

# JOURNAL OF INTERNATIONAL AGING LAW & POLICY

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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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Appendix: A Chart of Alternatives to Guardianship for Young Adults with Disabilities

### 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

<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

<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

<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 1: 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\\_reform.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_agda_reform.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

<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 I, 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/adaap.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>

<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, approved, 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.unher.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

<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/dds/self\\_determination/building\\_circles\\_of\\_support\\_\(part\\_1\).pdf](http://www.ct.gov/dds/lib/dds/self_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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