee supports the

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<sup>287</sup> *Id.*

<sup>288</sup> *Id.*

<sup>289</sup> FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES: HANDBOOK FOR PARLIAMENTARIANS ON THE CONVENTION OF THE RIGHTS OF PERSONS WITH DISABILITIES AND ITS OPTIONAL PROTOCOL 101 (2007), available at <http://www.ipu.org/PDF/publications/disabilities-e.pdf> [hereafter HANDBOOK]; see also MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY, 53 (2010), available at <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>; Dinerstein, *supra* note 22, at 10.

<sup>290</sup> See Comm. on the Rights of Persons with Disabilities, Rep. on its 1st Sess., Feb. 23–27, CRPD/C/1/2, 16 (Oct. 8, 2009), <http://www.unhcr.org/refworld/docid/4ae57ad32.html> (stating the need to “transition from the medical model to the human rights and social model of disability.”).

<sup>291</sup> *Convention on the Rights of Persons with Disabilities General Comment No. 1 (2014), Article 12: Equal Recognition Before the Law* 1 (May 19, 2014), available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en) (select the document language hyperlink of your choice) [hereinafter *CRPD General*

view that in order to comply with Article 12 of the CRPD, supported decision-making should replace guardianship laws as we know them today.<sup>292</sup> Further, the CRPD Committee also reflects a broad consensus that Article 12 changes the focus of legal capacity decisions from a medical model of disability that addresses the deficit of the individual to a social model that seeks to offer support to a person in exercising his or her legal capacity on an equal basis with others.<sup>293</sup> As the CRPD Committee has observed, “[h]istorically, persons with disabilities have been discriminatorily denied their right to legal capacity in many areas via substitute decision-making regimes such as guardianship . . . [t]hese practices need to be abolished to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.”<sup>294</sup>

Article 12 of the CRPD was proposed in response to concerns about guardianship laws in many countries; similar concerns resulted in the guardianship reform efforts in the United States, described in the previous section of this Article.<sup>295</sup> The drafters of the CRPD were well aware of the fact that although guardianship laws and procedures vary, most, if not all countries’ guardianship laws deny the ward the right to make his or her own decisions. In fact, many guardianship laws worldwide include no enforceable requirement that guardians even consult with their wards, not to mention make decisions that the ward would have made if able to do so.<sup>296</sup> Nor do they require that the guardian make decisions that are in the ward’s best interest.<sup>297</sup> Indeed, because a guardian is free to substitute his or her own decision for

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*Comment*].

<sup>292</sup> *Id.* at 12.

<sup>293</sup> Some have argued that Article 12 imposes a clear obligation on states to eliminate substituted decision-making regimes based on “the first three paragraphs of Article 12, as well as in the overall object and purpose of the CRPD, which is to firmly establish that people with disabilities have their human rights respected on an equal basis with others.” Flynn & Arstein-Kerslake, *supra* note 112, at 11; *see also* Minkowitz, *supra* note 145.

<sup>294</sup> *Id.* at para. 7.

<sup>295</sup> *See generally* ARLENE S. KANTER, THE DEVELOPMENT OF DISABILITY RIGHTS UNDER INTERNATIONAL LAW: FROM CHARITY TO HUMAN RIGHTS 251–58 (2015) (discussing the drafting of Article 12 of the CRPD).

<sup>296</sup> *See id.* at 243.

<sup>297</sup> *Id.*

the ward's decision, the guardian is legally permitted to make decisions that the ward may oppose.<sup>298</sup> In such cases, there is little or no recourse for the ward to overturn the guardian's decision. Accordingly, the drafters of the CRPD viewed the substitute decision-making model as a human rights violation and recommended that countries abandon its use and develop in its place legislation that provides for supported decision-making.<sup>299</sup>

According to the CRPD's recent General Comments on Article 12, determinations of incapacity must now be eliminated and guardianship laws, which rely on a substitute decision-making model, should be replaced by a system of decision-making that is premised on a support model.<sup>300</sup> Thus, according to the CRPD, people who are considered "incompetent" or "lacking in capacity" must be afforded the same right to supports as people without disabilities.<sup>301</sup> One court in New York, recently cited Article 12 in support of its decision requiring periodic reporting and review of guardianships, concluding that "state interventions, like guardianships, . . . must be subject to periodic review to prevent the abuses which may otherwise flow from the state's grant of power over a person with disabilities."<sup>302</sup>

The development of support networks is essential to maintaining the person's independence under the supported

<sup>298</sup> See *id.*

<sup>299</sup> See *CRPD General Comment*, *supra* note 291, at 12; Dhanda, *supra* note 126; Kanter, *Law: What's Disability Studies Got to Do*, *supra* note 10; Tina Minkowitz, *The United Nations Convention on the Rights of Persons with Disabilities and the Right to be Free from Nonconsensual Psychiatric Interventions*, 34 SYRACUSE J. INT'L L. & COM. 405 (2007).

<sup>300</sup> See *CRPD General Comment*, *supra* note 291, at 12; Dhanda, *supra* note 126, at 460–61 (discussing the importance of a careful reading of Article 12, because although "the text of Article 12 does not prohibit substituted decision-making and there is language which could even be used to justify substitution," the CRPD represents a paradigm shift); see also LEGAL OPINION ON ARTICLE 12 OF THE CRPD 4 (June 21, 2008), available at <http://www.internationaldisabilityalliance.org/en/ida-position-papers-and-statements> (follow "Legal opinion on Article 12" hyperlink); Bach & Kerzner, *supra* note 289, at 55–57; Oliver Lewis, *Advancing Legal Capacity Jurisprudence*, 6 EUR. HUM. RTS. L. REV. 700 (2011); Minkowitz, *supra* note 299; Perlin, *supra* note 110.

<sup>301</sup> Arlene S. Kanter, *The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People under International Law*, 25 GA. ST. U. L. REV. 527, 563 (2009).

<sup>302</sup> *In re Mark C.H.*, 906 N.Y.S.2d at 433.

decision-making model. The individual is the decision maker and the supporter's role is not to make decisions for the person but to "explain[] the issues, when necessary, and interpret[] the signs and preferences of the individual."<sup>303</sup> By appointing his or her own network to help with decision-making, the individual retains his or her self-determination and autonomy.<sup>304</sup> Moreover, because the supports are tailored to the person's individual needs, the individual can arrange to get help in those areas of most need, such as support for paying rent and other bills, or making health care decisions. But other decisions, such as where and with whom to live and what to eat or wear, are more appropriately left to the individual alone. Thus, the support network assists the individual in identifying and implementing his or her own preferences, which enables the person to practice important decision-making skills.

Today in the United States, supported decision-making happens naturally for people with and without disabilities among family members, friends, and within social support networks.<sup>305</sup> For people with intellectual or developmental disabilities, support networks may be referred to as Circles of Friends,<sup>306</sup> or Circles of Support.<sup>307</sup> More important than any specific method of support, is the "connecting role of one or more people (family members, staff members, friends, neighbors, etc.) who can spend time and energy for this purpose."<sup>308</sup> As envisioned in the CRPD, supported decision-making occurs when a person or a group of people agree

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<sup>303</sup> HANDBOOK, *supra* note 289, at 89–90.

<sup>304</sup> Bach & Kerzner, *supra* note 289, at 55–57.

<sup>305</sup> Conn. Dep't of Development Servs., *Building Circles of Support (Part 1)*, CT.GOV, [http://www.ct.gov/dds/lib/ddself\\_determination/building\\_circles\\_of\\_support\\_\(part\\_1\).pdf](http://www.ct.gov/dds/lib/ddself_determination/building_circles_of_support_(part_1).pdf) (last visited July 28, 2015); Circles Network, *Circles of Support*, CIRCLES NETWORK, [http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent\\_id=115](http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115) (2015).

<sup>306</sup> ROBERT PERSKE, CIRCLE OF FRIENDS: PEOPLE WITH DISABILITIES AND THEIR FRIENDS ENRICH THE LIVES OF ONE ANOTHER (1988).

<sup>307</sup> NATURAL SUPPORTS IN SCHOOL, AT WORK, AND IN THE COMMUNITY FOR PEOPLE WITH SEVERE DISABILITIES (Jan Nisbet ed., 1992); *see also* Kim Davis, *Creating a Circle of Support*, INDIANA INSTITUTE ON DISABILITY & COMMUNITY (2005), <http://www.iidc.indiana.edu/?pageId=411>; Circles Network, *supra* note 305.

<sup>308</sup> Zana Marie Lutfiyya, *The Importance of Friendships Between People With and Without Mental Retardation*, (Sept. 1997), <http://www.recreationtherapy.com/articles/lutfiyya.htm>.

to meet on a regular basis to help a person with a disability solve issues, carry out activities, and accomplish personal visions or goals.<sup>309</sup> Supported decision-making, therefore, provides both a model and a legal context for sustaining practices that promote the individual's independence and self-determination. As such, supported decision-making is not only consistent with the IDEIA, but furthers its stated goals in a way that guardianship cannot.

### VIII. CONCLUSION AND RECOMMENDATIONS

Within the IDEIA, transition planning is required to facilitate a student's movement from school to life after school. Nowhere in the IDEIA's transition planning process are parents required to become guardians for their children with disabilities as they reach the age of majority. Yet, as a practical matter, many parents believe that becoming their young adult child's guardian is the next step in the transition process. Rather than considering less restrictive alternatives to guardianship, parents, often at the school's urging, file guardianship petitions as their young adult child is about to reach the age of majority. It appears that the "[a]ssignment of guardianship to parents is all too often a rite of passage for people with developmental disabilities as they enter adulthood."<sup>310</sup>

As a legal procedure, guardianship cedes control from the young adult child to the guardian. As such, it de-emphasizes the

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<sup>309</sup> JOHN O'BRIEN & CONNIE LYLE O'BRIEN, *MEMBERS OF EACH OTHER: PERSPECTIVES ON SOCIAL SUPPORT FOR PEOPLE WITH SEVERE DISABILITIES IN NATURAL SUPPORTS IN SCHOOL, AT WORK, AND IN THE COMMUNITY FOR PEOPLE WITH SEVERE DISABILITIES* 17, 53 (Jan Nisbet ed., 1992); Whitney Barrett & Leisa Randall, *Investigating the Circle of Friends Approach: Adaptations and Implication for Practice*, 20 EDUC. PSYCHOLOGY IN PRACTICE 353, 355 (2004); see also ANGELA R. NOVAK AMADO, *FRIENDSHIPS AND COMMUNITY CONNECTIONS BETWEEN PEOPLE WITH AND WITHOUT DEVELOPMENTAL DISABILITIES* (1993); ZANA MARIE LUTFIYYA, *PERSONAL RELATIONSHIPS AND SOCIAL NETWORKS: FACILITATING THE PARTICIPATION OF INDIVIDUALS WITH DISABILITIES IN COMMUNITY LIFE* (1991), available at <http://files.eric.ed.gov/fulltext/ED335853.pdf>; PERSKE, *supra* note 307.

<sup>310</sup> Barbara L. Ludlow, *Life After Loss: Legal, Ethical, and Practical Issues*, in AGING, RIGHTS AND QUALITY OF LIFE: PROSPECTS FOR OLDER PEOPLE WITH DEVELOPMENTAL DISABILITIES 189, 198 (Stanley S. Herr & Germain Weber eds., 1999).

student's interest in developing self-determination skills and potentially robs the student of his or her decision-making authority, and just at the time in the student's life when the student should be supported to exercise his or her decision-making and self-determination skills. As a result, the appointment of a guardianship for a young adult student with a disability undermines one of the primary purposes of the IDEIA: to prepare students "to lead productive and independent adult lives, to the maximum extent possible."<sup>311</sup> In fact, if parents knew more about what guardianship entails, especially its life-long label of incompetency for their adult child, it is likely that fewer parents would choose guardianship. Young adults without disabilities also need help in making all sorts of decisions, but we do not subject them to guardianship orders. Thus, the level of a person's decision-making ability should not be "something which should have any impact on an individual's right to legal capacity. [E]very person has an inherent right to legal capacity and equal recognition before the law."<sup>312</sup>

In order to better prepare students to become self-determined adults, parents and education professionals should resist pursuing guardianship and instead explore less restrictive alternatives to support their young adult children who may need help in decision-making, including how best to take care of themselves. Supported decision-making models should be considered instead of guardianships since they are more consistent with the IDEIA's primary goal to "prepare [students] for further education, employment, and independent living."<sup>313</sup>

Supported decision-making is now being used informally throughout the United States.<sup>314</sup> It has also been enacted into law in several jurisdictions outside of the U.S.<sup>315</sup> New York State and Massachusetts are currently working to develop pilot projects for

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<sup>311</sup> 20 U.S.C. § 1400 (c)(5)(A)(ii).

<sup>312</sup> Flynn & Arstein-Kerslake, *supra* note 112, at 2.

<sup>313</sup> 20 U.S.C. § 1400(d)(1)(A).

<sup>314</sup> See Glen, *supra* note 22, at 139–40.

<sup>315</sup> *Id.* at 140–53.

supported decision-making models that may be applied to young adults and others with intellectual disabilities.

As the success of supported decision-making models in the United States and elsewhere becomes known, state legislatures will likely begin introducing new laws on supported decision-making to replace the current substitute decision-making standard that is now included in most state guardianship laws. Moreover, the United States Department of Education and state education agencies also have an obligation to raise awareness about alternatives to guardianship. These agencies should consider adopting specific federal and state regulations or issuing opinion letters to specify that guardianship is not consistent with the IDEIA's transition planning process and that less restrictive alternatives to guardianship must be considered. Lawyers who represent families and school districts and judges who preside over guardianship cases also should become better informed about the problems inherent in guardianship for young adults with disabilities and the many less restrictive alternatives to guardianship that now exist.

Such changes will not occur overnight. Nothing short of a paradigm shift is necessary to overcome the fears and concerns of many parents that perpetuate the presumption of incompetence inherent in most, if not all, guardianship laws. However, by focusing on the language and purpose of the IDEIA, federal, state, and local education agencies, as well as school personnel, teachers, parents and the students themselves, will develop positive constructions of disability so that students with all types of disabilities may be accepted for their strengths, abilities, and their potential to make their own decisions, with or without help, rather than being devalued and disempowered for their "incompetence." Only then will young adults with disabilities be able to practice and develop the skills they need to lead the most self-determined, self-sufficient and independent life possible, as envisioned by the IDEIA. In short, only by changing the current transition planning practices that lead parents to become legal guardians for their

young adult children will we further the goals and purposes of the IDEIA and support the rights of students with intellectual and developmental disabilities to act as the primary constituents of their own lives just as students without disabilities are entitled to do. The IDEIA requires no less.

Appendix: A Chart of Alternatives to Guardianship for Young Adults with Disabilities<sup>316</sup>

Legal/ Formal Alternative	Explanation
Advanced Directive or Living Will	<p>A written document that the person with a disability can sign, in advance, providing instructions about his or her medical treatment. An advance directive is written and signed when the person is considered competent and takes effect once a person becomes unable to speak or communicate decisions about medical treatment. “A living will instructs doctors to withdraw or withhold artificial life support if the person becomes medically ‘terminal’ [and] only apply to artificial life-sustaining procedures.”</p> <p>Typically, these documents appoint someone as the “agent” to make another person’s medical decisions. These documents are prepared easily, using “state-specific forms, readily available either online or in most hospitals.”</p>

<sup>316</sup> Adapted by Arlene S. Kanter, from Jo Ann Simons, THE DOWN SYNDROME TRANSITION HANDBOOK: CHARTING YOUR CHILD’S COURSE TO ADULTHOOD 96–97 (2010).

\*\* Arlene Kanter edited the original chart and added supported decision-making.



Authorization to Advocate or Represent	<p>“A document signed by [an] individual . . . that appoints another person to be [the person’s] personal representative or advocate and to assist in managing [the person’s] affairs without limiting the individual’s rights. These documents can be individualized to meet the [specific] needs of the person . . . . If [an individual] has [this] document, it can [generally] prevent [a third party] from using the lack of a guardian as an excuse not to talk to family members.”</p>
General/Durable Power of Attorney	<p>“General” powers of attorney convey the authority for one person to make decisions and engage in transactions on behalf of another person. “A Power of Attorney becomes “durable” when the document indicates [that] the agent’s authority does not stop if [the person] become[s] incapacitated. Financial and medical Powers of Attorney can be made durable. Powers of Attorney should be drafted by a lawyer [to conform to the relevant state law], and [should] be [dated and] notarized.”</p>

Medical (Durable) Power of Attorney or Health Care Proxy	This is a “type of a Power of Attorney that appoints an agent to provide informed consent to surgery, medical treatment, personal care, and other medical or health-related matters. A Medical Durable Power of Attorney covers a broader spectrum of medical procedures than [Advance Directives or] Living Will[s] can.”
Financial (durable) Power of Attorney	This is a “type of a Power of Attorney that appoints an agent to make financial decisions and/or handle financial transactions.”
Representative Payee	“A person designated by [] Social Security Administration to receive monthly benefit checks on behalf of a beneficiary if [it] is determined to be in the beneficiary’s best interest,” such as when an adult beneficiary is physically or mentally unable to manage his or her own funds.
Special Needs Trust	“A trust used to provide supplemental funds for a person with a disability without jeopardizing access to government programs.”
Special Bank Accounts	Special bank accounts may be set up to require “co-signor[s] to access funds, write checks, or transact business.” They also include “accounts that are in the name of [one person] for the benefit of another person.”

Supported Decision- Making	An arrangement that allows one person who needs help making a decision to identify another person or group of people to help the person to make a decision. A supporter can help the person to think through the decision-making process, communicate decisions, ask for clarification, and review together relevant information that may otherwise be restricted from the supporter under privacy laws.
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# THE USE OF THE TRUST IN ADULT GUARDIANSHIP IN CHINA: PROSPECTS AND CHALLENGES

*Rebecca Lee\**

## *I. INTRODUCTION*

In 2010, the National Bureau of Statistics of China carried out the sixth national population census. The statistics released underline the enormous challenges of a rapidly aging population with huge demographic shifts.<sup>1</sup> The latest statistics released by the China Research Center on Aging<sup>2</sup> shows that, as of 2013, the population 60 years old<sup>3</sup> or above amounted to 200 million, representing almost 14.8 percent of the country's population.<sup>4</sup> Given the sheer size of China's aging population, it is very likely that the government may not have sufficient time to establish an adequate social security and healthcare system for its elderly. In the past, China depended heavily on its family system to support the elderly who invariably shared the same household.<sup>5</sup> But the country's one-child policy,<sup>6</sup> implemented in the 1970s, has

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<sup>1</sup> Carl Haub, China Releases First 2010 Census Results (Population Reference Bureau 2011) available at <http://www.prb.org/Publications/Articles/2011/china-census-results.aspx>.

<sup>2</sup> The Research Center is approved and subsidized by the Ministry of Human Resources and Social Security of the People's Republic of China. For details, see <http://www.crca.cn/index.jsp> (in Chinese).

<sup>3</sup> People aged 60 or above are defined as "elderly." Law of the People's Republic of China on Protection of the Rights and Interests of the Elderly, art. 2 (2013), available at <http://www.lawinfochina.com/display.aspx?id=12566&lib=law> (for an unofficial English Translation, found in Order 72 of the President of the People's Republic of China).

<sup>4</sup> WU YUHAN & DANG JUNWU, CHINA REPORT OF THE DEVELOPMENT ON AGING CAUSE (中国老龄事业发展报告) 2 (Social Sciences Academic Press (China) 2013) (in Chinese).

<sup>5</sup> In the past, family care was based on the Confucian principle of filial piety, a fundamental value dictating that one must respect and look after one's parents.

<sup>6</sup> See Constitution of the People's Republic of China, art. 53 (1978) ("The state advocates and encourages family planning"); Constitution of the People's Republic of China, art. 49 (1982) ("Both husband and wife have the duty to practice family planning"); see also the Law of the People's

drastically changed its demography and traditional family structure. The migration of rural Chinese to the cities has left the “empty-nests” elderly in the villages.<sup>7</sup> These changes have placed increasing constraints on the family-centred old age support system in China.<sup>8</sup> Since the 2000s, the Chinese government has looked into various solutions to the aging challenge, including improving the health and social care systems for the elderly;<sup>9</sup> reviewing its strict one-child birth control policy;<sup>10</sup> and reforming its adult guardianship regime.<sup>11</sup>

Until very recently, the elderly per se were excluded from the general guardianship provisions in the General Principles of Civil Law (“GPCL”), which was enacted in the late 1980s.<sup>12</sup> Part II of this Article first critically examines the deficiencies of the general guardianship provisions and then provides an analysis of the recent promulgation of the Law of the People’s Republic of China on Protection of the Rights and Interests of the Elderly (“Elderly Protection Law”)<sup>13</sup> in 2013, which brought about a new

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Republic of China on Population and Family Planning, art. 18 (2002) (“The State stabilizes the existing birth policies, encourages citizens to marry and bear a child at a late age, and advocates that one wife bear only one child...”). The policy has been in place since 1979 to reduce population and stimulate economic growth, but it has been relaxed recently: couples in which one parent is an only child (as opposed to both) will be allowed to have a second child.

<sup>7</sup> See, e.g., Bai Yang, *Empty Nesters Increase Fast in China*, CCTV (Dec. 29, 2012, 11:23 BJT), <http://english.cntv.cn/program/china24/20121229/116655.shtml>; Y. Zhang, *The Chinese Senior Population’s Living Arrangements, Health, and Nursing Care Analysis of Data from the Sixth Population Census*, in 2 CHINESE RESEARCH PERSPECTIVES ON SOCIETY 135–39 (Peilin Li, Guangjin Chen & Yi Zhang eds., 2015).

<sup>8</sup> See HSIAO-HUNG NANCY CHEN & TSUNG-HIS FU, *Older People’s Income Security in China: The Challenges of Population Ageing*, in AGEING IN EAST ASIA: CHALLENGES AND POLICIES FOR THE TWENTY-FIRST CENTURY 37, 46–47 (Tsung-hsi Fu & Rhidian Hughes eds., 2009); XIAOMEI PEI & YOUCAI TANG, *Rural Old Age Support in Transitional China: Efforts Between Family and State*, in AGING IN CHINA: IMPLICATIONS TO SOCIAL POLICY OF A CHANGING ECONOMIC STATE 61, 61–81 (Sheying Chen & Jason L. Powell eds., 2012).

<sup>9</sup> See H. J. Zhan et al., *Recent Developments in Institutional Elder Care in China: Changing Concepts and Attitudes*, 18 J. AGING & SOC. POL’Y 85 (2006).

<sup>10</sup> Chris Buckley, *China to Ease Longtime Policy of 1-Child Limit*, N.Y. TIMES, Nov. 15, 2013, <http://www.nytimes.com/2013/11/16/world/asia/china-to-loosen-its-one-child-policy.html>.

<sup>11</sup> See discussions in Part II(B) below.

<sup>12</sup> General Principles of Civil Law, (1987), available at [http://www.npc.gov.cn/englishnpc/Law/2007-12/12/content\\_1383941.htm](http://www.npc.gov.cn/englishnpc/Law/2007-12/12/content_1383941.htm) [hereinafter GPCL] (for an unofficial English Translation, found in Order No. 37 of the President of the People’s Republic of China).

<sup>13</sup> Law of the People’s Republic of China on Protection of the Rights and Interests of the Elderly (China).

landscape in elder law by embodying modern principles of autonomy and empowerment and introducing a system of voluntary guardianship for the elderly in China.<sup>14</sup> There is, however, a lack of operational details in the new legislation. Therefore, part III of this Article explores the feasibility of supplementing the new adult guardianship system in China with the trust institution, which was introduced to China by legislation in 2001.<sup>15</sup> This Article suggests that while a guardianship trust is able to enhance performance of guardians, as well as respect and recognize the rights of elderly persons under guardianship, there are also inherent difficulties with appealing to the trust that has hitherto been used in the commercial but not the domestic context in China.

## II. *GUARDIANSHIP OF THE ELDERLY IN CHINA: RESPONDING TO THE AGING CHALLENGE*

### A. Excluding the Elderly from General Guardianship Laws

The adult guardianship system in China is still very rudimentary. Guardianship laws are found in a few articles in the GPCL, supplemented by the Opinions of the Supreme People's Court on Several Issues concerning the Implementation of the GPCL of the People's Republic of China (for Trial Implementation) ("Opinions").<sup>16</sup> Article 13 of the GPCL states that "mentally ill persons"—defined as persons with no or limited capacity for civil conduct<sup>17</sup>—must be represented by an agent to perform civil functions, the extent of which depends on the elder's

<sup>14</sup> See *id.*

<sup>15</sup> See discussions in Part III(B) below.

<sup>16</sup> Opinions of the Supreme People's Court on Several Issues Concerning the Implementation of the GPCL (Trial Implementation) (1988), available at <http://www.lawinfochina.com/display.aspx?lib=law&id=3700> [hereinafter "Opinions"] (for an unofficial English translation).

<sup>17</sup> GPCL, art. 13 (1987).

respective mental incapacity.<sup>18</sup> Article 17 of the GPCL then provides for the appointment of guardians for these mentally ill persons according to a statutory priority of guardianship.<sup>19</sup> Whether a person has capacity for civil conduct is assessed on the basis of his age, cognitive development and mental state.<sup>20</sup> Articles 4 and 5 of the Opinions further elaborate on these criteria and add that the person's ability to understand and foresee, capacity for judgment and self-protection, or ability to appreciate the consequences of conduct are also relevant in deciding whether the person is mentally ill.<sup>21</sup>

Such rudimentary framework is deficient in a number of ways. First and foremost, the most striking feature is probably that these guardianship laws exclude the elderly *per se*. The guardianship system under the GPCL applies to "mentally ill persons," rather than "mentally incapacitated persons."<sup>22</sup> The concept of "mental incapacity" is therefore narrowly defined to cover "mental illness" only under the guardianship provisions in the GPCL. Although Article 8 of the Opinions attempts to extend the scope of mental illness to dementia patients,<sup>23</sup> an elderly person may lose his or her capacity for decision-making without attaining the dementia threshold. There is no consideration of the elderly who experience a deterioration of their intellectual, physical, and mental capacity over time but who may not be mental patients. Consequently, the scope of the guardianship

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<sup>18</sup> *Id.* (stating that persons with no capacity for civil conduct cannot perform civil functions and must be represented by an agent *ad litem* and that those with limited capacity may engage in activities appropriate to their mental health, but must be represented by agent in other activities).

<sup>19</sup> According to Article 17 of the GPCL, relatives (in the order of spouse, parent, adult child, near relative, closely connected relative) shall be the guardian for the individual concerned, otherwise an approved closely connected friend may take up this role. Article 12 of the Opinions defines "close relative" to include spouse, parents, children, brothers and sisters, paternal and maternal grandparent, and paternal and maternal grandchildren.

<sup>20</sup> GPCL, arts. 11-13.

<sup>21</sup> Opinions, arts. 4-5.

<sup>22</sup> GPCL, art. 13.

<sup>23</sup> Opinions, art. 8 (stating "[w]here any party or interested party proposes that one party suffers from the psychosis (including dementia), and the people's court believes it necessary to make a determination, it shall make judgment on whether the parties have the capacity for civil conduct").



provisions under the GPCL covers only mentally ill patients but not the elderly per se.<sup>24</sup>

Secondly, the GPCL provides only for a system of statutory guardianship whereby prescribed guardians must represent mentally ill persons.<sup>25</sup> This statutory guardianship takes an all-or-nothing approach: once a guardian is appointed, he or she takes over management and representation of all aspects of the ward's affairs and substitutes the ward's decision-making power with his or her own.<sup>26</sup> There is no room for other, perhaps less draconian forms of guardianship that cater to individual circumstances of persons subject to guardianship. Adding to this inflexibility is the rigidity displayed in the statutory priority of guardians laid down in Article 17, which is not designed with the elderly in mind.<sup>27</sup> There is no room for the ward to make provisions about the appointment of his or her guardian in advance or to exercise his or her residual capacity upon the onset of mental incapacity. Additionally, such rigid appointment mechanism may not be workable for guardianship of the elderly whose spouse or parents would often be too old to act as guardian or have already died.<sup>28</sup>

Last but not least, notwithstanding the extensive powers given to guardians, there is relatively no supervision of guardians to avoid abuse of their powers. Consequently, not only do the general guardianship laws in China fail to sufficiently protect the vast majority of the elderly with diminished capacity, even when

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<sup>24</sup> Minors are also covered by the guardianship provisions in the GPCL. See GPCL, art. 12. Guardianship of minors is not discussed in this Article.

<sup>25</sup> See, e.g., GPCL, arts. 13, 17 (referring to "mentally ill" persons).

<sup>26</sup> GPCL, art. 13 ("A mentally ill person who is unable to recognize his own conduct shall be a person having no capacity for civil conduct and shall be represented in civil activities by his agent ad litem.").

<sup>27</sup> See GPCL, art. 17.

<sup>28</sup> According to GPCL, art. 17, adult child can also act as guardian. However, unless the spouse or parent of the mentally ill are not available to act as guardians, they would take priority over the adult child.

the elderly falls within the scope of the GPCL, the relevant provisions fail to respect their residual autonomy.<sup>29</sup>

## B. Recent Reforms

The traditional family-oriented approach to elder care in China may explain the country's apparent lack of protection of the elderly by way of guardianship.<sup>30</sup> However, this traditional system has become increasingly difficult to implement under the one-child policy and the increasing mobility of the Chinese workforce. Moreover, since the 1980s, principles of normalisation and self-determination have been gaining prominence in Western guardianship systems.<sup>31</sup> These principles aim at ensuring that persons with disabilities can take part fully in society and enjoy life as much as ordinary people do.<sup>32</sup> Even if the judgment ability of an individual is insufficient, that ability should still be respected and treated as effective so long as it is not completely lost. There should also be safeguards to ensure that people under guardianship are not unnecessarily restricted.

The combined effect of the breakdown of the traditional guardianship system and influence of Western ideas has led to the amendment to the Elderly Protection Law, which came into effect on July 1, 2013,<sup>33</sup> and is a major recent breakthrough in the elder law regime in China. The Elderly Protection Law was first enacted

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<sup>29</sup> See, e.g., J. H. Li et al, *Chinese Civil Code Should Develop an Adult Guardianship System* (*Zhongguo Minfadian ying goujian laonian jianhu zhidu* 中国民法典应构建老年监护制度), 11 SOC. SCI. FRONT 186, 186–93 (2012) (critiquing the guardianship laws under the GPCL); X. LI, STUDY ON ADULT GUARDIANSHIP SYSTEM –FROM A HUMAN RIGHTS PERSPECTIVE (CHENGNIAN JIANHU ZHIDU YANJIU – YI RENQUAN DI SHIJIAO 成年监护制度研究 - 以人权的视角) (China Univ. of Pol. Sci. Law Press 2012) (in Chinese).

<sup>30</sup> See CORA CHAN & REBECCA LEE, *Adult Guardianship Law in China: Traditional Values and Modern International Developments*, in *COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP LAW*, at ch. 9 (Kim Dayton ed., 2014).

<sup>31</sup> See, e.g., S. Burningham, *Adult Guardianship and Co-Decision-Making Law*, 18 DALHOUSIE J. LEGAL STUD. 119 (2009); S.N. Then, *Evolution and Innovation in Guardianship Laws: Assisted Decision-Making*, 35 SYDNEY L. REV. 133, 136–44 (2013).

<sup>32</sup> *Id.*; see also U.N. Convention on the Rights of Persons with Disabilities, art. 3 (adopted Dec. 13, 2016) available at <http://www.un.org/disabilities/convention/conventionfull.shtml>.

<sup>33</sup> Law on Protection of the Rights and Interests of the Elderly, (China).

in 1996 and amendments passed in December 2012,<sup>34</sup> which expanded it from six chapters (50 articles) to nine chapters (86 articles) with three new chapters added. Significantly, rather than excluding the elderly from the guardianship regime, the revised Elderly Protection Law broadens the scope of the guardianship provisions in the GPCL to cover the elderly generally and introduces voluntary (*yiding* 意定) guardianship, which embodies the principle of self-determination, into the law.<sup>35</sup> Article 26 of the revised Elderly Protection Law states

[t]he elderly who have full civil capacity may determine, through negotiation, their guardians among their close relatives or other individuals or organizations that have close relationships with them and are willing to bear the guardianship. The guardians shall bear the guardianship according to law when the elderly totally or partially lose their civil capacity.<sup>36</sup>

When the elderly do not determine their guardians in advance, when they totally or partially lose their civil capacity, the guardians shall be determined for them in accordance with the provisions of relevant laws.<sup>37</sup> Voluntary guardianship enables residual capacity of the elderly to be respected. It empowers the elderly to choose their own guardians while they have capacity for civil conduct. However, when they have not exercised this power *in advance*, Article 26 resorts to the use of other forms of guardianship *in accordance with the relevant laws*, thus allowing the default guardianship regime in the GPCL to become applicable upon the elderly's mental incapacity.<sup>38</sup> Article 26 is significant to

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<sup>34</sup> *Id.*

<sup>35</sup> *Id.*

<sup>36</sup> *Id.* at art. 26.

<sup>37</sup> *Id.*

<sup>38</sup> *See id.*

the establishment of a modern adult guardianship regime in China in a number of ways. First, it introduces voluntary guardianship to elder law. Second, it makes clear the law's preference for voluntary guardianship, and respects the choice and autonomy of the elderly. Third, Article 26 also broadens the scope of application of the general guardianship provisions under the GPCL to elderly people who have limited or no capacity for civil conduct as well (as opposed to mental patients only).

Unfortunately, Article 26 is merely a broad-brushed provision; while, the introduction of voluntary adult guardianship into China is a welcome initiative, it does not come with the necessary operational details. Voluntary guardianship—in addition to statutory guardianship—is also available in Japan.<sup>39</sup> There, it allows the use of a voluntary mandate contract in which the mandator commissions and entrusts a mandatary to act as a guardian with power of representation relating to the mandator's life, nursing and care, and property management in the event that the mandator's capacity of judgment has become insufficient.<sup>40</sup> The agreement will take effect from the time the supervisor for the voluntary guardian is appointed.<sup>41</sup> The question for China is how its own new voluntary guardianship system should be developed, in particular, whether it is possible to utilize existing legal frameworks to develop a more comprehensive guardianship system.

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<sup>39</sup> Mokoto Arai, *Japan's Adult Guardianship Law: Current Status and Issues*, in *IMPLODING POPULATIONS IN JAPAN AND GERMANY: A COMPARISON*, at 383, 383–96 (2011). Statutory guardianship is designed for people whose judgment ability is insufficient due to mental disorder such as dementia, mental retardation or psychiatric disorder.

<sup>40</sup> *Id.*

<sup>41</sup> See Japanese Act on Voluntary Guardianship Contract, art. 2 (1999); Y. Mizuno & Y. Nanba, *Aging Society and the Adult Guardianship System*, 3 *GERIATRICS & GERONTOLOGY INT'L*, 225, 229 (2003); M. Arai & A. Homma, *Guardianship for Adults in Japan: Legal Reforms and Advances in Practice*, 24 *AUSTRALASIAN J. ON AGEING*, S19, S22 (2005).

### III.      *TRUST AND ADULT GUARDIANSHIP*

While it is a welcome initiative for the Elderly Protection Law to introduce a voluntary adult guardianship system by which the elderly can choose their guardians according to their own wishes and grant powers of attorney, the operational details have yet to be fleshed out. This Article now explores the feasibility of supplementing the adult guardianship system with the trust institution. The Article also examines how the existing guardianship system under the GPCL may be improved as a result such supplementation.

The trust is a flexible and popular mechanism used widely in common law jurisdictions to manage property relations, commercial transactions and community affairs. As economies in civil law jurisdictions in Asia began to prosper in the last few decades, appreciation for the trust's utility in developing financial instruments and for its use in strong commercial incentives for pension trusts and collective investment schemes has heightened.<sup>42</sup> In 2001, China introduced the trust system by enacting the Trust Law of the People's Republic of China,<sup>43</sup> as well as administrative regulations to govern the licensing and operation of trust companies.<sup>44</sup> Thus far, the trust has been utilized predominantly in the commercial context and demand for the use of the trust in the domestic context has remained lukewarm.<sup>45</sup>

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<sup>42</sup> See Lusina Ho & Rebecca Lee, *Reception of the Trust in Asia: a Historical Perspective*, in *TRUST LAW IN ASIAN CIVIL LAW JURISDICTIONS: A COMPARATIVE ANALYSIS*, at ch. 2 (Lusina Ho & Rebecca Lee eds., 2013).

<sup>43</sup> Trust Law of the People's Republic of China, (2001), available at [http://www.npc.gov.cn/englishnpc/Law/2007-12/10/content\\_1383444.htm](http://www.npc.gov.cn/englishnpc/Law/2007-12/10/content_1383444.htm) [hereinafter "Trust Law"] (for an official translation).

<sup>44</sup> Measures for the Administration of Trust Companies, (2007).

<sup>45</sup> See Lusina Ho, Rebecca Lee & Jin Jinping, *Trust Law in China: A Critical Evaluation of its Conceptual Foundation*, in *TRUST LAW IN ASIAN CIVIL LAW JURISDICTIONS: A COMPARATIVE ANALYSIS*, *supra* note 42, at ch. 6 (for an overview of the Chinese Trust Law).

The trust is a flexible institution that regulates the tripartite relationship of the settlor, trustee and beneficiary. In some jurisdictions, the trust has been seen as an alternative to guardianship for people with disabilities.<sup>46</sup> The rights and obligations of these parties are clearly delineated. A guardianship trust is created when an individual transfers his property to his guardian to manage the property for his benefit, and the guardian has to perform his duties as trustee, which includes management of the ward's property.<sup>47</sup> It is submitted that this will usually take the form of a self-declared trust when the individual is both the settlor and the beneficiary. As a guardianship trust, the guardian-trustee will also have to perform the duties of a guardian.

#### A. Prospects and Advantages of Introducing Guardianship Trust into China

Both guardianship and trust share a very similar theoretical foundation. Both are based on trust and confidence of the elderly ward/settlor in the guardian/trustee. Guardianship—particularly statutory guardianship—is based on trust in family members while there are not necessarily any personal ties between settlor and trustee.<sup>48</sup> A trust system, which is also based on trust and confidence, ensures that the theoretical foundation of the guardianship is entrenched. Apart from theoretical foundations, the use of the trust in the adult guardianship system can also bring about practical benefits to the adult guardianship system. A guardianship trust can supplement voluntary guardianship by ensuring that the autonomy and residual capacity of the elderly is respected. It also accords with the moving trend towards respect for individuals and normalization in adult guardianship systems.<sup>49</sup>

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<sup>46</sup> See, e.g., J. S. Welber, *The Trust as an Alternative to Guardianship*, <http://www.michiganallianceforfamilies.org/wp-content/uploads/2012/09/Trust-as-an-Alternative-to-Guardianship.pdf> (last visited July 27, 2015). For example, the special needs trusts in the United States are sometimes used as an alternative to guardianship.

<sup>47</sup> GPCL, art. 18.

<sup>48</sup> Trust Law, art. 24 (“The trustee shall be a natural person or legal person who has full capability for civil conduct.” *Id.* It does not specify the requirement of any familial ties with the settlor.).

<sup>49</sup> S. Burningham, *supra*, note 31, at 119; United Nations Convention on the Rights of People with Disabilities.

The current provisions of the GPCL recognize only statutory (*fading* 法定) guardianship, namely guardianship by relatives automatically on declaration of a person as mentally ill on application of his relatives.<sup>50</sup> As mentioned above, the list of persons specified in Article 17(1) (such as the spouse of the mentally ill person) will automatically and immediately be designated by law as guardian in the order of priority stipulated therein.<sup>51</sup> When the specified guardians above are not available, the GPCL has specified designated guardians, namely local communities, neighbourhood or village committee of the mentally ill person or the local civil affairs department, to act as guardians.<sup>52</sup> Statutory guardianship is not able to accommodate the elderly person's will throughout the guardianship process<sup>53</sup> because it does not require any special involvement of the elderly person concerned. This reflects the archaic goal of the adult guardianship system in China to protect security of transactions and societal interest at large at the expense of individual autonomy or protecting the rights of individuals with diminished capacity.<sup>54</sup>

The underlying rationale of adult guardianship, as reflected by the Elderly Protection Law, is respect for individual autonomy and a guardianship trust can help to better realize this objective.

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<sup>50</sup> GPCL, art. 13.

<sup>51</sup> *Id.* at art. 17.

<sup>52</sup> *Id.*

<sup>53</sup> Except for the stipulation that courts may consult an individual with limited civil capacity before appointing his guardian. Opinions, art. 14.

<sup>54</sup> See, e.g., Li Wen Sheng, *Adult Guardianship Reform in American Law and Its Benefits to Our Future Civil Law* (*Meiguo chengnianren jianhufa de gaige ji dui woguo weilai minfadian ji jiejian yiyi* 美国成年人监护法的改革及对我国未来民法典之借鉴意义), 23 J. GUANGXI ADMIN. CADRE INST. OF POL. & L. 107, 112 (2008).

First, a guardianship trust can be created while the elder still has full capacity for civil conduct.<sup>55</sup> This allows elders—while still in good health—to make provisions for themselves about how their affairs will be managed when their mental capacity deteriorates. There will thus be more room for the inclusion of more effective but less intrusive and restrictive form of support with regard to residential and financial matters, as well as to health care. Under current guardianship laws in China, the guardian is specifically empowered to deal with the elder's personal health, property, civil activities, and education, among other matters.<sup>56</sup> There is almost blanket removal of an individual's rights once he or she is classified as mentally ill, as the guardian takes control of the elder's rights to vote, marry, buy or sell property, or enter into contracts.<sup>57</sup> Such extensive powers conferred on guardians may compromise the rights and autonomy of the individual. A guardianship trust, in contrast, allows assisted, as opposed to substitute, decision-making by allowing the elderly settlor to stipulate the scope of powers of the guardian-trustee in advance.

Secondly, a guardianship trust would allow elders to select their own trustees. Under the constraints of statutory guardianship imposed by Article 17 of the GPCL, even when an elder (with sufficient mental incapacity) falls within the scope of its protection, there are rigid stipulations on the order of persons who can be his guardian, yet very little safeguards on proper qualifications of the guardians beyond physical health and economic conditions.<sup>58</sup> A guardianship trust can overcome these constraints by allowing personal choice in the selection and qualifications of the guardian-trustees. There is also room for paid professional persons or organizations to provide guardianship service. This enables greater scope for professional management of property and personal supervision, and hence, opening up the

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<sup>55</sup> Trust Law, art. 19.

<sup>56</sup> Opinions, art. 10; *see* Opinions, art. 22 (China) (permitting the guardian to entrust all or part of these duties to an agent).

<sup>57</sup> GPCL, art. 13.

<sup>58</sup> GPLC, art. 17 (China); Opinions, art. 11.



possibility of bringing in specialized expertise into the guardianship system.

B.      Challenges and Future Directions of Guardianship Trusts

The discussion above shows that a guardianship trust is able to enhance the performance of guardians, as well as increase respect and recognition of the rights of elderly persons under guardianship. However, there are also inherent difficulties with supplementing the guardianship system with a trust. Thus far, the trust legislation has been drafted primarily with commercial objectives in mind, and it has been utilized predominantly in the commercial context. Its application to domestic context in China must therefore be scrutinized carefully.

*1. How to create a guardianship trust and when should the guardianship trust take effect?*

The Trust Law of China requires a trust to be established by contracts, wills, or other documents authorized by laws or administrative regulations.<sup>59</sup> The trust is thus a three-party contract involving the settlor, the trustee and the beneficiary.<sup>60</sup> Accordingly, a written guardianship contract is required to establish a guardianship trust, and the guardianship trust is created upon signing of the guardianship contract. However, in line with the concept of voluntary guardianship, a guardianship trust should take place when an individual loses his mental capacity (namely, upon declaration of mental incapacity according to the GPCL and

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<sup>59</sup> Article 8 states that “[t]he creation of a trust shall take the form of writing. The form of writing shall consist of trust contracts, testament, or other documents specified by laws and administrative regulations.” Trust Laws, art. 8. The trust information should also disclose details such as the purpose of the trust, the names and domiciles of all trust parties (including, where appropriate, the class of beneficiaries) and the scope of trust property. *Id.* at art. 9.

<sup>60</sup> *Id.* at art. 2.

Opinions<sup>61</sup>). At that point the trustee should take care of personal and financial management.<sup>62</sup> This scheme differs from the Trust Law, which characterizes the trust as a contract and hence renders it effective upon signing of the trust contract.<sup>63</sup>

In terms of substantive requirements for creating a trust, the most peculiar feature of the Chinese Trust Law is that it uniquely defines a trust as a situation whereby “the settlor . . . *entrusts* his property rights to the trustee and allows the trustee to . . . administer or dispose of such property in the interest of a beneficiary or for any intended purpose.”<sup>64</sup> This departs from its Asian and Anglo-American counterparts, which require the property to have been vested with the trustee (or the declaration of the settlor himself as trustee). In Chinese law, the term “entrustment” typically refers to the appointment of agents who are not vested with ownership.<sup>65</sup> Accordingly, it is possible for a Chinese trust to be established merely upon the entry into a trust contract without transferring the trust property to the trustee. A difficult question arises as to whether the trustee can compel a settlor who has entered into a trust contract to then transfer the trust property to the trustee, on the ground that the trust has already become effective. This is likely to present some difficulties for the guardianship trust: if an elder fails to transfer his or her property before he or she becomes incapacitated, there is no provision in the Trust Law stipulating a duty on the part of the settlor to make such a transfer or that on the part of the trustee to get in trust property, let alone any direct right on the part of the beneficiary to compel the settlor to constitute the trust.

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<sup>61</sup> Whether an individual has capacity for civil conduct is only measured by his ability to judge, understand and foresee. Opinions, arts. 4–5. Yet neither is there sufficient training of physicians on the evaluation of competency, nor is there adequate physician understanding of the relevant laws.

<sup>62</sup> GPCL, art. 13.

<sup>63</sup> Article 8 states, “Where a trust is created in the form of trust contract, the trust shall be deemed created when the said contract is signed. Where a trust is created in any other form of writing, the trust is deemed created when the trustee accepts the trust.” Thus, trusts established by wills are effective upon acceptance of the trustee.

<sup>64</sup> Trust Law, art. 2 (emphasis added).

<sup>65</sup> *Id.* at art. 30 (referring to the “entrustment” of agents by the trustee); GPCL, arts. 64–65.

## 2. *Who can be guardian-trustees?*

As mentioned above, a guardianship trust can benefit from professional management by either professional trust corporations or designated trustees appointed by the settlor. The trustees may delegate certain matters, such as personal care and medical decisions, to professional bodies.<sup>66</sup> The settlor can also stipulate expressly that the trustee has to possess the qualifications for the appointment of a guardian as well before he can be appointed as trustee.<sup>67</sup>

However, while the Trust Law stipulates that any natural person, legal person, or legally established organization with full civil capacity may act as settlor or beneficiary, legally established organizations with full civil capacity (but not legal personhood) are not allowed to act as trustee.<sup>68</sup> This excludes trusteeship social organizations that are likely to be an impediment to the development of guardianship trusts because some elderly are unlikely able to afford the service of professional trustees and lay, individual trustees may not be entirely suitable in some instances.

## 3. *What are the guardian-trustee's duties?*

The Trust Law has listed out the trustee's duties as the duties to comply with the terms of the trust document;<sup>69</sup> segregate the trust property from his own property and other property held by

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<sup>66</sup> Trust Law, art. 30 ("The trustee ... may entrust another person to handle such affairs on his behalf where the trust documents provide otherwise or he has to do so for reasons beyond his control.").

<sup>67</sup> *Cf* the Opinions, art. 11 (providing that the guardianship ability shall be determined according to such factors as the physical health and economic conditions of the guardian, and the connection between the guardian and his ward).

<sup>68</sup> Trust Law, art. 24.

<sup>69</sup> "The trustee shall abide by the provisions in the trust documents." *Id.* at art. 25.

him, through separate management and accounting;<sup>70</sup> maintain and provide accounts of the trust property initially when he takes up trusteeship and annually thereafter;<sup>71</sup> make distributions to beneficiaries;<sup>72</sup> and provide upon demand information about the trust accounts to interested parties and provide all documents and information relating to the administration of the trust to the settlor, his heirs and the beneficiaries.<sup>73</sup> Particularly relevant to guardianship is that the trustee should manage the trust himself and not delegate trust management unless such delegation is provided for in the trust document or circumstances render it necessary.<sup>74</sup> Thus, delegation of a guardian-trustee's duty of personal supervision and care to professional bodies is allowed.

However, there are some noticeable gaps in the Trust Law, such as the absence of a fair-dealing rule, lack of specification as to the obtaining of profits through the use of the trustee's position or through information obtained in the course of trust administration (such as secret commission and diversion of maturing business opportunity), and the duty to avoid conflicts of duties. The absence of these provisions is particularly problematic for guardianship trusts in the domestic context, as the settlor-beneficiary may not be in a position to monitor the discharge of the trustee's duties. The situation may be exacerbated by a lack of monitoring authority to supervise the administration of the trust.

#### 4. *Who should supervise the guardianship trust?*

Alongside the problem of inexperienced statutory guardians, another perennial problem with statutory guardianship is that it is difficult to monitor the guardians because there are few concurrent safeguards against abuse of powers. The GPC

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<sup>70</sup> "The trust property shall be segregated from the property owned by the trustee." *Id.* at art. 16.  
"The trustee shall administer the trust property separately from his own property and keep separate accounting books." *Id.* at art. 29.

<sup>71</sup> *Id.* at art. 33.

<sup>72</sup> *Id.* at art. 34.

<sup>73</sup> *Id.* at arts. 20, 49.

<sup>74</sup> *Id.* at art. 30.

requires a guardian to protect his ward,<sup>75</sup> and guardians who fail to perform their duties may be liable to pay compensation or even termination of their guardianship duty.<sup>76</sup> However, the relevant laws do not specify which authority or persons have the right to monitor the guardians. Given that it may not be practicable for the elderly to enforce the laws, the absence of supervisors to monitor the guardians may render the statutory protection of the ward more apparent than real. There is also an absence of state involvement or judicial oversight over the appointment of guardians. The court system is not involved, except in very limited situations such as when there is a dispute over the appointment, which cannot be resolved by the local committees or when the designated guardian is dissatisfied with the designation and seeks an alteration.<sup>77</sup>

Unfortunately, the current trust law regime in China may be equally inadequate in terms of supervision of guardian-trustees. Under the Trust Law, a trust is regarded as a private arrangement between private parties and hence there is no court supervision except for charitable trusts.<sup>78</sup> However, a guardianship trust should not be seen as just a private matter between the relevant parties: the government has an obligation to tackle the problem of aging and the Elderly Protection Law has also stipulated the role of the state in establishing social security for the elderly and that the state should act as a last resort as caretaker of the elderly.<sup>79</sup>

A few deficiencies under the current trust law regime in this regard can be discerned. First, it is noteworthy that little effort has been made in the Trust Law to put in place the role of

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<sup>75</sup> GPCL, art. 18.

<sup>76</sup> It seems implicit in the context of Article 18 that the grounds of disqualification would include: failing to perform the duties as guardian, infringing the lawful rights and interests of the ward, and causing property loss to the ward. *Id.*

<sup>77</sup> See *id.* at art. 17; Opinions, art. 16; see also Opinions, arts. 18–19.

<sup>78</sup> Trust Law, arts. 59–73.

<sup>79</sup> Law on Protection of the Rights and Interests of the Elderly, art. 5 (China).

trusteeship as an office. In contrast, at common law, this is a crucial aspect of trusteeship, and involves the trustee's exercise of discretion independent of the influence of settlor and beneficiaries. It is also significant that the Trust Law does not seek to preserve the independent discretion of the trustee in acting in a manner that the trustee considers to be the best interest of the beneficiaries.

Second, in the context of a private trust, one may not expect the courts in China to play such a vigilant role. However, courts should play a more active role if guardianship trusts are introduced. For example, the courts should have inherent jurisdiction to give directions to the trustee and even to execute the trust itself as in common law jurisdictions.<sup>80</sup> Besides, upon termination of the trustee's appointment, such as on death or dismissal, the Trust Law allows the appointment of a new trustee according to the provisions of the trust contract or by the settlor or beneficiary.<sup>81</sup> However, when an elder has failed to provide for a replacement guardian-trustee in the trust contract, it is highly unlikely that the elder would be able to make a new appointment then. The Trust Law fails to provide for the court to appoint new guardian-trustees in the circumstances.

Third, a guardianship board should be set up to discharge several functions. First, it can supervise the creation of the guardianship trust, including qualifications of trustee and content of guardianship contract. This ensures that the individual can entrust his property and personal care to the trustee. Second, after the trust is created, it can supervise the administration of the trust and the performance of the trustee's duties (keeping trust accounts, for example). In the event of breach, the guardianship board can sue on behalf of the ward.

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<sup>80</sup> *McPhail v. Doultton*, A.C. 424 (1971).

<sup>81</sup> Trust Law, art. 40.

#### *IV. CONCLUSION*

Family care has been the major support mechanism for the elderly in China. However, as the demographic and socio-economic structures of the Chinese society have changed rapidly in recent decades, a system of elder care based solely on family responsibility has become increasingly inadequate and unsustainable. The need to develop a comprehensive and systematic elder law regime has become imminent, but adult guardianship law in China is still in infancy. The introduction of voluntary guardianship to the elder law regime in China shows the country's commitment to push the existing elder law regime forward toward a better balance between necessary traditional family support for the elderly and respect for their rights. Unfortunately, the Elderly Protection Law fails to provide any operational details of the new system. The present Article attempts to plug this gap by exploring the feasibility of utilizing the trust to supplement the existing guardianship system in China. It shows how China may make use of the flexibility and versatility of the trust institution to enhance and modernise the adult guardianship system in China. At the same time, however, the legal and cultural challenges involved in invoking the trust in the domestic context should not be under-estimated.





# MAKING MEDIATION WORK IN GUARDIANSHIP PROCEEDINGS: PROTECTING AND ENHANCING THE VOICE, RIGHTS, AND WELL-BEING OF ELDERS

*Jennifer L. Wright\**

## *I. INTRODUCTION*

For a long time, the presumption of adult guardianship systems has been that guardianship, if done right, will protect and improve the well-being of wards. Guardianship debates and reforms have centered around the supposed trade-off between the individual rights and the well-being of respondents and wards. Unfortunately, no direct data support the assumption that guardianship has a generally beneficial effect on the well-being of wards, to be balanced against the costs imposed by guardianship on wards' right to make their own decisions. Many studies indicate that, in fact, guardianship, far from improving well-being, is often a significant negative factor in the well-being of wards.<sup>1</sup> This outcome is not really surprising, in the light of extensive psychology research indicating that autonomy and internal locus of control are important components for physical health and functional abilities of elders, as they are for all people.<sup>2</sup> These data

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<sup>1</sup> Jennifer L. Wright, *Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA*, 33 INT'L J. L. & PSY. 350, 354 (2010) [hereinafter *Guardianship for Your Own Good*].

<sup>2</sup> *Id.* at 355–56 (citing studies that found “how powerful the positive effects of control over one’s own life and the negative effects of lack of such control can be”); Jennifer L. Wright, *Protecting Who from What, and Why, and How?: A Proposal for an Integrative Approach to Adult Protective*

indicate that, at the very least, the cases in which the costs to well-being of the ward of imposing a guardianship are outweighed by the benefits to the ward's well-being are a much smaller subset of the whole than has been assumed. This conclusion calls into serious question the entire system of adult guardianship, given the fact that guardianship, on its own terms, has no reason for being if it does not enhance the well-being of wards.<sup>3</sup>

Many legal scholars have written about the common failure of guardianship proceedings in actual practice to follow the requirements of guardianship statutes.<sup>4</sup> This well-established problem deserves continuing attention and study. However, even in those cases in which the system functions as it is designed, there are still serious threats posed to the well-being of respondents and wards. I have previously analyzed the anti-therapeutic consequences of the guardianship system when using the analytical lens of therapeutic jurisprudence.<sup>5</sup> As currently conceived, guardianship systems impose serious anti-therapeutic consequences on respondents and wards, even when they function as intended by statute. The lack of adequate public resources that continues to prevent guardianship systems from functioning as designed today<sup>6</sup> will become a system-wrecking problem when the "grey wave" crests in the courts, with the rapid growth of impaired elders in the population.

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*Proceedings*, 12 ELDER L.J. 53, 78 (2004) [hereinafter *Protecting Who from What*]; Gayle Fawcett, David Stonner & Harold Zepelin, *Locus of Control, Perceived Constraint, and Morale Among Institutionalized Aged*, 11 INT'L J. AGING HUM. DEV. 13 (1980).

<sup>3</sup> Wright, *Protecting Who from What*, *supra* note 2, at 55–56, 65–72.

<sup>4</sup> *Id.* at 60–62; Guardianship Work Group, *Adult Guardianships in Oregon: A Survey of Court Practices* 6 (1999); A. Frank Johns & Vicki Joiner Bowers, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Protected Older Americans in the Twenty-First Century – A March of Folly? Or Just a Mask of Virtual Reality?*, 27 STETSON L. REV. 1, 27–66 (1997) (analyzing significant empirical research projects and studies finding "a striking composite of how far changes in the laws have come, and how implementation of those changes has gone virtually nowhere"); Joan L. O'Sullivan & Diane E. Hoffmann, *The Guardianship Puzzle: Whatever Happened to Due Process?*, 7 MD. J. CONTEMP. LEGAL ISSUES 11, 11–13 (1996) (finding in the State of Maryland that the "way the system works in practice differs significantly from the way the guardianship statute is written").

<sup>5</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 357–361.

<sup>6</sup> Susan J. Butterwick et al., *Evaluating Mediation as a Means of Resolving Adult Guardianship Cases*, THE CENTER FOR SOCIAL GERONTOLOGY, 126–30 [http://www.tcsog.org/mediation/SJI\\_01.pdf](http://www.tcsog.org/mediation/SJI_01.pdf) (2001).

All of these concerns about guardianship indicate the serious need for a complete rethinking of the presumptions, procedures, and structure of the guardianship system. This Article focuses on one of the most promising alternatives: elder law mediation. In part II, I examine briefly some of the deep-rooted concerns with the adult guardianship system, as it currently exists, including the developing insights of international human rights law into guardianship. In part III, I describe what is encompassed in the idea of “elder law mediation,” giving a working definition, describing the parties and issues likely to be involved in such mediations, examining the role of elder law mediation in guardianship proceedings, and describing the therapeutic potential of elder law mediation to correct some of the most serious problems in the current adult guardianship system. I will describe some of the more prominent efforts to make elder law mediation a regular and significant part of preventing and resolving guardianship petitions. In part IV, I report on the results of a survey of attorneys, mediators and judges in several jurisdictions around the United States asking about their experiences and perception of elder law mediation in guardianship. In part V, I describe some of the main challenges to effective elder law mediation in guardianship and the kinds of best practice standards that are needed to protect the well-being of elders. Finally, in part VI, I indicate some of the steps that must be taken to make elder law mediation a useful, practical part of the guardianship system.

## *II. THE TROUBLES WITH GUARDIANSHIP*

Over the past thirty-five years, there have been repeated investigations and reports documenting the widespread failure of guardianship systems to provide in actual practice the protections

for respondents' and wards' rights that they promise in theory.<sup>7</sup> Despite decades of statutory reform, many of these protections remain illusory in the majority of cases.<sup>8</sup> Anecdotes of abuse of elders under the guardianship system continue to abound.<sup>9</sup> Guardianship has many strikes against it as a safeguard for the well-being of the impaired elderly.

#### A. Human Need for Self-Determination

As a method of seeking to improve the well-being of impaired elders, guardianship suffers from an inherent challenge. Guardianship, by its nature, deprives wards of their right and ability to make their own decisions or to control central aspects of their life, including where they will live, who they will see, where they will go, what medical treatment they will receive, how their money will be spent, and even how they will die.<sup>10</sup> As I discussed

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<sup>7</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 353; David Hardy, *Who Is Guarding the Guardians? A Localized Call for Improved Guardianship Systems and Monitoring*, 4 NAELA J. 1, 25–29 (2008) (giving suggested reform to address ongoing problems despite statutory reform in Nevada); Mary F. Radford, *Is the Use of Mediation Appropriate in Adult Guardianship Cases?*, 31 STETSON L. REV. 611, 642–43 (2002); Guardianship Work Group, *supra* note 4 (indicating survey results suggest a “difference exists between legislative policy and legal practice”).

<sup>8</sup> See *supra* note 7.

<sup>9</sup> The National Organization to End Guardianship Abuse, *Legal Guardians Steal Millions from Elderly, Report Says*, NOTEGA.ORG, <http://notega.org/2012/04/24/legal-guardians-steal-millions-from-elderly-report-says/> (Apr. 24, 2012); Marti Oakley, *Granny-Knapping: One Iowa Family Fights to Free Their Mother from a Predatory Guardianship*, THE PPJ GAZETTE, <http://ppjg.me/2011/02/03/granny-knapping-one-iowa-family-fights-to-free-their-mother-from-a-predatory-guardianship/> (Feb. 3, 2011); U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-10-1046, *Guardianships: CASES OF FINANCIAL EXPLOITATION, NEGLECT, AND ABUSE OF SENIORS* (2010); see also Hardy, *supra* note 7, at 4.

<sup>10</sup> SUBCOMMITTEE ON HEALTH & LONG-TERM CARE OF THE HOUSE SELECT COMMITTEE ON AGING, 100TH CONG., *ABUSES IN GUARDIANSHIP OF THE ELDERLY AND INFIRM: A NATIONAL DISGRACE* (Comm. Print 1987) (prepared statement of Chairman Claude Pepper). Chairman Claude Pepper stated that

[t]he typical ward has fewer rights than the typical felon . . . . By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty. . . . Guardianship proceedings are often highly adversarial, pitting children against parents, spouses against stepchildren, and siblings against each other. Guardianship proceedings are often commenced for the convenience of state case workers or long-term care facilities, or to relieve adult children of the ongoing need to worry about the risks run by an aging parent attempting to remain independent . . . . The issues at stake in an adult

at length in a previous article,<sup>11</sup> psychological research has established that the ability to control outcomes in one's personal life is an important component of well-being in human beings, and specifically, in the elderly. Loss of control over one's life is associated with reductions in subjective happiness, ability to function and perform activities of daily living, health, and longevity of the elderly.<sup>12</sup> Guardianship must provide benefits to wards' well-being sufficient to outweigh the substantial cost it imposes through the deprivation of wards' ability to determine the shape of their own lives. These costs are the by-product of guardianship even in situations in which the guardianship system functions as it should.

B.      A Therapeutic Jurisprudence Analysis of  
Guardianship Systems

Therapeutic jurisprudence is a mode of legal analysis that "seeks to apply social science to examine law's impact on the mental and physical health of the people it affects."<sup>13</sup> Therapeutic jurisprudence looks at the effects of laws, legal procedures, and legal actors on the physical and psychological well-being of those involved in the legal system. While other goals may be primary, therapeutic jurisprudence argues that anti-therapeutic

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guardianship often pose difficult conflicts among highly personal values and priorities, without a clear or objective 'right' answer.

<sup>11</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 355–56.

<sup>12</sup> *Id.* "[W]ell being refers to people's capacity to achieve the beings and doings they value. Evaluating wellbeing involves measuring people's command over assets and entitlements, together with their capacity to transform these into functionings. The extent to which they are able to exercise control in selecting those functionings they value is also important. From this perspective, wellbeing must be evaluated in a multidimensional framework, because it is intrinsically multidimensional. [This] approach pays due attention to heterogeneity in people's ability to transform assets into functionings, and also to agency." Armando Barrientos & Casilda Lasso de la Vega, *Assessing Wellbeing and Deprivation in Later Life: A Multidimensional Counting Approach* 2–4 (Univ. of Manchester Brooks World Poverty Inst., BWPI working paper 151, 2011).

<sup>13</sup> BRUCE J. WINICK, *THERAPEUTIC JURISPRUDENCE APPLIED: ESSAYS ON MENTAL HEALTH LAW* 3 (1997).

consequences of all laws must be recognized and, when possible, minimized. Therapeutic jurisprudence also emphasizes the importance of using empirical methods to determine the actual effects of the law on the real people involved.

When guardianship of the elderly is examined through the lens of therapeutic jurisprudence, several anti-therapeutic consequences of the guardianship system become evident. Guardianship generally functions as an all-or-nothing determination,<sup>14</sup> whereas it is clear that capacity to make one's own decisions is fluid and indeterminate, exists along a spectrum, and can be facilitated or inhibited by the environment in which decision-making occurs.<sup>15</sup> Guardianship is often used as a way to cut the elder out of difficult, high-stakes discussions about key issues of his or her life. Family members and care providers become frustrated with the process of trying to persuade the elder to accept help that he or she does not want and for which he or she cannot understand or accept the necessity. Guardianship is a means of imposing the decisions of others without the need to continue trying to persuade the elder to accept those decisions.

Guardianship proceedings force the parties into hardened and extreme positions. The petitioner, in order to prove the case by clear and convincing evidence, is motivated to exaggerate the elder's cognitive limitations. Every small slip up is seized on as further evidence of decline. The elder tends to deny that there is

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<sup>14</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 360.

<sup>15</sup> Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 SASK.L.REV. 75, 82–83 (2010) (finding that “[s]upported decision making allows us to move away from the view of individuals as either possessing capacity or not. We can embrace a view of individuals as possessing a variety of faculties and abilities”, because there are different “level[s] of a person’s mental or intellectual disability.”); Convention on the Rights of Persons with Disabilities, Gen. Cmt. No 1, Art. 12: Equal recognition before the law; COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES, U.N. HUMAN RIGHTS: OFFICE OF THE HIGH COMM’N FOR HUMAN RIGHTS, 11TH SESS., Mar. 31–Apr. 11, 2014, art. 12, § II, ¶ 14, U.N. Doc. CRPD/C/GC/1 (May 19, 2014) [hereinafter Gen. Cmt. No 1, Art. 12]. This General Comment stated that

[t]he concept of mental capacity is highly controversial in and of itself. Mental capacity is not, as it commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity.

any problem at all, for fear of having an unacceptable solution imposed upon him or her. Guardianship proceedings embarrass and shame the elder. The petitioner puts forward all the evidence that he or she can muster of the elder's decline and inability to function. This information is generally in the public record, and the elder is faced with seeing and hearing family members, friends, and care providers detailing his or her failings in court.

Guardianship proceedings tend to destroy relationships that are important to the well-being of the elder. Whether or not the petitioner prevails in the proceeding, the guardianship process can create intense resentment and may cause estrangement between the elder and the petitioner and the petitioner's witnesses. Guardianship often benefits the well-being of family members and caregivers rather than that of the elder. Guardianship, which frequently results in the placement of the elder in a nursing home or other institutional care setting,<sup>16</sup> provides a sense of security and peace of mind to the elder's family members. They have the sense that the elder is safe and that they have done their filial duty. However, statistics indicate that nursing home placement greatly increases the risk to elders of falls, infection, abuse, depression, loss of function, and death.<sup>17</sup>

The appearance of safety is often only an illusion. The guardianship process often confuses and frightens elders without giving them an effective voice. They are frequently unable to obtain counsel of their choice.<sup>18</sup> Appointed counsel (if any) often fails to effectively represent the wishes and perspective of the elder.<sup>19</sup> The elder may find it difficult even to attend the hearing,

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<sup>16</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 360–61.

<sup>17</sup> *Id.*

<sup>18</sup> *Id.* at 361.

<sup>19</sup> *Id.*

due to transportation and mobility problems. If the elder attends the hearing, he or she may find it difficult to express his or her perspective effectively in the unfamiliar and intimidating context of the courtroom, or indeed to hear and understand what is happening in the proceedings. The guardianship process is very time-consuming and expensive, especially for the elder. In most states, all costs of establishing a guardianship, including attorneys' fees of all parties, will be paid out of the elder's funds.<sup>20</sup>

To best sum up the anti-therapeutic consequences of guardianship perhaps is by saying that, in guardianship, the elder is often treated as an object, rather than a subject. Respect for human subjectivity is closely allied in our society with respect for human dignity.<sup>21</sup> In a well-functioning guardianship system, the incapacitated elder will be treated as a valued and important object of deep concern to all participants. Nevertheless, the guardianship process results in depriving the elder of subjective control over, and even input into, his or her own life decisions. Once a guardianship is imposed, in most cases, the elder is effectively removed from the conversation about what his or her life should be like. In order to justify this denial of respect for the elder's human subjectivity, the guardianship process focuses on the elder's failings, lacks, and diminishments. The guardianship system does not foster similar close attention to the elder's remaining strengths and capabilities. The elder in guardianship is reduced to an object, and that object is defined solely according to its weaknesses and failings.

### C. The Demands of International Human Rights

Another potential challenge to existing guardianship systems in the United States lies in developing international human rights law. The United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the UN on

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<sup>20</sup> Wright, *Protecting Who from What*, *supra* note 2, at 97–98.

<sup>21</sup> JAMES RACHELS, *THE ELEMENTS OF MORAL PHILOSOPHY* 114–17 (1986) (finding that “humans have ‘an intrinsic worth, i.e., dignity,’ because they are rational agents—that is, free agents capable of making their own decisions, setting their own goals, and guiding their conduct by reason”).



December 13, 2006, and entered into force for all ratifying state parties on August 16, 2008.<sup>22</sup> The CRPD was developed with strong input from the international disabled community and focuses intensely on the rights of disabled persons to autonomy, equal treatment, and legal capacity.<sup>23</sup>

The provisions of the CRPD, particularly of Article 12—equal recognition before the law—make it clear that guardianship law in all nations who ratify the Convention will have to be extensively revised or replaced.<sup>24</sup> Article 12 requires all state parties to the Convention to recognize and protect legal personhood *and legal capacity* for all disabled persons on an equal basis with the non-disabled.<sup>25</sup> Article 12 requires state parties to provide necessary supports to help disabled persons exercise their legal capacity and to provide systems of oversight to ensure that disabled persons are not exploited or taken advantage of by their helpers.<sup>26</sup> Article 14 provides that, under the CRPD, state parties may not deprive disabled persons of their liberty on the basis of their disability.<sup>27</sup> Article 19 specifically prohibits state parties from depriving disabled persons of the right to decide where they will live on the basis of their disability.<sup>28</sup> These provisions present clear conflicts with guardianship systems whose essential function is to declare people legally incapacitated due to their mental

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<sup>22</sup> Anita Smith, *Are Guardianship Laws and Practices Consistent with Human Rights Instruments?*, in

COMPARATIVE PERSPECTIVES ON ADULT GUARDIANSHIP 252 (A. Kimberley Dayton, ed., 2014).

<sup>23</sup> *Id.* at 251.

<sup>24</sup> *Id.* at 262 (citing the Thematic Study on Enhancing Awareness and Understanding of the Convention on the Rights of Persons with Disabilities, U.N. OFFICE OF THE HIGH COMM’N OF HUMAN RIGHTS, 45, U.N. DOC.

A/HRC/10/48 (Jan. 26, 2009)).

<sup>25</sup> Gen. Cmt. No 1, Article 12, *supra* note 15, at § I, ¶ 7.

<sup>26</sup> *Id.*

<sup>27</sup> Committee on the Rights of Persons with Disabilities (CRPD), U.N. HUMAN RIGHTS: OFFICE OF THE HIGH COMM’N FOR HUMAN RIGHTS, art. 14 (2014), *available at*

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#>.

<sup>28</sup> *Id.* at art. 19.

disabilities and to take away their rights to make their own decisions about their health care, finances, and residence as a result.

Many commentators on the CRPD originally believed that, while extensive revisions to most guardianship systems would be required for state parties, guardianship itself could remain part of the spectrum of supports provided to mentally disabled persons.<sup>29</sup> However, the CRPD included the creation of a Committee on the Rights of Persons with Disabilities (the Committee), empowered to receive and evaluate regular reports from state parties about their compliance with the CRPD.<sup>30</sup> The Committee thus has the primary role in interpreting the meaning of the CRPD and in applying the requirements of the CRPD to the legal systems of the state parties.

In April of 2014, the Committee issued its General Comment No. 1 on the CRPD. The General Comment made it clear that the Committee considers that guardianship is a *per se* violation of the CRPD:

Historically, persons with disabilities have been denied their right to legal capacity in many areas in a discriminatory manner under substitute decision-making regimes such as guardianship, conservatorship and mental health laws that permit forced treatment. These practices must be abolished in order to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others.<sup>31</sup>

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<sup>29</sup> Smith, *supra* note 22, at 268.

<sup>30</sup> CRPD, *supra* note 27, at art. 34.

<sup>31</sup> Gen. Cmt. No 1, Article 12, *supra* note 15, at § I, ¶ 7 & § III, ¶ 24 (stating “[s]tates parties have an obligation to respect, protect and fulfil the right of all persons with disabilities to equal recognition before the law.”).

The General Comment rejected substitute decision-making in any situation other than as a last recourse when the disabled person's will and preferences simply cannot be determined, despite intensive efforts.<sup>32</sup> In that case, the General Comment still indicates that a "best interests" standard may not be used, but rather a standard based on what the disabled person would have chosen, had he or she been able to express a preference.<sup>33</sup>

The United States is a signatory state to the CRPD.<sup>34</sup> However, the treaty has not yet been ratified by Congress and therefore has no force of law in the United States at this point in time. The Senate surprised many supporters when it failed to ratify the CRPD by only five votes on December 4, 2012.<sup>35</sup> The CRPD was negotiated by President George H. W. Bush, was signed by President Barack Obama, had the support of Senator John McCain, and was lobbied strongly by former Senator Bob Dole.<sup>36</sup> At the time of the 2012 vote, many senators indicated that their opposition to the CRPD was due to concerns about the breadth of its impact, citing the pending case of *Bond v. United States*.<sup>37</sup> In *Bond*, the Third Circuit Court of Appeal had upheld the application of the Convention on the Prohibition of the Development, Production, Stockpiling and Use of Chemical Weapon and on Their Destruction to the prosecution of a jealous wife, who put

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<sup>32</sup> *Id.* at § II, ¶ 15; § I, ¶ 7; § IV, ¶ 41; *see id.* at § III, ¶ 27 (defining "substitute decision-making").

<sup>33</sup> *Id.* at § II, ¶ 17.

<sup>34</sup> U.N., *United Nations Treaty Collection*, TREATIES.UN.ORG (July 26, 2014, 1:42:35 PM), <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&msgid=IV-15&chapter=4&lang=en>.

<sup>35</sup> C.R.P.D., *Convention on the Rights of Persons with Disabilities*, DISABILITYTREATY.ORG, <http://www.disabilitytreaty.org/crpd> (last visited July 3, 2015).

<sup>36</sup> Jim Lobe, *U.N. Disabilities Treaty Rejected by U.S. Senate*, INTER PRESS SERVICE NEWS AGENCY, IPSNEWS.NET, <http://www.ipsnews.net/2012/12/u-n-disabilities-treaty-rejected-by-u-s-senate/> (Dec. 4, 2012).

<sup>37</sup> Roll Call, *Dole, Harkin Renew Disability Treaty Push After SCOTUS Decision*, BLOGS.ROLLCALL.COM, <http://blogs.rollcall.com/wgdb/dole-harkin-renew-disability-treaty-push-after-scotus-decision/#comments> (June 3, 2014).

irritating chemicals on the car door, mailbox and doorknob of her husband's lover.<sup>38</sup> The case was cited as an example of how international treaties could have overly invasive and wide-ranging effects on U.S. laws.<sup>39</sup> The overturning of the Third Circuit's decision by the U.S. Supreme Court<sup>40</sup> on June 2, 2014, has led to many calls for the Senate to vote again on ratification of the CRPD.<sup>41</sup> Once ratified, the requirements of the CRPD will have to be taken into account by lawmakers in the guardianship area. Regardless of ratification by the United States, the CRPD represents a sea change in the way that human rights are viewed in the guardianship context.

#### D. The Oncoming Demographic Challenge

The rapid increase in the numbers and proportion of elders in the U.S. population has become a well-documented truism. The population of persons 65 and older grew from 35.5 million in 2002 to 43.1 million in 2012 (a 21% increase) and is anticipated to grow to 92 million by 2060.<sup>42</sup> The average 65-year-old today will live nearly 20 more years.<sup>43</sup> Nor is this population shift merely a matter of age. An even greater rate of increase in the numbers of the impaired elderly is expected. The population of persons 85 and older grew from 4.2 million in 2000 to 5.7 million in 2010 (a 36% increase)<sup>44</sup> and is expected to grow to 14.1 million in 2040.<sup>45</sup> In 2005, 56% of persons over 80 reported a severe disability and 29%

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<sup>38</sup> *Bond v. United States*, 681 F. 3d 149, 151–52 (3d Cir. 2012), *cert. granted*, 133 S. Ct. 987 (2013), *rev'd* 134 S. Ct. 2077 (2014).

<sup>39</sup> *Id.* at 159–62 (noting “[as long as treaties met the subject matter requirement] it was accepted that treaties could affect domestic issues”).

<sup>40</sup> *Bond v. United States*, 134 S. Ct. 2077 (2014).

<sup>41</sup> U.S. International Council on Disabilities, *Chamber of Commerce, Veteran, Disability, and Civil Rights Leaders Call for Ratification of CRPD*, USICD.ORG, <http://www.usicd.org/template/index.cfm> (2014).

<sup>42</sup> ADMINISTRATION ON AGING, *A Profile of Older Americans: 2013*, DEP'T OF HEALTH & HUMAN SERVICES, 3, [http://www.aoa.gov/Aging\\_Statistics/Profile/2013/docs/2013\\_Profile.pdf](http://www.aoa.gov/Aging_Statistics/Profile/2013/docs/2013_Profile.pdf) (2013) [hereinafter AOA 2013].

<sup>43</sup> *Id.* at 2.

<sup>44</sup> ADMINISTRATION ON AGING, *A Profile of Older Americans: 2009*, DEP'T OF HEALTH & HUMAN SERVICES, [http://www.aoa.gov/Aging\\_Statistics/Profile/2009/docs/2009profile\\_508.pdf](http://www.aoa.gov/Aging_Statistics/Profile/2009/docs/2009profile_508.pdf) (2009) [hereinafter AOA 2009].

<sup>45</sup> AOA, 2013, *supra* note 42, at 1.

of the over 80 population reported that they needed assistance with activities of daily living.<sup>46</sup>

The rapid and dramatic increase in the number of disabled elders will be reflected in a similar increase in the number of potential guardianship cases. If the guardianship system remains unchanged, this demographic shift would require an enormous increase in the courtrooms, judges, and court resources devoted to guardianship proceedings. Courts are already starved for resources and have trouble meeting their criminal dockets in a timely manner, much less their civil dockets.<sup>47</sup> With all the other demands on the courts, it is unlikely, to the point of near impossibility, that the necessary resources will be forthcoming for the guardianship system. The system for meeting the needs for assistance of incapacitated elders will need to change dramatically in ways that decrease the reliance on formal court proceedings.

### III.      *THE BENEFITS OF ELDER LAW MEDIATION*

For many years, practitioners, scholars and policy makers have considered the potential for mediation to improve guardianship proceedings by reducing the burden on the courts, reducing financial and non-financial costs to the parties, and increasing the likelihood that elders will have some input in the key decisions that affect their lives.<sup>48</sup> Despite this recognition of the therapeutic potential of mediation in guardianship, it has generally proved difficult in practice to successfully integrate

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<sup>46</sup> AOA, 2009, *supra* note 44, at 16.

<sup>47</sup> Stephen N. Zack, *With Our Courts Starved for Resources, the ABA Will Redouble Its Advocacy Effort*, ABAJOURNAL.COM (Apr. 1, 2011), available at [http://www.abajournal.com/magazine/article/with\\_our\\_courts\\_starving\\_for\\_resources\\_the\\_aba\\_will\\_redouble\\_its\\_advocacy/](http://www.abajournal.com/magazine/article/with_our_courts_starving_for_resources_the_aba_will_redouble_its_advocacy/).

<sup>48</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 365; see generally Radford, *supra* note 7; Butterwick, et al., *supra* note 6.

mediation into the guardianship process.<sup>49</sup> Some of this difficulty has been due to different understandings about what is meant by “elder law mediation” in guardianship, different perspectives on the ethical issues involved, and different ideas about the proper roles of the elder, the mediator, and the other parties in elder law mediation.<sup>50</sup> In order to try to resolve some of the misunderstandings that have attended the discussion of elder law mediation in guardianship, I will make explicit my definitions and ethical positions.

#### A. Definition, Issues, Parties, and Relation to Guardianship

Elder law mediation can be defined as mediation of issues regarding the life situation of a person (who may or may not be elderly), where the issues arise due to the actual or perceived diminished mental and/or physical capacity of the person.<sup>51</sup> Elder law mediation thus constitutes a distinct category of mediation defined not by the age of the parties but by the nature of the issues. “Elder law” mediation can be a useful tool when addressing the needs of impaired adults, regardless of age.

Elder law mediation may involve issues such as: the elder’s place of residence; what medical treatment he or she will receive; whether and what long-term care and supportive services the elder will receive; what assistance with activities of daily living he or she will receive and who will provide such assistance; how the elder’s finances will be managed and by whom; whether and how the elder’s assets will be sold or given to others; who will

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<sup>49</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 365-366; Butterwick, et al., *supra* note 6.

<sup>50</sup> Telephone Interview with Erica Wood, Associate Staff Director, A.B.A. Commission on Legal Problems of the Elderly (Sept. 2, 2011) (notes on file with Author).

<sup>51</sup> Basing the definition of elder law mediation on the nature of the issues to be mediated rather than the age of the participants parallels the common definition of “elder law,” which encompasses certain areas of law which tend to be of greatest concern to the elder population, but which are also applicable to many younger disabled adults. For example, elder law has never been understood to include “any legal problem experienced by a person over 65.”

participate in daily life choices of the elder; and end of life decisions.<sup>52</sup>

Parties involved in an elder law mediation may include the elder himself or herself, family members, appointed agents, financial fiduciaries, professional health and personal care providers, close friends, attorneys and advocates for the parties, social service agency personnel (e.g., adult protection), and/or court personnel (e.g., court visitor).<sup>53</sup>

For most of the issues described above, the legal alternative to an agreed-upon solution is guardianship.<sup>54</sup> Elder law mediation occurs in the shadow of the guardianship statutes and procedures. In that sense, nearly all elder law mediation can also be seen as guardianship mediation, although that term is generally reserved for mediations begun after a petition for guardianship has been filed with the court. Several pilot programs for guardianship mediation have attempted to include pre-petition mediation as an option.<sup>55</sup>

Elder law mediation in guardianship generally involves the petitioner, respondent, and interested parties meeting as a group, or in caucus, with a trained elder law mediator (see description of elder law mediator training requirements, below). In many ways, elder law mediation in guardianship is the same as any other mediation. The elements of a mediation process are simple on the surface: the use of private sessions and group meetings led by a neutral facilitator who monitors and manages the process while

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<sup>52</sup> Butterwick et al., *supra* note 6, at 7–8.

<sup>53</sup> *Id.* at 4–6.

<sup>54</sup> *Id.* at 2.

<sup>55</sup> There is a report on four pilot programs in Ohio, Florida, Wisconsin, and Oklahoma that allowed a pre-petition route to mediation, which resulted in a small number of cases mediated in those programs. *Id.* at 134.

upholding the key principles of confidentiality, voluntary participation, mediator neutrality, informed consent, and self-determination.<sup>56</sup>

While mediation is a common and routine feature of the civil litigation system in nearly all jurisdictions, guardianship has generally been an exception to this general rule.<sup>57</sup> There are many reasons given for the exclusion of guardianship from the mediation processes that are an integral part of most other civil litigation. Guardianship was long thought of as a non-adversarial process, in which the parties and the court could straightforwardly act in the elder's best interests without the need for many procedural protections or requirements.<sup>58</sup> Since the parties were perceived in most cases not to have adverse interests, there appeared to be no need for a process to enable the parties to work out their interests through mediation. In addition, since many courts appeared to accept an allegation of incapacity as established fact,<sup>59</sup> and since many courts understood capacity as an all-or-nothing state,<sup>60</sup> it was

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<sup>56</sup> Rikk Larsen & Crystal Thorpe, *Elder Mediation: Optimizing Major Family Transitions*, 7 MARQ. ELDER'S ADV. 293, 296 (2006) (citation omitted).

<sup>57</sup> Catherine Anne Seal & Michael A. Kirtland, *Using Mediation in Guardianship Litigation*, 39 THE COL. LWY. 37, 38 (2010). In fact, in the state of Minnesota, guardianship is one of the few kinds of cases specifically exempted by statute from mediation requirements. See Other Rules Distinguished, Title X, Rules of Guardian Ad Litem Procedure, MINN. R. GEN. PRAC. § 908.02 (1999).

<sup>58</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 352; Wright, *Protecting Who from What*, *supra* note 2, at 59–60; see also Norman Fell, *Guardianship and the Elderly: Oversight Not Overlooked*, 25 U. TOL. L. REV. 189, 194–95 (1994).

<sup>59</sup> Hardy, *supra* note 7, at 7 (stating that in Nevada, criticism of the court through an investigative news series identified that guardianships were often granted without meaningful review and incapacity assessments were based upon ill-defined criteria); Eleanor M. Crosby & Rose Nathan, *Adult Guardianship in Georgia: Are the Rights of Proposed Wards Being Protected? Can We Tell?*, 16 QUNNIPIAC PROB.L.J. 249, 261–64 (2003); Radford, *supra* note 7, at 642–43 (noting general misconceptions about capacity linked to guardianship proceedings not practicing the protections the statutes would seem to guarantee); Guardianship Work Group, *supra* note 4 (noting the court's need "to receive better information concerning the functional status of the respondent"); Butterwick et. al, *supra* note 6, at 2–3 (finding "[a]pproximately 94% of all guardianship petitions filed are granted, and the vast majority of these are for full guardianship").

<sup>60</sup> *Id.*; Johns & Bowers, *supra* note 4, at 41–66 (finding in a national study that "[c]ourts routinely granted absolute guardianships, rarely utilizing partial or limited guardianships"); Crosby & Nathan, *supra* note 54, at 261–64 (finding statutes do not encourage evidence of the proposed ward's ability to care for their own safety, attend to necessities, or get medical care, but instead granting guardianships based solely on a diagnosis or condition of the proposed ward); O'Sullivan & Hoffmann, *supra* note 4, at 11–13 (finding that guardianship orders in the state of Georgia frequently award all of the powers available to the guardian even if not requested).



generally assumed that respondents and wards in guardianship would have no ability to participate in guardianship mediation. Even if some respondents had capacity to participate in mediation, many believed that they would suffer from an imbalance of power that would make mediation ethically questionable.<sup>61</sup> Finally, since it was assumed that the vast majority of petitions would result in the appointment of a guardian,<sup>62</sup> and since a guardian for an adult can be appointed only by decision of a court, not by agreement among the parties,<sup>63</sup> it appeared that mediation would be unable to resolve the vast majority of guardianship cases.

Along with other challenges to the guardianship systems, these assumptions indicating that mediation is of little value in guardianship have been examined and rejected by many over the last 20 years. Immediately following the Wingspan Conference<sup>64</sup> in 2001, a seminal article was published by Mary F. Radford, a Wingspan participant, examining the use of mediation in guardianship.<sup>65</sup> She discussed the work done by The Center for Social Gerontology (TCSG) in Ann Arbor, Michigan, to research

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<sup>61</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 366.

<sup>62</sup> *Id.* at 360.

<sup>63</sup> See Unif. Guardianship & Protective Proceedings Act, Article I, §102 (2007) (defining guardian as a “person appointed by the court to make decisions regarding the person of an adult. . . .”); see e.g. MINN. STAT. § 524.5-303 (2013).

<sup>64</sup> There have been three national conferences on guardianship law over the last 25 years: the Wingspread Conference, held in Wisconsin in 1988; the Wingspan Conference, held in Florida in 2001, and the 3<sup>rd</sup> National Guardianship Summit, held in Utah in 2011. These conferences were sponsored and attended by a wide range of groups, including the National Academy of Elder Law Attorneys, the Borchard Center of Law and Aging, the Center for Social Gerontology, the ABA Commission on Law and Aging, the National College of Probate Judges, the National Guardianship Association, AARP, the Alzheimer’s Association, and the National Center for State Courts. See e.g. National Guardianship Network, *Organizations and Websites*, NATIONALGUARDIANSHIPNETWORK.ORG, [http://www.naela.org/NGN/Summits\\_on\\_Guardianship/History/NGN/Summits\\_on\\_Guardianship/History.aspx?hkey=ed8f7a49-dc08-44b0-b9be-b4313011f515](http://www.naela.org/NGN/Summits_on_Guardianship/History/NGN/Summits_on_Guardianship/History.aspx?hkey=ed8f7a49-dc08-44b0-b9be-b4313011f515) (last visited July 3, 2015); Marshall B. Kapp, *Reforming Guardianship Reform: Reflections on Disagreements, Deficits, and Responsibilities*, 31 STETSON L. REV. 1047 (2002).

<sup>65</sup> Radford, *supra* note 7.



B.      Therapeutic Potential for Elder Law Mediation in Guardianship

A therapeutic jurisprudence analysis immediately highlights the therapeutic potential for elder law mediation in guardianship. There are many ways in which elder law mediation could achieve the goals of guardianship proceedings with greater therapeutic and/or less anti-therapeutic effects on the participants, particularly the elder.

1.    *Preserving and Protecting the Meaningful Voice and Participation of the Elder*

Elder law mediation in guardianship returns the attention of participants to the personhood of the elder, encouraging a focus on the elder's strengths and capacities, and well as his or her values, choices, and desires.<sup>70</sup> The focus of elder law mediation is on enabling the voice of the elder to be fully heard and respected, whatever that goal may require:

[F]acilitative mediation is . . . particularly appropriate in cases involving older adults. Unlike a traditional adjudicative process, mediation allows for and indeed encourages both traditionally logical or rational knowledge (privileged by court processes) and what Michael Polanyi called 'tacit knowledge', the implicit, personal and interpreted knowledge the co-exists and shapes our

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<sup>70</sup> "[A] strengths-based approach to elder mediation involved assessing the strengths of the older adult and the other parties to the mediation, and facilitating the use of these strengths throughout the intake, preparation for mediation, and the mediation itself." Gemma Smyth, *Mediation in Cases of Elder Abuse and Mistreatment: The Case of University of Windsor Mediation Services*, 30 WINDS. REV. OF L. & SOC. 121, 134 (2010).

understanding of phenomena, as well as what phenomenologists might call 'lived experience.'<sup>71</sup>

Elder law mediation thus aims at preserving continuity of the identity and life experience of the elder, rather than the dramatic change of guardianship, cutting off the patterns and choices of the past and substituting new decision-makers and decisions.

In the experience of one elder law mediation program, specifically aimed at mediation of some of the most difficult issues involving elder mistreatment, a researcher described an example of a mediation involving an elder who was perceived by her children to be making irrational decisions; "All but one of her children had given up bargaining with their mother, and their narrative increasingly assumed her incompetence in all areas of her life. However, their mother's tacit understanding of her complex, lifelong relationships and her emotional experiences made her decision both understandable and logical."<sup>72</sup> Participants in this elder mediation program found that "older adults' understanding of themselves, others, the specific disputes, and disputing generally—along with 'facts' and how they are experienced—were essential to a fuller conception of the conflict."<sup>73</sup>

## *2. Maintaining Important Relationships and Improving Communication Among the Parties*

One commonly cited benefit of mediation in general is the ability to preserve ongoing positive relationships among the parties.<sup>74</sup> This effect is of particular importance to elders because strong social relationships are highly correlated with elder well-

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<sup>71</sup> *Id.* at 129.

<sup>72</sup> *Id.*

<sup>73</sup> *Id.*

<sup>74</sup> "[O]ne of the reasons mediation has become more accepted in family law matters is its potential to reduce conflict. Similarly, in contested guardianship cases, mediation has been considered because of the potential to reduce conflict among family members and help create an environment where the parties can work together for the best interests of the ward." Seal & Kirtland, *supra* note 57, at 41; see also Radford, *supra* note 7, at 639.

being.<sup>75</sup> Contested guardianships litigated through the courts often result in the shattering of family ties and leave a legacy of suspicion and alienation, regardless of the outcome. Elders can ill afford to sacrifice close relationships with family and other caregivers, even (or especially) if they defeat a guardianship petition. Family and caregivers may find the work of the guardian made infinitely more difficult because of the ongoing resentment of the elder ward.

If the [potential guardianship] case is handled through usual court procedures, it will be resolved through litigation or settlement, but real underlying issues may not be addressed, and relationships may be soured. The parties, and especially the older person involved, are likely to come away feeling as if they are powerless and the ‘system’ is not interested in them. Both the older person and his or her family members may feel as if the problem that brought them to court has not been solved. Anger and resentment will remain.<sup>76</sup>

In contrast, elder law mediation in guardianship offers the opportunity for the elder and other concerned parties to come to mutual understanding of each person’s values and concerns. The parties can gain a better understanding of each other and can develop trust in working together to achieve their common goals.

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<sup>75</sup> Wright, *supra* note 1, at 360; Pernilla K. Hilleras et al., *Life Satisfaction Among the Very Old: A Survey on a Cognitively Intact Sample Aged 90 Years or Above*, 52 INT’L J. AGING & HUM. DEV. 71, 73, 84 (2001).

<sup>76</sup> Susan D. Hartman, *Mediation of Disputes Arising in Adult Guardianship Cases*, 30 CLEARINGHOUSE REV. 597, 597–98 (1996–1997).

They are also more likely to see the final resolution as fair and be more motivated to help carry out its provisions.<sup>77</sup>

### 3. *Helping Elders Face up to Unpalatable Realities of Aging in a Supportive Environment*

The adversarial process of resolving a contested guardianship case and the limited range of outcomes generally available in the guardianship process<sup>78</sup> together push elders to deny that they suffer from any impairment at all. Elders fear, not unreasonably, that any concession of impairment or disability will be used against them in the guardianship proceeding to justify the imposition of a plenary guardianship. However, most guardianship petitions are filed for some reason. Frequently, the respondent/elder has experienced some change in functioning that has given rise to fears for his or her safety or well-being. In many cases, the change may be a change in physical abilities or in cognition or memory, which could be accommodated, leaving the elder with his or her decision-making rights intact. However, in the bi-modal, adversarial context of a contested guardianship, the elder is pushed to deny these changes and to refuse to accept the need for any accommodation. The result may be either a plenary guardianship that imposes an unnecessary deprivation of the elder's decision-making rights, or the dismissal of the guardianship petition, leaving the elder in a position where he or she has cut himself or herself off from assistance that could significantly improve his or her well-being.<sup>79</sup>

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<sup>77</sup> Larsen & Thorpe, *supra* note 56, at 294 (stating that “[w]hen family members participate in a decision-making process that allows them to feel heard and understood, they often feel better about the transition. They develop a stronger stake in the evolving solution and may strengthen tender relationships along the way.”); *see also* Seal & Kirtland, *supra* note 57, at 41 (finding “one of the reasons mediation has become more accepted in family law matters is its potential to reduce conflict. Similarly, in contested guardianship cases, mediation has been considered because of the potential to reduce conflict among family members and help create an environment where the parties can work together for the best interests of the ward.”).

<sup>78</sup> While many statutes indicate that limited orders of guardianship are the preferred outcome, if a guardian is required, in most jurisdictions, the courts continue to either grant plenary guardianship or dismiss the guardianship petition. *See supra* note 7. Guardianship remains, for most participants, a mostly all-or-nothing procedure. *Id.*

<sup>79</sup> “[A]s far as elders are concerned, it might be the cultural stereotype of *incompetence*, or the fear of its label, that hinders elders from acknowledging their suffering.” Yvonne Craig, *Elder Mediation*:

Even outside the highly charged context of a contested guardianship, it can be very difficult for people to admit to themselves, and to others, that they are not able to function exactly as they did in the past. Indeed, some degree of denial of impairment can actually be an important component of healthy psychological functioning.<sup>80</sup> The problem-solving focus of mediation can allow elders to accept the value of accommodations or assistance as a means of resolving concerns of the parties without having to explicitly concede the loss of functional ability. It may also allow the elder to acknowledge the reality of functional decline, in a context in which that acknowledgment will not be used as a tool to wrest decision-making power from the elder.

#### 4. *Encouraging and Enabling Connection to Community Resources*

As discussed above, a contested guardianship proceeding can lead an elder to reject assistance that may be available to him or her in the community. In other cases, family members or caregivers may seek guardianship because they are unaware of services available to maintain the independence of elders in the community. For many years, the presumption has been that a significantly impaired elder must be cared for in a nursing home.<sup>81</sup>

For most elders, involuntary admission to a nursing home is among their worst nightmares.<sup>82</sup> If nursing home admission is

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*Can It Contribute to the Prevention of Elder Abuse and the Protection of the Rights of Elders and Their Careers?*, 6 J. ELDER ABUSE & NEGLECT 83, 87 (1994) (emphasis in original).

<sup>80</sup> Graham C. Russell, *The Role of Denial in Clinical Practice*, 18 J. ADV. NURSING 938, 939–40 (1993).

<sup>81</sup> Eric Carlson & Gene Coffey, *10-Plus Years After the Olmstead Ruling: Progress, Problems, and Opportunities*, –4, 20–23 (Nat'l Senior Citizens Law Ctr. Special Report Sept. 2010).

<sup>82</sup> Paula Span, *Assisted Living or Nursing Home?*, NEW YORK TIMES (June 10, 2011, 10:58 AM), [http://newoldage.blogs.nytimes.com/2011/06/10/assisted-living-or-a-nursing-home/?\\_php=true&\\_type=blogs&\\_r=0](http://newoldage.blogs.nytimes.com/2011/06/10/assisted-living-or-a-nursing-home/?_php=true&_type=blogs&_r=0); T.J. Mattimore et al., *Surrogate and Physician*

seen as the only available solution to an elder's care needs, and an elder refuses to consider entering a nursing home, family members or caregivers may see a guardianship as the only option. Guardianship proceedings tend to focus mainly on whether the elder suffers from a significant impairment that affects their ability to make and carry out rational decisions. Once impairment is found, a plenary guardianship is the most common outcome, despite many guardianship statutes' provisions for seeking the least restrictive alternative to protect the elder from harm.<sup>83</sup> The tendency of guardianship proceedings is to focus on the bimodal question: "guardian or no guardian?" There is no part of the process that requires participants to consider and discuss all the many intermediate options that might meet the needs of the parties.

Elder law mediation in guardianship introduces a key figure—the elder law mediator—who should have a broad and deep institutional knowledge of the resources available to meet the various needs of elders in the relevant community. Such knowledge is part of the essential training and resource base of a qualified elder law mediator (see discussion in section V(D), below). One important function of an elder law mediator is to help expand the range of creative solutions under consideration and to introduce parties to options of which they are not aware.<sup>84</sup> Participation in elder law mediation will ensure that parties are made aware of community resources that may address concerns of family members or caregivers about the safety and well-being of the elder without depriving the elder of his or her home and preferred lifestyle. Flexible and creative use of available services

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*Understanding of Patients' Preferences for Living Permanently in a Nursing Home*, 45(7) JOURNAL OF THE AMERICAN GERIATRIC SOCIETY 818 (1997).

<sup>83</sup> Guardianship Work Group, *supra* note 4, at 5 (finding in Oregon that "guardianship petitions are rarely denied and rarely limited in their powers despite statutory requirement to show less restrictive alternative); Hardy, *supra* note 7, at 7 (noting that a nationwide investigation uncovered "[g]uardianships were often granted without meaningful review"); Butterwick et al., *supra* note 6, at 2–3 (finding "[a]pproximately 94% of all guardianship petitions filed are granted, and the vast majority of these are for full guardianship"); Unif. Guardianship & Protective Proceedings Act, Comment to Article III, §311 ("A guardian is to be appointed only when no less restrictive alternative will meet the respondent's identified needs.").

<sup>84</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 362.



can result in better care and greater autonomy for the elder at a lower cost, in a truly win-win-win outcome.

5. *Enabling Caregiving to Continue within a  
Workable Structure*

One of the disadvantages of the guardianship system, ironically, is its ostensible single focus on the well-being of the respondent or ward. Most guardianship statutes direct the court's attention to the needs and interests of the respondent or ward alone.<sup>85</sup> This framework leaves out the needs and concerns of other persons involved in the elder's life. This lacking can be labeled as the "ostensible" focus of guardianship, because, as many have noted, the guardianship system in fact is often far more effective at serving the needs of other participants than those of the elder.<sup>86</sup> However, in the guardianship system, the needs of others are served without direct acknowledgment or examination, because these needs generally have no official acknowledgment within the guardianship proceeding.

By contrast, elder law mediation acknowledges the needs, values, and goals of all the participants. While the needs and desires of the elder must be given a privileged and protected position (see discussion at section V(D), below), mediation honors and provides a place for the discussion and integration of the needs and desires of family members, caregivers, and all other participants. The elder can be made aware of the burdens and stresses that pursuit of his or her goals and desires may impose on others. The participants can seek creative solutions that take into account the needs and desires of all. The goal of elder law

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<sup>85</sup> UNIF. PROBATE CODE § 5-311; see e.g. MINN. STAT. § 524.5-310.

<sup>86</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 353 (citing Am. Bar Ass'n Comm. on the Mentally Disabled & Comm. on Legal Problems of the Elderly, *Guardianship: An Agenda for Reform*, 13 MENTAL & PHYSICAL DISABILITY L. REP. 271, 277 (1989)).

mediation is not to establish a “winner” who can decide everything as he or she chooses, but rather to find the best outcome that all can accept.

#### *6. Permitting and Encouraging Creative Problem Solving*

Due in part to the effects discussed above, elder law mediation tends to open up the range of possible solutions and to encourage parties to design and adopt outcomes that meet the unique and specific needs of the participants. The elder’s perspective cannot be overridden or ignored in elder law mediation, as it often is in guardianship proceedings, even if the elder’s view of his or her own well-being is eccentric or the elder is cognitively impaired. Elder law mediation’s opening of the discussion to consider the many potential resources in the community, as well as its explicit acknowledgment and incorporation of the needs and values of all the interested parties, encourage a focus on the particular situation. Guardianship’s tendency to default to a one-size-fits-all resolution is avoided. When the process of elder law mediation restores or maintains respect and trust among the participants, it encourages accommodation and compromise among the needs and goals of all. Elder law mediation agreements can incorporate outcomes that a guardianship court has neither the inclination, nor generally the power, to impose. Examples from my practice have included agreements to participate in family counseling, promises to speak to each other always with respect and kindness, and an agreement to repay money taken from the elder by mortgaging the responsible person’s homestead (which would have been exempt from collection attempts in a civil lawsuit).

Guardianship, by its very nature, offers a standard solution to the wide range of challenges posed to elders’ well-being by the aging process. In order to function efficiently and effectively, guardianship systems must establish a universal structure for resolving the issues, including a defined set of possible outcomes.

Efforts to encourage courts to draft individualized guardianship orders, limited to the specific situation and needs of the individual ward, have for the most part been unavailing.<sup>87</sup> This outcome is not surprising. As a probate judge once said to me:

“If I do as you ask and limit this order, I know that all of you will probably be right back here in my courtroom in a few months or a year, because the needs of the ward will continue to change. If I grant a plenary guardianship, as the petitioner requests, I know that I can probably be done with this case for good.”<sup>88</sup>

Judicial economy will always mitigate against limiting and tailoring guardianship orders in the general run of guardianship cases.

Elder law mediation, by contrast, has no need to regularize or limit the range of possible outcomes. The process, by its very nature, is customized to the specific situation and participants. The mediation process can be ongoing as needed. In addition, participants can agree to processes to resolve future disagreements and can plan for how to deal with foreseeable contingencies as they arise.

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<sup>87</sup> See e.g. Butterwick et al., *supra* note 6, at 2–3, 6 (noting that 94% of guardianship petitions are granted with a vast majority being full guardianships despite the court’s ability to appoint a limited guardianship).

<sup>88</sup> Here I paraphrase a comment from a conversation about twelve years ago with Jennifer Todd, then a pro tem judge in the Marion County Probate Court in Salem, Oregon, now a member of the faculty of Willamette University College of Law. To her eternal credit, Judge Todd did grant the limited order in that case, something rare in my more than twenty years of elder law practice. And, of course, she was right—the case did eventually return to her docket.

### 7. *Reducing Costs to Participants and Court Systems*

Guardianship is expensive, both for the courts<sup>89</sup> and for the parties, particularly the elder.<sup>90</sup> In the Twin Cities of Minnesota, an *uncontested* guardianship generally costs the ward's estate over \$2,000 (not including the costs to the court).<sup>91</sup> If the guardianship is contested, the price goes up exponentially.<sup>92</sup> There are many cases in which, once the guardianship is resolved, the elder's estate has been totally depleted, leaving the elder indigent and dependent upon government benefits for survival.<sup>93</sup> Even if the outcome of guardianship proceedings serves the well-being of the elder, the draining of his or her estate does not.

In addition to the financial costs, guardianship is also very costly in terms of time. Until recent efforts to improve timeliness, the average delay between the filing of petition and the initial

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<sup>89</sup> Micheal J. Corbin, *What Is the Average Lawyer Charge for Conservator & Guardianship for an Elderly Dad Who Has Cognitive Dysfunction & Resistant?*, AVVO.COM, <http://www.avvo.com/legal-answers/what-is-the-average-lawyer-charge-for-conservator--992541.html> (2014) (noting that contested guardianship hearings will require a public defender appointed for the elder); Robert Fleming, *How Much Does It Cost to Get a Guardian and/or Conservator Appointed?*, LEGALISSUES NEWSLETTER (2014), available at <http://issues.flemingandcurti.com/2012/10/21/how-much-does-it-cost-to-get-a-guardian-and-or-conservator-appointed/> (noting the court may have to pay court-appointed attorney and the court-appointed investigator if there are no assets available from the family). Note, every guardianship petition requires a court hearing, which is both expensive and time-consuming for the court. See Unif. Guardianship & Protective Proceedings Act, Article I, §102; see e.g. MINN. STAT. § 524.5-303.

<sup>90</sup> *Id.* Note, "[i]f not otherwise compensated for services rendered, a guardian, conservator, lawyer for the respondent, lawyer whose services resulted in a protective order or in an order beneficial to a protected person's estate, or any other person appointed by the court is entitled to reasonable compensation from the estate." Unif. Probate Code § 5-417. Also note, "all costs and expenses of the proceeding, including respondent's attorney's fees, will be paid from the respondent's estate." MINN. STAT. § 524.5-303 (d)(4).

<sup>91</sup> "In the Twin Cities, an uncontested guardianship generally costs about \$2,500 to \$3,000. If it becomes contested, the sky's the limit." Telephone Interview with Adam Rohne, Associate Attorney, Hansen, Dordell, Bradt, Odlaug & Bradt, P.L.L.P. (July 28, 2014) (notes on file with Author). "It's about 10 to 15 hours of billable time. At \$225 per hour, that is \$2,225 to \$3,375, but the hourly rate varies dramatically among attorneys. You can't predict the cost of a contested guardianship—it can get very expensive." Telephone Interview with Monica Lewis, Attorney at Law, Estate & Elder Law Service (July 28, 2014) (notes on file with Author).

<sup>92</sup> *Id.*

<sup>93</sup> *Id.* Brenda K. Uekert & Thomas Dibble, *Guardianship of the Elderly: Past Performance and Future Promises*, 23 THE COURT MANAGER 9, 10 (2008), available at <http://cdm16501.contentdm.oclc.org/cdm/ref/collection/ctadmin/id/1570> (noting "[i]n individual cases, guardianships can result in the total loss of a ward's resources . . .").

hearing in a guardianship case in Hennepin County Probate Court (where the City of Minneapolis, MN, is located) was 11 to 12 weeks.<sup>94</sup> This time lag is typical, in my practice experience. These time frames mean that it may be three months or more from the time that a petition is filed until there is any action taken to address threats to the well-being of an elder. Again, this time delay can increase to many more months, or even a year or more, before final resolution in a contested guardianship.

This time cost is a concern for two reasons. On the one hand, as noted above, most guardianship petitions are filed in response to some real concern or problem. Therefore, elders at risk are left at risk with no action taken, while the guardianship case makes its slow way through the courts. On the other hand, when the elder is not actually in need of intervention, the filing of a guardianship petition itself creates a perception that the elder is unable to handle his or her own affairs or make his or her own decisions. I have represented many respondents in guardianship who found that their nursing homes were concerned about allowing them to make their own health care decisions, or that banks or other financial institutions were reluctant to acknowledge their legal rights to handle their own affairs pending the final resolution of the guardianship proceedings.<sup>95</sup> The time delays in guardianship leave elder respondents living under a cloud for a long while, with their basic rights to self-governance subject to question at every turn.

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<sup>94</sup> Judge Jay Quam, *Probate/Mental Health Court: Rapidly Challenging and Always Interesting*, THE HENNEPIN LAWYER (Dec, 23, 2010), available at <http://hennepin.timberlakepublishing.com/article.asp?article=1492&paper=1&cat=147>.

<sup>95</sup> Virtually every guardianship statute does make provision for emergency proceedings. An emergency guardianship generally can be obtained in a much shorter time frame and can provide interim protections for the elder while the regular guardianship proceeding is pending. I don't address emergency guardianship in detail, only noting that it can be even more expensive and often plays fast and loose with the due process rights of respondents. See e.g. *Grant v. Johnson*, 757 F. Supp. 1127 (D. Or. 1991).

Elder law mediation, in contrast, is generally substantially quicker and less expensive than guardianship proceedings. In the one jurisdiction that has made a statewide commitment to encouraging elder law mediation in guardianship, the average cost of resolving a case through elder law mediation was \$1,380,<sup>96</sup> far, far below the cost of guardianship in any jurisdiction.<sup>97</sup> Participants in that program, including institutional participants such as public guardians and court visitors, indicate that the elder law mediation process saves time as well.<sup>98</sup> In my own experience in cases handled by the Elder Law Practice Group of the Legal Services Clinic of the University of St. Thomas School of Law, elder law mediation, when parties agree to participate, resolves problem situations much, much faster than guardianship proceedings in similar situations.

C. Compliance with International Human Rights Norms Through Elder Law Mediation in Guardianship

As noted in section II(C), above, current guardianship systems face potential challenges based on rapidly evolving norms of international human rights.<sup>99</sup> Some of the most intense debates over the Committee's interpretation of the demands of the CRPD have focused on the risks and benefits of supported decision-making as compared to guardianship.<sup>100</sup> The CRPD, as interpreted by the Committee, requires that state parties replace guardianship systems with supported decision-making systems.<sup>101</sup>

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<sup>96</sup> Teresa W. Carns & Susan McKelvie, *Alaska's Adult Guardianship Mediation Project Evaluation*, ALASKA JUDICIAL COUNCIL 4 (2009), available at <http://www.ajc.state.ak.us/reports/adultguard.pdf>.

<sup>97</sup> Corbin, *supra* note 89; Fleming, *supra* note 89.

<sup>98</sup> Telephone conversation with Karen Largent, Mediation and Facilitation Services Manager, Alaska Court System & Project Coordinator, Alaska Guardianship Mediation Project (July 20, 2011) (notes on file with Author) [hereinafter Largent Telephone Conversation].

<sup>99</sup> When and if the CRPD is ratified by the U.S. Senate, it will become "... the supreme law of the land" under the United States Constitution, article VI, clause 2.

<sup>100</sup> See, e.g. Smith, *supra* note 22; Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?*, 117 PENN ST. L. REV. 1111, 1136-39, 1156 (2013) (concluding "there is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights").

<sup>101</sup> CRPD, *supra* note 27, at art. 4, art. 12.

The CRPD requires state parties to ensure that mentally disabled persons have access to support networks to help with their decision-making, and measures of oversight to protect disabled persons from coercion, undue influence and exploitation by their helpers and others.<sup>102</sup> Critics of the notion of supported decision-making have pointed out the risks of such informal systems and the difficulty in establishing effective systems for monitoring and protecting the rights and interests of the mentally disabled in supported decision-making.<sup>103</sup>

Elder law mediation provides a way to reconcile the demands of the CRPD and to uphold the disabled person's autonomy rights, while also providing protection against exploitation or undue influence. In elder law mediation, the values, goals and preferences of the disabled person are central to the process. No one in the elder law mediation process has the power to take away or trump the disabled person's right to make his or her own decisions. Elder law mediation anticipates the involvement of a network of supporters, potentially including family, friends, neighbors, health care providers, social service providers, etc. Elder law mediation also requires the involvement of a neutral professional, the elder law mediator, who has special training in how to ensure that disabled persons are participating on an equal basis in mediation discussions and that their voices are heard and respected. Elder law mediators are also trained to recognize and respond to maltreatment or exploitation of vulnerable adults. They provide a chance for oversight and quality control in the decision-making process, while preserving the flexibility and informality of the supported decision-making process.

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<sup>102</sup> *Id.* at art. 12, § 4.

<sup>103</sup> Kohn et al., *supra* note 100, at 56.

#### D. Examples of Elder Law Mediation Programs in Guardianship

There have been many attempts to institute or encourage elder law mediation in guardianship over the past twenty years. In guardianship mediation, “a legal finding of capacity or incapacity is not the issue. Rather, the issue may be whether there are ways that a person can reduce risks to health and safety within a context of dignified autonomy.”<sup>104</sup> The entity that has worked the longest and provided the most information about the process and results of elder law mediation is The Center for Social Gerontology (TCSG) in Ann Arbor, Michigan.<sup>105</sup> TCSG began studying issues related to elder guardianship in the 1970s.<sup>106</sup> TCSG researchers and policy advocates became convinced that the guardianship process itself, despite reforms, resulted in many negative consequences for elders and their family members.<sup>107</sup> Concerns about negative consequences associated with adversarial guardianship proceedings led TCSG to promote mediation as a valuable alternative to guardianship in many cases.<sup>108</sup> TCSG saw one of the primary values of elder law mediation in guardianship cases as a shift in focus.

Beginning in 1995, TCSG helped establish four pilot adult guardianship mediation projects, in Ohio, Florida, Wisconsin, and Oklahoma.<sup>109</sup> They provided training resources and materials and helped to design and promote the projects.<sup>110</sup> These projects were studied by TCSG researchers for over a two-year period.<sup>111</sup> While the results in terms of numbers of cases mediated and the ongoing

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<sup>104</sup> *Id.* at 7.

<sup>105</sup> Butterwick et al, *supra* note 6, at 4, 8 (indicating that their first guardianship mediation pilot began in 1991).

<sup>106</sup> *Id.* at 3.

<sup>107</sup> *Id.* at 3–4.

<sup>108</sup> *Id.* at 4–6.

<sup>109</sup> *Id.* at 8.

<sup>110</sup> *Id.* at 8–9.

<sup>111</sup> *Id.* at 12.



vitality of the projects were disappointing, the researchers were able to draw some interesting inferences from the data.<sup>112</sup>

The overall conclusion from the TCSG study was that, while elder law mediation in guardianship provided more positive experiences and outcomes in those cases that were mediated,<sup>113</sup> the barriers to long-term, significant guardianship mediation programs are substantial.<sup>114</sup> Of all the projects studied, only the two that were connected with and supported by the courts were still in operation by the end of the study.<sup>115</sup> The number of cases actually mediated, as a percentage of the total number of guardianship cases was extremely small, too small to support any statistically significant conclusions. The information that was collected did support TCSG's prediction that mediation can provide a superior way of resolving the issues that bring families and individuals into the guardianship system.<sup>116</sup> However, the study's results also indicated that the challenges to creating effective elder law mediation programs in the guardianship context are more substantial than the researchers anticipated.<sup>117</sup>

September of 2004, the Maryland Department of Aging, with support from TCSG, the ABA Commission on Law and

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<sup>112</sup> *Id.* at 12–18.

<sup>113</sup> *Id.* at 123.

<sup>114</sup> “Guardianship mediation programs . . . are likely to be small in scope (referrals to mediation are relatively rare), organizationally unstable (the programs are not well coordinated with the probate courts and their guardianship proceedings) and difficult to sustain over time (one of the community-based programs studied no longer exists, and another continues to operate more in theory than reality, with few referrals).” *Id.* at 125–41.

<sup>115</sup> *Id.* at 18.

<sup>116</sup> “Participants are well satisfied with the mediation process and its outcomes. In addition, participants, program administrators, and mediators believe the mediation in adult guardianship cases is effective in finding better or more satisfactory resolutions such as fewer guardianships, less restrictive orders, or limited rather than full guardianships.” *Id.* at 1.

<sup>117</sup> “[The study] confirmed that because many – including judges and attorneys – do not thoroughly understand guardianship mediation, much individual and group discussion and education would need to be done to assure that these groups are supportive and will refer cases.” *Id.* at 9.

Aging, AARP, and the Montgomery County Elder Mediation Project, started the Maryland Senior Mediation Project.<sup>118</sup> This project's scope went beyond providing opportunities for elder mediation in the context of guardianship proceedings. The project aimed to provide mediation resources in “. . . family caregiver planning and conflicts, contested guardianship disputes, housing, assisted living, nursing home conflicts, neighbor disputes and other matters involving older persons.”<sup>119</sup>

Those involved in the project felt strongly about the need for special training, knowledge and expertise for elder law mediators.

[T]he essence of high quality senior mediation requires a mediator to develop an understanding of aging, including an awareness of ageism and age discrimination. . . The mediator should be aware of any possible circumstances, including mental, physical, emotional, cognitive or other factors that any party may have, that may limit his or her ability to participate and seek to provide appropriate accommodations . . . The mediator should develop an adequate substantive understanding of the matters under consideration to assist the parties in developing the information they need to reach informed choices.<sup>120</sup>

The project provided the necessary training and support for elder law mediators, as well as outreach and publicity about the project to stakeholders and constituents.<sup>121</sup>

Robert Rhudy, one of the main organizers, supporters, and fundraisers for the project, on August 9, 2011, indicated that the

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<sup>118</sup> Robert J. Rhudy, *Senior Mediation Reaching the Tipping Point*, 41 Md. B.J. 12, 14–16 (2008).

<sup>119</sup> *Id.* at 13.

<sup>120</sup> *Id.* at 17.

<sup>121</sup> *Id.* at 17–18.

project, while it had had some significant successes, was no longer in operation.<sup>122</sup> When the initial leaders moved on to other work, the project petered out. Mr. Rhudy indicated that one of most significant barriers was the cost of mediation to the participants.<sup>123</sup> Many participants were unfamiliar with mediation and would not participate without a court order.<sup>124</sup> Courts were unwilling to order parties into mediation if they would be required to pay the elder law mediator, which is rather ironic, given the extremely high costs to respondents and wards in court proceedings in guardianship.<sup>125</sup> Mr. Rhudy also indicated the crucial importance of getting major participants in the aging services system, including adult protection units, to appreciate the value of elder law mediation.<sup>126</sup> He stated that the quality and training of the elder law mediator and of the attorneys involved is very important. He felt that it was crucial for the elder to be represented by counsel or by some qualified advocate. Out of the forty or so mediations that Mr. Rhudy recalled under the project, the success rate was about 80%. He believed that the results were superior to what would have been achieved through a guardianship proceeding, and the participants were less likely to return to court afterward.<sup>127</sup>

Perhaps the most successful guardianship mediation program was started in Alaska in 2005.<sup>128</sup> The program was initiated by the state courts and funded by the Alaska Mental Health Trust Authority.<sup>129</sup> The founders of the program worked with the support and guidance of TCSG, which helped with

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<sup>122</sup> Telephone Interview with Robert J. Rhudy, President, Senior Mediation and Decision-Making, Inc. (Aug. 9, 2011) (notes on file with Author).

<sup>123</sup> *Id.*

<sup>124</sup> *Id.*

<sup>125</sup> *Id.*

<sup>126</sup> *Id.*

<sup>127</sup> *Id.*

<sup>128</sup> Carns & McKelvie, *supra* note 96, at 6–7.

<sup>129</sup> *Id.* at 4.

defining the structure of the program and creating standards for training of the mediators.<sup>130</sup> The founders defined as the goal of the program:

to develop an approach to guardianship and conservatorship concerns using mediation to preserve the autonomy and dignity of these adults, while assisting and enabling family to resolve problems, which if left unresolved, could destroy the family and caregiver support system and result in the affected adult's loss of independence and rights, institutionalization, or in financial exploitation, neglect or abuse.<sup>131</sup>

The program is voluntary,<sup>132</sup> and there is no cost to participants.<sup>133</sup> Cases can be referred to the program by judges, court visitors, adult protection workers, or any party,<sup>134</sup> and are screened to determine whether they are appropriate for mediation.<sup>135</sup> Mediations are conducted by a panel of mediators specifically trained for elder law mediation,<sup>136</sup> who are paid by the program through funding provided by the state.<sup>137</sup>

A 2009 report assessing the program's outcomes published included data from 103 mediations that were conducted over the first four years of the program.<sup>138</sup> Around 9% of the total adult guardianship filings in Alaska were mediated over the course of

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<sup>130</sup> *Id.* at 14.

<sup>131</sup> *Id.* at 13.

<sup>132</sup> *Id.* at 3.

<sup>133</sup> *Id.* at 17.

<sup>134</sup> *Id.* at 16.

<sup>135</sup> "In general, cases appropriate for mediation were those in which parties could not agree on basic issues, including whether there should be a guardian, who the guardian should be, or what limitations should apply to the guardian's role." *Id.* at 5.

<sup>136</sup> "Mediation in adult guardianship issues is highly specialized and requires a variety of competencies." *Id.* at 15.

<sup>137</sup> *Id.* at 17.

<sup>138</sup> *Id.* at 1.

the study.<sup>139</sup> This is a rate and total number of guardianship elder law mediations that significantly exceed other guardianship mediation programs. Full or partial settlement was reached in 87% of all cases mediated, with 91% of participants reporting satisfaction with the process.<sup>140</sup> The average cost was \$1,380 per referral<sup>141</sup>—substantially less than the cost of even a simple, uncontested guardianship.<sup>142</sup> Typical mediations included the respondent/ward, family members, attorney or guardian ad litem for the respondent/ward, other attorneys, court visitor, guardian (if already appointed), caregivers, support people, and, in about half the cases, Adult Protective Services.<sup>143</sup>

All of the cases mediated in the program were referred to mediation after a guardianship petition was filed.<sup>144</sup> About half were referred shortly after the filing of a petition and before a court determination.<sup>145</sup> The rest were filed at some later point in the process, including a significant number filed after a guardian had been appointed.<sup>146</sup> “It was also contemplated that the project would serve pre-judicial filing cases in its later years, and although protocols have been developed involving Long Term Care Ombudsman and Adult Protective Services referrals, to date no such referrals have been made.”<sup>147</sup>

On July 20, 2011, I spoke at length with Karen Largent, the developer of the Alaska Guardianship Mediation Project and the

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<sup>139</sup> Out of 1210 total adult guardianship filings from 2005 to 2008, 113 cases were mediated. *Id.* at 1, 28.

<sup>140</sup> *Id.* at 1.

<sup>141</sup> *Id.* at 17.

<sup>142</sup> See *supra* note 91.

<sup>143</sup> *Id.* at 16.

<sup>144</sup> *Id.* at 14.

<sup>145</sup> *Id.* at 4.

<sup>146</sup> *Id.* at 4–5.

<sup>147</sup> *Id.* at 14.

current mediation and facilitation services manager for the Alaska court system.<sup>148</sup> Ms. Largent indicated that, at that point in time, the program continued to function well and noted the constant, ongoing need to continually reach out to stakeholders and to keep them informed about the program, its goals, and its benefits. She stated that in a court-connected program, there are fewer players who need to be kept in the information loop, and there are firmer and more regular connections with those players. The fact that the program is paid for by the state, and there are no out-of-pocket costs to participants is an important factor in the success of the program.

Ms. Largent spoke of the crucial importance of ongoing training and mentoring for elder law mediators in guardianship. She indicated that the mediators working with the program are among the most highly trained, experienced, and respected mediators in the state. She emphasized the importance of careful pre-mediation preparation in these cases. The mediator and all participants need to be prepared to address all the issues that are necessary to resolving the matter. They also need to be prepared to ensure that the elder's voice is heard, and the elder's needs remain central to the discussion.

Ms. Largent said that the program to that date had only involved post-petition mediations. She noted the benefits of giving people access to mediation before the point of petitioning for guardianship, but also indicated that there are significant risks to vulnerable elders, who may not be cognitively able to protect their own interests without assistance. The managers of the program wanted to find some way to ensure adequate advocacy on behalf of and protection of vulnerable elders in pre-petition mediations, but they had not yet come up with what they considered adequate safeguards. They were continuing to explore possible options, such as creating a pro bono elder law attorney panel to represent elders or training community mediators or long-term care

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<sup>148</sup> Largent Telephone Conversation, *supra* note 98.

ombudsmen to serve as advocates for vulnerable elders in pre-petition mediations.

Ms. Largent noted that, while most participants had been won over to the benefits of elder law mediation in guardianship, it was still not clear whether the program had directly saved money for the courts. The program was seen as valuable mostly because it produced better outcomes, not because it had reduced the costs to the state associated with guardianship proceedings. She noted that cases were carefully screened for referral to elder law mediation, and that probate judges were therefore able to concentrate their time and energy on those cases that required their attention. Other stakeholders—court visitors, adult protection workers, and public guardians—had seen an improvement in the outcomes of their work for vulnerable elders.<sup>149</sup>

The University of Windsor, in Ontario, Canada, began the Elder Mistreatment Mediation Project in 2007, in partnership with local non-profit agencies.<sup>150</sup> This program focused on community mediation of conflicts involving elder abuse and exploitation.<sup>151</sup> While not planned or marketed as a guardianship mediation program, the description of the service indicates that it dealt with cases that would be likely to end in guardianship proceedings, if the issues were not resolved. In this sense, this program is an example of what I have referred to as a pre-petition guardianship mediation program. This program relied on volunteer mediators,<sup>152</sup> who received special training in elder law mediation, including training about ageism, elder abuse, gerontology, Alzheimer's and dementia, wills and estates, legal meaning of

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<sup>149</sup> *Id.*

<sup>150</sup> Gemma Smyth, *Mediation in Cases of Elder Abuse and Mistreatment: The Case of University of Windsor Mediation Services*, 30 WINDSOR REV. OF LEGAL & SOC. ISSUES 121, 123–24 (2010).

<sup>151</sup> *Id.* at 132–33.

<sup>152</sup> *Id.* at 135.

capacity and consent, powers of attorney, ethics, and the mediator's professional identity and role in elder law mediation.<sup>153</sup>

In the pre-petition context, concerns about protecting the autonomy and rights of vulnerable elders in the mediation process loom particularly large. To deal with these concerns, the program screened potential elder participants for the ability to participate fully, either alone or with advocacy support.<sup>154</sup> The program offered elders both a citizen advocate and a social work advocate, to ensure that the elder is able to participate freely and fully in the mediation and that the elder has access to information about available resources to meet his or her needs.<sup>155</sup> This aspect of the program generated some concern and complaint from other parties, who felt that the provision of advocacy resources only to the elder implied bias on the part of the mediator and the program.<sup>156</sup>

The greatest challenge to the program was sustaining the high level of training demanded of the community mediators.

[T]he program was premised on thorough but accessible training in ageism, elder abuse, Power of Attorney, wills and estates, consent and capacity, gerontology, negotiation and mediation training, as well as inter-professional dialogue. Although the facilitative model does not necessarily require subject matter expertise, familiarity with these concepts – particularly concepts in gerontology and elder abuse – shaped the mediators' understanding of the "facts" of the dispute as well as the perspectives and lived experiences of older adults.<sup>157</sup>

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<sup>153</sup> *Id.* at 135–36.

<sup>154</sup> *Id.* at 137–38.

<sup>155</sup> *Id.* at 136.

<sup>156</sup> *Id.* at 139.

<sup>157</sup> *Id.* at 140–41.



*IV. A REPORT FROM PRACTITIONERS REGARDING  
ELDER LAW MEDIATION*

In order to gather more information about the attitudes of some key stakeholders in the guardianship system toward elder law mediation, one of my law students<sup>158</sup> and I conducted a survey of mediators, elder law attorneys and judges in several states. We sent emails to all members of the elder law sections and the alternative dispute resolution sections of Alaska, Florida, Hawaii, Maryland, Minnesota, New York, Oregon, Pennsylvania, and Tennessee, inviting them to complete a survey about their perceptions and experiences of elder law mediation.<sup>159</sup> We received a total of 74 completed surveys in response to our invitation. Approximately a third of the responses came from Oregon, a third from Florida, and a third from the six other states combined.<sup>160</sup>

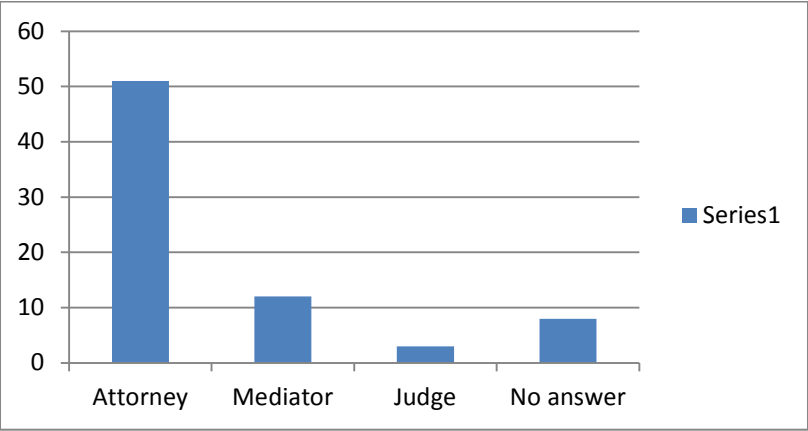
Two-thirds of those responding reported their primary profession as attorney, with the most of the rest working primarily as mediators.

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<sup>158</sup> Thanks to Jaclyn Fox, who did excellent work in drafting and disseminating the survey.

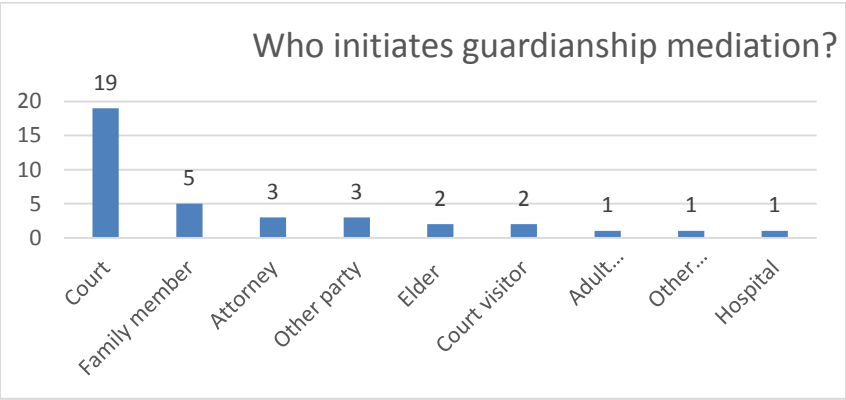
<sup>159</sup> Survey form is on file with the Author.

<sup>160</sup> We received no responses from Hawaii, but received two from attorneys who presumably were members of the Oregon bar, but practicing in Washington State, and one from an attorney practicing in California, who somehow received the invitation.

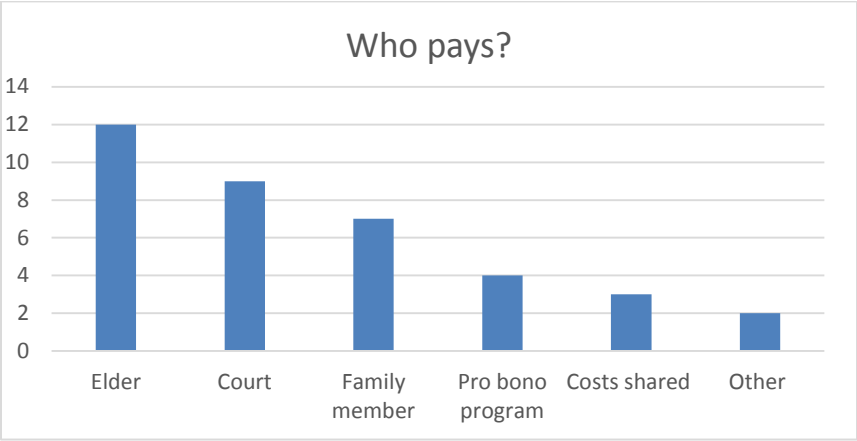


Over a third of those responding to the question about their role in guardianship mediation had never participated in elder guardianship mediation. By far the largest group of those who had participated in guardianship mediation had done so as attorneys, with nearly equal numbers representing petitioners and respondents. A smaller number had participated as mediators, and two had participated as judges. Some responders had participated in multiple guardianship mediations, with experience representing both petitioners and respondents.

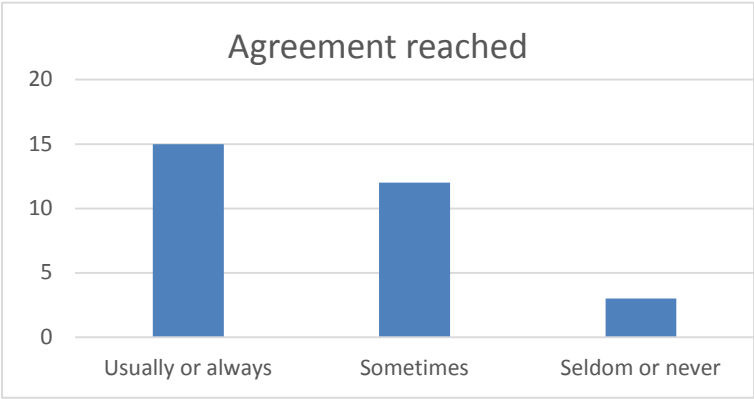
A majority of responders reported that elder guardianship mediations were usually initiated by the court.



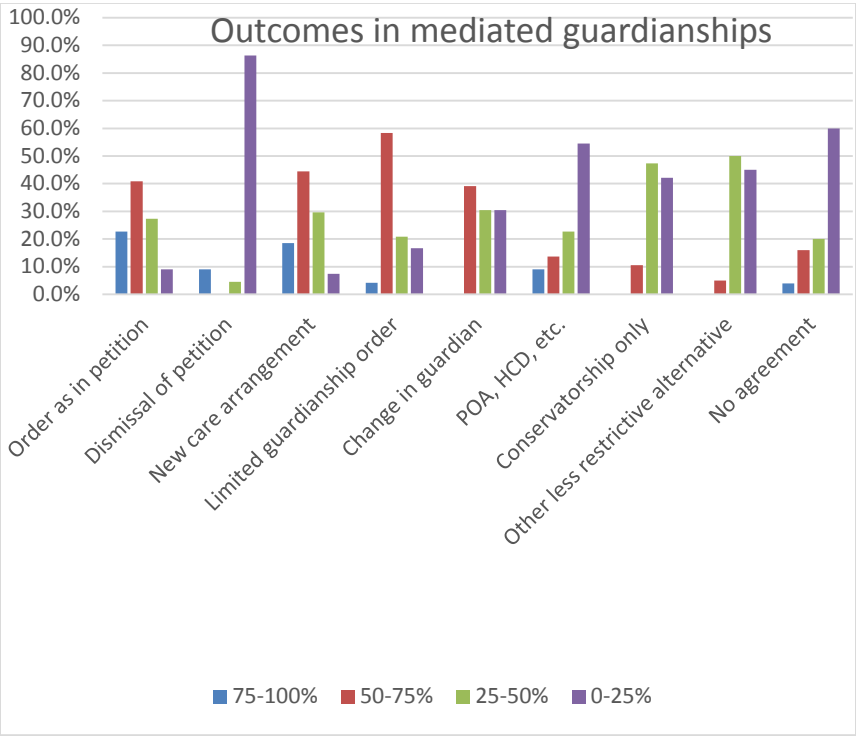
About a third of responders reported that the costs of elder guardianship mediation were borne by the elder.



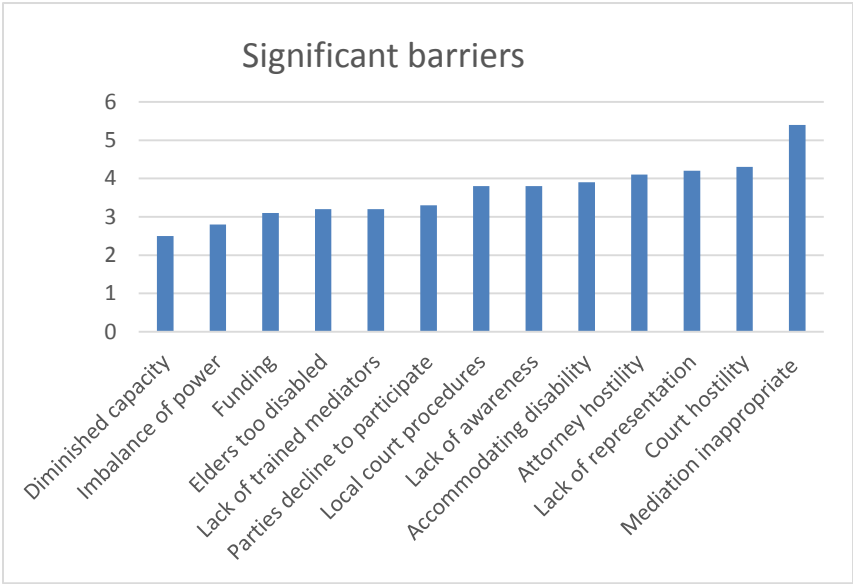
Half of responders reported that, in their experience, agreement was reached in elder guardianship mediations usually or always.



Responders reported that mediation in guardianship generally did result in agreement. The most common outcomes were an order of guardianship as requested in the guardianship petition, a change in the care arrangements for the elder, or a limited order of guardianship. Dismissal of the guardianship petition was reported as very unusual. Execution of other decision-making documents, appointment of a conservator only, or other less restrictive alternative to guardianship were also reported as fairly uncommon results of guardianship mediation. These findings lend support to the argument that, in most guardianship cases, there is a real need for decision-making authority, and that less intrusive alternatives generally are considered before a guardianship petition is filed.



When asked to rank potential barriers to elder law mediation in guardianship proceedings, responders ranked as most significant their own belief that mediation is generally inappropriate in guardianship. Interestingly, issues commonly cited by literature on guardianship mediation,<sup>161</sup> including issues related to the diminished capacity and/or inability of the elder to participate, an inherent imbalance of power between the parties, lack of funding, lack of trained elder law mediators, and difficulty in bringing parties to the mediation table were seen by responders as relatively less significant barriers.

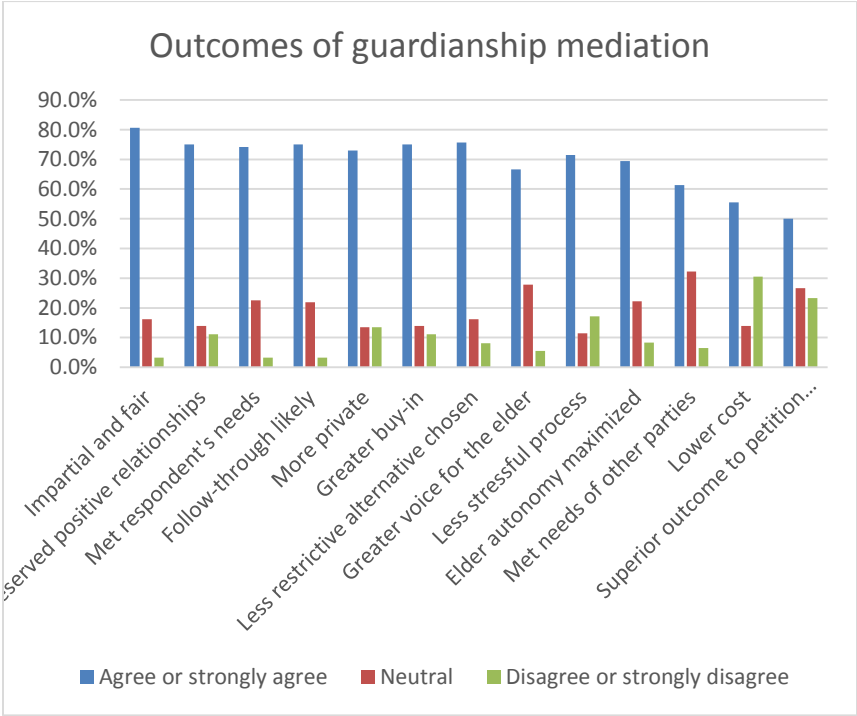


The responders to the survey were self-selected, choosing to respond to an inquiry directed to a broad group of practitioners. The sample size is small, limiting the significant conclusions that

<sup>161</sup> See *supra* note 67.

can be drawn from the data. This sample is certainly not representative of all elder law or ADR attorneys in the states included in the survey, or of all such attorneys who have participated in elder guardianship mediation. In addition, practices and experiences likely vary widely from state to state.

However, those members of the elder law and ADR sections in eight states who responded to the survey had a strongly positive reported experience of elder law mediation in guardianship. The majority of participants believed (75% or more) that the mediation process was impartial and fair, that it met respondents' needs, and that follow-through on mediated agreements was likely. A substantial majority (70% or more) concluded that, in comparison to guardianship outcomes in the courts, mediation in guardianship was more likely to preserve positive relationships among the parties, provided more privacy to the parties, led to less restrictive outcomes for the elder, was less stressful for the parties, and served to maximize elder autonomy. There was less consensus as to whether mediation in guardianship led to a superior outcome to that which was requested in the guardianship petition, resulted in lower costs to the parties, met the needs of parties other than the respondent/elder, and, interestingly, gave the elder greater voice in the proceeding.



V. *THE CHALLENGES AND REQUIREMENTS OF ELDER LAW MEDIATION*

An examination of the reported successes and failures of guardianship mediation yields some useful hypotheses about what is needed for a successful guardianship mediation program and some of the greatest challenges faced by such programs.

A. Getting People in the Door

One of the greatest challenges reported by elder mediation programs in the guardianship context is that it has proved difficult

to persuade stakeholders to participate.<sup>162</sup> One of the strongest findings of the 2001 TCSG study of pilot guardianship mediation programs was that “[g]uardianship mediation programs . . . are likely to be small in scope, . . . organizationally unstable, . . . and difficult to sustain over time.”<sup>163</sup> In that study, four pilot programs yielded a total of only 52 cases mediated during the study period, which ranged from 18 months to 5 years in the different locations.<sup>164</sup> The sample size was too small to allow the researchers to draw any significant conclusions.

A common experience in trying to establish a guardianship mediation program is that attorneys, court personnel, professional guardians, and social service and care providers are often unfamiliar and uncomfortable with elder law mediation. The presumptions, values, and processes of elder law mediation are often at odds with traditional understandings of guardianship system. Elder law mediation presumes that elder autonomy and the right to continue to be involved in decisions regarding major life issues are key components of elders’ well-being. The guardianship process assumes that autonomy is in conflict with protecting elders’ well-being, and a compromise must be made between the two.<sup>165</sup> Elder law mediation presumes that many elders can participate meaningfully in discussions and decision-making, despite cognitive impairments, provided they receive the necessary support and understanding of their needs. The guardianship process often serves to cut the impaired elder out of the decision-making process.<sup>166</sup> Elder law mediation assumes that there are potential creative solutions to the specific problems posed

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<sup>162</sup> This conclusion is not strongly supported by the survey data. However, it should be noted that the respondents in the survey were evaluating mediation only after the filing of a guardianship petition. See e.g. Butterwick et al., *supra* note 6, at 80 (noting the ratio of callers showing interest in mediation compared to the low numbers of actual mediations was either “because the initiator lost interest or the intake coordinator was unable to convince the other ‘respondent’ parties to try mediation.”).

<sup>163</sup> Butterwick, et. al, *supra* note 6, at 1.

<sup>164</sup> *Id.* at 19–112, 124.

<sup>165</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 356.

<sup>166</sup> *Id.* at 354 (noting that the current guardianship process allows us to “ignore the voice of the incapacitated ward at our peril”).



by a particular elder's declining capacity, as opposed to the one-size-fits-all solution of guardianship.<sup>167</sup> Elder law mediation also recognizes that a single solution will often not be possible to all the potential future problems that may arise from progressive decline. The process takes into account the likelihood of the need for future discussions to deal with newly arising problems. Guardianship seeks to impose a one-time solution to meet all future needs, and therefor often extends far beyond the needs of the moment.<sup>168</sup>

Some attorneys and parties fail to understand the value of mediating with a trained, skilled elder law mediator. They may see the process as just another attempt to talk through the problems, when many such attempts to resolve disagreements have failed in the past. Frequently, the best answer to such skepticism as to whether a qualified elder law mediator can really make a difference is an experience of the process. Many elder law attorneys have become sold on the value of elder law mediation through directly experiencing its ability to resolve difficult cases.<sup>169</sup>

Elders and their family members and friends may be reluctant to directly address the issues posed by declining capacity because of the embarrassment to the elder and the violation of familial relationship norms. They may resist facing the issues until a crisis erupts, at which point immediate action is needed, leaving no time for mediation. In order to encourage an earlier engagement in joint problem solving, elder law mediation needs to be

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<sup>167</sup> *Id.* at 356–66.

<sup>168</sup> *Id.* at 356 (stating that “[w]hile the problems of rapidly expanding caseload are and will be experienced in guardianship courts, the imposition of a guardian is seen as a solution with a relatively low cost to the court and a relatively low rate of “recidivism”).

<sup>169</sup> I myself was initially a somewhat reluctant convert to the advantages of elder law mediation. Fairly early in my career as an elder law attorney, I was surprised by some superior resolutions of difficult cases through elder law mediation. Since then, I have managed to convert several of my elder law colleagues through similar positive experiences.

normalized and made more salient to elders, their family members, counselors, and care-givers. The advantages of dealing with emerging problems early, before the range of possible resolutions narrows drastically, must be communicated more broadly.

### B. Issues of Cost

Despite the acknowledged high cost of guardianship proceedings, which is significantly higher than the cost of most mediations,<sup>170</sup> cost continues to be perceived as a significant barrier to elder law mediation in guardianship.<sup>171</sup> Guardianship statutes generally authorize the payment of court costs and attorney fees for all parties out of the estate of the respondent elder,<sup>172</sup> reducing the cost barrier to family members or friends who may petition for guardianship. If instead, a concerned family member initiates a mediation process to address these same concerns, the elder may not be willing to pay for mediation costs, requiring the family member to foot or share the bill. If court systems are to encourage elder law mediation as part of, or as an alternative to, the guardianship process, they will need to address concerns about costs of mediation. The most successful guardianship mediation program provided mediation services at no cost to participants.<sup>173</sup>

### C. Importance of Court Involvement

Both the survey and accounts of guardianship mediation successes and failures indicate the crucial importance of court support for, and involvement in, guardianship mediation programs. The court is a permanent and central player in the guardianship process. It alone has the power to require all other players to participate in elder law mediation. Of the established institutional players in the guardianship system, courts have the most direct incentives to make elder law mediation a viable alternative or

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<sup>170</sup> See, e.g. Smith, *supra* note 22; Kohn, et al., *Supported Decision-Making*, *supra* note 100. Interview with Adam Rohne, *supra* note 91.

<sup>171</sup> Although cost was not perceived as a substantial barrier by the attorneys, judges and mediators who participated in the survey. Survey attached as Appendix 1.

<sup>172</sup> See Unif. Probate Code § 5-417, *supra* note 90. See Minn. Stat. § 524.5-303 (d)(4), *supra* note 90.

<sup>173</sup> Largent Telephone Conversation, *supra* note 98.

complement to guardianship. By resolving disputes without court intervention, or by reducing the number of disputed issues requiring court involvement, elder law mediation offers the potential for significant savings in court time and resources. The courts can also direct public investment in the recruitment, retention, and training of qualified elder law mediators, and can establish standards for elder law mediator training and practice. Finally, the court can help to set and enforce normative standards that value and encourage the use of elder law mediation to achieve the goals of the guardianship system – protecting the rights and autonomy of persons with disabilities while enhancing their well-being and ensuring that their needs are met. Lack of court support for, or active court hostility to, elder law mediation in guardianship has been found to be a significant barrier to success.<sup>174</sup>

#### D.      Importance of Trained and Qualified Mediators

Currently, there are no legally obligatory standards for elder law mediators, either related to training and qualifications or to best practices. The Section on Elder Decision-Making and Conflict Resolution of the national Association for Conflict Resolution (ACR),<sup>175</sup> has published training objectives for elder law mediators.<sup>176</sup> These include training objectives for elder law mediation when there is no imminent appeal to guardianship proceedings and additional training objectives for mediations in which a guardianship petition has been, or is about to be, filed.

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<sup>174</sup> Survey attached as Appendix 1.

<sup>175</sup> The ACR is a “. . . national professional association for mediators, arbitrators, educators and other conflict resolution practitioners...” Assoc. for Conflict Resolution, *About Us*, [www.imis100us2.com](http://www.imis100us2.com), [http://www.imis100us2.com/acr/ACR/About\\_ACR/About\\_Us/ACR/About\\_ACR/About\\_US.aspx?hkey=c52a2d0d-d1c3-4279-a03a-b4b98db0ffe4](http://www.imis100us2.com/acr/ACR/About_ACR/About_Us/ACR/About_ACR/About_US.aspx?hkey=c52a2d0d-d1c3-4279-a03a-b4b98db0ffe4) (last visited July 24, 2014).

<sup>176</sup> Assoc. for Conflict Resolution, *Elder Care and Elder Family Decision-Making Mediation: Training Objectives and Commentary*, [WWW.SCRIBD.COM](http://www.scribd.com/doc/49354625/Elder-Care-and-Elder-Family-Decision-Making-Mediation-Training-Objectives-and-Commentary#fullscreen), <http://www.scribd.com/doc/49354625/Elder-Care-and-Elder-Family-Decision-Making-Mediation-Training-Objectives-and-Commentary#fullscreen> (July 30, 2012).

The ACR's training standards for non-guardianship elder law mediation encompass a wide range of topics, including the following:

- Understanding the complexities of the aging process;
- Recognizing and addressing stereotypes and biases associated with old age;
- Understanding how to recognize, understand, and remove the barriers to full participation by elders in the mediation process;
- Accommodating mental and physical disabilities;
- Understanding the elder abuse and the adult protection system;
- Awareness of the role and dynamics of families and other extended support networks in the lives of elders;
- Enough knowledge of legal issues, particularly issues related to government benefits, to recognize when to encourage participants to seek expert advice about such issues;
- Knowledge of community resources available to elders;
- Understanding ethical issues associated with elder law mediation; and
- Best practices for intake, pre-mediation preparation, and the mediation process itself.<sup>177</sup>

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<sup>177</sup> *Id.*

The ACR standards call for mediators to have basic mediation training and experience before embarking on training to become elder law mediators.<sup>178</sup> The committee that developed the training standards indicated that somewhere in the range of 40 hours of elder law mediation training would likely be needed to adequately address all the identified objectives.<sup>179</sup>

The ACR proposed additional standards for elder law mediators who are mediating in the context of ongoing or imminent guardianship proceedings. In addition to the substantial training described above, the ACR recommends advanced training in issues including:

- the guardianship law and procedure;
- working effectively with disabled and vulnerable adults to ensure that they are able to participate effectively in the mediation;
- specific ethical and legal issues that arise in the context of guardianship; and
- working effectively with courts and other institutional actors in the guardianship system.<sup>180</sup>

These training standards represent the pooled consideration and experience of many of the top elder law mediators in the United States. They are an important resource for encouraging proper training and skills on the part of elder law mediators. However, there is no requirement in any jurisdiction that, before beginning an elder law mediation practice, mediators participate in the kind of training described in the ACR standards. There is no

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<sup>178</sup> *Id.*

<sup>179</sup> *Id.*

<sup>180</sup> *Id.*

requirement that any mediator have any special training at all before acting as a neutral in an elder law setting.

It can very be difficult to find appropriate and accessible elder law mediation trainings, depending on the geographic location of the would-be elder law mediator. While excellent trainings are offered in some localities,<sup>181</sup> the cost of travel and accommodation, in addition to the registration costs for a multi-day training, can be prohibitive. Given the relative newness of the field of elder law mediation, there is a serious shortage of qualified, trained elder law mediators in many areas. There can be a chicken-and-egg problem, in that it may not be economically feasible for mediators to invest in lengthy and expensive training when there is limited demand for those skills, for all the reasons described in section V(A), above. In turn, it is difficult to build substantial demand for elder law mediation when there are very few qualified elder law mediators available. In order to overcome the reluctance of many individual and institutional actors to participate, elder law mediation must become more routine, mainstream, understood and accepted. So long as elder law mediation remains a rare and exceptional mode of resolving disputes that arise around elders' life situations, it will lack the conditions necessary to spur the broad growth of elder law mediation. At some point, this frustrating cycle must be broken.

While I applaud and deeply respect the work of the ACR's Section on Elder Decision-Making and Conflict Resolution, I would argue for some additional requirements for best practices for elder law mediators. Some of these requirements will be controversial among mediators. While the training objectives refer to understanding issues related to autonomy and well-being, elder law mediators, as well as all other institutional participants in elder

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<sup>181</sup> See e.g. Agreement Resources, LLC, *Elder/Adult Family Mediation Training*, [www.ELDERDECISIONS.COM](http://www.ELDERDECISIONS.COM), [http://www.elderdecisions.com/pg19.cfm?inf\\_contact\\_key=78e6c6c2a3b780e37ea740500ed6c49ba39a6c6120e3c2806566560b98173ac9](http://www.elderdecisions.com/pg19.cfm?inf_contact_key=78e6c6c2a3b780e37ea740500ed6c49ba39a6c6120e3c2806566560b98173ac9) (last visited July 28, 2014); ACR Section on Elder Decision-Making & Conflict Resolution, *List of Training Providers*, [WWW.ACRELDER.ORG](http://www.ACRELDER.ORG), <http://www.acrelder.org/useful-resources/training-providers/> (2014).

law mediation and/or guardianship, should be specifically educated in the psychological research indicating the crucial role that self-determination plays in human well-being.<sup>182</sup> For too long, guardianship systems, and indeed elder care and support systems in general, have been based on assumptions about the relationship between autonomy and well-being that are contrary to what psychological research tells us about human flourishing. The traditional mindset continues to see autonomy and well-being as frequently conflicting goals that need to be traded off and balanced against each other. In order to “first, do no harm,”<sup>183</sup> as guardianship must, in order to justify its massive invasion of otherwise strictly protected rights, guardianship systems and their institutional actors must pay close and constant attention to the data about how and under what circumstances human beings flourish. The data indicate that the benefits to elders’ well-being that are supposedly bought at the cost of limitations on elders’ autonomy are often imaginary, due in large part to the fact that autonomy and control of one’s own life are themselves essential components of human well-being. The cost of deprivation of autonomy is greater, and the benefit less, than the guardianship system has long assumed. These psychological facts must be instilled in institutional actors within the guardianship system, including elder law mediators. This information may not be known to individual participants (e.g., elders and their family members), and such ignorance may lead to unintended adverse consequences from a mediated settlement that fails to meet the elder’s need for autonomy.

Secondly, I would advocate for a role somewhat outside the usual norms for a mediator in elder law mediation. One of the

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<sup>182</sup> Wright, *Guardianship for Your Own Good*, *supra* note 1, at 358, 366.

<sup>183</sup> CM Smith, *Origin and Uses of Primum Non Nocere—Above All, Do No Harm!*, 45 J. CLIN. PHARMACOL. 371, 371–77 (2005).

nearly universally accepted maxims of mediation is that a mediator must be neutral. Indeed, mediators are often referred to as “neutrals.” On the other hand, many mediators and writers acknowledge that mediators may uphold or defend certain goals or values without necessarily compromising their duty of neutrality. For example, many mediators would welcome a mediator who encouraged and upheld norms of civil discussion in mediation (although some mediators would reject such a position as improper).<sup>184</sup> Many mediators take a position of encouraging the resolution of disputes (although some reject this position as improper as well). In custody mediations, most mediators will remind both parties of the importance of considering the interests of the children in the mediation. All of these departures from absolute neutrality (which I personally believe is not possible, let alone helpful, but then I am a lawyer, not a mediator) have a common aspect. In these instances, mediators maintain neutrality as to the specific positions of the parties and specific content of a mediated agreement. However, they encourage certain norms of dispute resolution, which are commonly (although not universally) shared by participants in mediation—the desires for productive and civil discussion, for arriving at a mutually acceptable resolution, and for maintaining a focus on shared values and goals of the parties.

Elder law mediation in guardianship poses risks to the elder. Some have concluded that these risks are serious enough that elder law mediation is an inappropriate means of dealing with guardianship issues.<sup>185</sup> Elder law mediation is a possible way to fill the gap between private resolution of disagreements over the life choices of elders, which may result in undue influence, coercion, exploitation, and/or abuse of vulnerable elders, and the formal guardianship process, which can be overly rigid, costly, and

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<sup>184</sup> In my experience, one can find some mediator who will disagree with almost anything one can say about mediation. The art and science of mediation is not reducible to any unanimously accepted framework. See Stephen K. Erickson & Marilyn S. McKnight, *THE PRACTITIONER'S GUIDE TO MEDIATION: A CLIENT-CENTERED APPROACH*, 1–23 (2001) (noting that “there are different models of mediation . . .”).

<sup>185</sup> Survey attached as Appendix 1.



extreme in its outcome.<sup>186</sup> Elder law mediators provide a professional perspective and influence on an otherwise private ordering of elders' lives, which could serve to foster informal supported decision-making while preventing many of the possible abuses of such a system. In order to play this salutary role, elder law mediators in guardianship should have a duty to make sure that the elder's well-being and voice are given a privileged position in the mediation. The elder law mediator should maintain positional neutrality among possible outcomes, while upholding the duty of all parties to respect and protect the rights and well-being of the elder. This duty is shared by all parties and actors in the guardianship system, which is designed to protect the well-being of the impaired elder. While the interests and concerns of other parties can be more thoroughly explored and considered in the mediation process than in the courtroom, the interests and concerns of the elder, whose life, after all, is at stake, should remain primary. The properly trained elder law mediator can act to ensure that the elders and their desires, values, and well-being remain central to the mediation discussion.

## *VI. CONCLUSION: PUTTING ELDER LAW MEDIATION INTO PRACTICE*

If elder law mediation can, as argued above, play an invaluable role in helping guardianship to achieve the goals for which it exists, then we need to look for ways to overcome the barriers which have hindered the development of guardianship mediation programs. The first crucial step is to gather and share information about elder law mediation, its promise, its risks, and its availability. There is a growing network of elder law mediators across the country, many of which are members of the ACR Section on Elder Decision-making and Conflict Resolution.

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<sup>186</sup> See discussion in section II(B) above.

Mediate.com is a website providing a broad array of articles by elder law mediators. There are many websites advertising the services of local elder law mediators. What is required is some way to bring this information to the attention of the general public and of other institutional actors in the guardianship process—especially courts, attorneys, adult protection programs, care providers, and case managers. Grant funding could provide the resources for a public service information campaign about elder law mediation. Targeted continuing professional education modules could reach specific institutional audiences. Once people are aware of the existence and potential benefits of elder law mediation, demand for elder law mediators will increase, making it economically feasible for more mediators to get elder law mediation training. Elder law mediation has stood at a tipping point for far too long, in which its relative public obscurity has been a barrier to its growth and success. The time is ripe to make a strong, broad-based push to overcome that obscurity and set a virtuous cycle in motion.

Secondly, mediators must understand the unique demands of elder law mediation. There is a significant risk of mediators trying to expand their practices into what is seen as a growth field without comprehending the challenges and the extensive additional training required. Once mediators understand the need for elder law mediation training, increased demand for such training will result in the training being made locally available, which will reduce the cost of such training significantly. Trained elder law mediators have a direct incentive to continue to publicize the availability and importance of working with a qualified elder law mediator.

Thirdly, elder law attorneys who represent petitioners and respondents in guardianship, and who counsel elders and their families in areas including advance planning for incapacity, health care, long-term care, and elder abuse and exploitation, must become comfortable with the use of elder law mediation to resolve disputes over elders' life decisions. Attorney resistance to elder law mediation has several roots. Some attorneys are uncomfortable

with what they perceive as a loss of attorney control in mediation generally. They fear that their clients will be brought to agree to an outcome that does not meet their full needs. These attorneys need to be educated about the voluntary and non-coercive process of mediation—preferably by experiencing it first hand, but also through continuing legal education. Some attorneys feel that they are unnecessary or irrelevant in the mediation process. Attorneys can make two big mistakes in mediation. One is to continue to act like a litigator, disrupting and subverting the process of discussing values and concerns in a non-adversarial setting in an attempt to find a resolution that meets the needs of all parties. The other is to sit like a bump on a log and take no part in making sure that the attorney's client's voice is being heard, that the concerns the client has expressed to the attorney are being taken into account, and that barriers to discussion and agreement are identified and addressed. There should be an increase in educational and training opportunities for attorneys to learn how to represent clients in mediation, particularly in elder law mediation. Some attorneys who share a mindset that guardianship is the best possible way to provide for the well-being of impaired elders will need to be educated in the significant harm that guardianship can cause and the benefits of alternatives that preserve elders' autonomy. Finally, some attorneys may have a shortsighted fear that greater use of elder law mediation will reduce the fees that they can earn in guardianship proceedings. I expect that the huge increase in the numbers of impaired elders will provide plenty of opportunities for gainful employment for attorneys in the future.

Fourthly, the essential role of the courts in increasing the use of elder law mediation in guardianship cannot be overstated. Dramatic changes in attitudes and in the habitual mode of functioning of a system generally require strong support from the top leadership. Within the legal system, the courts are the top

leaders. The court is the one institutional actor that is always involved in the guardianship system. The courts are the only players who have the power to require parties to participate in elder law mediation. They also have strong persuasive power over parties. Courts must be convinced that elder law mediation can provide impaired elders with adequate protection from exploitation and maltreatment, can create durable and effective resolutions to guardianship disputes, and can save court time and resources. The successful experience of the Alaska Guardianship Mediation Project should provide an excellent model for other courts to follow and should reduce judges' concerns about elder law mediation in guardianship.<sup>187</sup>

Finally, and most importantly, in order for elder law mediation in guardianship to meet its potential to improve the lives of impaired elders, official standards for training and qualifications of elder law mediators and for best practices in conducting elder law mediations must be established and enforced. Private professional bodies can help by establishing norms and requirements for their members to participate in elder law mediation. The market can encourage elders and their families to seek out elder law mediators who meet these standards. However, there is no completely adequate substitute for legally established and enforced standards, at least for mediation in cases in which a guardianship petition has been filed. The promulgation of official standards is a long way off and elder law mediation in guardianship will likely continue to grow for some time in a more informal, unregulated way. I look forward to the day when elder law mediation finally fulfills its potential to become the primary means of ensuring that our impaired elders' needs for care and assistance are met.

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<sup>187</sup> Carns & McKelvie, *supra* note 96; *see also* Largent Telephone Conversation, *supra* note 98.

# CONTINUING POWER OF ATTORNEY AND TRUSTS

*Makoto Arai*<sup>†</sup>

## *I. THE SIGNIFICANCE OF CONTINUING POWER OF ATTORNEY*

In December 1999, the following acts were established in Japan: the Act for Partial Revision of the Civil Code,<sup>1</sup> the Act on Voluntary Guardianship Contract,<sup>2</sup> the Act on Coordination, etc. of Related Acts in Line with Enforcement of the Act for Partial Revision of the Civil Code,<sup>3</sup> and the Act of Guardianship Registration.<sup>4</sup> These four laws are collectively referred to as the “Adult Guardianship Laws,” but it is the Act on Voluntary Guardianship Contract (hereinafter “the Continuing Power of Attorney Law”) that I find the most noteworthy. My interest stems from the fact that the law was created as a result of the legislation of the continuing power of attorney system, which has hitherto been disregarded in Japan.<sup>5</sup>

The Adult Guardianship Law consists of two types of entities: continuing power of attorney and statutory guardianship. Continuing power of attorney can be described as a sort of advance directive system, in which the ward makes clear, prior to becoming incapacitated, their wishes regarding their care, management of their assets, and any instructions for guardians to act accordingly.<sup>6</sup>

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<sup>1</sup> Act for the Partial Revision of the Civil Code, Act No. 149 of 1999.

<sup>2</sup> Act on Voluntary Guardianship Contract, Act No. 150 of 1999.

<sup>3</sup> Act on Coordination, Act No. 151 of 1999.

<sup>4</sup> Act of Guardianship Registration, Act No. 152 of 1999.

<sup>5</sup> MAKOTO ARAI, SHINTAKUHO (TRUST LAW) 518 (2014).

<sup>6</sup> *Id.*

Statutory guardianship, on the other hand, is an ex-post facto system, in which, if a person becomes incapacitated before they have made clear their wishes about how they want their assets managed and how they want to be cared for, the guardians then act paternalistically but not according to the wishes of the ward.<sup>7</sup> In recent years there has been a growing acknowledgement that it is desirable to respect a ward's right to self-determination as much as possible. From this perspective, continuing power of attorney (voluntary guardianship) is given precedence over statutory guardianship. This is the principle of precedence of continuing power of attorney, and because of this, statutory guardianship is only granted as a supplement. I thoroughly support the principle of precedence of continuing power of attorney, because it attributes more respect to the right to self-determination.

Incidentally, it is possible to confer trusts with continuing power of attorney-like functions. What is the relationship between the continuing power of attorney system that was legally established by the Continuing Power of Attorney Law and trusts, which are possible to use in a continuing power of attorney-like system? This article will discuss their relations and make recommendations concerning new methods for utilizing trusts in Japan.

## II. *THE CONTINUING POWER OF ATTORNEY MECHANISM*

The continuing power of attorney system pursuant to the Continuing Power of Attorney Law is a new scheme under the Adult Guardianship Law based on the voluntary agent system, which is accompanied by the supervision of an official body.<sup>8</sup> In

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<sup>7</sup> *Id.*

<sup>8</sup> MAKOTO ARAI, KOREI SHAKAI NO SEINEN KOKEN HO (ADULT GUARDIANSHIP LAWS IN AN AGING SOCIETY) 176-77 (1999).

the following paragraphs I will explain the basic characteristics of this system.

The focus of the revision to the adult guardianship system was to respect an individual's right of self-determination and establish an easily usable system that would enable flexible responses to the varied judgmental capabilities of each principal and the extent of protection they will require.<sup>9</sup> The system of continuing power of attorney (voluntary guardianship) operates by the authority of voluntary representation, which is established by creating a voluntary guardianship contract based on the wishes of the parties concerned. This system respects an individual's right to self-determination. If the concept of the right to self-determination is the keystone of the continuing power of attorney system, then the system should be designed with the goal of securing one's maximum individual autonomy.

At the same time, in comparison to the statutory guardianship system, the continuing power of attorney system, the mode of supervision by the courts, should be limited to an indirect format. While statutory guardianship is conducted under the direct supervision of the courts, the supervision of continuing power of attorney—which pays due respect to self-determination—can only be indirectly conducted by the courts. This allows the creation of a systematic framework for the protection of the principal in accordance with the individual purport of the contract and the principal's wishes. In order to protect the principal and prevent misuse of the powers of the attorney guardian, a public body based supervisory system that functions after the principal's judgmental faculties have weakened should be created.

It is worth noting that in comparative law, similar continuing power of attorney systems that involve the supervision

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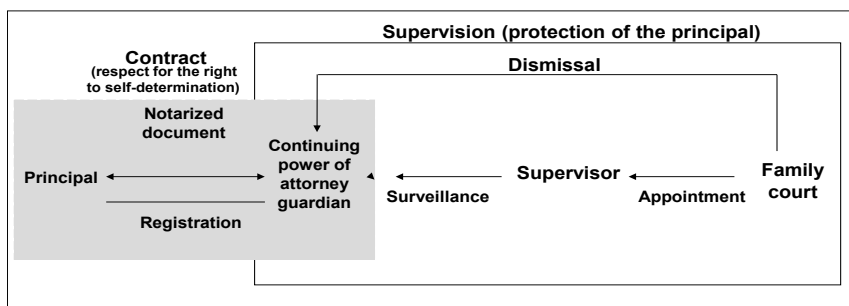
<sup>9</sup> ARAI, *supra* note 5, at 519.

of public bodies can be traced back to enduring power of attorney systems recently introduced in nations under British and American legal systems, most particularly the Enduring Powers of Attorney Act that came into force in the United Kingdom on March 6, 1986.<sup>10</sup>

The basic framework of the Japanese continuing power of attorney system under the Continuing Power of Attorney Law consists of the following two points: 1) the continuing power of attorney contract created by the principal and the attorney guardian; and 2) a supervisory system in which a supervisor is selected by a family court.<sup>11</sup> This was established to systematically prevent misuse of the powers of the attorney guardian according to the continuing power of attorney contract. Since the parties, particularly the principal, decide for themselves the scope of the continuing power of attorney through the contract, the maximum respect for the right to self-determination is assured (refer to the shaded part of Fig. 1 below), while at the same time the appointment of a supervisor by a family court achieves a reconciliation with the protection of the principal (refer to dotted lines in Fig. 1 below).

Figure 1

Fundamental structure of the continuing power of attorney system



<sup>10</sup> ARAI, *supra* note 8, at 9–17, 50–82.

<sup>11</sup> ARAI, *supra* note 5, at 520.



Because the continuing power of attorney contract is a commission contract granting an agent rights, the duties of the attorney guardian are restricted to legal activities. However, an attorney guardian's legal activities are not limited to asset management. Their appropriate scope may also include acts for the personal affairs of the principal, such as negotiating medical or nursing contracts, housing contracts, contracts regarding entering or leaving care facilities, and contracts regarding education and rehabilitation.<sup>12</sup>

Additionally, if an attorney guardian uses their agent right regarding legal actions related to personal affairs, their actions will be interpreted by the Duty of Care of Mandatary, an article of the Japanese Civil Code.<sup>13</sup> A mandatary has a "duty to administer the mandated business with the care of a good manager"<sup>14</sup> and an obligation to consider the physical wellbeing of the principal.<sup>15</sup> A mandatary is the party entrusted in the content of mandate. Under Japanese law an agent may also be regarded as a mandatary. Additionally, Article 6 of the Act on Voluntary Guardianship Contract stipulates that "in the course of fulfilling the business commissioned to him the attorney guardian shall respect the wishes of the principal, and must pay due consideration to the principal's physical and mental state and the conditions of their life."<sup>16</sup>

Because there is a need for coordination within the statutory guardianship system, when requests for statutory guardianship are screened, it must be determined whether or not a

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<sup>12</sup> *Id.*

<sup>13</sup> Article 644 of the Japanese Civil Code stipulates that "[a] mandatary shall assume a duty to administer the mandated business with the care of a good manager compliance with the main purport of the mandate." Duty of Care of Mandatary, Act No. 89 of 1896, art. 644.

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> Voluntary Guardianship Contract, Act No. 150 of 1999, art. 6 (stipulating what is referred to as the obligation of respect for the intentions and personal considerations of the adult ward. This is a compulsory stipulation.).

continuing power of attorney contract has been created.<sup>17</sup> This is why the continuing power of attorney contract registration system was established.<sup>18</sup> Furthermore, a continuing power of attorney contract is regarded as being a formal action requiring the preparation of notarized deeds.<sup>19</sup> Subsequently, it is possible to

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<sup>17</sup> Voluntary Guardianship Contract, Act No. 150 of 1999, art. 4. This article 4 stipulates “[w]hen a Voluntary Guardianship Contract has been registered, in the event that impairment of the mental capacities renders the principal insufficiently able to appreciate his or her own situation, then on the request of the principal, the spouse, a relative within the fourth degree of relationship, or a mandatary of voluntary guardianship, the the family court will appoint a voluntary guardianship supervisor. However, this shall not apply in the following cases.

(i) When the principal is a minor.

(ii) When the principal is an adult ward, a person under curatorship, or a person under assistance, and continuation of the guardianship, curatorship, or assistance relating to the principal is recognized to be especially necessary for the interests of the principal.

(iii) When the mandatary of voluntary guardianship is one of the following.

a. A person enumerated in the items (excepting Item (4)) of Article 847 of the Civil Code (Act No. 89 of 1896).

b. A person who is engaging or has engaged in litigation against the principal, and the spouse or a lineal relative by consanguinity of such a person.

c. A person who has engaged in an unlawful act or grave misconduct, or for whom there is other such reason that the person is not suitable for duty as a voluntary guardian.

(2) In the event that a voluntary guardianship supervisor is to be appointed according to the provisions of the preceding paragraph, when the principal is an adult ward, a person under curatorship, or a person under assistance, then the family court will make a ruling on the commencement of guardianship, the commencement of curatorship, or the commencement of assistance relating to the principal must therefore be rescinded.

(3) In order to appoint a voluntary guardianship supervisor at the request of a person other than the principal according to the provision of Paragraph 1, the consent of the principal must be obtained in advance. This shall not apply, however, when the principal is unable to declare his or her own intention in this regard.

(4) In the event that there is a vacancy in the position of voluntary guardianship supervisor, then the family court may appoint a voluntary guardianship supervisor at the request of the principal, a relative of the principal, or the voluntary guardian, or by its own authority.

(5) Even when a voluntary guardianship supervisor has been appointed, the family court may, when it recognizes the necessity, appoint a new voluntary guardianship supervisor at the request of a party enumerated in the preceding paragraph or by its own authority.”

*Id.*

<sup>18</sup> Guardianship Registration, Act No. 152 of 1999, art. 1.

<sup>19</sup> Voluntary Guardianship Contract, Act No. 150 of 1999, art. 3.

compel a notary to tender a registration in accordance with the requests of the registration body with regard to all continuing power of attorney contracts.<sup>20</sup>

The Continuing Power of Attorney Law is a special law of Japan's Civil Code. There are three reasons for this. First, as the continuing power of attorney system confers public supervision on the agent's contract of mandate, conceptually, it is a system that introduces principles that are different from the private autonomy principles in the Civil Code. Further, because the continuing power of attorney system creates a special mandate for agents, stipulates a

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<sup>20</sup> Guardianship Registration, Act No. 152 of 1999, art. 5. Article 5 of the Act on Guardianship Registration provides

“Registration of a Voluntary Guardianship Contract shall be made, upon commission or application, by recording the following particulars in a file of Guardianship Registration, etc.:

- (i) The name and office of the notary who created the notarial deed regarding the Voluntary
- (ii) Guardianship Contract, as well as the number and date of creation of the notarial deed.
- (iii) The name, date of birth, address, and registered domicile (in the case of a foreign national, the nationality) of the mandator under the Voluntary Guardianship Contract (hereafter referred to as the "Principal of the Voluntary Guardianship Contract").
- (iv) The name and address (for a corporation, the name or trade name and the main office or principal place of business) of the mandator of voluntary guardianship or of the voluntary guardian.
- (v) The scope of the authority of representation of the mandator of voluntary guardianship or of the voluntary guardian.
- (vi) If it is provided that two or more voluntary guardians should exercise authority jointly, a statement of that provision.
- (vii) If a voluntary guardianship supervisor is appointed, the name and address (for a corporation, the name or trade name and the main office or principal place of business) of that supervisor, as well as the date on which the ruling of appointment thereof became final and binding
- (viii) If it is provided that two or more voluntary guardianship supervisors should exercise authority jointly or by assuming the affairs assigned to them separately, a statement of that provision.
- (ix) When the Voluntary Guardianship Contract has terminated, the grounds for and date of the termination.
- (x) Of particulars relating to provisional orders, those particulars that are stipulated by Cabinet Order.
- (xi) The registration number.”

mechanism based on the statutory guardianship supervisor, and eliminates decisions to begin statutory guardianship within a certain scope, it requires the creation of many stipulations regarding ability, agents, mandates and guardianship in the Civil Code, and therefore it is difficult to stipulate these within the specific confines of the Civil Code. Finally, rather than scattering stipulations across the various editions and chapters of the Civil Code, it makes it easier for the public to understand if the stipulations are made on an all-embracing flow of temporal procedures.<sup>21</sup>

Through the use of the aforementioned continuing power of attorney system, one is able, while one still has one's mental capacities, to make decisions about the details of guardianship (asset management and livelihood supervision) in the event that one's mental capacities are impaired. There have been previous discussions about the possibility of endowing the current legal systems for agents and trusts with the alternative role of continuing power of attorney.<sup>22</sup> The Continuing Power of Attorney Law can be described as an epoch-making law that was created to enshrine the continuing power of attorney system, and also as a special provision of the Civil Code under a special act.

### *III. COLLABORATION BETWEEN TRUSTS AND CONTINUING POWER OF ATTORNEY*

Trusts are a sustainable system, providing the settlor establishes a trust while they still have full mental capacity. Therefore, while trusts are a system based on personal autonomy, they can serve as an alternative system to continuing power of attorney.

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<sup>21</sup> ARAI, *supra* note 5, at 521.

<sup>22</sup> *Id.*

Once the settlor establishes the purpose of the commission and commissions the settlor with the management of their assets, the trust system enables the trustee to continue to manage the assets on the beneficiary's behalf in accordance with the commission's objective, even in the event that the settlor loses their mental capacity or if they have to be cared for until death. It is also possible for a competent settlor to establish a third party benefit trust for a beneficiary who has lost their mental capacity or lacks competence.<sup>23</sup>

Under the old Trust Act<sup>24</sup> the settlor and beneficiary had a protected status, and there was a beneficiary protection mechanism to ensure that the trustee could not misuse their rights of management and disposal.<sup>25</sup> This mechanism was useful in situations in which it was not possible to supervise the trustee.<sup>26</sup> The old Trust Act also strictly stated obligations, including a duty to administer the trust business "with the care of a good manager in compliance with the tenor and purport of the trust,"<sup>27</sup> the prohibition of turning the trust assets into his or her own assets,<sup>28</sup> the obligation to separately manage his or her own assets and trust assets,<sup>29</sup> the obligation of self-execution of trust business,<sup>30</sup> and the obligation of compensation in the event of losses due to violation of the trust.<sup>31</sup>

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<sup>23</sup> *Id.* at 522.

<sup>24</sup> Trust Law of 1922, Law No. 62 of 1922.

<sup>25</sup> ARAI, *supra* note 5, at 522.

<sup>26</sup> *Id.*

<sup>27</sup> Trust Law of 1922, Law No. 62 of 1922, art. 20.

<sup>28</sup> *Id.* at art. 22.

<sup>29</sup> *Id.* at art. 28.

<sup>30</sup> *Id.* at art. 26.

<sup>31</sup> Article 27 of the Old Trust Act provides that

In cases where the trustee has inflicted losses upon the trust property through mismanagement, or disposed of the trust property in violation of the tenor and purport of the trust, the settlor, his or her heir, the beneficiary, and other trustees may demand of the trustee indemnification of losses or restitution of the trust property.

*Id.* at art. 27. In addition, Article 29 of the Old Trust Act provides

The provisions of Article 27 shall apply mutatis mutandis in cases where the trustee has administered the trust property in violation of the provisions of the

The old Trust Act also made clear the wide-ranging involvement of juridical courts.<sup>32</sup> Because there was a mechanism to prevent a trustee from misusing their rights, it was possible for the settlor's wishes (the trust's objective) to be sustained even after they had lost capacity. In British and American law there are places under statutory law in which functions similar to the statutory agent system exist, and have previously been described as the 'resolution freezing functions' of trusts.<sup>33</sup>

However, under the New Trust Act<sup>34</sup> the obligations of trustees are much less restricted, and the stipulation concerning the right of courts of general supervision<sup>35</sup> has been abolished.<sup>36</sup> In the other asset management systems based mainly on the keystone of personal autonomy, the degree of involvement of the courts is small or negligible, but in the case of trusts, the system in place under the old Trust Act (a system in which, after the establishment of the trust relationship, the trustees themselves disengage from the trust relationship and as a result, the ordinary interests of the beneficiary are defended through the public involvement of the courts and the trustee is regulated) has now vanished.<sup>37</sup> The new Trust Act does not maintain this system, and in order to protect beneficiaries who have lost mental capacity, it will be necessary to collaborate with the continuing power of attorney system, which enjoys this resolution freezing function.<sup>38</sup>

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preceding Article. 2. In the case mentioned in the preceding paragraph, if losses have been inflicted upon the trust property, the trustee shall not be relieved of his or her responsibility by reason of causes beyond his or her control, unless it is proved that the losses should have been inflicted even if it were separately administered.

*Id.* at art. 29.

<sup>32</sup> *Id.* at art. 23.

<sup>33</sup> ARAI, *supra* note 5, at 522.

<sup>34</sup> Trust Law of 2006, Law No. 108 of 2006.

<sup>35</sup> Trust Law of 1922, Law No. 62 of 1922, art. 41.

<sup>36</sup> ARAI, *supra* note 5, at 522.

<sup>37</sup> *Id.* at 523.

<sup>38</sup> *Id.*

Moreover, trusts are designed to manage assets, not to protect the livelihoods of people.<sup>39</sup> In this sense they resemble the United Kingdom's Enduring Powers of Attorney Act, which concentrates solely on asset management.<sup>40</sup> Under that law, whenever there is even a hint of livelihood protection its application is refused.<sup>41</sup> In other words, the United Kingdom's Enduring Powers of Attorney Act deals solely and exclusively with asset management. With regard to elderly or disabled people who request both asset management and livelihood protection, collaboration between trusts and the continuing power of attorney is required.<sup>42</sup>

In British and American law, however, trust laws have a function similar to that of the statutory agent system under German and other continental law, in which the trust (*Treuhand*) has not developed to the same extent, and the usual practice is to use a statutory agent rather than asset management in trust for people of insufficient capacity. In these two nations, in order to further enrich the continuing power of attorney-like functions in the trust business, enthusiastic use has been made of trusts, including the twin features of discretionary trust and power of appointment.<sup>43</sup> These are linked with estate planning and are regarded as the most advanced contemporary formats for trusts.<sup>44</sup>

Whereas fixed trusts in British and American law establish beforehand, through a trust deed, who the beneficiary is and what benefits the beneficiary should receive, however, trusts involving discretionary trust and power of appointment do not establish beforehand the beneficiary or what they should receive.<sup>45</sup> Instead,

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<sup>39</sup> *Id.*

<sup>40</sup> *Id.*

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*

<sup>43</sup> *Id.*

<sup>44</sup> *Id.*

<sup>45</sup> *Id.* at 524.

the beneficiary and the benefits they should receive is established for the first time when the trustee's right of discretion is used in the case of a discretionary trust, and in the case of power of appointment, when the person with the power of appointment uses the power of appointment.<sup>46</sup>

For the remainder of this article, I would like to focus on my arguments on discretionary trusts. The discretionary rights in discretionary trusts and the rights in power of appointment are quite different in terms of both their historical backgrounds and jurisprudence. As it is not possible to detail the differences here, I solely wish to discuss the discretionary rights in discretionary trusts. This is because the power of appointment and discretionary rights have virtually the same functions, and Japanese legal professionals will more easily understand discretionary rights.

The central question is whether or not Japan can, under its Trust Law, accept discretionary trusts, which are a system peculiar to common law with the exercising of discretionary right by the trustee. My position has been that it would be feasible to accept discretionary trusts under the old Trust Act. From that stance, I have previously written as follows:

This trustees' function allows the trustee to exercise the discretionary right to specify the beneficiary who will actually benefit from among the candidate beneficiaries nominated by the settlor. In this way it is possible to select the beneficiary who is most suited to the objectives of the trust, adequately catering for the circumstances after the creation of the trust that the settlor could not have considered at the time. To give a concrete example, if the trustee is

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<sup>46</sup> *Id.*



given the discretionary right to choose beneficiaries according to the economic hardships faced by the beneficiaries at the time of receipt, or to choose the person who made the greatest contribution to the care of the settlor after the creation a trust deed, there is no need for the settlor to specify the beneficiary at the time of creating the trust deed, and it becomes possible for the trustee to select the beneficiary by exercising his or her discretionary right in a flexible manner and in line with whatever changes may occur to the circumstances.<sup>47</sup>

Ordinarily in Japan's trust practices even if a trustee has a discretionary right regarding the management and operation of the trust, it has probably been considered that this right does not go as far as allowing them to select the beneficiary. This is because in Japanese trust practice, the self-benefit trust is most common, and there has been a strong awareness of the settlor's authority to give directions. However, trusts are a system in which the settlor is the only person who can also be the holder and party with the right of disposal of assets, and have the exclusive management rights. It is in fact normal for the trustee to enjoy a wide range of discretionary rights. This can probably be seen from the examples of how discretionary trusts are used under American Law. I would like to propose that trusts are made into a more flexible system in Japan through the use of trustees' execution of discretionary rights. I suspect that the fact is that there is a considerable need for trustees to be handed discretionary power and identify beneficiaries. The Supreme Court of Japan approved the conferral of discretionary powers upon executors and permission to let them select legatees (the court noting that the matter concerned public legacies) on January 19, 1993 (Minshu Vol. 47. No. 1, page 1) and this can be

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<sup>47</sup> *Id.* at 523.

regarded as a reflection of those needs. If the executor's right to select legatees can be approved, it naturally follows that the trustee's right to select beneficiaries should be allowed, and the Trust Act has various mechanisms for regulating this with the prerequisite that a wide range of discretionary powers exist for the trustee. Surely it is these sorts of functions that should in the future be put to use under the Trust Act.

The function of discretionary rights of trustees that I have mentioned are in fact nothing more than the functions of discretionary trusts under common law. This sort of discretionary trust is the future for trusts in Japan, and with respect to this point, there should be no differences from the common law nations of Britain, America, and Canada, as there are needs in the asset management of contemporary society that are common to both Japan and those common law nations. More concretely, discretionary trusts could be considered for use in the following areas: the asset management and livelihood protection of elderly people (continuing power of attorney), support for disabled people (countermeasures after the death of parents), education and care of descendants, business takeovers of family businesses, and measures against spendthrifts.

Discretionary trusts would allow the execution of the following four powers: (1) Identifying concrete beneficiaries from among a certain scope of latent beneficiaries; (2) deciding upon the details of the benefits to be enjoyed by the beneficiaries identified; (3) deciding upon under what conditions the benefits in (2) will be granted to the beneficiary in (1); and (4) deciding in what method the details of the benefits in (3) will be granted. In the following example, this sort of authority through discretionary power would be fully exercised concerning the asset management of an elderly person.

Imagine an elderly couple, both age 75. They have no children or close relations, and the husband is caring for his wife, who is showing the first signs of dementia, but he is also losing confidence in his own health. The husband has some financial assets, but it has become difficult for him to manage them due to advancing age. The husband sets up a trust for these assets, and during the period while he is still able to manage them, the trustee transfers at the husband's request the principal and profits of the assets. This is a self-benefit trust in which the husband is the beneficiary, and when the husband loses his capacity to manage the assets himself, the husband and his wife will become joint beneficiaries. This is a discretionary trust in which when one of them dies the other will become the beneficiary. The decision as to whether or not the husband has the capacity to manage the assets is made by a doctor. The trustee of the discretionary trust would then be able to make the necessary payments for the care of the husband and wife and parties to whom they owe money.

In addition to providing the husband with preparations for old age regarding the management of his assets and his livelihood before his mental capacities become restricted, this kind of discretionary trust also accounts for the livelihood of the wife after her husband's death. The authorities (1) to (3) listed above are at work here. The January 19, 1993 Supreme Court judgment mentioned earlier stated that

If the will in question is combined with the will designated by the executor of the will, it means that the testator himself does not specifically designate a legatee and the will includes the commissioning of that selection to the executor of the will . . . the scope of those selected too . . . is restricted and whoever is chosen as a legatee will be close to the wishes of the testator; therefore, as no risk can be admitted regarding

the misuse of the right of selection by those selected there can be no warrant for denying the validity of the will in question.<sup>48</sup>

The validity of commissioning the executor of a will with the selection of legatees was thus recognized.<sup>49</sup> If the granting of the executor's right to select legatees is deemed valid, obviously the right of a trustee to elect beneficiaries is valid, as I have already mentioned. It is arguable that this judgment of the Supreme Court illustrates that there are real needs in Japan to confer the right to select legatees or beneficiaries to executors or trustees.<sup>50</sup> The discretionary trust meets these needs.

I have ardently argued for the utilization of discretionary trusts in response to the needs that are present in Japan. As a result, I would like to record my praise for the fact that Article 89-6 of the new Trust Act clearly mentions that it is possible for a trustee to retain the right to designate beneficiaries and the right to change beneficiaries.<sup>51</sup>

#### *IV. ANALYSIS OF THE PRESENT STATE AND PROSPECTS FOR THE FUTURE*

As I explained in part III above, it is absolutely vital that discretionary trusts become popularized throughout Japan and I hope that, with this, the continuing power of attorney-like functions of trusts will also become more effectively exercised. However, these are little more than my own desires. A cool analysis of the current state of affairs indicates that trusts in which the trustee exercises his or her discretionary rights are, with a few exceptions, virtually unheard of. This is due to three reasons: (1)

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<sup>48</sup> *Id.* at 524.

<sup>49</sup> *Id.*

<sup>50</sup> *Id.*

<sup>51</sup> *Id.*

The vast majority of trust products in Japan are self-benefit trusts, and as self-benefit trusts enjoy a legal character similar to the proxies and mandates under the Japanese Civil Code, rather than the trustees themselves exercising their discretionary rights and carrying out the trust business, it is more common that the trustee acts in accordance to the instructions given by the settlor;<sup>52</sup> (2) In Japan, a trust bank is usually the trustee. While a trust bank is a financial institution, the exercising of discretionary rights tends to extend to livelihood protection, and the banks—fearing involvement in trouble between family members concerning the exercising of discretionary rights related to livelihood protection—are extremely reluctant to exercise discretionary rights as a financial institution;<sup>53</sup> (3) The exercising of discretionary rights necessitates a multifaceted and comprehensive knowledge of law, taxation, accounting, social welfare, medical care, and nursing. However, the trust banks, which are governed under the supervision of the Financial Services Agency, are generally not required to have this sort of comprehensive knowledge. Moreover, there are restrictions in attorney and tax accountancy laws regarding the discretionary aspects of law and taxation.<sup>54</sup> In contrast, American financial institutions collaborate with social workers and respond to the livelihood protection requirements of their clients.<sup>55</sup>

Additionally, in several American states, “Vulnerable Adults” laws have been enacted, which strengthens the responsibilities of the fiduciary, preventing any self-serving use of the trust’s assets by the trustee, and imposing new obligations to ensure the care of the beneficiary.<sup>56</sup> How very different the situations between Japan and America are!

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<sup>52</sup> *Id.* at 525.

<sup>53</sup> *Id.*

<sup>54</sup> *Id.* at 527.

<sup>55</sup> *Id.*

<sup>56</sup> *Id.*

Considering this situation, I question whether there is any path for the popularization of discretionary trusts in Japan. Even if the trust banks—that have hitherto not undertaken discretionary trusts, and lack detailed knowledge regarding the business involved in executing discretionary rights—are suddenly asked to become the trustees for discretionary trusts, making this a reality would probably be impossible. I hope that Japanese trust banks will one day renew their systems and start to accept discretionary trusts, but until that day arrives, I would like to suggest the creation, through the interlinking of continuing power of attorney and trusts, of a function that is essentially the same as discretionary trusts.

I will explain this recommendation using the aforementioned example of the 75-year-old couple. The husband sets up a trust, which is a self-benefit trust in which he is the beneficiary while he still has his mental capacities. As before, both he and his wife become the joint beneficiaries in the event that he loses his mental capacities, and the remaining spouse becomes the sole beneficiary when either of them dies, under a discretionary trust. The difference this time is that the husband appoints an attorney guardian at the same time that he sets up the trust. As explained in part II, the work of an attorney guardian begins when the mental capacities of the principal falter or fail and a supervisor is appointed.<sup>57</sup> The attorney guardian makes decisions concerning the livelihood of the principal in particular, and instructs the trustee accordingly. The trustee transfers the original principal and profits as per the instructions. It is preferable that the wife also appoints an attorney guardian if she still has the mental capacity to do so.

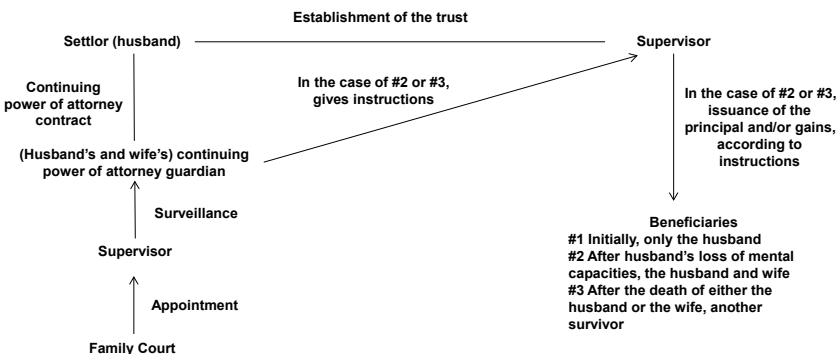
The continuing power of attorney system is a system that was created through legislation, as detailed in the opening paragraphs, and prevails even if a situation occurs in which the

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<sup>57</sup> *Id.* at 528.

principal's mental capacities are weakened or lost.<sup>58</sup> Moreover, continuing power of attorney imposes an obligation to consider the livelihood of the principal, and the supervisor prevents any misuse of the attorney guardian's rights. Such an attorney guardian is extremely appropriate as the executor of the wishes of the principal in the event that he or she requires protection, and if a person with a social welfare background can be appointed as an attorney guardian then the principal will doubtless be able to enjoy peace of mind regarding the execution of decisions about his or her livelihood protection.

Figure 2  
Continuing power of attorney-associated discretionary trusts



In the scheme that I recommend (hereinafter “continuing power of attorney-associated discretionary trusts”), as shown in Figure 2, enthusiastic use would be made of the continuing power of attorney system that has been introduced through the Act on Voluntary Guardianship Contract.<sup>59</sup> This would be linked to trusts, and the trustees of trusts would devote their energies to managing

<sup>58</sup> *Id.*

<sup>59</sup> *Id.* at 529.

and disposing of the principal's assets, while the attorney guardian would execute the wishes of the principal. By enabling the trustees and the attorney guardians to concentrate upon the business with which they are most familiar, the scheme strikes a balance between their twin roles, and as a result brings to Japan the functions of discretionary trusts. Through such a scheme, it would be possible for trusts to be reborn as an asset management system that can also pay due consideration to the livelihood protection of beneficiaries.

#### *V. COLLABORATION WITH STATUTORY GUARDIANSHIP*

In addition to the continuing power of attorney-associated discretionary trusts, it would also be useful to use statutory guardianship-associated discretionary trusts as a tool after the death of parents. The continuing power of attorney-associated discretionary trusts are recommended for elderly people to enable them to make decisions prior to the weakening or loss of their mental capacities. But in the case of mentally disabled people who have already lost their mental capacities, the only answer is to invoke statutory guardianship. On the other hand, if the parents of these disabled people use their own assets to set up a discretionary trust and make their children the beneficiaries, it would be possible to exercise the same functions as I mentioned above. Therefore, it would be possible to create a system, with the cooperation of adult guardians in statutory guardianships and discretionary trust trustees, which can contribute to lifestyle support, particularly livelihood protection. In other words, it would be possible to further reinforce the post-parental death measures coupled with guardianship and trust systems through the use of statutory guardianship-associated discretionary trusts. We are now in a time in which the joint use of trusts with the adult guardianship system to support the livelihood of principals is more effective than using trusts independently, and trusts provide a backup for adult guardianship.



## VI. THE EMERGENCE OF GUARDIANSHIP SUPPORT TRUSTS

There has been a significant development regarding the collaboration with statutory guardianship mentioned above. In order to stem wrongdoing by family guardians, the family court introduced the new option of guardianship support trusts, and from 2012, several trust banks started to provide trust products in line with the mechanism of guardianship support trusts.<sup>60</sup>

Guardianship support trusts allow the assets of a minor person to be managed by a family guardian. The guardian coordinates payment of every day expenses and leftover funds are placed with a trust bank.<sup>61</sup> The most significant feature of guardian support trusts is that in addition to concluding a trust contract, the involvement of the family court is required when repaying trust assets or cancelling a contract.<sup>62</sup> The family court, pursuant to Article 81(i) of the Provisions relating to Procedures for Domestic Relations Case, debates beforehand the suitability of a guardian support trust, issues a written order concerning repayment of trust assets or cancellation of a contract, and provides instructions.<sup>63</sup> The guardians receiving the instructions then conduct the repayment with the trust bank.<sup>64</sup>

Guardian support trusts aim to prevent wrongdoing by family guardians. Most family guardians appropriately manage assets, but some misuse their guardianship to dishonestly disburse the principal's assets. According to fact-finding research conducted by the Family Bureau of the Supreme Court's General Secretariat between June 2010 and March 2012, which is not currently publicly available, there were 538 cases of fraudulent behavior by

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<sup>60</sup> *Id.* at 529–30.

<sup>61</sup> *Id.* at 530.

<sup>62</sup> *Id.*

<sup>63</sup> *Id.*

<sup>64</sup> *Id.*

family guardians in Japan between June 2010 and March 2012.<sup>65</sup> The amount of money involved totaled around 5.26 billion yen.<sup>66</sup> Furthermore, it is estimated that by the year 2030, there will be 450 cases per year with total damages running to 4.5 billion yen.<sup>67</sup> In order to appreciate the significance of the introduction of the guardian support trusts, this background should be considered. Guardian support trusts elect the method of appointing professional lawyers or judicial scriveners as guardians or supervisors, and are positioned as an option for preventing fraudulent behavior by family guardians.<sup>68</sup>

The assets targeted by the guardian support trusts are cash and terminated deposits. They do not envisage the termination of insurance or sales of real estate for the purpose of entrusting termination fees or proceeds from sales.<sup>69</sup> Once the professional guardian concludes the trust contract, he resigns. With regard to family guardians, there are two formats: the multiple guardians type, in which family guardians and the professional guardian undertake the affairs of guardianship, and the relay type, in which the professional guardian resigns and then family guardians will be appointed.<sup>70</sup> Guardian support trusts have been criticized by the Japan Federation of Bar Associations, on the basis of the following three points.<sup>71</sup>

First, selecting a case appropriate for a guardian support trust is not necessarily easy, and caution is required as it is difficult to predict changes in the principal's personal condition and the

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<sup>65</sup> These are statistical compilations of cases relating to adult guardianship in family courts throughout the country that have been compiled by the Japan Supreme Court since 2000. They are titled "Supreme Court Statistical Information and Summary of Adult Guardianship Cases." Japan Sup. Ct., *Supreme Court Statistical Information and Summary of Adult Guardianship Cases* (on file with the Japan Supreme Court).

<sup>66</sup> *Id.*

<sup>67</sup> *Id.*

<sup>68</sup> *Id.*

<sup>69</sup> ARAI, *supra* note 5, at 530.

<sup>70</sup> *Id.* at 530–31.

<sup>71</sup> *Id.* at 531.

possibility of inter-family conflicts arising. Second, terminating the majority of the principal's savings and putting them in a trust may be contrary to the wishes of the principal. If the principal intended to deposit money at a financial institution, terminating these deposits may be in violation of the principal's wishes, and is possibly in violation of Article 858 of the Civil Code (Respect for Intention and Personal Consideration of Adult Ward).<sup>72</sup> Third, there is concern about the burden of the procedures create, since every disbursement requires the issuance of a written court order. Temporary funds are often needed when the physical state of the principal deteriorates, but it is possible that appropriate measures will not be taken because of aversion to the burden of the written order procedures.

The introduction of the guardian support trusts is a welcome development. The criticisms of the Bar Association are quite understandable. However, the operation of adult guardianship stands at an important juncture on all fronts; since the courts wish to prevent wrongdoing, the introduction of guardian support trusts should be taken seriously. The guardian support trusts involve the courts towards the conclusion of a trust contract and are a unique form of trusts that apply only to guardianship types. However, this is just the beginning, as there is hope for deeper theoretical and practical research. On the theoretical side, there is hope for comparisons with and examinations of the mechanisms for the creation of trusts by courts as an alternative to adult guardianship, as is seen in British and American trust law. On the practical front, the trusts that the parties can create link up with all the types of adult guardianship, and allow the possibility of avoiding adult guardianship altogether, through the creation of a trust. In either event, guardian support trusts exemplify the development of trusts

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<sup>72</sup> Article 858 of the Civil Code provides that "[a] guardian of an adult, in undertaking affairs related to the life, medical treatment and nursing, and administration of property of an adult ward, shall respect the intention of the adult ward, and consider his/her mental and physical condition and living circumstances."

in an aging society. The participation of institutions other than just trust banks is something that should be approved for their future operation. Finally, I would like to strongly appeal for the operation of guardian support trusts that pay consideration to the guiding ethos of adult guardianship.

## VII. *THE IMPORTANCE OF PERSONAL TRUSTS*

In this Article, I have suggested trusts as a method for managing the assets of the elderly or disabled, and examined some concrete examples of their use. I believe that it is vital to enable trusts to respond to varied individual needs. Trusts are ordinarily individual matters, and should center on personal trusts. However, thus far in Japan the focus of the trust business has been group trusts, and unfortunately the current situation makes it difficult to claim that personal trusts have sufficiently developed.<sup>73</sup> In light of the future aging society, it is desirable that the trust business attempts to move towards personal trusts. In order to accomplish this change, it is necessary not only to reform the awareness of the trust banks that carry out trust business, but also to launch a debate about the best way to regulate the supervisory authorities.

Although trusts are a system for managing assets, they are not a personal supervision system, so we must bear in mind the danger that using trusts will cause the personal supervision aspect of asset management to be neglected. Trusts are certainly a system for managing assets, and the settlor is the manager of the assets. Subsequently, even if the settlor creates a personal trust, all he or she must do is perform the asset management functions. However, it is difficult in personal trusts to distinguish between asset management and personal supervision. But it is unnecessary to do so. For example, the purpose of a special donation trust is “contributing to the stable life” of the beneficiary who is a person

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<sup>73</sup> ARAI, *supra* note 5, at 532.

with special disabilities.<sup>74</sup> But the concept of “contributing to the stable life” is not purely a matter of asset management; it is also a matter of personal affairs.<sup>75</sup> It is unnecessary for the settlor to take direct responsibility for the care of the beneficiary, but because the personal supervision matters are inevitably linked with the asset management of the trust, a forward-looking stance of acceptance is essential for the future popularization of personal trusts. At the very least, it should be entirely possible (for example, through coordination with adult guardianship under civil law) to position trusts within the system of support, including personal supervision, that is provided for all aspects of the lives of the elderly people who are the beneficiaries.

Furthermore, in order to popularize personal trusts, Japan must establish an awareness of paying appropriate trust fees. The notion that “welfare is a benefit provided by the government” needs to be eradicated and a change of perception is required in which users will understand more about “buying” personal trusts.<sup>76</sup> This will doubtless correspond with the increasing tendency for the trust business to be a fee-paying business. Of course, there will naturally be a need for settlors to enthusiastically build up their knowledge about personal trusts as fee-paying trusts, and give that knowledge back to users. Finally, in order to popularize personal trusts, it will be necessary to nurture corporate trustees that will be able to execute the trusts in an appropriate manner, because the financial infrastructure and knowhow of private (individual) trustees in Japan is currently inadequate.

There have been new movements regarding personal trusts, as I will illustrate with two examples. The first is the education fund donation trust. This is a new form of trust designed to transfer assets of the elderly to the younger generations and

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<sup>74</sup> *Id.*

<sup>75</sup> *Id.*

<sup>76</sup> *Id.* at 533.

support education and human resources. It was introduced pursuant to the tax exemption measures on donations relating to one-off education fund donations, in tandem with the revisions to the taxation system in 2013. For example, in the event that grandparents create a trust and appoint a trust bank as settlor for educational funds, of which the beneficiary will be a grandchild, and entrust the bank with cash, sums of up to 15 million yen would be exempt from donation tax. Trusts like this are a typical personal trust, and are often mentioned at the start of the representative British and American textbooks on trust law.<sup>77</sup>

The second type of trust uses special contract cash trust schemes to help systematically distribute funds for everyday life. The settlors deposit cash for their day-to-day life funds in a cash trust and receive regular payments to cover their living costs as the beneficiaries (self-benefit trusts). When the settlor begins to inherit, the recipient of the one-off payment (the second beneficiary), designated by the settlor from among the heirs presumptive, receives the one-off payment. After the settlor has begun to inherit, the person designated by the settlor from among the heirs presumptive to receive the residual funds (the second beneficiary) receives the residual funds of the trust. These trusts consist of a combination of the three patterns above.

These two types of trust represent a significant contribution to the development of personal trusts in Japan, and their future direction merits close attention.

### *VIII. EPILOGUE*

From December 19 to December 24, 1924, just after the Trust Act went into effect in Japan, Dr. Tetsuji Aoki wrote a series of articles under the title “The Story of Trusts,” which appeared in

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<sup>77</sup> DONOVAN W.M. WATERS, *WATERS' LAW OF TRUSTS IN CANADA* (4th ed. 2012).

the now defunct Jiji Shinpo (literally "Current Events") newspaper. I would like to end by sharing some quotations from this series of articles by the foremost proponent of the Trust Act in Japan.<sup>78</sup>

*The spiritual peace of mind of humans after death requires an appeal to religion in the spiritual realm, but in the physical realm it should be an appeal to trusts. Religion and trusts are the twin pillars of spiritual peace of mind in both the spiritual and the real worlds. Moreover, since if the material interests of one's children and grandchildren are not rigorously stabilized after death one's spirit will not receive peace of mind, it would not be an exaggeration to say that trusts are not merely the base of spiritual peace of mind in the physical world, but a blessing that helps spiritual peace of mind in the spiritual realm. This is something I will give an outline of below.*

*The wish to bequeath one's assets to one's bereaved family is a phenomenon in which there are almost no exceptions. However, are the assets you left for the sake of your wife, children and grandchildren actually safely being of use to them? If the children are feeble-minded it is even worse, but even if the children are extremely intelligent they can still be immature or unused to the ways of the world and therefore it is often the case that it proves difficult to maintain and manage the assets left to them. Under civil law persons with parental authority and guardians are stipulated but it is no easy*

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<sup>78</sup> Aoki Tetsuji, *The Story of Trusts*, JIJI SHINPO, Dec. 19–24, 1924, 2.

*matter for a widow who has hitherto only been involved in housework and dealing with ordinary social relations to maintain and manage the assets of her husband following his passing away.*

*So what should one do? The only answer lies in trusts. In other words, while you are still alive transfer all or most of your assets to the name of the party you trust the most and have them look after the assets for you, and get them to pay out from the profits of these assets the educational costs of your children and day-to-day living expenses of your surviving family members; when the children have grown up into fine young adults you can have the assets returned to their names.<sup>79</sup>*

The trusts that Dr. Aoki tried to popularize throughout Japan were personal trusts like this. After more than 90 years since the enactment of the old Trust Law, in this present day in which we face the onset of a fully-fledged aging society, will Professor Aoki's dream be finally realized?

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<sup>79</sup> *Id.*



# IS GUARDIANSHIP REFORM ENOUGH? NEXT STEPS IN POLICY REFORMS TO PROMOTE SELF-DETERMINATION AMONG PEOPLE WITH DISABILITIES

*Samantha Alexandra Crane\**

## I. INTRODUCTION

For most people, the often-difficult process of learning to make responsible choices about finances, housing, relationships, and health care is a central rite of passage from childhood to young adulthood. As young adults take on adult rights and responsibilities, it is expected that they will make mistakes—possibly grave ones—and will rely on the support of friends, family, teachers, and professionals in order to help them better understand the choices they face and the courses of action that are best for them.

People with disabilities—especially developmental, intellectual, or psychiatric disabilities—all too often are deprived of the right to undertake this important aspect of transition to adulthood. Instead, due to their real or perceived understanding of making important decisions, their parents, caregivers, or the state may petition the court to appoint a guardian or conservator<sup>1</sup> to

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<sup>1</sup> Some states use the term “guardian” to refer to an individual appointed to make decisions about the physical well-being of a person with a disability, and “conservator” to refer to an individual appointed to manage the property of a person with a disability. For the purposes of the remainder of this article, the term “guardian” is used to refer to any court-appointed substituted decision-maker for an adult with a disability, including conservators.

make decisions on their behalf.<sup>2</sup> Once placed under guardianship, the person with a disability no longer has final decision-making authority over a range of aspects of his or her life, including health care, housing, management of finances, and even marriage or voting.

Over the course of the past several decades, there has been increasing consensus among disability and civil rights advocates that the existing guardianship system infringes significantly on the civil rights of people with developmental, intellectual, and psychiatric disabilities.<sup>3</sup> Research has shown that individuals under guardianship suffer worse life outcomes due to the lack of autonomy and lack of opportunities to develop life skills.<sup>4</sup> Individuals under guardianship are also vulnerable to neglect or abuse by guardians, particularly when there is conflict in the family, or the guardian is a professional who lacks a close relationship with the individual.<sup>5</sup>

Attempts to reform the guardianship system by creating increased due process protections, increasing safeguards against abuse, or encouraging limited guardianship appointments, however, have so far provided little relief for those with significant decision-making support needs. Despite legislative requirements to

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<sup>2</sup> See, e.g., FLA. STAT. § 744.3201 *et seq.* (2014); CAL. PROB. CODE §§ 1800.3, 1820 (West 2015); MICH. COMP. LAWS § 700.5306 (2009); N.Y. MENTAL HYG. LAW § 81.02 (McKinney 2015).

<sup>3</sup> See Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans With Disabilities Act*, 81 U. COLO. L. REV. 157, 171-73 (2010) [hereinafter “Salzman 2010”]; Kristen Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 COLUM. HUM. RTS. L. REV. 93, 138-139 (2012) (describing emerging consensus among National Guardianship Conference attendees in favor of viewing “legal capacity as a human right”).

<sup>4</sup> Leslie Salzman, *Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?*, 4 ST. LOUIS U. J. HEALTH L. & POL’Y 279, 289-293 (2011) [hereinafter “Salzman 2011”].

<sup>5</sup> Glen, *supra* n. 3, at 121 n. 132.

consider less restrictive alternatives,<sup>6</sup> a review of recent published guardianship decisions reveals that courts continue to appoint guardians over people with significant decision-making support needs out of concern that these needs cannot be met outside the guardianship model. According to data collected by the National Core Indicators Project, at least 45% of adults with developmental disabilities living in states that participated in the project are under some form of guardianship.<sup>7</sup>

The supported decision-making model offers a viable alternative to guardianship for people with significant decision-making support needs. Under this model, individuals rely on the assistance of a chosen person or group of people in order to make decisions concerning their lives.<sup>8</sup> The individual has the final say in the decision-making process and retains the legal capacity to act across all domains of his or her life.<sup>9</sup> Sources of assistance may include family, friends, and professional providers of home and community-based services and supports.<sup>10</sup>

Although many countries have already adopted legal reforms that recognize supported decision-making as an alternative to guardianship<sup>11</sup> in at least some cases, no state within the United

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<sup>6</sup> See, e.g., FLA. STAT. § 744.344 (2015); N.H. REV. STAT. ANN. § 464-A:9 (2015); N.Y. MENTAL HYG. LAW § 81.02-81.03 (McKinney 2015); VA. CODE ANN. § 64.2-2007 (2015).

<sup>7</sup> NAT'L CORE INDICATORS [NCI], *2012–13 Person Has a Legal/Court-Appointed Guardian*, NCI CHARTS, <http://www.nationalcoreindicators.org/charts/?i=7> (last visited Mar. 23, 2015) (43% of respondents are under full guardianship and an additional 5% of respondents are under limited guardianship).

<sup>8</sup> *Salzman 2011*, *supra* note 4, at 306.

<sup>9</sup> *Id.*

<sup>10</sup> See, e.g., *id.* at 311 n.148.

<sup>11</sup> E.g., *Representation Agreement Act*, R.S.B.C. 1996, c. 405; Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship?* 117 PENN ST. L. REV. 1111, 1119n.27

States has passed legislation recognizing supported decision-making arrangements.<sup>12</sup> It is critical that states adopt legislation through which people with significant decision-making support needs can make legally enforceable decisions with the assistance of a chosen support network.

States may also promote supported decision-making through policy reforms that increase access to supports and eliminate systemic bias toward guardianship arrangements. States should also ensure that supported decision-making principles are incorporated into their services systems, including Medicaid-funded home-and community-based services (HCBS).<sup>13</sup> For example, recent regulations applicable to HCBS programs require that states include individuals with disabilities and their chosen supporters in a “person-centered planning process”<sup>14</sup> to develop individuals’ service plans.<sup>15</sup> In addition, states can support decision-making by providing HCBS funding for services such as financial and job coaching.<sup>16</sup> States should curb systemic referrals into the guardianship system by school administrators,

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(2013); Statutes of Saskatchewan 2000, The Adult Guardianship and Co-decision Making Act, Ch. A-5.3 § 14(1).

<sup>12</sup> See Glen, *supra* note 3, at 140–153.

<sup>13</sup> See Section 1915(c), (i), (j), and (k) of the Social Security Act, 42 U.S.C. § 1396n(c), (i), (j), (k) (2012). Home-and-Community-Based Services are optional services that states may provide to help individuals with disabilities live in the community. They may be provided through the State Plan or through a waiver program. *Id.* These services may include case management services, homemaker services, home health services, personal care services, adult day health services, habilitation services (including supported employment services), and respite care. See 42 C.F.R. § 440.182(c) (2014).

<sup>14</sup> 42 C.F.R. § 441.725 (2014) (final rule issued on January 16, 2014, 79 Fed. Reg. 2948).

<sup>15</sup> *Id.*

<sup>16</sup> See Section 1915(c), (i), (j), and (k) of the Social Security Act, 42 U.S.C. § 1396n(c), (i), (j), (k); 42 U.S.C. 1396n(c)(4)(B), (5)(A) (describing services that may be offered through home-and-community-based services waiver, including “habilitation services” that are “designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings”); 42 C.F.R. § 440.180(c) (describing “expanded habilitation services” to include educational services not otherwise available through a local educational agency and supported employment services). Similar home-and-community-based services may also be provided through the statewide plan instead of through a waiver. See 42 U.S.C. § 1396n(i)(1), (k)(1)(B)(i).

caseworkers, and other state employees, and instead ensure that youth and adults with disabilities, and their families, receive accurate information about alternatives to guardianship.

Finally, it is necessary to expand research on outcomes of different supported decision-making systems, including comparisons across other countries that have adopted some institutional framework for supported decision-making arrangements.

## II. GUARDIANSHIP IN THE UNITED STATES

The fundamental approach of the United States legal system toward adults who face difficulties managing their own affairs—appointment of an individual to serve as a substituted decision-maker for an individual with a mental disability—dates back at least to medieval England.<sup>17</sup> State courts—often specialized ones focused on family law or estate matters—appoint guardians over individuals deemed mentally “incapacitated,” usually upon a petition by the individuals’ family members or the state.<sup>18</sup> Courts typically determine an adult to be “in need” of a guardian if he or she has a diagnosed mental disability—including intellectual disability, psychiatric disability, developmental disability, or dementia—and if he or she appears unable to manage his or her own affairs independently.<sup>19</sup>

In many states, the court is empowered to appoint “limited” guardians who are authorized to make only some decisions

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<sup>17</sup> Salzman 2010, *supra* note 3, at 164 n. 15.

<sup>18</sup> Glen, *supra* note 5, at 107–119.

<sup>19</sup> *Id.*

concerning the individual's life, such as health care or management of finances.<sup>20</sup> Like traditional "plenary" guardians, limited guardians act as substituted decision-makers within the scope of their authority, and may exercise that authority even over the objections of their wards.<sup>21</sup>

The court has discretion to choose a guardian that it determines is best suited to act in the ward's best interests.<sup>22</sup> Although the guardian is often either the petitioner or another person suggested by the petitioner or person with a disability, the court is usually free to select any individual or organization—including a professional guardian employed by the state or by private nonprofit organizations—that it believes will best protect the interests of the person with a disability.<sup>23</sup> Professional guardians typically receive payment for their services and serve as guardian for multiple individuals with disabilities at the same time.<sup>24</sup>

Although some states require courts to consider less restrictive alternatives, such as informal support arrangements or powers of attorney,<sup>25</sup> the courts that oversee guardianship matters

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<sup>20</sup> *Id.* at 114.

<sup>21</sup> *Id.* at 115.

<sup>22</sup> *See, e.g.*, UNIF. ADULT GUARDIANSHIP & PROTECTIVE PROCEEDINGS ACT § 310 (1998) [hereinafter "UGPPA"].

<sup>23</sup> *Id.*

<sup>24</sup> *See, e.g.*, *In re Guardianship of G.S.*, 953 A.2d 414 (N.H. 2008) (appointing the office of public guardian as guardian over a prison inmate); *Ross v. Hatch*, No. CWF120000426P-03, available at [http://jennyhatchjusticeproject.org/docs/justice\\_for\\_jenny\\_trial/jhjp\\_trial\\_final\\_order.pdf](http://jennyhatchjusticeproject.org/docs/justice_for_jenny_trial/jhjp_trial_final_order.pdf) (Va. Cir. Ct. Newport News, August 2, 2013) (discussing prior appointment of a nonprofit organization as temporary guardian over a woman with Down Syndrome); *In re Mark C.H.*, 28 Misc. 3d 765 (N.Y. Sur. Ct. 2010) (appointing the attorney of an adult's deceased mother as guardian for the adult).

<sup>25</sup> *See, e.g.*, UGPPA § 311(a)(1)(B). A power of attorney is a legal agreement through which one individual, known as the principal, appoints an agent (known as the "attorney-in-fact") to manage some or all of the principal's affairs. A related agreement, durable power of attorney, comes into effect only if and when the principal loses the ability to make his or her own decisions (such as in the event of unconsciousness, severe illness, or progressive disability). Depending on the scope of the agreement, the attorney-in-fact may execute contracts, deposit or withdraw funds from the

typically cannot, and do not, create such alternatives if none already exist. For example, outside express authorization in a statute, a court overseeing guardianship proceedings typically cannot make a supported decision-maker legally responsible for assisting the individual in making his or her own enforceable decisions.<sup>26</sup> Courts also typically cannot order the state to provide case management or educational services that would help an individual avoid guardianship, unless the state is already a party to the proceeding.

Courts from state to state may vary in their degree of supervision of guardians once the guardians have been appointed. Guardians may be required periodically to show that the individual remains in need of assistance and that they have fulfilled their duties responsibly.<sup>27</sup> In theory, like parents and guardians of minor children, guardians of adults with disabilities are often required to make decisions in what the guardians determine to be their wards' "best interests" or decisions that reflect what their wards would have chosen if "competent."<sup>28</sup> Some states also encourage or require guardians to consult with their wards before making

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principal's bank account, make purchases, or sign a lease on the principal's behalf. The attorney-in-fact may not act without the principal's consent and may be forced to reimburse the principal for any harm resulting from acting without such consent. Unfortunately, as discussed in further detail below, people with disabilities may be unable to execute valid power of attorney agreements if a court determines that they lacked mental "capacity" at the time of execution.

<sup>26</sup> For example, in *Ross v. Hatch*, No. CWF120000426P-03, the court appointed a temporary guardian but "strongly recommend[ed]" the guardian to follow the principles of supported decision-making during the duration of the guardianship. The court's instructions to the parties in its final order focused solely on actions during the duration of the guardianship. The Virginia guardianship statute does not include any provision for court orders imposing care obligations on persons other than guardians. See Va. Code Ann. § 64.2-2009 (2015) (listing potential outcomes of a hearing on a petition for guardianship).

<sup>27</sup> See, e.g., *In re Mark C.H.*, 28 Misc. 3d at 787.

<sup>28</sup> Glen, *supra* note 5, at 116–117.

decisions.<sup>29</sup> Nevertheless, guardians retain broad discretion to make choices for their wards' "own good," even if those choices conflict with the desires of the wards, and courts accord these choices great deference.<sup>30</sup>

### A. Civil Rights Implications of Guardianship

Legal scholar Leslie Salzman has argued that guardianships violate individuals' rights under *Olmstead v. L.C.*,<sup>31</sup> a landmark Supreme Court decision holding that the Americans with Disabilities Act required states to provide services to individuals with disabilities in the most integrated setting appropriate to their needs.<sup>32</sup> Salzman argues that guardianship, by stripping individuals with disabilities of the legal authority to act independently, "constructive[ly] isolate[es]" those individuals from the rest of the community.<sup>33</sup>

An individual under guardianship typically lacks the authority to consent even to routine medical and dental treatment; to choose where to live; to decide when and where to travel; to apply for and receive government benefits; to marry and have custody of his or her own children; and to decide when and with whom to socialize or engage in sexual activity.<sup>34</sup> Some, but not all, states deny the right to vote to people under guardianship.<sup>35</sup> In a

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<sup>29</sup> *Id.*

<sup>30</sup> *Id.* at 118.

<sup>31</sup> 527 U.S. 581 (1999).

<sup>32</sup> See generally Salzman 2011, *supra* note 4; Salzman 2010, *supra* note 3.

<sup>33</sup> Salzman 2010, *supra* note 3, at 167–170.

<sup>34</sup> *E.g.* 20 Pa. Cons. Stat. § 5512.1(c) (2014).

<sup>35</sup> See Ala. Const. art. VIII, § 177(b); Ariz. Const. art. VII, § 2(C); La. Const. art. 1, § 10(A); Md. Const. art. 1, § 4; Mo. Const. art. VIII, § 2; Mont. Const. art. IV, § 2; Nev. Const. art. II, § 1; N.Y. ELEC. LAW § 5-106(6) (McKinney 2015); S.C. Const. art. II, § 7; S.D. Const. art. VII, § 2; Utah Const. art. IV, § 6; Va. Const. art. II, § 1; W. Va. Const. art. IV, § 4-1; Wyo. Const. art. VI, § 6; State Laws Affecting the Voting Rights of People with Mental Disabilities, BAZELON CTR. FOR



few states, guardians are even empowered to consent to psychotropic medication or hospitalization/institutionalization over the objection of the ward, bypassing the normal procedural safeguards against such involuntary treatment.<sup>36</sup>

This loss of decision-making rights deprives individuals with disabilities of numerous opportunities to participate in daily community life. For example, individuals under guardianship may not be able to bank, shop, apply for jobs, or seek routine health care without the participation and consent of the guardian. This lack of autonomy can cause individuals under guardianship to withdraw from community life and become disengaged from management of their own affairs.<sup>37</sup> Thus disengaged, they also lose opportunities to practice previously acquired decision-making skills or build new ones.<sup>38</sup>

Although some states require that guardians consider the wishes of the ward before making a decision,<sup>39</sup> this requirement is rarely enforced since individuals under guardianship do not have an enforceable right to have their wishes and decisions respected.<sup>40</sup> As a result, despite efforts to encourage guardians to take their wards' wishes and interests into account, individuals subject to guardianship lose meaningful control over life decisions and suffer from poor outcomes, disengagement, and vulnerability to abuse.

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MENTAL HEALTH L., <http://www.bazelon.org/LinkClick.aspx?fileticket=1kgFTxMFHZE%3d&tabid=315> (last visited Mar. 23, 2015).

<sup>36</sup> Salzman 2011, *supra* note 4, at 289–290.

<sup>37</sup> Kohn et al., *supra* note 11, at 1119 n.27.

<sup>38</sup> *Id.*

<sup>39</sup> E.g. COLO. REV. STAT. § 15-14-214 (2013); HAW. REV. STAT. § 560:5-314 (2011); 755 ILL. COMP. STAT. 5/11a-17(e) (2014); MINN. STAT. § 524.5-120(2) (2014).

<sup>40</sup> Salzman 2011, *supra* note 4, at 297.

Individuals under guardianship frequently report feeling isolated or lonely.<sup>41</sup>

Guardianship may also facilitate placement of individuals, against their wishes, in restrictive settings such as intermediate care facilities or group homes.<sup>42</sup> Guardians, especially family members who have conflicted relationships with their wards or institutional guardians who have large caseloads and limited contact with each ward, may favor these settings due to the perceived difficulty obtaining and monitoring home-and community-based services in many states. In a recent case from New York, for example, an attorney seeking guardianship over his deceased client's autistic son admitted to the court that he had never visited the son in the institution in which the son lived, nor had he made arrangements for the son to participate in activities outside the institution.<sup>43</sup> In another high-profile case, the Supreme Court of Washington found that professional guardians who represented dozens of wards at a time had engaged in extensive activities to ensure their wards' continued residence in an institutional setting, without regard to the "individualized best interest"<sup>44</sup> of the wards themselves.<sup>45</sup>

Because guardianship affects many of the most intimate details of an individual's life, individuals under guardianship may also find themselves deprived of even basic rights to bodily autonomy or social interaction with others. In the case of "Mary

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<sup>41</sup> Salzman 2010, *supra* note 3, at 168–170.

<sup>42</sup> See, e.g., N.Y. MENTAL HYG. LAW § 81.22 (McKinney 2015) (guardian may make choices about where a ward lives); *In re Mary J.*, 290 A.D.2d 847, 848–850 (N.Y. App. 2002) (Upholding grant of guardianship to two adult children who favored nursing home placement instead of a third adult child who favored in-home care).

<sup>43</sup> See *In re Mark C.H.*, 28 Misc. 3d at 766–769.

<sup>44</sup> *In re Guardianship of Lamb*, 265 P.3d 876, 877 (Wash. 2011) (en banc).

<sup>45</sup> See, e.g., *In re Guardianship of Lamb*, 265 P.3d 876.

Moe,” the parents of a woman with schizophrenia sought guardianship in order to override their daughter’s decision not to terminate her pregnancy.<sup>46</sup> The judge not only awarded guardianship but also ordered that Moe be permanently sterilized.<sup>47</sup> The Appeals Court in that case reversed the decision.<sup>48</sup> In another case in Virginia, the mother and stepfather of a young woman with Down Syndrome used their powers as guardians to restrict her access to friends and coworkers that she had made while living in the community.<sup>49</sup>

## B. Outcomes of Prior Efforts at Guardianship Reform

In recognition of the significant civil rights implications of guardianship, many states have in the past two decades attempted to reform their guardianship laws to better protect the rights of people with disabilities.<sup>50</sup> Some states now require courts to consider the availability of less restrictive alternatives before appointing a guardian, such as a power-of-attorney,<sup>51</sup> a living will,<sup>52</sup> a health care proxy,<sup>53</sup> or a supported decision-making system that allows the person to make decisions autonomously with assistance from friends, family or professionals.<sup>54</sup> Still other states, such as Georgia, merely require a finding that “the adult

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<sup>46</sup> *In re Guardianship of Moe*, 960 N.E.2d 350 (Mass. App. 2012).

<sup>47</sup> *Id.*

<sup>48</sup> *Id.*

<sup>49</sup> *See Ross v. Hatch*, No. CWF120000426P-03.

<sup>50</sup> Salzman 2010, *supra* note 3, at 171.

<sup>51</sup> *See, e.g., In re Albert S.*, 286 A.D.2d 684 (N.Y. App. 2001) (living will and power of attorney obviated need for guardianship).

<sup>52</sup> *Id.*

<sup>53</sup> *See, e.g., In re N.W.*, 897 N.Y.S.2d 671 (N.Y. Sup. Ct. 2009) (health care proxy and power of attorney provided a sufficient alternative to guardianship).

<sup>54</sup> *See Salzman 2010, supra* note 3, at 231–240 (describing supported decision-making models in use in Canada and Sweden).

lacks sufficient capacity to make or communicate significant responsible decisions concerning his or her health or safety”<sup>55</sup> and that the appointment is in the best interests of the adult.<sup>56</sup> Many states now also require numerous procedural protections for those who are subject to a petition for guardianship, including heightened standards of proof of disability, the right to be represented by an attorney, and the requirement that guardianships be narrowly tailored to the individual’s specific needs.<sup>57</sup> These efforts at reform have been met with only limited success, due in part to the continued absence of systematic support for guardianship alternatives and in part to courts’ failure to fully implement the new requirements.<sup>58</sup>

*1. Existing law renders certain supported decision-making arrangements invalid.*

Under the supported decision-making model, an individual selects a person or group of people to assist him or her in understanding and executing decisions concerning his or her life.<sup>59</sup> In order for this model to succeed, the individual must be recognized as having the legal capacity to select a support person and make decisions with support. Existing legal paradigms, however, may take an all-or-nothing view of capacity under which, if an individual is not able to make decisions *without* support, the individual is also presumed unable to make decisions *with* support and thus in need of a guardian.<sup>60</sup>

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<sup>55</sup> GA. CODE ANN. § 29-4-1(a) (2014).

<sup>56</sup> *Id.* at (c).

<sup>57</sup> Salzman 2010, *supra* note 3, at 171–173.

<sup>58</sup> *Id.* at 174–175.

<sup>59</sup> See generally Salzman 2011, *supra* note 4, at 306.

<sup>60</sup> See, e.g., *Ross*, No. CWF120000426P-03, at 2–3 (noting that, although experts agreed the plaintiff could make decisions “with appropriate support,” the court “must make its determination based upon the present situation”).

Individuals with disabilities may, for example, seek to avoid guardianship by executing documents such as health care proxies or powers of attorney. These documents enable the support person to obtain information on the disabled individual's behalf, to execute transactions at the direction of the individual, and to carry out the individual's previously stated wishes in the event that he or she is temporarily unable to communicate them. If a court later determines that the individual had a mental impairment at the time he or she executed these documents, however, it may declare them to be invalid.<sup>61</sup> Having invalidated alternative arrangements, the court may then find that there are no less restrictive alternatives and appoint a guardian over the individual.<sup>62</sup>

*2. Courts view broad guardianship powers as desirable.*

Another obstacle to full implementation of guardianship reform efforts is courts' perception that broad guardianship powers are necessary to ensure that people with disabilities receive adequate protection and support. As a result, when a statute requires that a court consider less restrictive alternatives, courts may fail to identify alternatives other than those proposed by the parties, or may even reject alternatives *because* they are less restrictive.

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<sup>61</sup> See, e.g., *In re Mary J.*, 290 A.D.2d at 848–850 (holding that a woman's health care proxy and power of attorney were invalid because she was suffering from dementia at the time she executed them, and that the woman therefore was in need of a guardian. Notably, the court awarded guardianship to the same people whom the woman had sought to designate as her health care proxy and attorney-in-fact).

<sup>62</sup> See, e.g., *id.*

This pattern is due in part to the perception that people with mental disabilities are likely to make harmful decisions unless they have a guardian authorized to override them. Courts may also fear that grants of only limited guardianship will result in inefficient use of court resources, as the guardian will simply return to court at some later date requesting broader authority.<sup>63</sup>

In *Guardianship of E.L.*, for example, a New Hampshire court denied a prison inmate's petition to terminate an award of guardianship that had been in force for ten years.<sup>64</sup> The court had initially awarded guardianship on the grounds that he had mental illness and did not wish to take medication.<sup>65</sup> In its published opinion, the Merrimack County Probate Court limited its discussion of alternatives to guardianship to three sentences:

A power of attorney would not be sufficient because [E.L.] could cancel it. A springing guardianship would not meet [E.L.'s] needs because it would require [E.L.] to decompensate before it could be implemented. This would make further treatment more difficult and could result in an injury to [E.L.] or some other person during the time he decompensated.<sup>66</sup>

The New Hampshire Supreme Court affirmed.<sup>67</sup>

In another case in New York, the son of A.G., a man with dementia asked the court to appoint a special guardian who would have authority only over A.G.'s property.<sup>68</sup> The court awarded the

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<sup>63</sup> Salzman 2011, *supra* note 4, at 295.

<sup>64</sup> *In re Guardianship of E.L.*, 154 N.H. 292, 294 (2006).

<sup>65</sup> *In re Guardianship of E.L.*, 154 N.H. 292, 294 (N.H. 2006). E.L. was assigned a "designated staff guardian," Bonnie Ham, who works for the Tri-County Community Action Program. *Id.*

<sup>66</sup> *Id.* at 303 (quoting the probate court opinion).

<sup>67</sup> *Id.* at 302–304.

<sup>68</sup> *In re Restaino*, 37 Misc. 3d 586 (N.Y. Sup. Ct. 2012).

son guardianship authority not only over the A.G.'s property but also over A.G.'s housing and health care decisions.<sup>69</sup> Although the court recognized the fact that A.G.'s son was already empowered to make medical decisions for A.G. as his health care surrogate, and there was no evidence that this arrangement had proven ineffective, the court rejected the surrogate arrangement as a less restrictive alternative to guardianship because it did not allow A.G. to override A.G.'s decisions without a court order.<sup>70</sup> The court also reasoned that a guardianship, unlike appointment of a health care surrogate, would empower A.G.'s son to make decisions about other aspects of A.G.'s life, such as his housing, that were not at issue in the proceedings.<sup>71</sup>

These cases illustrate a pattern of court preference for broad guardianship authority.<sup>72</sup> For example, a 2007 study of Colorado guardianship orders revealed that courts continue to award more plenary guardianships in the majority of cases and that even most "limited" guardianships were actually plenary guardianships with limited "cut-outs."<sup>73</sup>

### *3. Courts view alternatives to guardianship as novel and unproven.*

In 2012, Jenny Hatch, a woman with Down Syndrome, fought a high-profile battle against her mother and stepfather's

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<sup>69</sup> *Id.*

<sup>70</sup> *Id.*

<sup>71</sup> *Id.* at 587–591.

<sup>72</sup> Salzman 2010, *supra* note 3, at 174–175.

<sup>73</sup> Salzman 2011, *supra* note 4, at n.73; *see also* Salzman 2010, *supra* note 3, at 174–175.

petition for guardianship.<sup>74</sup> Arguing that she could make her own decisions with the assistance of Medicaid-funded case management and a support network she had built in the community, Hatch became a test case for supported decision-making as a less restrictive alternative to guardianship.<sup>75</sup> At the final guardianship hearing, the court heard expert testimony explaining the supported decision-making model.<sup>76</sup> The experts further explained that Hatch had already enjoyed some success living in the community with the support of her friends and would benefit even further from supported decision-making services in the form of Medicaid-funded home-and-community-based services.<sup>77</sup> With these services, the experts testified, Hatch could manage her affairs without a guardian.<sup>78</sup>

The probate court nevertheless appointed a limited guardian over “medical and safety”<sup>79</sup> issues, reasoning that “the Court must make its determination based on the present situation and not what it may speculatively become in the future.”<sup>80</sup> The guardianship would terminate automatically after a year.<sup>81</sup>

Success of the supported decision-making model, however, requires that it be implemented before, and not after, appointment of a guardian over the disabled individual. Decision-making skills develop through practice and engagement, and guardianship itself may hinder that development process. Individuals subjected to

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<sup>74</sup> Theresa Vargas, *Virginia Woman with Down Syndrome Becomes Hero to the Disabled*, Wash. Post, Aug. 17, 2013.

<sup>75</sup> *Id.* (describing her guardianship case as “testing the rights of adults with disabilities to choose how they live”).

<sup>76</sup> Ross, No. CWF120000426P-03, at 2.

<sup>77</sup> Testimony is on file with Jonathan Martinis, her attorney.

<sup>78</sup> *Id.*

<sup>79</sup> Ross, No. CWF120000426P-03, at 5.

<sup>80</sup> *Id.* at 3.

<sup>81</sup> *Id.* at 5.



guardianship may become disengaged from the management of their own affairs, which in turn may lead to a subsequent determination that the individuals require continued guardianship.<sup>82</sup>

*4. Individuals, families, and courts lack awareness  
of available alternatives.*

Even in states where courts are required to consider less restrictive alternatives to guardianship, judges and family members may lack awareness of the full range of alternatives. Parents may, for example, be told that they must seek guardianship once their child reaches adulthood if they wish to participate in their children's special education planning process.<sup>83</sup>

### III. SUPPORTED DECISION-MAKING: AN ALTERNATIVE

The supported decision-making model offers an alternative structure for assisting individuals with intellectual, developmental, and psychiatric disabilities in decision-making while preserving their autonomy and legal capacity. Under this model, individuals with decision-making support needs select one or more support persons to assist them in collecting and understanding important information about important decisions, identifying options that best further their personal goals, and carrying out the decisions they make.<sup>84</sup> The support persons may be family, friends, home-and

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<sup>82</sup> See, e.g., Salzman 2011, *supra* note 4, at 291–292 (discussing disengagement from the decision-making process among individuals with mental illness subject to guardianship).

<sup>83</sup> Kohn et al., *supra* note 11, at 1118.

<sup>84</sup> See generally Salzman 2011, *supra* note 4, at 306.

community-based service providers, or a combination thereof.<sup>85</sup> The disabled individual, known as the principal, retains the authority to cancel the supported decision-making relationship and the support person cannot act without the principal's consent.<sup>86</sup> The principal retains legal capacity and can enter into legally enforceable contracts through the supported decision-making process.<sup>87</sup>

No jurisdiction in the United States formally recognizes supported decision-making relationships.<sup>88</sup> Nevertheless, supported decision-making relationships may still exist, and be recognized as such by courts considering guardianship. For example, in one recent published opinion, Judge Kristen Booth Glen found that a woman with intellectual disability was not in need of guardianship because she received extensive decision-making support from her husband, cousins, neighbors, and a social worker.<sup>89</sup> These supports, the court found, were significantly less restrictive and thus preferable to guardianship.<sup>90</sup>

Other countries, such as Canada and Sweden, have passed laws recognizing supported decision-making relationships. These laws vary in the extent of court involvement in these relationships and the degree to which the authority to act is transferred from the principal to the supporter.

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<sup>85</sup> *Id.*

<sup>86</sup> *Id.*

<sup>87</sup> *Id.*

<sup>88</sup> Glen, *supra* note 3, at 152 (noting that supported decision-making statutes such as Canada's are "unlike any existing statutory scheme in the United States").

<sup>89</sup> *In re Guardianship of Dameris L.*, 38 Misc. 3d 570, 576 (N.Y. Sur. Ct. 2012). Ultimately, the court terminated guardianship on the ground that the individual had relocated to Pennsylvania and was no longer subject to the jurisdiction of the New York court system. *Id.* Nevertheless, Judge Glen's discussion of the informal supports that the individual used is instructive.

<sup>90</sup> *Id.*

A. Supported Decision-Making in British Columbia

British Columbia's Representation Agreement Act (RAA),<sup>91</sup> passed in 1996, permits individuals with disabilities to appoint a "representative" to assist in managing their affairs. The representation agreement resembles a power of attorney agreement in that (1) a person may enter into a representation agreement privately, without the involvement of the court system; (2) the principal retains legal capacity and may cancel the agreement at any time; and (3) the representative may be required to reimburse the principal for harm if he or she acts outside the scope of his or her authority.<sup>92</sup>

Representation agreements differ from traditional power of attorney agreements in two key ways: (1) a person with a disability can enter into a representation agreement even if he or she would be seen as lacking the capacity to enter into a power of attorney agreement, and (2) a representative may go against the wishes of the principal if the principal's wishes are not "reasonable" or if it is not reasonably possible to determine what the principal's wishes are.<sup>93</sup>

Because the representative is empowered to go against the wishes of the principal when those wishes are "unreasonable," the RAA is not fully consistent with the principles of supported decision-making. The RAA, however, does incorporate certain safeguards to protect the interests of principals. Under standard representation agreements, the representative may not make certain

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<sup>91</sup> *Representation Agreement Act*, supra note 11.

<sup>92</sup> *Id.*

<sup>93</sup> *Id.* at pt. 1 s.3, pt. 2 s. 8, pt. 3 s. 16.

kinds decisions, such as refusing lifesaving treatment on behalf of the individual, placing the individual in an institution, limiting the individual's contact with others, or consenting to treatment over the individual's objection.<sup>94</sup> In addition, when the representation agreement includes management of the person's finances, the principal must also name a financial monitor to oversee the representative's management of financial affairs.<sup>95</sup>

Growing evidence suggests that British Columbia's system is effective at increasing individuals' involvement in the decisions affecting their lives in comparison to guardianship arrangements. In one unpublished study on use of Representation Agreements for health care decision-making in British Columbia, over 80 percent of participants with Representation Agreements who spoke with their representative spoke with their representative at least several times a week.<sup>96</sup> These discussions included conversations about individuals' feelings, values, and goals with respect to their health care.<sup>97</sup>

## B. Supported Decision-Making in Sweden

In Sweden, unlike British Columbia, formalized supported decision-making arrangements are not private agreements between individuals. Rather, the municipal government is authorized to appoint a "god man," or mentor, for a person with a disability who is found to be in need of decision-making support.<sup>98</sup> The disabled individual need not consent to appointment of a "god man," but must consent to all non-routine transactions and may challenge and

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<sup>94</sup> *Id.* at c. 405, pt. 2 §. 7(2.1)(a), 9(1), 12.

<sup>95</sup> *Id.*

<sup>96</sup> Wendy Harrison, *Representation Agreements in British Columbia: Who Is Using Them and Why?* (unpublished M.A. thesis, Simon Fraser University 2008).

<sup>97</sup> Kohn et al., *supra* note 11, at 1136.

<sup>98</sup> *Id.* at 1124.

invalidate transactions or contracts entered into by the “god man” that are inconsistent with his or her wishes.<sup>99</sup>

### C. Supported Decision-Making in Saskatchewan

In Saskatchewan, a court may appoint a co-decision-maker for a person with a disability who is found to be in need of decision-making support.<sup>100</sup> The co-decision-maker resembles a guardian in that the individual in need of support loses the authority to execute contracts or other documents without the participation of the co-decision-maker.<sup>101</sup> However, unlike guardianship, the co-decision-maker also cannot execute contracts or other documents without the participation of the individual, and the co-decision-maker is required to agree to any decision that the individual wishes to make “if a reasonable person could have made the decision in question and no harm to the adult is likely to result from the decision.”<sup>102</sup> Moreover, the court cannot appoint a co-decision-maker without the consent of the individual in need of support.<sup>103</sup>

Because Saskatchewan’s co-decision-maker system requires the involvement of the court system and requires that the individual give up the legal capacity to make decisions without the consent of the co-decision-maker, it may be seen as one of the more restrictive supported decision-making frameworks in use. It is also, perhaps due to the requirement of court involvement, very

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<sup>99</sup> Salzman 2010, *supra* note 3, at 235–236.

<sup>100</sup> Statutes of Saskatchewan 2000, The Adult Guardianship and Co-decision Making Act, Ch. A-5.3 § 16(1).

<sup>101</sup> *Id.*

<sup>102</sup> *Id.* at § 17(2).

<sup>103</sup> *Id.* at § 21(1).

rarely used in comparison to British Columbia's representation agreements.<sup>104</sup>

D. Public Funding for Supported Decision-Making Services: The United Kingdom

Other countries have not passed legislation formalizing the supported decision-making relationship, but provide publicly funded, ad hoc supported decision-making services to individuals in need of them. The United Kingdom, for example, has created an Independent Mental Capacity Advocate (IMCA) program that assists individuals with decision-making support needs who are faced with significant life decisions and do not have family or friends who are willing and able to provide the necessary supports.<sup>105</sup> IMCAs may become involved when an individual needs support to make a specific decision about long-term care, serious medical treatment, seeking adult protective services, or review of the long-term supports they receive.<sup>106</sup> IMCAs do not typically make final decisions on behalf of individuals with disabilities.<sup>107</sup> Instead, they interview the individual to ascertain his or her priorities and wishes, collect all relevant information, and interface with relevant service providers before finally issuing a report to the housing, medical care, or service provider recommending a course of action.<sup>108</sup>

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<sup>104</sup> Kohn et al., *supra* note 11, at 1130.

<sup>105</sup> See UNITED KINGDOM OFFICE OF THE PUBLIC GUARDIAN, MAKING DECISIONS: THE INDEPENDENT MENTAL CAPACITY ADVOCATE (IMCA) SERVICE (2007), *available at* <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/making-decisions-opg606-1207.pdf>.

<sup>106</sup> *Id.*

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*

1. *Promoting Access to Supported Decision-Making as an Alternative to Guardianship: Proposals for Reform*

- a. Increase availability of decision-making supports for people with mental disabilities.

A major contributor to the prevalence of guardianship in the United States is the lack of availability—real or perceived—of alternate forms of decision-making support. Although many supported decision-making arrangements are informal and consist of networks of family and friends, it may be difficult to put reliable supports in place for individuals who do not already have strong, trusting relationships with friends and family members or for those whose friends and family networks are unable to provide the level of support they need.

Although there is limited direct data on availability of supports to people with significant decision-making support needs, recent data reveals that adults with developmental disabilities lack opportunities to make important decisions about their own lives, even when they are not under guardianship.<sup>109</sup> Among states that participate in the National Core Indicators project, 45% of people

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<sup>109</sup> NAT'L CORE INDICATORS [NCI], *2011–12 Person Has a Legal/Court-Appointed Guardian*, NCI CHARTS, <http://www.nationalcoreindicators.org/charts/?i=7> (last visited Mar. 23, 2015) (showing percentage of respondents in participating states who had guardians); NAT'L CORE INDICATORS [NCI], *2011–12 Chose Home*, NCI CHARTS, <http://www.nationalcoreindicators.org/charts/?i=137> (last visited Mar. 23, 2015) (showing percentage of respondents in participating states who chose where they lived); NAT'L CORE INDICATORS [NCI], *2011–12 Chooses What to Buy with His/Her Spending Money*, NCI CHARTS (showing percentage of respondents in participating states who chose what to buy with their spending money).

with developmental disabilities are independent of guardianship,<sup>110</sup> yet only 22% of adults with developmental disabilities chose where they lived<sup>111</sup> and little more than half choose how to use their spending money.<sup>112</sup>

Moreover, although many adults with disabilities may rely on family members and friends for informal assistance with decision-making, for many people these networks may be limited or may lack the capacity to provide adequate levels of support. Research on individuals found in need of public guardianship is instructive. Those found in need of public guardianship are typically individuals who are found to have significant support needs, but lack family, friends, or other acquaintances willing to serve as guardian or assets that could be used to fund a private professional guardian.<sup>113</sup> These individuals would be highly likely to also lack informal support networks of family and friends that are willing and capable of providing adequate decision-making support. In Florida alone, over 2,200 individuals had a public guardian as of 2009, and 418 additional individuals were on a waiting list for public guardianship, despite the fact that no public guardian program exists in 70% of counties within the state.<sup>114</sup>

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<sup>110</sup> NAT'L CORE INDICATORS [NCI], *2011–12 Person Has a Legal/Court-Appointed Guardian*, NCI CHARTS, <http://www.nationalcoreindicators.org/charts/?i=7> (last visited Mar. 23, 2015) (showing percentage of respondents in participating states who had guardians).

<sup>111</sup> NAT'L CORE INDICATORS [NCI], *2011–12 Chose Home*, NCI CHARTS, <http://www.nationalcoreindicators.org/charts/?i=137> (last visited Mar. 23, 2015) (showing percentage of respondents in participating states who chose where they lived).

<sup>112</sup> NAT'L CORE INDICATORS [NCI], *2011–12 Chooses What to Buy with His/Her Spending Money*, NCI CHARTS (showing percentage of respondents in participating states who chose what to buy with their spending money).

<sup>113</sup> PAMELA B. TEASTER ET AL., *WARDS OF THE STATE: A NATIONAL STUDY OF PUBLIC GUARDIANSHIP*, CH.1, 5 (2005), <http://apps.americanbar.org/aging/publications/docs/wardofstatefinal.pdf> (last visited Mar. 23, 2015).

<sup>114</sup> PAMELA B. TEASTER et al., *The Florida Public Guardian Programs: An Evaluation of Program Status and Outcomes* 3 (2009), available at <http://elderaffairs.state.fl.us/doca/Evaluation/Statewide%20Public%20Guardianship%20Annual%20Report,%202009.pdf>.



Florida's public guardianship programs cost the state over \$2 million between July 2007 and June 2008.<sup>115</sup>

To supplement existing support relationships, states should create programs that would provide professional supported decision-making services to individuals who are in need of such support. Supports would include financial coaching, person-centered planning for housing and daily activities, assistance with routine financial management tasks such as monitoring bills and bank statements, and assistance with making doctor's appointments and understanding important medical decisions.

The vast majority of these services could be funded through existing Medicaid waiver programs for home-and-community-based services (HCBS). Many HCBS programs already explicitly include supported decision-making within the scope of services to be provided.<sup>116</sup> Although there is limited data on the cost of such services, diverting individuals from the public guardianship system to supported decision-making services would enable the state to draw on federal Medicaid funding.<sup>117</sup> Such funding is not available to defray the costs of public guardianship, including the cost to the state court systems charged with overseeing guardianships and the cost of public guardianship programs themselves.<sup>118</sup>

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<sup>115</sup> *Id.*

<sup>116</sup> See, e.g., Colorado Dep't of Human Svcs., *Supported Living Services*, <http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251586997293> (last visited Mar. 23, 2015).

<sup>117</sup> See Section 1915(c), (i), (j), and (k) of the Social Security Act, 42 U.S.C. § 1396n(c), (i), (j), (k); 42 U.S.C. 1396n(c)(4)(B), (5)(A).

<sup>118</sup> See *id.*; 42 U.S.C. § 1396d (defining "medical assistance" eligible for federal funding through Medicaid).

Many individuals at risk of guardianship may not be enrolled in Medicaid. These individuals may be youth transitioning to adulthood who have not yet applied for Medicaid coverage, adults who are eligible for Medicaid but who have not yet applied, or individuals with disabilities who exceed the asset limits for Medicaid coverage through the Supplemental Security Income (SSI) program and who live in states that have not expanded Medicaid coverage to all individuals earning less than 133% of the federal poverty level.<sup>119</sup> Jenny Hatch, for example, had not enrolled in Virginia's HCBS waiver program at the time that she was first placed under guardianship, despite being eligible.<sup>120</sup>

To ensure that this population does not slip through the cracks in service delivery systems, states must also offer interim decision-making support services to individuals with disabilities who are found in need of such support but who are not yet enrolled in Medicaid. At a minimum, such services should be offered to all individuals who are subject to a petition for guardianship and are found to have insufficient informal supports already in place. Because many individuals with disabilities who would otherwise be subject to guardianship are likely to also be eligible for Medicaid, it is likely that, in most cases, the state would need to provide independent funding for these services only until the individual successfully enrolls in the state's HCBS waiver program and becomes eligible for supported decision-making services through that program.

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<sup>119</sup> *National Federation of Independent Business v. Sebelius*, 567 U.S. (2012), 132 S.Ct 2566 (discussing ACA Medicaid expansion and holding that states must be allowed to "opt-out" of provision that would have expanded coverage to everyone within 133% of FPL). As a result, not all states have expanded Medicaid. See <http://kff.org/health-reform/slide/current-status-of-the-medicaid-expansion-decision/>.

<sup>120</sup> See Theresa Vargas, *Virginia Woman with Down Syndrome Seeks Power to Control Her Own Life*, WASH. POST, JULY 20, 2013, available at [http://articles.washingtonpost.com/2013-07-20/local/40695386\\_1\\_group-home-guardianship-jim-talbert](http://articles.washingtonpost.com/2013-07-20/local/40695386_1_group-home-guardianship-jim-talbert).

Preparation for adulthood, including assistance with developing a decision-making support network, must also be incorporated into the individualized education plans (IEPs) of students with disabilities who may experience decision-making challenges upon transition to adulthood. Such services may not only help smooth the transition to adult decision-making responsibilities but may also assist in educating students' families on appropriate, less restrictive alternatives to guardianship.

- b. Promote legislation recognizing formal supported decision-making arrangements.

Even in the presence of adequate supports and services through informal arrangements such as powers of attorney, some courts have shown reluctance to embrace these arrangements. Most significantly, courts may invalidate powers of attorney or other similar documents if they find that the principal lacked "capacity" at the time that he or she executed the document. In *Mary J.*, for example, a New York court found that a disabled woman's durable power of attorney was not a viable alternative to guardianship because she was already suffering from dementia at the time that she executed the document.<sup>121</sup>

Individuals with developmental, intellectual, or other long-term disabilities affecting communication or decision-making ability, therefore, face significant legal uncertainty when executing powers of attorney, health care proxies, or similar agreements that facilitate the supported decision-making process. If they at some

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<sup>121</sup> *In re Mary J.*, 290 A.D.2d at 848—850; see also *In re Guardianship of E.L.*, 911 A.2d at 37 (holding that a power of attorney would not be a viable less restrictive alternative because the respondent "could cancel it").

later point become subject to a guardianship petition, a court may decide that the same disability that gives rise to their decision-making support needs also renders their existing legal arrangements invalid. This legal uncertainty may also make individuals and businesses unwilling to enter into major contracts—such as lease agreements or automobile loans—with individuals with disabilities who do not have guardians, as a court may at some later point determine that the individual lacked capacity to enter into such contracts and therefore declare them invalid. Similarly, health care providers may be unwilling to provide treatment requested by a disabled individual, for fear that a court will later determine that the individual lacked capacity to consent to treatment.

States must therefore pass legislation permitting individuals with disabilities to appoint a supporter (or supporters) and enter into enforceable contracts with such support. Such appointments must be legally recognized even if the principal had significant intellectual, developmental, or other cognitive disability at the time of the appointment.

Advocacy groups have already begun to develop proposed legislation to accomplish these goals. As part of its toolkit on supporting individuals with intellectual and developmental disabilities as they approach adulthood, the Autistic Self Advocacy Network (ASAN) has published model legislation to recognize supported decision-making agreements in health care contexts.<sup>122</sup> In addition, the Texas Guardianship Reform and Supported Decision Making Group recently developed a bill that would

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<sup>122</sup> AUTISTIC SELF ADVOCACY NETWORK, MODEL LEGISLATION: AN ACT RELATING TO THE RECOGNITION OF A SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT FOR ADULTS WITH DISABILITIES (2014), *available at* <http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf>.

recognize supported decision-making agreements across a range of contexts, including health care and financial decision-making.<sup>123</sup> Both proposed laws would permit individuals with significant decision-making support needs to appoint a decision-making support person.<sup>124</sup> This supporter would assist in collecting information, understanding options and consequences necessary to make a decision, and communicating the individuals' decisions to others. The ASAN model legislation includes specific language clarifying that the agreements are valid and enforceable even if the person with a disability needs significant support to make decisions.<sup>125</sup> Supporters would not be authorized to make decisions or enter into contracts unilaterally on behalf of principals.<sup>126</sup>

These proposed laws enjoy key components that have proven successful in other countries that have passed supported decision-making legislation. Like the Representation Agreement Act, they permit individuals to name representatives without the expenses and delays associated with court involvement.<sup>127</sup> As noted above, this feature may explain why British Columbia's supported decision-making system is used more extensively than systems such as Saskatchewan's, which require court involvement.

To further ensure that individuals have actual access to decision-making support, it is necessary to develop additional legislation or promulgate regulations that ensure individuals'

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<sup>123</sup> TEX. HOUSE BILL 3624 (84th Leg.) (as of Mar. 23, 2015 referred to Human Services).

<sup>124</sup> AUTISTIC SELF ADVOCACY NETWORK, *supra* note 122; TEX. HOUSE BILL 3624 (84th Leg.).

<sup>125</sup> AUTISTIC SELF ADVOCACY NETWORK, *supra* note 122 at § 9(d)(1).

<sup>126</sup> *Id.* at § 5(b); TEX. HOUSE BILL 3624, § 1 (proposed TEX. ESTATE CODE § 1357.051, 1357.056(a), authorizing supporters to help obtain information and communicate decisions, but noting that the supporter is "not allowed to make decisions for" the principal).

<sup>127</sup> AUTISTIC SELF ADVOCACY NETWORK, *supra* note 122; TEX. HOUSE BILL 3624 (84th Leg.).

access to Medicaid-funded supported decision-making services and reinforce individuals' right to enter into legally enforceable contracts with supports as needed. In particular,

Individuals who receive publicly funded supported decision-making services should be permitted to incorporate those services into the supported decision-making agreement, either in addition to or in place of unpaid supporters such as friends or family members. The draft Texas legislation explicitly prohibits supporters from receiving compensation for their services and would therefore preclude use of paid-service providers as supporters.<sup>128</sup>

The legislation should explicitly affirm that the principal's decisions, made with support, are legally enforceable unless circumstances unrelated to the principal's disability (such as duress or fraud) render them unenforceable. This affirmation may be subject to additional safeguards, such as those contained in the RAA, for decisions that have a high potential impact on the principal's well-being, such as the decision to place the principal in a residential care facility.

With respect to financial or other matters in which supporters may face significant conflicts of interest, legislation should incorporate additional safeguards against exploitation that have proven successful in other countries, such as the RAA's requirement of an independent financial monitor to safeguard against financial exploitation. Additional safeguards could include restrictions on decisions that reflect a conflict of interest, such as financial gifts from the principal to the supporter.

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<sup>128</sup> AUTISTIC SELF ADVOCACY NETWORK, *supra* note 122 at 119.

It is necessary to develop supported decision-making models that meet the needs of individuals with limited access to language-based communication. Such legislation should ensure that all individuals enjoy legally enforceable rights to autonomy, dignity and respect, while providing a robust process to be followed by designated support persons in order to determine individuals' actual wishes.

- c. Replace systematic referrals into the guardianship system with referrals to supported decision-making resources.

As individuals with disabilities transition to adulthood, their families may be unaware of alternatives to guardianship and may feel that guardianship is necessary in order to ensure that their loved ones with intellectual disabilities obtain medical care or other supports.<sup>129</sup> In many cases, this lack of awareness is compounded when service providers, such as school administrators, encourage families of young adults to seek guardianship in order to continue managing their benefits.<sup>130</sup>

States should ensure that the systems that deliver services to people with disabilities, such as school education systems or departments of social services, do not become institutional pipelines into the guardianship system. Agencies should refrain from recommending, as a routine matter, that families of people with disabilities seek guardianship in order to help them obtain

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<sup>129</sup> Kohn et al., *supra* note 11, at 1120; Arc & Am. Assoc. on Intellectual & Developmental Disabilities, *Position Statement: Guardianship* (2009), available at <http://www.thearc.org/page.aspx?pid=2351>.

<sup>130</sup> Kohn et al., *supra* note 11, at 1128–1129.

services. Instead, agencies should maintain resources on person-directed support arrangements, including powers of attorney, health care proxies, and formalized supported decision-making agreements and should provide these resources to individuals with disabilities and any family members interested in assisting them.

- d. Collect more data on the outcomes of specific supported decision-making systems.

Although the supported decision-making model is not new and has been formally recognized in some jurisdictions for decades,<sup>131</sup> a recent review of the literature has found that there is still limited research analyzing the outcomes of specific frameworks.<sup>132</sup> This absence of data may be explained in part by the difficulty of defining what constitutes a “good outcome” of the supported decision-making process, as the right decision for one individual may be the wrong decision for another.<sup>133</sup> Nevertheless, numerous indicators, such as self-reported life satisfaction, employment rates, housing trends, and other quality-of-life measures may serve as benchmarks against which to measure the success of the supported decision-making process.

It is crucial that, as states expand supported decision-making services and create legal frameworks recognizing supported decision-making arrangements, they simultaneously collect and disseminate data on utilization rates and outcomes. Important questions for researchers include the following:

Have expansion of supported decision-making services and legal recognition of supported decision-making relationships

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<sup>131</sup> British Columbia’s Representation Agreement Act, for example, was passed in 1996.

<sup>132</sup> Kohn et al., *supra* note 11, at 1118.

<sup>133</sup> *Id.* at 1141–1143.



resulted in a decrease in the number of individuals under some form of guardianship?

As compared to individuals under guardianship and individuals who do not have access to supported decision-making, do individuals who participate in supported decision-making have better life outcomes (including increased overall health, access to employment and housing, financial security, and reported quality of life)?

Does access to decision-making support vary according to race, income, education, gender, age, type of disability, or the education and income of the individual's family of origin?

Among those jurisdictions that provide supported decision-making services and/or recognize supported decision-making relationships, which have proven most successful at decreasing rates of guardianship, increasing access to supports, and promoting favorable life outcomes? Which factors are driving any differences across jurisdictions?

#### IV. CONCLUSION

The right to have the final say in important decisions concerning one's own life—such as housing, employment, and what to do during the day—is an essential part of adulthood. Many people with disabilities may need support in order to make important decisions. Instead of providing such support, however, guardianship systems in the United States respond by revoking individuals' decision-making rights and granting them to third parties.

Past efforts to limit guardianship, without increasing access to other forms of decision-making supports, have failed to help people with significant support needs. As a result, policymakers must promote programs and legislation to ensure availability of supported decision-making as an alternative to guardianship. Medicaid and state-funded supported decision-making services, such as financial coaching, health care coaching, and person-centered planning, will ensure that individuals can access the supported decision-making model even if they lack an existing informal network capable of providing such support. Legal recognition of supported decision-making arrangements, including recognition of the enforceability of decisions made with support, will provide individuals with a convenient means of establishing support relationships and the security of knowing that their decisions will not be called into question or invalidated at some later date. States should ensure that agencies disseminate accurate information about alternatives to guardianship, including supported decision-making, instead of routinely recommending guardianship as a tool for families to assist their loved ones with disabilities. Finally, states should compile data on the outcomes of these policy changes, including service utilization rates and the effect of policies on guardianship rates and on various quality of life indicators.

# GRANDMA GONE WIRED: THE PROS, CONS, AND ALTERNATIVES OF MEDICALLY MONITORING THE ELDERLY

*Sushil Preet K. Cheema* \*

## I. INTRODUCTION

At 6:30 a.m., Fran DiNapoli's cellphone starts buzzing in Chicago.<sup>1</sup> It is a text message alert, notifying Fran that the front door at her eighty-year-old mother Rose's home in Bradenton, Florida, has opened, well before 7:00 a.m. when Rose usually leaves to retrieve the newspaper from the driveway. Fran immediately calls her mother, but she finds there is no cause for alarm: Rose had spotted a woodpecker from the window and simply wanted to observe it up close. No, she is not going anywhere but back into the house to read the paper, watch the morning news shows, play some online word games, and enjoy digital pictures on a touchscreen device. Later in the day, the same device will remind Rose to take her medications and will let Fran know if her mother's house is getting too hot or too cold.

Though she suffered a brain aneurysm several years ago and now has occasional seizures, Rose, a widow, wants to stay in Bradenton—she has no intention of leaving the home in which she raised her daughter to live in an assisted care facility or to move in

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<sup>1</sup> This fictional story was inspired in part by a 2010 *New York Times* article by Eric A. Taub, and a 2011 *Los Angeles Times* article by Walter Hamilton. Eric A. Taub, *The Technology for Monitoring Elderly Relatives*, [http://www.nytimes.com/2010/07/29/garden/29hometech.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2010/07/29/garden/29hometech.html?pagewanted=all&_r=0) (last visited July 29, 2015); Walter Hamilton, *Elder care goes high tech*, <http://articles.latimes.com/2011/jun/17/business/la-fi-boomer-homes-20110617> (last visited July 29, 2015).

with her daughter more than 1,000 miles away in the cold Midwest. At first she was resistant to the idea of cameras and other technological devices monitoring her every move, and, after someone stole her credit card information and ran up a huge bill, she worried about her privacy being breached in a similar way. But she conceded to the electronic monitoring system because it allows her to age in place<sup>2</sup>—and because it provides Fran with some peace of mind, as she no longer feels the need to call and check in constantly. If something goes wrong or seems awry, Fran can rely on the technology in place to alert her. Additionally, if Rose falls, she can simply press a button on the wristlet she wears to alert local emergency services that she needs help.

The rapid development of technology that allows elders like Rose to age in place is a comfort to family members who live far away and who cannot check in on a loved one personally.<sup>3</sup> The technology also allows the elders themselves a degree of autonomy and self-sufficiency they might not otherwise have had.<sup>4</sup> However, such technology poses some problems: What if the devices fail? What if hackers get access to the sensitive healthcare information the devices contain? What are the implications of autonomy on elders' emotional health? Thus, although wearable GPS devices and smart-home technology<sup>5</sup> provide elders like Rose with a degree of freedom and enable them to live on their own, this article argues that the use of such devices should be minimized to protect individuals from hackers, to preserve the right to privacy, and to prevent social isolation.

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<sup>2</sup> To "age in place" means "remaining living in the community, with some level of independence, rather than in residential care." James L. Wiles et al., *The Meaning of 'Aging in Place' to Older People*, 52 GERONTOLOGIST 357, 357 (2011).

<sup>3</sup> See generally Taub, *supra* note 1.

<sup>4</sup> *Id.*

<sup>5</sup> "Smart homes" are those outfitted with intricate connectivity that allows owners to turn on or activate lights, televisions, and other gadgets from afar. Kashmir Hill, *When 'Smart Homes' Get Hacked: I Haunted a Complete Stranger's House via the Internet*, FORBES (July 26, 2013, 9:15 AM), <http://www.forbes.com/sites/kashmirhill/2013/07/26/smart-homes-hack/>.

Part II of this Article looks at current demographics and the expanding elder population in the United States. It examines the need to monitor any population at all and explores why such monitoring of the elderly is helpful. It also considers the rapid development in healthcare devices and elder-monitoring systems that has taken place over nearly three decades. Part III further explores the problems associated with monitoring elders. The final part concludes by offering alternatives that will not be so detrimental but will still keep elders safe.

## *II. HISTORICAL BACKGROUND*

Over the last few decades, the demographics of the United States have shifted significantly, creating a large elder population. This part first looks at the numbers behind the population change and then explores why monitoring elderly and disabled people is necessary. The last section of this part looks at the development of devices targeted directly at the elderly and how they have changed over time.

### *A. Demographics*

It is no secret that the American population is getting older. In the 2010 census, more people reported being over the age of 65 than in any other previous census.<sup>6</sup> That age group increased by more than 9 million people in just two decades: in 1990, it numbered 31.2 million and in 2010 jumped to 40.3 million.<sup>7</sup> In 2011, more than 41 million people, or about 13.3% of the population, was aged 65 or more, according to the Administration

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<sup>6</sup> Carrie A. Werner, *The Older Population: 2010*, <http://www.census.gov/content/dam/Census/library/publications/2011/dec/c2010br-09.pdf> (last visited July 29, 2015).

<sup>7</sup> *Id.* at 3.

on Aging.<sup>8</sup> That age group is projected to grow to nearly 80 million people by 2040, or 21% of the population, and 92 million people by 2060.<sup>9</sup> Further, those people aged 85 or more will likely number 14.1 million people by 2040, triple the 5.7 million in that age group in 2011.<sup>10</sup>

According to the Administration on Aging, a “relatively small” percentage<sup>11</sup> of the population aged 65 or more in 2011 lived in an institutional setting, but the agency noted that the “percentage increases with age,” from 1% for those aged 65 to 74, to 3% for those aged 75 to 84, and 11% for those 85 or older.<sup>12</sup> In 2012, a majority of older Americans not living in institutions lived with a spouse.<sup>13</sup> However, as age increases, the likelihood of living alone also increases, particularly for women; in fact, only 32% of women over the age of 75 lived with a spouse in 2012.<sup>14</sup> Of those living outside an institution, about 28%, or 11.8 million people, lived alone.<sup>15</sup> The chances of living alone increase with age, with women more likely to be in such a condition than men, particularly since women tend to live longer than men.<sup>16</sup>

As people age, their chances of developing a disability also increase.<sup>17</sup> The American Community Survey by the U.S. Census categorizes disabilities as a hearing difficulty,<sup>18</sup> a vision

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<sup>8</sup> U.S. Dep’t of Health & Human Servs., *A Profile of Older Americans: 2012*, [http://www.aoa.gov/Aging\\_Statistics/Profile/2012/docs/2012profile.pdf](http://www.aoa.gov/Aging_Statistics/Profile/2012/docs/2012profile.pdf) (last visited July 29, 2015).

<sup>9</sup> *Id.*

<sup>10</sup> *Id.*

<sup>11</sup> *Id.* The specific number is 15 million people or 3.6% of the population aged at least 65. *Id.*

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> *Id.*

<sup>15</sup> *Id.*

<sup>16</sup> *Id.* “About 28% (11.8 million) of all noninstitutionalized older persons in 2012 lived alone (8.4 million women, 3.5 million men). They represented 36% of older women and 19% of older men. The proportion living alone increases with advanced age. Among women aged 75 and over, for example, almost half (46%) lived alone.” *Id.*

<sup>17</sup> Wan He & Luke J. Larsen, *Older Americans with a Disability 2008–2012: American Community Survey Reports*, <http://www.census.gov/content/dam/Census/library/publications/2014/acs/acs-29.pdf> (last visited July 29, 2015).

<sup>18</sup> *Id.* A hearing difficulty means being “deaf or having serious difficulty hearing.” *Id.*

difficulty,<sup>19</sup> a cognitive difficulty,<sup>20</sup> an ambulatory difficulty,<sup>21</sup> a self-care difficulty,<sup>22</sup> or an independent living difficulty.<sup>23</sup> While individuals who were either born with a disability or developed one early in life previously died by their thirties, they are now living longer, creating a new set of difficulties as they age since more social services and medical services are needed to accommodate them.<sup>24</sup>

Though advances in medical technology have made treatment for these disabilities possible, the fact remains that people need more help with their daily activities as they age.<sup>25</sup> Among these activities are those of daily living, such as eating, dressing, toileting, or bathing, as well as instrumental activities of daily living, such as meal preparation, money management, and shopping.<sup>26</sup> Many older Americans want to age in place despite such problems with aging.<sup>27</sup> But despite the difficulties of aging in place, the alternative is to use facilities and related resources, which simply cannot support a large population of elders.<sup>28</sup>

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<sup>19</sup> *Id.* A vision difficulty means being “blind or having serious difficulty seeing, even when wearing glasses.” *Id.*

<sup>20</sup> *Id.* A cognitive difficulty means that a person has “difficulty remembering, concentrating, or making decisions” because of “a physical, mental, or emotional problem.” *Id.*

<sup>21</sup> *Id.* An ambulatory difficulty means “having serious difficulty walking or climbing stairs.” *Id.*

<sup>22</sup> *Id.* A self-care difficulty means “having difficulty bathing or dressing.” *Id.*

<sup>23</sup> *Id.* An independent living difficulty means that a person has “difficulty doing errands alone, such as visiting a doctor’s office or shopping” because of “a physical, mental, or emotional problem.” *Id.*

<sup>24</sup> William N. Myhill & Peter Blanck, *Disability and Aging: Historical and Contemporary Challenges*, 11 MARQ. ELDER’S ADVISOR 47, 56–57 (2009).

<sup>25</sup> *Id.*

<sup>26</sup> National Cancer Institute, *NCI Dictionary of Cancer Terms*, <http://www.cancer.gov/dictionary?cdrid=430402> (last visited July 29, 2015).

<sup>27</sup> Rodney Harrell et al., *What Is Livable? Community Preferences of Older Adults*, [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/liv\\_com/2014/what-is-livable-report-AARP-ppi-liv-com.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/liv_com/2014/what-is-livable-report-AARP-ppi-liv-com.pdf) (last visited July 29, 2015). “Most members of the 50+ population want to age in their homes and communities.” *Id.*

<sup>28</sup> Marjorie Skubic et al., *A Smart Home Application to Eldercare: Current Status and Lessons Learned*, 17 TECH. & HEALTH CARE 183, 183 (2009).

## B. Why Do We Monitor?

Tools that remotely monitor elders' health and habits are a viable option to preserve their independence and to keep them safe. Such monitoring has already proven effective for other populations. For example, the presence of Global Positioning System, or GPS, technology in cell phones and in cars allows those who have gone missing to be found.<sup>29</sup> Microchipped pets that have had a small device placed under their skin are returned to their owners regularly, even if they have wandered many miles from home.<sup>30</sup> People subject to house arrest are monitored with ankle bracelets in order to make sure they comply with the parameters of their punishment and to keep other people safe.<sup>31</sup> Teenagers fall into a unique category in that they are monitored to keep both themselves and others safe, especially once they are granted the privilege of driving and are on the road.<sup>32</sup>

But when it comes to the elderly, monitoring is useful for an additional number of reasons. Assessing physical and cognitive function can provide caregivers and healthcare providers with information that will allow them to catch early indications of

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<sup>29</sup> Nerissa Knight, *Girl Reported Missing by Mother Reported Safe Thanks to 911 Call*, <http://ktla.com/2014/11/07/girl-reported-missing-by-mother-found-safe-thanks-to-911-call/> (last visited July 29, 2015). In this November 2014 case, emergency officials were able to find and rescue a teenager from a man's San Diego-area home after she called 911 from a cell phone containing a GPS device—even though she did not know where she was. *Id.*

<sup>30</sup> WPVI-TV, *Missing Dog from Arizona Found 1,800 Miles away in Wisconsin*, <http://6abc.com/pets/missing-dog-found-1800-miles-away/516212/> (last visited July 29, 2015). In this February 2015 story, a small Yorkshire Terrier was returned to his owner in Arizona after being “found 1,800 miles away in Wisconsin.” *Id.*

<sup>31</sup> Maya Schenwar, *The Quiet Horrors of House Arrest, Electronic Monitoring, and Other Alternative Forms of Incarceration*, <http://www.motherjones.com/politics/2015/01/house-arrest-surveillance-state-prisons> (last visited July 29, 2015). This article argues that house arrest and monitoring via ankle-bracelet does more harm than traditional forms of incarceration. *Id.*

<sup>32</sup> Lydia Mulvany, *New Devices Monitor Driving, but Trust a Concern for Teens, Parents*, <http://www.jsonline.com/news/traffic/new-devices-monitor-driving-but-trust-a-concern-for-teens-parents-b99127551z1-229457791.html> (last visited July 29, 2015). The line between independence and privacy has been an issue ever since devices were developed to monitor teen driving habits on the road: bad behavior or reckless driving sends an alert to the teen's parents, encouraging the teens not to make mistakes. *Id.* About 20% of public high schools now also use drug tests to monitor students, a measure designed to incentivize students to stay off drugs that has been controversial; a negative result can lead to “loss of extracurricular activities or even expulsion from school.” Schenwar, *supra* note 31.



decline, thereby allowing early interventions to alleviate the problems that arise.<sup>33</sup> For example, falls are a leading cause of injury—even fatality—among older Americans.<sup>34</sup> Sensors can detect “gait patterns, walking speed, balance, posture, and detection of falls” and can also show the location of the elder in the home.<sup>35</sup> Such technology thus allows for better healthcare and for monitoring a vulnerable person who is alone.

### C. Development of Devices for the Elderly

It was not long ago that LifeCall,<sup>36</sup> an emergency medical device memorable for its “I’ve fallen, and I can’t get up!” commercials,<sup>37</sup> seemed to be the only elder-care device available on the market. The device itself consists of a small pendant worn around the neck or a wrist with a button that, when pushed, contacts emergency personnel in the event of a fall or other medical emergency, regardless of whether the person can reach a telephone.<sup>38</sup>

Since LifeCall’s founding in 1987, however, the elder-care device market has expanded rapidly. The market for so-called advanced patient monitoring systems is expected to reach \$20.9 million in 2016, largely due to accommodation of an aging

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<sup>33</sup> Skubic et al., *supra* note 28, at 183. In a study of TigerPlace, an “aging-in-place” facility in Columbia, Mo., researchers found that the use of technology, including motion sensors, video sensors, and bed sensors, showed an increase in residents functional ability. *Id.* at 184.

<sup>34</sup> Ctrs. for Disease Control & Prevention, *Check for Safety: A Home Fall Prevention Checklist for Older Adults*, <http://www.cdc.gov/HomeandRecreationalSafety/Falls/CheckListForSafety.html> (last visited July 29, 2015). In 2002, nearly 13,000 older adults suffered from fatal falls in the U.S., and an additional 1.67 million older adults were treated in emergency rooms for falls. *Id.*

<sup>35</sup> Skubic et al., *supra* note 28, at 189.

<sup>36</sup> *LifeCall*, <http://lifecall.com/> (last visited July 29, 2015).

<sup>37</sup> YouTube.com, *LifeCall Commercial: “I’ve Fallen and I Can’t Get Up!”* <https://www.youtube.com/watch?v=bQlpDiXPZHQ> (last visited July 29, 2015). Note: this video was not posted by LifeCall itself but rather by a random Internet user.

<sup>38</sup> *LifeCall*, *supra* note 36.

population, reduction of costs in healthcare, and efforts to ease emergency-room crowding.<sup>39</sup> Today, there are a variety of products available to measure a range of elder activities,<sup>40</sup> ranging from dispensers that show whether a person has taken his or her medications<sup>41</sup> to canes that help predict falls.<sup>42</sup> The electronics market also includes more comprehensive systems like grandCARE Systems,<sup>43</sup> which monitors the elder's activities, including whether he or she has gotten out of bed, whether he or she is pacing and becoming confused, and whether he or she has opened doors in the home.<sup>44</sup> Other devices can even measure the elder's health needs, such as glucose levels<sup>45</sup> and blood pressure for patients with diabetes or obesity.<sup>46</sup>

<sup>39</sup> Nicole Lewis, *Remote Patient Monitoring Market to Double by 2016*, <http://www.informationweek.com/mobile/remote-patient-monitoring-market-to-double-by-2016/d-id/1105484> (last visited July 29, 2015). In 2007, the market was \$3.9 billion, and in 2011, it was \$8.9 billion. *Id.*

<sup>40</sup> Taub, *supra* note 1.

<sup>41</sup> One example is the Philips Medication Dispensing Service. *The New York Times* described the device in a 2010 article as

a tabletop ... machine [that] can be loaded with up to 60 doses of medication, each contained in a small plastic cup. When programmed by a nurse or family member, the dispenser will remind users with a spoken message that their medication is ready. Pushing a button releases a dosage cup into a tray. If, after 90 minutes of reminders, the button is not pushed, the device sends a message to a designated caregiver.

Taub, *supra* note 1. The article notes that it is not possible to determine whether the user actually has taken the pills, only whether the button dispensing them was pushed. *Id.* Together, the device and service cost \$75 a month. *Id.*

<sup>42</sup> Jonah Comstock, *UCLA Partners with Startup to Build Smart, Connected Cane*, <http://mobihealthnews.com/27694/ucla-partners-with-startup-to-build-smart-connected-cane/> (last visited July 29, 2015). The University of California at Los Angeles's Wireless Health Institute and startup Isowalk have teamed up to develop a cane that will monitor gait and help predict falls. *Id.* Additionally, Fujitsu has developed the "Next Generation Cane" to serve not only as a navigation device but also track temperature and heart rate. BBC News, *Fujitsu Makes 'Smart Walking Stick' to Help Elderly*, <http://www.bbc.com/news/technology-21620624> (last visited July 29, 2015). Falls are a problem for one of three adults over the age of 65 and can lead to hip fractures and head traumas, among other injuries. Ctrs. for Disease Control and Prevention, *Older Adult Falls: Get the Facts*, <http://www.cdc.gov/homeandrecreationalsafety/falls/adultfalls.html> (last visited July 29, 2015).

<sup>43</sup> *grandCARE Systems*, <http://www.us.grandcare.com/> (last visited July 29, 2015).

<sup>44</sup> Taub, *supra* note 1. This *New York Times* article describes how one woman monitors her mother's activities using the grandCARE System and how she will be able to adjust the parameters it measures as her mother's needs change. *Id.*

<sup>45</sup> Libor Safar, *Translating Medical Devices of the Future*, MULTILINGUAL, 44, 44 (2014). Google and pharmaceutical company Novartis have developed a prototype of a contact lens that contains "electronics thinner than a human hair" and measures glucose levels in tears. *Id.*

<sup>46</sup> IDEAL Life, *About*, <http://ideallifeonline.com/aboutus/> (last visited July 29, 2015).

While implantable medical devices, such as pacemakers, defibrillators, and cochlear implants, have long been in use, they are being transformed into wireless gadgets that transmit information to computers and other devices.<sup>47</sup> Former Microsoft software developer Ramez Naam has even proposed taking the idea of implantable medical devices, or IMDs, further, suggesting that RFID chip implantation be used to monitor the location of elders who have Alzheimer's disease.<sup>48</sup> On another end of the device spectrum are online games such as one developed by Oregon Center for Aging & Technology at Oregon Health and Science University with help from Intel Corp. that can help keep track of cognitive abilities and potential abnormalities by monitoring keystrokes and typos.<sup>49</sup> So, technology can not only help track elders' health, but also actively help detect cognitive decline.

### III. ANALYSIS: THE PROBLEMS THAT STEM FROM MONITORING

Despite the boom in technology and the arguments for implementing and expanding its use, there are several problems with having devices that store or transmit medical data or information related to a person's habits. Among these troubling issues are the risk of sensitive information being hacked, the problem of invasions of privacy, and the dangers of social isolation.

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<sup>47</sup> Marc Goodman, *Who Does the Autopsy?*, [http://www.slate.com/articles/technology/future\\_tense/2015/03/implantable\\_medical\\_devices\\_hacking\\_who\\_does\\_the\\_autopsy.html](http://www.slate.com/articles/technology/future_tense/2015/03/implantable_medical_devices_hacking_who_does_the_autopsy.html) (last visited July 29, 2015). This article suggests that criminals may target these devices for "financial gain, for attention, or simply to cause fear." *Id.*

<sup>48</sup> John Brandon, *Is There a Microchip Plant in Your Future?*, <http://www.foxnews.com/tech/2014/08/30/is-there-microchip-implant-in-your-future/> (last visited July 29, 2015). Such methods of chip implantation with GPS monitoring devices or for storing medical records have long been controversial. *Id.*

<sup>49</sup> Hamilton, *supra* note 1.

### A. Hacking and Cyber Security

Hackers' capabilities reach new heights regularly, as evidenced by several high-profile cases involving foreign governments attacking Hollywood;<sup>50</sup> British tabloid reporters targeting missing children,<sup>51</sup> celebrities, and royals;<sup>52</sup> and unknown foreign groups using malware to steal from financial institutions across the globe.<sup>53</sup> The U.S. government has even spied on its own citizens, collecting data on Internet and phone use.<sup>54</sup>

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<sup>50</sup> Michael S. Schmidt, Nicole Perlroth & Matthew Goldstein, *F.B.I. Says Little Doubt North Korea Hit Sony*, <http://www.nytimes.com/2015/01/08/business/chief-says-fbi-has-no-doubt-that-north-korea-attacked-sony.html> (last visited July 29, 2015). One of the most recent hacking scandals targeted Hollywood: early in 2015, the F.B.I. held North Korea responsible for the November 2014 hacking of Sony Pictures. *Id.* North Korea was allegedly upset that a Sony movie, *The Interview*, portrayed the assassination of the North Korean president. *Id.* The scandal included the release of "embarrassing" email messages exchanged by studio executives, as well as information about the executives' salaries. Martin Fackler, *North Korea Warns U.S. Not to Take Sony Action*, <http://www.nytimes.com/2014/12/21/world/asia/north-korea-denying-sony-attack-proposes-joint-investigation-with-us.html> (last visited July 29, 2015). President Obama chastised Sony for deciding to withhold *The Interview*, "saying that it had created a precedent of studios giving in to intimidation." *Id.*

<sup>51</sup> Nick Davies & Amelia Hill, *Missing Milly Dowler's Voicemail Was Hacked by News of the World*, <http://www.theguardian.com/uk/2011/jul/04/milly-dowler-voicemail-hacked-news-of-world> (last visited July 29, 2015). Rupert Murdoch's British tabloid *The News of the World* found itself on the wrong side of headlines in 2011 when daily newspaper *The Guardian* revealed that the tabloid's editors and reporters had hacked into the voicemail of a missing teenager, deleting messages and consequently giving her family "false hope" that she was still alive. *Id.*

<sup>52</sup> Katrin Bennhold & Alan Cowell, *Ex-Tabloid Executive Acquitted in British Phone Hacking Case*, [http://www.nytimes.com/2014/06/25/world/europe/rebekah-brooks-found-not-guilty-in-phone-hacking-case.html?ref=topics&\\_r=1](http://www.nytimes.com/2014/06/25/world/europe/rebekah-brooks-found-not-guilty-in-phone-hacking-case.html?ref=topics&_r=1) (last visited July 29, 2015). The subsequent investigation into the now-defunct tabloid's standard practices revealed that it routinely "eavesdropped on" and accessed voicemails of celebrities and politicians to get scoops. *Id.* Rebekah Brooks, the tabloid's former executive, and Andy Coulson, the former deputy at the tabloid, were acquitted of charges against them in 2014. *Id.* One phone-hacking victim, actor Sadie Frost, testified that she became a "nervous wreck," even suspecting her own mother of selling stories to the press. Josh Halliday, *Sadie Frost: Phone Hacking Wrecked My Life*, <http://www.theguardian.com/uk-news/2015/mar/12/sadie-frost-phone-hacking-wrecked-my-life-mirror> (last visited July 29, 2015).

<sup>53</sup> David E. Sanger & Nicole Perlroth, *Bank Hackers Steal Millions via Malware*, <http://www.nytimes.com/2015/02/15/world/bank-hackers-steal-millions-via-malware.html> (last visited July 29, 2015). In February 2015, Moscow-based cybersecurity firm Kaspersky Lab reported that "more than 100 banks and other financial institutions in 30 nations" had been victims of an elaborate bank theft involving malware that monitored the institutions' internal computers and employees' work on them. *Id.* The hackers hail from Russia, China, and Europe and have stolen at least \$300 million from financial institutions and banks in Russia, Japan, Switzerland, the Netherlands, and the U.S. *Id.*

<sup>54</sup> Biography.com, *Edward Snowden Biography*, <http://www.biography.com/people/edward-snowden-21262897#aftermath> (last visited July 29, 2015). Edward Snowden, a former employee of the National Security Agency, or NSA, collected data on the agency's monitoring of citizens'

Hacking scandals have not yet been seen in the medical-device industry. However, the danger of such incidents is a real one,<sup>55</sup> as hackers become increasingly sophisticated and target an increasingly wide range of industries, including healthcare. Since 2009, healthcare providers and organizations have reported more than 1,150 healthcare data breaches to the Department of U.S. Health and Human Services' Office of Civil Rights.<sup>56</sup> Those breaches—which include theft of laptops and desktop computers, loss of papers, and hacking of network servers<sup>57</sup>—have affected more than 41 million people.<sup>58</sup> In March 2015, an attack on Premiera Blue Cross became the “largest cyberattack involving medical information to date,” affecting 11 million people.<sup>59</sup> Additionally, an attack on health-insurance giant Anthem<sup>60</sup> exposed health records of nearly 80 million customers and employees of the company, which owns and operates Blue Cross

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Internet and phone use. *Id.* Hailed as a traitor by some and a hero by others, he currently lives in Russia while the U.S. seeks extradition. *Id.* In March 2015, online encyclopedia Wikipedia sued NSA in an effort to protect its users. Jimmy Wales & Lila Tretikov, *Stop Spying on Wikipedia Users*, [http://www.nytimes.com/2015/03/10/opinion/stop-spying-on-wikipedia-users.html?smid=nytnow-share&smprod=nytnow&\\_r=0](http://www.nytimes.com/2015/03/10/opinion/stop-spying-on-wikipedia-users.html?smid=nytnow-share&smprod=nytnow&_r=0) (last visited July 29, 2015). “We’re doing so because a fundamental pillar of democracy is at stake: the free exchange of knowledge and ideas,” site founder Jimmy Wales wrote in a *New York Times* op-ed. *Id.*

<sup>55</sup> Safar, *supra* note 45, at 45.

<sup>56</sup> U.S. Health & Human Serv. Office for Civil Rights, *Breaches Affecting 500 or More Individuals*, [https://ocrportal.hhs.gov/ocr/breach/breach\\_report.jsf](https://ocrportal.hhs.gov/ocr/breach/breach_report.jsf) (last visited Aug. 1, 2015).

<sup>57</sup> *Id.*

<sup>58</sup> Charles Ornstein, *Fines Remain Rare Even as Health Data Breaches Multiply*, <http://www.propublica.org/article/fines-remain-rare-even-as-health-data-breaches-multiply> (last visited Aug. 1, 2015). Despite the high number of incidents and large number of people affected, few penalties have been imposed. *Id.*

<sup>59</sup> Shirley Li, *The Next Cybersecurity Target: Medical Data*, <http://www.theatlantic.com/technology/archive/2015/03/the-next-cybersecurity-target-medical-data/388180/> (last visited Aug. 1, 2015). A recent report on cyber risks from Intel Security and Atlantic Council indicates that “44 percent of all registered data breaches in 2013 targeted medical companies, with the number of breaches increasing 60 percent between 2013 and 2014.” Jason Healey, et al., *The Healthcare Internet of Things: Rewards and Risks*, <http://www.mcafee.com/us/resources/reports/rp-healthcare-iot-rewards-risks.pdf> (last visited Aug. 1, 2015).

<sup>60</sup> Anne Wilde Matthews, *Anthem: Hacked Database Included 78.8 Million People*, <http://www.wsj.com/articles/anthem-hacked-database-included-78-8-million-people-1424807364> (last visited Aug. 1, 2015).

Blue Shield in several states.<sup>61</sup> In 2014, the United States saw 783 data breaches, with 42.5% of those incidents targeting the medical and healthcare industry, according to the Identity Theft Resource Center.<sup>62</sup> While victims of retail hacking often get almost instant notification of the attack and can immediately have their credit cards cancelled to prevent unwanted charges, the victims of medical hacking may face a year of waiting before their medical records are cleared up.<sup>63</sup>

Healthcare hacks give the attackers access not only to credit information but also to health history, lab results, social security numbers, and security pins.<sup>64</sup> The Michigan-based Ponemon Institute, which studies “privacy, data protection, and information security policy,”<sup>65</sup> said, in March 2014, that “criminal attacks on healthcare organizations have risen a startling 100 percent since we first conducted the study in 2010.”<sup>66</sup> Many factors have led to increased security risks in the healthcare space, including the requirement that healthcare providers either shift to electronic medical records or face strict penalties.<sup>67</sup> Despite the requirement, the “government’s own research and officials acknowledge [the technology] needs major improvement.”<sup>68</sup>

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<sup>61</sup> Anthem, *About Us*, <https://www.anthem.com/health-insurance/about-us/anthem-overview> (last visited Aug. 1, 2015). The states include Colorado, Nevada, Connecticut, Georgia, Indiana, Kentucky, Maine, Missouri, New Hampshire, Ohio, Virginia, and Wisconsin. *Id.*

<sup>62</sup> Identity Theft Resource Center, *Identity Theft Resource Center Breach Report Hits Record High in 2014*, <http://www.idtheftcenter.org/ITRC-Surveys-Studies/2014databreaches.html> (last visited Aug. 1, 2015).

<sup>63</sup> Marguerite McNeal, *Hacking Health Care*, <https://www.ama.org/publications/MarketingHealthServices/Pages/hacking-healthcare-fall-2014.aspx> (last visited Aug. 1, 2015). In one case, a man received a bill “for a \$44,000 surgery that he never received.” *Id.*

<sup>64</sup> *Id.*

<sup>65</sup> Ponemon Institute, <http://www.ponemon.org/> (last visited Aug. 1, 2015).

<sup>66</sup> Ponemon Institute, *Fourth Annual Benchmark Study on Patient Privacy & Data Security*, <http://lpa.idexperts.com/action/attachment/6200/f-012c/1/> (last visited Aug. 1, 2015).

<sup>67</sup> McNeal, *supra* note 63. In January, the American Medical Association, or AMA, led a group of 37 medical societies in sending a letter to the Department of Health and Human Services, stating that “today’s electronic records systems are cumbersome, decrease efficiency and, most importantly, can present safety problems for patients.” Laura Ungar & Jayne O’Donnell, *Feds move into digital medicine, face doctor backlash*, <http://www.usatoday.com/story/news/nation/2015/02/01/backlash-against-electronic-medicalrecords/21693669/> (last visited Aug. 1, 2015).

<sup>68</sup> Ungar, *supra* note 67. At the same time, even critics say that such technology is the wave of the future. *Id.*

It is not just hacking that causes a problem in healthcare—the theft of physical devices holding the sensitive health data can also cause problems. In 2013, the data of nearly 730,000 patients of California-based AHMC Healthcare Inc. was compromised when two password-protected laptops were stolen.<sup>69</sup> AHMC stated that “the computers contained data including patients’ names, Medicare/insurance identification numbers, diagnosis/procedure codes and insurance/patient payment records.”<sup>70</sup> Additionally, “[s]ome of the files contained Social Security numbers of Medicare patients.”<sup>71</sup>

In an interesting twist, some medical-device users have even been hacking their own devices to make them more efficient.<sup>72</sup> In one case, tech-savvy parents of diabetic children using glucose monitors made by continuous-glucose-monitoring company Dexcom<sup>73</sup> have created a way to transmit the information over the Internet, allowing parents to monitor their children’s blood-sugar levels from afar.<sup>74</sup> Such alteration of the device has concerned the FDA, among others, particularly because “devices need to work predictably and be comprehensible to patients who aren’t schooled in technology,” especially when the patients rely on alarm prompts that must work consistently and effectively.<sup>75</sup>

As homes increasingly become outfitted with medical and other technology devices, the threat of hacking becomes more and

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<sup>69</sup> Richard Winton, *Laptop Thefts Compromise 729,000 Hospital Patient Files*, <http://articles.latimes.com/2013/oct/21/local/la-me-hospital-theft-20131022> (last visited Aug. 1, 2015).

<sup>70</sup> *Id.*

<sup>71</sup> *Id.*

<sup>72</sup> Kate Linebaugh, *Citizen Hackers Tinker with Medical Devices*, <http://www.wsj.com/articles/citizen-hackers-concoct-upgrades-for-medical-devices-1411762843> (last visited Aug. 1, 2015).

<sup>73</sup> Dexcom, <http://www.dexcom.com/> (last visited Aug. 1, 2015).

<sup>74</sup> *Id.*

<sup>75</sup> *Id.*

more real, as evidenced by hacks on smart homes, or homes outfitted with technology that makes it easy to turn on or activate lights, televisions, and other gadgets from afar.<sup>76</sup> In 2013, a *Forbes* reporter woke a smart-home owner in Oregon and turned on and off his bedroom lights from her home in San Francisco for a story.<sup>77</sup> The smart home's connectivity allowed the reporter to trace its location—and that of seven others—quite easily.<sup>78</sup> In other instances, hackers have demonstrated their ability to open garage doors and pick locks from afar—an easy feat when the devices are connected to the Internet.<sup>79</sup> With such vulnerabilities in existing home technology, medical devices used to outfit homes—and elders—need to be designed with anti-hacking measures in place.<sup>80</sup>

## B. The Troubles of Privacy and Consent

In addition to examining the dangers hackers pose, discussions of medical monitoring devices for the elderly also need to include reflections on invasions of privacy. Though the idea of a right to privacy is relatively new in American jurisprudence, the idea of such privacy has long existed. In their well-known and well-regarded 1891 *Harvard Law Review* article simply titled, "The Right to Privacy," Samuel Warren and Louis Brandeis argued that technological advances had led to more intrusions into areas of

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<sup>76</sup> Hill, *supra* note 5. In some bizarre instances, baby monitors have been hacked, allowing hackers to watch—and frighten—young children, as well as their parents and other caregivers. Rachel Bertsche, *Nanny Freaks as Baby Monitor Is Hacked*, <https://www.yahoo.com/parenting/nanny-freaks-as-baby-monitor-is-hacked-109405425022.html> (last visited Aug. 1, 2015); *See also* Chenda Ngak, *Baby Monitor Hacked, Spies on Texas Child*, <http://www.cbsnews.com/news/baby-monitor-hacked-spies-on-texas-child/> (last visited Aug. 1, 2015) (in this instance a hacker cursed at and made sexually explicit comments to a sleeping child via a baby monitor that her parents had set up in her bedroom).

<sup>77</sup> Hill, *supra* note 5.

<sup>78</sup> *Id.*

<sup>79</sup> Danny Yadron, *Hackers Expose How Connected Toilets, Heaters and Lightbulbs Are at Risk*, <http://www.wsj.com/articles/SB10001424127887323997004578640310932033772> (last visited Aug. 1, 2015). When a *Wall Street Journal* reporter asked Korean hacker Seung Jin Lee how consumers could prevent hackers from targeting a smart TV, Mr. Lee responded, "Just unplug." *Id.*

<sup>80</sup> It should be noted that anti-failure measures should also be implemented—if a glucose-monitoring device fails, for example, a user could fall into a potentially fatal situation. Linebaugh, *supra* note 72. Additionally, the failure of a device that monitors when a door opens and closes to send an alert when unusual activity occurs could lead to an elder wandering. *Id.*



life that were once inaccessible; such interferences, they said, needed to be curbed, that the law needed to evolve appropriately to keep up with changes in technology that allowed these invasions.<sup>81</sup> In the article, the authors advocated for private citizens having a right to maintain their privacy, up to the point at which they consented to their intimate lives being made public.<sup>82</sup> They wrote, “The general object in view is to protect the privacy of private life, and to whatever degree and in whatever connection a man’s life has ceased to be private, before the publication under consideration has been made, to that extent the protection is to be withdrawn.”<sup>83</sup> Thus, only those aspects of private life that an individual has actively made public of his or her own volition should be disclosed.

One realm of privacy that applies directly to family members monitoring elders in their homes is intrusion, a “vaguely defined tort”<sup>84</sup> that is generally held to consist of the “right to be left alone.”<sup>85</sup> One case has even called such intrusion “an affront to

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<sup>81</sup> Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 194–97 (1890).

<sup>82</sup> *Id.* at 215.

<sup>83</sup> *Id.*

<sup>84</sup> See *Bauer v. Ford Motor Credit Co.*, 149 F. Supp. 2d 1106, 1111 (D. Minn. 2001) (“The court must give special regard to the circumstances under which the alleged intrusion occurred, and the expectations that a reasonable person would have under such circumstances.”); *Peterson v. Idaho First Nat. Bank*, 367 P.2d 284, 287 (1961) (stating that the tort of invasion of privacy is “primarily a mental one. It has been useful chiefly to fill the gaps left by trespass, nuisance, the intentional infliction of mental distress, and whatever remedies there may be for the invasion of constitutional rights.”).

<sup>85</sup> *Shorter v. Retail Credit Co.*, 251 F. Supp. 329, 331 (D.S.C. 1966). The case states that “the ‘right to be left alone’ might be thought of as a complex of several torts rather than just one, specifically: elements of this tort include ‘(1) appropriation of the plaintiff’s name or likeness (exploitation of the personality); (2) public disclosure of private fact; (3) intrusion of something secret, secluded, or private pertaining to the plaintiff.’” *Id.* at 330.

individual dignity.”<sup>86</sup> It is widely accepted that the intrusion, to be actionable,<sup>87</sup> must be “highly offensive to a reasonable person.”<sup>88</sup>

Intrusion becomes an issue in the context of monitoring elders because video cameras that shows a person’s location in his or her home or devices that monitor behaviors such as opening drawers and doors could be considered offensive since they prevent an elder from engaging in any private actions at all. This idea becomes particularly offensive when an individual’s most private behaviors, such as toileting and bathing, are monitored. These issues are most troubling when an elder has not been informed about the installation of such cameras and monitoring devices and thus has not consented to having personal behaviors recorded and transmitted to family members or third parties.<sup>89</sup> Additionally, users may sign away their rights to privacy and allow third parties to access the data they transmit simply because they fail to read the lengthy Terms of Use before agreeing to them.<sup>90</sup> Consent may be express or “implied from the conduct of the parties and the surrounding circumstances.”<sup>91</sup> Surely an elder who willingly wears a monitoring device fully knowing and understanding that it is designed to track heart rate or movement or who consents to sleeping in a bed outfitted with a device that

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<sup>86</sup> Shulman v. Group W. Prods., Inc., 955 P.2d 469, 489 (Cal. 1998).

<sup>87</sup> See *Nagy v. Bell Tel. Co. of Pa.*, 292 Pa. Super. 24, 30 (Pa. Super. Ct. 1981) (“An act which constitutes a tortious invasion of privacy must be committed ‘in such a manner as to outrage or cause mental suffering, shame or humiliation to a person of ordinary sensibilities.’” *Id.* at 31 (quoting *Hull v. Curtis Publ’g Co.*, 182 Pa. Super. 86, 99, 125 (Pa. Super. Ct. 1956)).

<sup>88</sup> RESTATEMENT (SECOND) OF TORTS: INTRUSION UPON SECLUSION § 652B and cmt. d (1977).

<sup>89</sup> In *The Right to Privacy* Warren and Brandeis state “[t]he intensity and complexity of life, attendant upon advancing civilization, have rendered necessary some retreat from the world, and man, under the refining influence of culture, has become more sensitive to publicity, so that solitude and privacy have become more essential to the individual; but modern enterprise and invention have, through invasions upon his privacy, subjected him to mental pain and distress, far greater than could be inflicted by mere bodily injury.” Warren, *supra* note 81, at 196. As such, the authors would likely consider elder monitoring, particularly nonconsensual monitoring, to be more egregious behavior than allowing the elder to suffer an injury while unattended.

<sup>90</sup> Rebecca Smithers, *Terms and Conditions: Not Reading the Small Print Can Mean Big Problems*, <http://www.theguardian.com/money/2011/may/11/terms-conditions-small-print-big-problems> (last visited Aug. 1, 2015).

<sup>91</sup> See *Reed v. Real Detective Publ’g Co.*, 162 P.2d 133 (Ariz. 1945); *Cohen v. Marx*, 211 P.2d 320 (Cal. Ct. App. 1949); *Pavesich v. New England L. Ins. Co.*, 50 S.E. 68 (Ga. 1905); *Cont’l Optical Co. v. Reed*, 88 N.E.2d 55 (Ind. Ct. App. 1949); *Martin v. F.I.Y. Theatre Co.*, 1 Ohio Supp. 19 (Ohio C.P. 1938).

measures movement is implicitly consenting to the transmission and review of the information, but the user may believe that he or she alone will have access to the data, not that a family or even an unknown third party will.

Questions of privacy become more complex when elders step outside the home and into government-run facilities such as Veteran's Hospitals. Monitoring elders at government-run nursing facilities, particularly with cameras installed to ensure that staff are not abusing residents, has raised a constitutional issue of privacy in recent years.<sup>92</sup> In one instance, a brain-damaged patient's family's discovery that a video surveillance camera (VSC) had been installed in the patient's hospital room at James A. Haley Veterans' Hospital in Tampa, Florida,<sup>93</sup> led to an internal investigation at the VA.<sup>94</sup> The investigation revealed that "all VA healthcare facilities are currently using VSCs."<sup>95</sup> The VA report stated that in the case of the brain-damaged patient whose surveillance prompted the investigation:

It was expected that the camera would ascertain who or what was interfering with nursing care of the patient, e.g., changing the incline position of the patient's bed, changing the rate of infusion on the patient's feeding and medication pumps, and/or repositioning the patient without orders to do so or apparent explanation. We concluded that given the

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<sup>92</sup> Dep't of Veterans Aff., Office of Inspector Gen., *Healthcare Inspection: Alleged Inappropriate Surveillance James A. Haley Veterans' Hospital Tampa, Florida*, <http://www.va.gov/oig/pubs/VAOIG-12-03939-175.pdf> (last visited Aug. 1, 2015).

<sup>93</sup> *Id.* at ii.

<sup>94</sup> *Id.*

<sup>95</sup> *Id.* The VA report stated that in the case of the brain-damaged patient whose surveillance prompted the investigation. *Id.*

documented evidence, the use of the camera for these patient safety concerns was reasonable.<sup>96</sup>

Despite the seemingly good intentions of the VA system in setting up the camera to protect the patient, its actions arguably violated the Constitutional right to privacy, particularly as it relates to privacy in the home—and when a person is institutionalized, that institution becomes the patient's home.

The right to privacy is not specifically outlined in the U.S. Constitution, but the Fourth Amendment guarantees “the right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures.”<sup>97</sup> While this Amendment offers protection from governmental intrusions, case law has expanded the idea that “at the very core [of the Fourth Amendment] stands the right of a man to retreat into his own home and there be free from unreasonable governmental intrusion.”<sup>98</sup> Additionally, case law has established that “every man's home is his castle,”<sup>99</sup> a place in which he can retreat and be protected from governmental intrusions.<sup>100</sup> While the Fourth Amendment was originally intended to prevent physical invasions upon private property by government officials, the fact remains that the law evolved to accommodate other forms of invasions.<sup>101</sup>

In deciding the 1965 case *Griswold v. Connecticut*,<sup>102</sup> the Supreme Court of the United States determined that a right to privacy and freedom from invasions by state governments also

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<sup>96</sup> *Id.*

<sup>97</sup> U.S. CONST. amend. IV.

<sup>98</sup> *Silverman v. United States*, 365 U.S. 505 (1961).

<sup>99</sup> *Weeks v. United States*, 232 U.S. 383, 389–92 (1913).

<sup>100</sup> *Id.*

<sup>101</sup> Warren, *supra* note 81, at 194–95. As outlined by Samuel D. Warren and Louis D. Brandeis in *The Right to Privacy*, the law has evolved to protect intellectual property, artistic productions, trade secrets, and trademarks, among others. *Id.* The pair particularly emphasized the problems of technological advancements in allowing the press to invade privacy, stating, “[i]nstantaneous photographs and newspaper enterprise have invaded the sacred precincts of private and domestic life; and numerous mechanical devices threaten to make good the prediction that ‘what is whispered in the closet shall be proclaimed from the house-tops.’” *Id.*

<sup>102</sup> *Griswold v. Connecticut*, 381 U.S. 479 (1965).

exists.<sup>103</sup> In that case, the Executive Director of the Planned Parenthood League of Connecticut and a licensed physician who was a professor at Yale Medical School, as well as a Medical Director for the League, were arrested for advising married couples about the proper use of contraception.<sup>104</sup> Connecticut authorities used two statutes in conjunction to arrest the physician and the professor: one provided that anyone who used contraceptive devices would pay a fine or face imprisonment, and the other stated that anyone who “assists, abets, counsels, causes, hires or commands another to commit any offense may be prosecuted and punished as if he were the principal offender.”<sup>105</sup> The appellate court and state supreme court affirmed the convictions.<sup>106</sup>

In its analysis, the Supreme Court of the United States determined that the First,<sup>107</sup> Third,<sup>108</sup> Fourth,<sup>109</sup> Fifth,<sup>110</sup> and Ninth Amendments,<sup>111</sup> read together, create “penumbras” that lead to a right to privacy when applied to the Fourteenth Amendment.<sup>112</sup> It further stated that the *Griswold* case at hand “concerns a relationship lying within the zone of privacy created by several fundamental constitutional guarantees.”<sup>113</sup> It specifically rejected the idea that government should invade upon the privacy of the marital bedroom, stating, “Would we allow the police to search the sacred precincts of marital bedrooms for telltale signs of the use of

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<sup>103</sup> *Id.* at 528–29.

<sup>104</sup> *Id.* at 480.

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> The First Amendment grants citizens the freedom of speech.

<sup>108</sup> The Third Amendment prohibits the government from forcibly quartering troops in private homes.

<sup>109</sup> The Fourth Amendment prohibits unwarranted searches and seizures of private homes.

<sup>110</sup> The Fifth Amendment grants the people freedom from self-incrimination.

<sup>111</sup> The Ninth Amendment covers, very broadly, “other rights.”

<sup>112</sup> *Griswold*, 381 U.S. at 484.

<sup>113</sup> *Id.* at 485.

contraceptives? The very idea is repulsive to the notions of privacy surrounding the marriage relationship.”<sup>114</sup>

Just as the Supreme Court rejected the idea of invading the marital bedroom, it would likely find the use of cameras and electronic monitors in elders’ home or government-run care facilities distasteful, particularly if the elders have not consented to the monitoring of their every move, including toileting, bathing, and other intimate activities. The idea of need for consent comes from the 1891 case of *Union Pacific R.R. v. Botsford*,<sup>115</sup> in which a defendant railroad company requested that the Court require an injured passenger, the plaintiff, to “submit to a surgical examination as to the extent of the injury sued for.”<sup>116</sup> The Court held that it could not compel the plaintiff to undergo such an examination.<sup>117</sup> It specifically stated, “No right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law.”<sup>118</sup>

Thus, as technology continues to advance, the rights and privacy of elders must be protected. The success of the monitoring devices “ultimately . . . depends on receptivity of potential users.”<sup>119</sup> While most elders have welcomed monitoring and sacrificing privacy to enable increased autonomy, many have at the same time rejected video-monitoring,<sup>120</sup> which is arguably the most invasive form of monitoring.<sup>121</sup> In one study of older

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<sup>114</sup> *Id.* at 485–86.

<sup>115</sup> *Union Pacific R.R. v. Botsford*, 141 U.S. 250, 251 (1891).

<sup>116</sup> *Id.*

<sup>117</sup> *Id.*

<sup>118</sup> *Id.*

<sup>119</sup> Linda Boise et al., *Willingness of Older Adults to Share Data and Privacy Concerns After Exposure to Unobtrusive Home Monitoring*, 11 GERONTECHNOLOGY 428, 428 (2013).

<sup>120</sup> *Id.* at 429.

<sup>121</sup> *Id.* Such measures can also be life-saving, as evidenced by the case of Eryetha Mayberry, whose family members installed a camera in the 96-year-old’s nursing-home room and discovered from it that an employee was abusing her. Anita Silvers, *Becoming Mrs. Mayberry: Dependency and the Right to be Free*, 30 HYPATIA 292, 292 (2015). Additionally, in February 2015, Illinois introduced a bill that would allow residents or their family members to install cameras at their own expense to combat elder abuse; however, this bill is controversial because it would potentially invade the

American's attitudes toward being monitored, most did not mind the collection of data and monitoring if it was useful for their doctors, but many did not want to be videotaped in their homes.<sup>122</sup> Many participants in the study also expressed concern that their information may be given to people who did not "have a right to it"<sup>123</sup> or "given to people who would use it to harm" them.<sup>124</sup> However, nearly all study participants were willing to share the data with family members and doctors,<sup>125</sup> suggesting that the elders were comfortable sharing their personal data with those they trust to help monitor their well-being.

### C. The Perils of Social Isolation

Threats of hacking and invasions of privacy are not the only reasons to curb technological monitoring of elders; it should also be limited because it presents problems of social isolation. While it would be nice to think that elders like Rose have more than just digital picture frames and televisions to keep them company—that they have their own forms of social support or are enjoying life at communities built just for them<sup>126</sup>—the reality is that many elders are isolated. As indicated above, about 28% of

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privacy of staff members and other residents, particularly roommates. Wes Venteicher, *Nursing Home Room Monitoring Cameras Would Be Allowed Under Illinois Bill*, <http://www.chicagotribune.com/news/local/breaking/ct-nursing-home-cameras-20150213-story.html> (last visited Aug. 1, 2015). Nursing homes in other states invoke HIPAA, or the Health Insurance Portability and Accountability Act, and argue that these cameras violate federal privacy laws. Paula Span, *In Nursing Homes, Eyes That Never Turn Away*, *New Old Age*, N.Y. Times Blog (Oct. 8, 2014, 12:53 PM), <http://newoldage.blogs.nytimes.com/2014/10/08/in-nursing-homes-eyes-that-never-turn-away/>.

<sup>122</sup> Boise, *supra* note 118, at 431. The percentage of people who were willing to be videotaped dropped from 20% to 7% after one year of such taping. *Id.* Participants' willingness to be monitored—even with the caveat—is likely high because the largely octogenarian participants in the study willingly chose to enroll in the home- and computer-monitoring study. *Id.* at 432.

<sup>123</sup> *Id.* at 431.

<sup>124</sup> *Id.*

<sup>125</sup> *Id.*

<sup>126</sup> Most likely to come to mind is the famed Villages, a retirement community for "active adults" complete with a golf course, movie theaters, houses of worship, and "town squares." The Villages, *Welcome to Our Hometown*, <http://www.thevillages.com/> (last visited Aug. 1, 2015).

those Americans 65 years or older living outside an institution live alone.<sup>127</sup> Although living alone does not automatically equate to social isolation, defined as “the absence of contact with other people,”<sup>128</sup> it does increase the chances of such isolation.<sup>129</sup> Additionally, elders who embrace medical monitoring devices—particularly those extensive setups that monitor their every move within their own homes—are at an increased risk of social isolation and the dangers associated with it because no one is checking in on them in person and providing them with necessary human contact.<sup>130</sup>

According to one study, elders typically make the choice to age in place between the age of 70 and 75.<sup>131</sup> The desire to stay in familiar surroundings often trumps changes in the surrounding community, such as a family, friends, and neighbors moving away—or even dying.<sup>132</sup> Neighborhoods may begin to change dramatically, with houses being replaced by high-rise buildings as the result of gentrification.<sup>133</sup> The study notes, “[t]he potential

<sup>127</sup> U.S. Department of Health & Human Servs., *supra* note 8, at 5.

<sup>128</sup> Annie Hawton et al., *The Impact of Social Isolation on the Health Status and Health-Related Quality of Life of Older People*, 20 QUAL. LIFE RES. 57, 57 (2011). Social isolation is also defined as “objective physical separation from other people, such as living alone or residing in a rural geographic area.” Joe Tomaka, Sharon Thompson & Rebecca Palacios, *The Relation of Social Isolation, Loneliness, and Social Support to Disease Outcomes Among the Elderly*, 18 J. AGING & HEALTH 359, 360 (2006). Loneliness, however, “refers to the more subjective feeling state of being alone, separated or apart from others. Loneliness has also been conceptualized as an unfavorable balance between actual and desired social contact.” *Id.*

<sup>129</sup> Sarah Stevenson, *20 Facts About Senior Isolation That Will Stun You*, Senior Living Blog (Oct. 17, 2014), <http://www.aplaceformom.com/blog/10-17-14-facts-about-senior-isolation/>.

<sup>130</sup> At least one study suggests that non-sexual human contact from a trusted individual can help reduce stress levels. Sheldon Cohen, Denise Janicki-Deverts, Ronald B. Turner & William J. Doyle, *Does Hugging Provide Stress-Buffering Social Support? A Study of Susceptibility to Upper Respiratory Infection and Illness*, 25 PSYCHOL. SCI. 135, 135–36 (2014). At least one study suggests that non-sexual human contact from a trusted individual can help reduce stress levels. *Id.*

<sup>131</sup> Neal E. Cutler, *Will the Internet Help Your Parents to Live Longer? Isolation, Longevity, Health, Death, and Skype*, 69 FIN. GERONTOLOGY 21, 21 (2015).

<sup>132</sup> *Id.* at 22.

<sup>133</sup> This phenomenon is illustrated most poignantly by the case of “The Edith Macefield House” in Ballard, a historic section of Seattle. Lynsi Burton, *Ballard “Up” House Attracts No Bids at Auction*, <http://www.seattlepi.com/local/article/Ballard-Up-house-attracts-no-bids-at-auction-6132517.php> (last visited Aug. 1, 2015). The late owner and namesake of the house refused a roughly \$1 million offer on the 1,000-square-foot house, which was built around 1900. *Id.* She willed it to a friend, a construction superintendent, before her death in 2008 at the age of 86. *Id.* The house, now in foreclosure, was up for auction but there were no bids. *Id.* It is affectionately known as the *Up!* House, as it echoes a home in the 2009 animated Disney movie of the same name. *Id.*



consequence is not only the reality of social isolation itself but the substantial negative impact that isolation has on both physical and mental health.”<sup>134</sup> The study further notes that isolation is not synonymous or interchangeable with other words such as “loneliness,” “living alone,” or “solitude,” though they do sometimes overlap.<sup>135</sup>

A 2012 study from the Proceedings of the National Academy of Sciences, or PNAS, indicates that social isolation is associated with an increased risk of mortality in adults aged 52 and older.<sup>136</sup> The physical consequences of elders living alone are clear: those people in this age group are at an increased risk for medical emergencies, and these emergencies often include “helplessness,” most often resulting from falls and leading to “dehydration, hypothermia, infections, and physical injuries.”<sup>137</sup> The incidence of mortality and admission to a residential care facility has a direct correlation with loneliness and social isolation.<sup>138</sup>

Of course, such “helplessness” and related injuries are just what the medical devices are designed to prevent. However, the same devices can be increasing social isolation that correlates to other forms of illness and mortality, causing problems with cardiovascular, neuroendocrine, immune, and pituitary functions, among others,<sup>139</sup> primarily by disrupting sleep patterns and

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<sup>134</sup> Cutler, *supra* note 130, at 22.

<sup>135</sup> *Id.*

<sup>136</sup> Andrew Steptoe et al., *Social Isolation, Loneliness, and All-Cause Mortality in Older Men and Women*, 110 PNAS 5797, 5798 (2013).

<sup>137</sup> Edward W. Campion, *Home Alone and in Danger*, 334 NEW ENG. J. MED. 1738, 1738 (1996). Over a three-month study of elders brought to a San Francisco emergency room, 367 were “found down” or “found on the floor, immobilized and unable to get up or even to reach a telephone.” Ninety of those individuals were dead. *Id.* One-third survived and were able to return home, while 10 percent died in the hospital. Roughly half were discharged to long-term care facilities. *Id.*

<sup>138</sup> *Id.*

<sup>139</sup> Tomaka, *supra* note 127, at 362.

increasing stress levels.<sup>140</sup> Additionally, when such devices are put in place, family members, neighbors, and others in the community may feel it is less necessary to check on a local elder, believing that the medical devices and cameras are sufficient support. This idea is analogous to cases in which a family member assumes care for an elder relative in his or her home, thus leading others to believe they do not need to intervene and to assume the person is being cared for sufficiently.<sup>141</sup>

In addition to the physical dangers of an elder living alone, elders face loneliness and depression. In the United Kingdom, where more than half the elderly live alone, “17 percent are in contact with family, friends and [neighbors] less than once a week, and almost five million say the television is their main form of company.”<sup>142</sup> Some elders are taking to the Internet to help find social connectedness.<sup>143</sup> As one study states, “while sitting at a computer, older adults can communicate with family, friends, and the world; conduct household activities such as shopping, paying bills, and banking; and enjoy movies, religious services, and sport events.”<sup>144</sup> In that way, technology plays a positive role in elders’ lives as they age. Socializing online benefits anyone over not

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<sup>140</sup> *Id.* At least one study suggests that non-sexual human contact from a trusted individual can help reduce stress levels. Cohen, *supra* note 129. Such stress reduction cannot be replicated by a machine. *Id.* at 136-137. Additionally, some researchers—and consumers—are concerned that “wearable tech” will one day be frowned upon as being a health hazard, the same way that cigarettes were once glorified but are now frowned upon. Nick Bilton, *The Health Concerns in Wearable Tech*, [http://www.nytimes.com/2015/03/19/style/could-wearable-computers-be-as-harmful-as-cigarettes.html?ref=fashion&\\_r=1](http://www.nytimes.com/2015/03/19/style/could-wearable-computers-be-as-harmful-as-cigarettes.html?ref=fashion&_r=1) (last visited Aug. 1, 2015).

<sup>141</sup> Jessica Vander Velde, *Family Faces Manslaughter in Neglect of Hillsborough Woman*, <http://www.tampabay.com/news/publicsafety/crime/four-charged-with-manslaughter-in-neglect-of-hillsborough-woman/2128714> (last visited Aug. 1, 2015). In one case from Hillsborough County, Florida, in June 2013, a 65-year-old woman suffering from rheumatoid arthritis that was “so bad she could not move” died while in the care of her husband and her three adult children, all of whom were charged with “aggravated manslaughter of an elderly or disabled person, a first-degree felony.” The local sheriff’s office indicated that the family allowed the woman to develop “infected bedsores that were so extensive they exposed her rib cage and fused her legs together.” Despite never seeing the woman, neighbors, however, did not intervene because they thought the family was “kind and well-meaning” and assumed sufficient care was being provided when they saw the family disposing of adult diapers. *Id.*

<sup>142</sup> Brian Brady, *Is This the Loneliest Generation?*, <http://www.independent.co.uk/life-style/health-and-families/health-news/is-this-the-loneliest-generation-8449305.html> (last visited Aug. 1, 2015).

<sup>143</sup> M. Kay Cresci & Julie M. Novak, *Information Technologies as Health Management Tolls: Urban Elders Interest and Ability in Using the Internet*, 38 EDUC. GERONTOLOGY 491, 492 (2012).

<sup>144</sup> *Id.*

socializing at all, but it is important to note that helping elders effectively use the Internet for social engagement needs to be accomplished by “[guiding] participants to accomplish specific Internet tasks motivated by their own interests” rather than simply teaching computer use.<sup>145</sup>

But such benefits of the Internet can only be experienced if elders actually embrace the technology and go online. According to a 2012 study by the Pew Research Center,<sup>146</sup> about 41% of adults aged 65 and older reported that they were not Internet users, and 23% reported that they did not have a cell phone.<sup>147</sup> Many elders cannot afford technology and thus cannot access the benefits that the vast Internet can provide.<sup>148</sup> Thus, the real benefits of the Internet in combatting social isolation should be viewed in a realistic manner.<sup>149</sup>

It is also important to note that studies show Internet use as a positive only when used as a complement to regular social interaction as a substitute.<sup>150</sup> Some researchers believe that robot companions with humanoid capabilities and perceived feelings are

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<sup>145</sup> Cutler, *supra* note 130, at 25. “When used as a substitute, the effects of [computer-mediated communication] on interpersonal relationships are negative and lead to a deindividuating experience, but when used as a complement to face-to-face interaction, [it] facilitates the maintenance of interpersonal relationships.” *Id.*

<sup>146</sup> Aaron Smith, *Older Adults and Technology Use*, <http://www.pewInternet.org/2014/04/03/older-adults-and-technology-use/> (last visited Aug. 1, 2015).

<sup>147</sup> *Id.*

<sup>148</sup> *Id.*

<sup>149</sup> Caitlin Dewey, *What It’s Like to Go on the Internet for the Very First Time—At Age 82*, <http://www.washingtonpost.com/news/the-intersect/wp/2015/03/12/what-its-like-to-go-on-the-Internet-for-the-very-first-time-at-age-82/?sf36943747=1> (last visited Aug. 1, 2015). A “digital divide” currently exists between younger generations and elders; many in the latter group do not even know how to use the Internet. *Id.* Future generations will likely be more open to having their entire lives connected and monitored.”

<sup>150</sup> Carlyne L. Kujath, *Facebook and MySpace: Complement or Substitute for Face-to-Face Interaction?*, 14 CYBERPSYCHOLOGY, BEHAV., & SOC. NETWORKING 75, 75 (2011).

another potential solution to social isolation,<sup>151</sup> while others see the downside of such technology replacing real friendships.<sup>152</sup> Sherry Turkle, the director of the MIT Initiative on Technology and Self, has been quoted specifically deriding this type of technology as companionship for the elderly.<sup>153</sup> She says, “[t]he elderly deserve to be able to talk about the end of their lives, what they have lost and what they have loved, with people who understand what love and loss is. A robot can never offer this.”<sup>154</sup> Thus, the consequences of social isolation should be considered carefully when outfitting elders with medical devices.

#### IV. PROPOSED ALTERNATIVES TO FULLY WIRED GOLDEN YEARS

While younger generations who have used technology since the start of their lives will likely readily embrace monitoring systems in their elder years,<sup>155</sup> alternative solutions must be found to help the current elder population maintain its autonomy, privacy, and mental health. Certain devices like the Life Alert pendants and bracelets<sup>156</sup> are excellent methods of helping elders call for help when they are alone and facing a medical emergency, but the problems of hacking, privacy, and social isolation that more complex technological devices can lead to must be addressed.

One solution is to allow elders to have an active role in deciding what devices will be installed and used to monitor them. Just as it has become common to encourage families to discuss the necessity of advance healthcare directives and healthcare proxies and to plan for the care of an elder in the event of a medical emergency or the development of dementia, it should be common

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<sup>151</sup> Michael Bonds, *Friends in High-Tech Places*, 222 NEW SCIENTIST, 40, 42 (2014). One Japanese company, ATR Intelligent Robotics and Communication Laboratories, has developed a robot, named Robovie, “whose basic interactive capabilities are sophisticated enough to convince 15-year-olds that it is a social being with feelings.” *Id.*

<sup>152</sup> *Id.*

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

<sup>154</sup> *Id.*

<sup>155</sup> Dewey, *supra* note 148.

<sup>156</sup> *LifeCall*, *supra* note 36.

practice to decide in advance what an elder's thoughts are on being monitored. As Michael Cantor states, elders should be allowed to provide not only informed consent to monitoring but also continued assent to it.<sup>157</sup> Additionally, the elders should be allowed to choose who has access to the data that the devices gather.<sup>158</sup> Finally, the elders themselves should have access to the data.<sup>159</sup>

In addition to strengthening the guidelines regarding the use of the technological monitoring devices, more emphasis should be placed on improving nursing facilities and creating more integrated communities for elders. One intriguing model is "Dementia Village," a residential facility near Amsterdam that is specifically for dementia patients.<sup>160</sup> There, the 160 residents live in "lifestyle groups" of seven people who "share similar interests and backgrounds."<sup>161</sup> *The Atlantic* wrote about Dementia Village in 2014,

Like most small villages, [Dementia Village] has its own town square, theater, garden, and post office. Unlike typical villages, however, this one has cameras monitoring residents every hour of every day, caretakers posing in street clothes, and only one door in and out of town, all part of a security system designed to keep the community safe.<sup>162</sup>

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<sup>157</sup> Michael D. Cantor, *No Information About Me Without Me: Technology, Privacy, and Home Monitoring*, 30 GENERATIONS 49, 52 (2006).

<sup>158</sup> *Id.*

<sup>159</sup> *Id.*

<sup>160</sup> Dementia Village Architects, *Dementia Village*, <http://dementiavillage.com/> (last visited Aug. 1, 2015). Dementia Village Architects, the group that designed the facility, describes it online as being "For those who have forgotten who they are. For those who no longer count time. For those to whom love and care is all that matters." *Id.*

<sup>161</sup> *Id.*

<sup>162</sup> Josh Planos, *The Dutch Village Where Everyone Has Dementia*, <http://www.theatlantic.com/health/archive/2014/11/the-dutch-village-where-everyone-has-dementia/382195/> (last visited Aug. 1, 2015).

Since residents have so much freedom, Dementia Village's use of cameras as a security measure allows residents to maintain a high degree of freedom and seeming normalcy.<sup>163</sup> Additionally, social workers serve as staff at the beauty salon, the grocery store, the post office and other facilities.<sup>164</sup> Most interesting perhaps is that the 27 homes are designed for specific decades—they are “furnished around the time period when residents’ short-term memories stopped properly functioning ... because it helps residents feel as if they’re home.”<sup>165</sup> Creating such a living environment and giving incapacitated elders freedom and a life as close to “normal” as possible allows them to maintain their dignity as they age.<sup>166</sup> CNN even reported in 2013 that residents thrive in the environment, stating that, compared to elders at traditional nursing facilities, the Dementia Village residents “require fewer medications,”<sup>167</sup> “eat better,”<sup>168</sup> and “live longer.”<sup>169</sup> Also, “[o]n a mental level, they also seem to have more joy.”<sup>170</sup>

Not all potential solutions to aging well involve technology. Another possible solution involves intergenerational living. According to one report, Dutch students are allowed to live rent-free in a nursing home, provided that they serve as companions to their elderly neighbors.<sup>171</sup> In Britain, a former care minister called traditional elder care facilities “islands of misery” and called for reforms that include creating housing for the elderly

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<sup>163</sup> *Id.*

<sup>164</sup> *Id.*

<sup>165</sup> *Id.* There are homes resembling the 1950s, 1970s, and 2000s, accurate down to the tablecloths, because it helps residents feel “as if they’re home.” *Id.*

<sup>166</sup> *Id.*

<sup>167</sup> Ben Tinker, ‘Dementia Village’ Inspires New Care, <http://www.cnn.com/2013/07/11/world/europe/wus-holland-dementia-village/> (last visited Aug. 2, 2015).

<sup>168</sup> *Id.*

<sup>169</sup> *Id.*

<sup>170</sup> *Id.*

<sup>171</sup> *Dutch Students Can Live in Nursing Homes Rent-Free (As Long As They Keep the Residents Company)*, <http://www.thejournal.ie/help-the-aged-1814698-Dec2014/> (last visited Aug. 2, 2015). As the article describes the arrangement, “[t]he university students pay no rent and in exchange spend at least 30 hours a month with some of the 160 elderly who live here, doing the things professional staff cannot always do—such as just hanging out.” *Id.*

and the disabled in shopping districts and college campuses “to prevent future generations of older people being cut off in care ghettos.”<sup>172</sup> The idea is to integrate generations and to build care homes and elder housing “on the same sites as gyms, libraries, doctors’ surgeries and children’s nurseries to [‘normalize’] them.”<sup>173</sup>

The idea of bringing elders and retirees to college campuses has also taken hold in America. Many Baby Boomers have, upon retirement, found themselves moving to retirement communities and then feeling isolated from the rest of society.<sup>174</sup> In an April 2014 article, Public Broadcasting Services (PBS) quoted Andrew Carle, an expert in senior housing and a professor at George Mason University on this phenomenon,<sup>175</sup> stating, “We’ve built a lot of really beautiful retirement communities in this country, but unfortunately they are in many ways completely separated from the rest of society,”<sup>176</sup> he said. “A bird in a gilded cage is still a bird in a cage.”<sup>177</sup>

Future technological devices may even allow elders to maintain independence outside the home. In 2014, tech-giant Google revealed its prototype for a self-driving car, called a “robocar,” that does not have a steering wheel, an accelerator, or brakes.<sup>178</sup> While such cars could face major regulatory hurdles, they would be helpful to elders as they age, particularly in

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<sup>172</sup> John Bingham, *House Elderly in Student Campuses Instead of ‘Islands of Misery’ Care Homes, Report*, <http://www.telegraph.co.uk/news/politics/11068990/House-elderly-in-student-campuses-instead-of-islands-of-misery-care-homes-report.html> (last visited Aug. 2, 2015).

<sup>173</sup> *Id.*

<sup>174</sup> Ellen Rolfes, *Why Boomers Are Retiring to College*, <http://www.pbs.org/newshour/updates/why-boomers-are-retiring-to-college/> (last visited Aug. 2, 2015).

<sup>175</sup> *Id.*

<sup>176</sup> *Id.*

<sup>177</sup> *Id.*

<sup>178</sup> Laura Hedli, *Why Self-Driving Cars Will Change Retirement*, <http://www.wsj.com/articles/why-self-driving-cars-will-change-retirement-1413147945> (last visited Aug. 2, 2015).

communities that lack solid public transportation systems and leave many seniors homebound.<sup>179</sup>

All of these alternatives allow elders to be part of a supportive community that keeps them engaged and keeps their health needs met, making the need for medical monitoring devices and other similar technology become less necessary, even when family members are far away. That said, some monitoring may still be helpful. Even in New York City, a seemingly quintessential mixed-use community, elders can find themselves in trouble, particularly if they have memory problems or are prone to wandering. A March 2015 article in *The New York Times* points out that “[g]etting lost in a sprawling city is as easy as going down the subway steps.”<sup>180</sup>

#### V. CONCLUSION

Wearable GPS devices and smart-home technology that allow monitoring of the elderly are laudable because they provide elders with a degree of autonomy and freedom that they would not otherwise have. However, these devices come with a price: a risk of hacking, a risk of decreased privacy, and a risk of social isolation. Hackers have become increasingly sophisticated in recent years, targeting not only financial institutions but also health insurance companies, putting personal data at risk. Smart homes have also been attacked, with hackers able to target homes and the devices within them with a simple Internet connection. Privacy issues are also problematic, particularly when an elder has not been consulted about the use of these types of technology. To combat that invasion, the elders should be consulted on a regular basis about its use and should be given access to the data that the devices provide. Finally, social isolation should be taken seriously, as mental health can easily deteriorate when the technology becomes a crutch and a substitute for real, live, personal contact.

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<sup>179</sup> *Id.*

<sup>180</sup> Mireya Navarro, *Warning New York City to Prepare as Its Population Ages*, [http://www.nytimes.com/2015/03/10/nyregion/warning-new-york-city-to-prepare-as-its-residents-grow-older.html?\\_r=0](http://www.nytimes.com/2015/03/10/nyregion/warning-new-york-city-to-prepare-as-its-residents-grow-older.html?_r=0) (last visited Aug. 2, 2015).



The technology does have a place, however, as long as it is properly implemented and not used as a control mechanism. Additionally, investing in creative communities and living arrangements will help elders live more fulfilling lives as they age. Using the technology as a supplement to care rather than a primary mechanism for care is most important.