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The Perils of Guardianship and the Promise of Supported Decision Making

BY KRISTIN BOOTH GLEN

Why, with all the problems that public interest lawyers confront, should we care about guardianship? What may seem like an arcane, specialized issue, affecting only older people with progressive cognitive decline, is, in fact, one of the most extensive deprivations of liberty in the justice system. Guardianship laws apply not only to older persons but also to those persons born with intellectual disabilities, to traumatic-brain-injury victims, such as returning veterans, and to persons with psychosocial (mental health) disabilities.[1] Guardianship is a real imposition. As Rep. Claude Pepper noted almost 30 years ago, "The typical ward has fewer rights than the typical convicted felon.... [Guardianship] is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty."[2]

Like so much else about how guardianship actually works, we have no hard information about how many individuals are currently under guardianship in the United States. The best estimate is 1.5 million, but the actual number may be as high as 3 million.[3] Compare this figure with the total number of people imprisoned in the United States—currently estimated at 2,228,424.[4] For most of those incarcerated, there will, at some point, be a return to liberty. For the vast majority of persons under guardianship, there will not.

So, what is guardianship, how did we get here, and what are the prospects of moving beyond a system that results in massive deprivation of liberty but that is only minimally accountable? And how does the paradigm shift from guardianship's substituted decision making to the supported decision making in Article 12 of the Convention on the Rights of Persons with Disabilities lead to dignity, equality, and inclusion for people with a wide variety of intellectual disabilities?

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The Current Regime and How We Got Here

Guardianship, or something like it, has been around since Roman times, and guardianship laws have existed in this country since the 18th century.[5] Premised on the *parens patriae* power of the state, guardianship is understood as necessary to protect persons whose lack of cognitive intellectual capacity places them in danger and who are unable to understand the consequences of that impaired (or lack of) mental capacity. Guardianship has undergone a transformation from a status model (a person was a "lunatic" or an "idiot" under English law) to a medical model, based on diagnoses as indeterminate (and now discredited) as "organic brain syndrome," to most recently a more functional inquiry. The issue now is what, specifically, an impaired person is incapable of doing, such that a guardian must be given the legal power to make decisions for that person, over that domain?

A reform effort that began in the mid-1980s led to significant procedural protections for the subjects (now often called "allegedly incapacitated persons") of guardianship proceedings, including notice, hearing, the right to cross-examination, the right to counsel (including, in some instances and in some states, a publicly paid lawyer), and a higher burden of proof. Many states have court-appointed or court-annexed evaluators to investigate the allegedly incapacitated person's circumstances and make recommendations. In addition to these apparent protections in the hearing process, most states allow (and express an explicit preference for) limited or "tailored" guardianships. On paper, at least, these limited guardianships

1 Most states have a single guardianship statute that covers all of these groups. Five states have separate, additional statutes for persons with intellectual disabilities generally defined as beginning at birth or before the age of 21 (Cal. Prob. Code § 1850.5; Conn. Gen. Stat. §§ 45a-669–45a-684; Idaho Code Ann. § 15-5-301; Ky. Rev. Stat. Ann. §§ 387.500-387.800; Mich. Comp. Laws §§ 700.5401-700.5433; N.Y. Surr. Ct. Proc. Act §§ 1750–1761).

2 Chairman of the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging, 100th Congress, Abuses in Guardianship of the Elderly and Infirm: A National Disgrace 4 (Comm. Print 1988).

3 Brenda K. Uekert & Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*, in National Center for State Courts, Future Trends in State Courts 2011, at 107, 109 (2011).

4 International Centre for Prison Studies, United States of America ([2012]).

5 For a comprehensive description of the history of guardianship, guardianship reform, and the effect of Article 12 of the Convention on the Rights of Persons with Disabilities, see my *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond*, 44 Columbia Human Rights Law Review 93 (2012).

are a far cry from the plenary guardianships that transferred absolute power over an allegedly incapacitated person's life to a guardian and frequently terminated the person's civil rights, including voting, marriage, and the right to contract. These reform statutes generally require periodic reporting by guardians and review by the appointing court—ranging from paper review to personal visits or hearings on the need for continued guardianship.

Despite these major reforms and the enormous efforts of so many advocates that brought them about, the guardianship system all too frequently, as a Utah Judicial Council found, "terminate[s] this fundamental and basic right (to make decisions for oneself) with all the procedural rigor of processing a traffic ticket."[6] Even with a clear statutory preference for limited guardianships, most petitioners request, and most courts grant, plenary guardianships; a 2007 study found that, in about 90 percent of guardianship proceedings, allegedly incapacitated persons were deprived of all of their liberty and property rights.[7] Cuts in court budgets, competing demands for services, and a variety of other factors mean that, in many jurisdictions, postappointment monitoring is minimal, especially as to personal rather than financial reporting. Having given a guardian total and complete power over an incapacitated person, the court may have no way of ever knowing whether that power is being used to foster the allegedly incapacitated person's well-being or to exploit or abuse the person.

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To be sure, there are fine guardians who work to maximize the autonomy of their wards; there are excellent lawyers, often legal aid lawyers, who insist on the procedural protections of reform guardianship statutes, avoid guardianship for their clients, and sometimes even terminate guardianships previously imposed.[8] Volunteer monitoring project workers review reports and visit persons under guardianship and thereby ensure that, at the very least, those in whose lives the state has so dramatically intervened are no worse off than they were before guardians were appointed.[9]

Despite all this good work, the guardianship system has not fulfilled the hopes of reformers for a regime that adequately protects liberty interests and satisfies the requirements of both procedural and substantive due process. But even more important, in 2014, the guardianship system fundamentally violates the emerging—in the United States, at least—*human* right of legal capacity.

Legal Capacity and Supported Decision Making: A New Paradigm

The Convention on the Rights of Persons with Disabilities is described elsewhere in this May–June 2014 issue of Clearinghouse Review.[10] Among the convention's many provisions in support of the rights of persons with disabilities is Article 12, which says that the right of legal capacity shall be enjoyed equally by all persons, without regard to disability.[11] Legal capacity means the right to make one's own decisions *and* the right to have them legally recognized.[12] This means choosing where and with whom to live and how to spend one's money, make health care decisions, and enter into contracts such as leases. Legal capacity recognizes that many persons with intel-

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6 Utah Judicial Council's ad hoc Committee on Probate Law and Procedure (Feb. 2009), quoted in Uekert & Van Duizend, *supra* note 3, at 107.

7 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 96 (2007).

8 For an excellent example of this work, see Robin Thorner, *Challenging Guardianship and Pressing for Supported Decision-Making for Individuals with Disabilities*, Sargent Shriver National Center on Poverty Law Advocacy Stories (Jan. 7, 2014).

9 For information on volunteer monitoring projects and a manual for creating such a project, see American Bar Association Commission on Law and Aging, Court Volunteer Guardianship Monitoring Handbooks (n.d.); Ellen M. Klem, American Bar Association, Volunteer Guardianship Monitoring Programs: A Win-Win Solution (2007).

10 See David T. Hutt, *The Disability Rights Treaty and Advocacy Strategies Using International Human Rights*, 48 Clearinghouse Review 4 (May–June 2014).

11 Article 12 states: "(1) [P]ersons with disabilities have the right to recognition everywhere as persons before the law. (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." (Convention on the Rights of Persons with Disabilities art. 12, Dec. 13, 2007, 2515 U.N.T.S. 3).

12 The United Nations high commissioner for human rights has expansively defined legal capacity to include "the 'capacity to act,' intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status or relationship with another individual and more in general, to create, modify or extinguish legal relationships" (Office of the United Nations High Commissioner for Human Rights, Legal Capacity 20 (n.d.)).

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lectual disabilities need support to make decisions and to communicate them to others, but it insists that all persons have the human right to make those decisions and that the state has an obligation to give whatever supports are necessary. Thus guardianship, which imposes *substituted* decision making through the imposition of state power, must, as a matter of human rights, give way to *supported* decision making, with all that may entail.

The guarantee of legal capacity is hugely radical; it disengages familiar notions of cognition and functional assessment of *mental* capacity from the right to *legal* capacity. Given ever-decreasing public resources for the poor, the vulnerable, and the marginalized, supported decision making may seem unbelievably utopian. And yet, around the world, less wealthy countries are moving to develop supported decision-making projects and to alter or abolish their existing guardianship laws.[13]

Supported Decision Making and How to Get There

Each person is different. Some may communicate in nontraditional ways and need someone who knows them well to interpret their wishes for others. Some need support in understanding choices and consequences. Some may wish to make certain decisions—such as where to live or with whom to have relationships—on their own but welcome support in making financial decisions. The relationship between the individual and the individual's supporters—for there may be many—is critical, but for the full exercise of legal capacity, supporters must be afforded legal recognition by third parties such as health care professionals and financial institutions. So long as critical third parties, including the educational system and benefits offices, refuse to honor the choices of individuals with intellectual disabilities, guardianship is the default position and the sole means by which those individuals can interact with the world. Implementation of Article 12's guarantees thus ultimately requires legislation that recognizes and legitimates supported decision making. Efforts to write and enact such legislation are ongoing in many countries that have ratified the Convention on the Rights of Persons with Disabilities.[14]

Equally if not more important are efforts designed to create, measure, and evaluate supported decision making on the ground to demonstrate that persons, even those with severe disabilities, can make decisions with appropriate supports.[15] Showing supported decision making in the real world is critical to persuading the skeptical (judges, policymakers, benefits providers, legislators, lawyers) as well as the families (of persons with intellectual disabilities) whose understandable desire to protect their loved ones has heretofore had a single legally sanctioned form: guardianship.

Although the United States has one small pilot project, other countries have had, or

13 See, e.g., Bulgarian Center for Not-for-Profit Law, Bulgarian Center for Not-for-Profit Law Launches an Online Training Program for Supported Decision-Making (Dec. 17, 2013); Mental Disability Advocacy Center, Europe (2011); Doris Rajan, Institute for Research and Development on Inclusion and Society, IRIS' International Work on Legal Capacity—Zambia (Dec. 21, 2013).

14 While the United States has signed but not ratified the Convention on the Rights of Persons with Disabilities, Canada has been in the forefront of this work, with a comprehensive effort, involving multiple stakeholders, over a period of years. Canadian proposals, and a representative set of principles from a similar effort in Ireland, may be found among the online resources of the American Bar Association Commission on Disability Rights (American Bar Association, Article 12 (n.d.)).

15 See Nina A. Kohn et al., *Supported Decision-Making: A Viable Alternative to Guardianship*, 117 Pennsylvania State Law Review 1111 (2013) (calling for more examples and research).

are conducting, far more robust projects.[16] The evidence from these projects and the individual stories of dignity and empowerment they produce powerfully demonstrate the efficacy and workability of supported decision making. Also powerful are the innumerable stories, as yet uncollected, of families, friends, and communities that have created networks of support to permit persons with intellectual disabilities to live good, pleasurable, dignified, and productive lives, without the necessity of state intervention that deprives them of liberty and their fundamental human rights.[17] Those stories are critical in persuading parents that they need not seek guardianship and in persuading judges that they should not impose it. The stories and data from more formalized supported decision-making initiatives are essential for the legislative change necessary to enshrine the right to legal capacity, without regard to disability, in our legal system.

Actions to Take Now

Shortly after the Convention on the Rights of Persons with Disabilities took effect, a leading international organization for the rights of persons with intellectual disabilities cautioned that a system of supported decision making "will take time to develop and would run the risk of becoming dysfunctional, if all existing measures of traditional guardianship [were] declared illegal at the same time, without the conditions in place that make supported decision-making effective for a particular individual."[18]

Advocates and providers need to develop replicable models of supported decision making on the ground to pave the way for more comprehensive legislative reform, in accordance with Article 12. Meanwhile, however, several other strategies can move that project forward and protect and enforce the existing rights of persons with intellectual disabilities.

First, litigation can push courts to incorporate supported decision making into existing statutory schemes, as an alternative, where feasible, for persons facing guardianship. One excellent and nationally publicized example of this approach is the case of Jenny Hatch, a courageous young woman with Down syndrome. Hatch led an independent and productive life for all of her young adulthood until her parents sought guardianship and placed her in a restrictive group home. Jenny was fortunate to be vigorously represented by Quality Trust, a Washington, D.C., advocacy organization, with the assistance of Prof. Robert Dinerstein and the American University Law School Disability Rights Clinic. After a year of litigation and a six-day trial, with expert witnesses and moving testimony by Jenny herself, the court granted a one-year temporary guardianship to the friends with whom she had been living; the court directed them to use supported decision making to help Jenny learn how to handle her affairs independently. Jenny's case is believed to be the first time that a court has ordered supported decision making.[19]

Buoyed by the victory and the interest aroused by Jenny's story, Quality Trust has established the Jenny Hatch Project to challenge "over-reliance on guardianship [and] share resources and knowledge gained from her case and promote alternatives to guardianship for people with disabilities."[20]

A second promising path to advancing supported decision making within the current system is by a more expansive focus on the "least restrictive alternatives" requirement of many existing guardianship statutes. Describing that requirement as a constitutional imperative, one court held that supported decision making must be explored and attempted before the drastic remedy of guardianship may be ordered.[21] The decision not only relied on a statutory and constitutional analysis but also specifically referenced Article 12 and the human right of legal capacity.[22]

Third, in an analogous vein, Prof. Leslie Saltzman makes an insightful and provocative argument that guardianship violates the Americans with Disabilities Act (ADA) because it isolates people with intellectual disabilities, thus removing them from participation in the larger world

16 The U.S. project is a collaboration between the Center for Public Representation and Nonotuck Resource Associates in Northampton, Massachusetts (see Center for Public Representation, Supported Decision-Making (n.d.)). The Soros Foundation has supported significant pilot projects in Bulgaria, Zambia, and Colombia (see, e.g., Bulgarian Center for Not-for-Profit Law, *supra* note 13. South Australia has completed a trial of a "stepped model of supported and substituted decision making," which involved a "non-statutory supported decision-making agreement" (South Australia Office of the Public Advocate, Supported Decision Making (n.d.)).

17 Many providers in the United States are working to implement supported decision making on a more informal basis; a number of manuals and publications detail their efforts (see, e.g., Joan Kakascik et al., Where Human Rights Begin: Human Rights and Guardianship for Individuals with Developmental Disabilities—in Plain Language (2013); Dohn Hoyle, The Arc Michigan, Rethinking Guardianship (n.d.)).

18 Inclusion Europe, Key Elements of a System for Supported Decision-Making (2008).

19 Michelle Diament, *Center to Promote Alternatives to Guardianship*, Disability Scoop, Oct. 25, 2013.

20 *Id*. The results of a symposium that the Jenny Hatch Project held in October 2013 make an excellent introduction to alternatives to guardianship and a blueprint for practical action (Supported Decision-Making: An Agenda for Action (Feb. 2014)).

21 *In re Dameris L*., 956 N.Y.S.2d 848 (N.Y. Sur. Ct. N.Y. Cnty. 2012). That case involved termination of guardianship for a woman with intellectual disabilities on a finding that there was now a support network in place that enabled her to make her own decisions. (Disclosure: this was my decision on my last day as surrogate, before my mandatory retirement.)

22 "The internationally recognized right of legal capacity through supported decision making can and should inform our understanding and application of the constitutional imperative of least restrictive alternative … where a person with an intellectual disability has the 'other resource' of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian…. Terminating the guardianship recognizes and affirms Dameris's constitutional rights and human rights and allows a reading and application of [the New York statute] that is consistent with both" (*id*. at 856).

and inhibiting the growth of which they are capable.[23] Drawing on the inclusion mandate of *Olmstead v. L.C.*, Saltzman's ADA analysis can reinforce arguments that meaningful attempts at supported decision making must be made before the more restrictive, more isolating alternative of guardianship is permissible.[24]

Advocates can explore a fourth, more systemic possibility to influence legislation. The Uniform Law Commissioners recently formed a committee to consider changes in the Uniform Guardianship Protection and Procedures Act in response to recommendations of the Third National Guardianship Summit.[25] This review process is an opportunity for advocacy to include supported decision making as a least-restrictive alternative that must be explored before guardianship can be imposed.

Finally, but of enormous practical importance, is the issue of restoration. At a 2012 national roundtable, "Supported Decision-Making: Beyond Guardianship," convened by two American Bar Association Commissions with the support of the Agency for Intellectual and Developmental Disabilities, self-advocates argued passionately for legal strategies and litigation to free individuals currently under guardianship.[26]

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While much effort went into legislating procedural protections where guardianship is sought, restoration of rights—or termination of guardianship—is surprisingly undertheorized and, at least with regard to reported decisions, underlitigated. In a comprehensive survey undertaken in response to the 2012 roundtable, the American Bar Association Commission on Law and Aging published a report and 50-state survey of the laws relating to restoration.[27] The report found that

> the statutory legal procedure for restoration is often unclear and ambiguous. The procedural process, as well and [sic] the duties of the court and of the guardian, vary significantly by state, court, and judge. Due to the inconsistency among state statutes, variations in practice, and lack of hard data on restoration proceedings, it is unclear whether current guardianship law adequately protects an individual's right to restoration.[28]

The best restoration provisions are found in the Uniform Guardianship Protection and Procedures Act, which requires guardians to encourage the person under guardianship to work toward regaining capacity and which gives the person seeking restoration the same rights and protections found in the establishment of the guardianship.[29]

A key issue is the burden of proof. Logic (and perhaps constitutional imperative) would seem to dictate that the party opposing restoration should be required

23 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 University of Colorado Law Review 157 (2010).

24 See *Olmstead v. L.C.*, 527 U.S. 581 (1999).

25 See *Third National Guardianship Summit Standards and Recommendations*, 2012 Utah Law Review 1191 (2012). While the recommendations generally adhere to a substituted decision-making model, they specifically reference supported decision making with regard to health care and housing decisions.

26 The two convening committees were the American Bar Association Commission on Disability Rights and the American Bar Association Commission on Law and Aging (see American Bar Association, *supra* note 14). Interestingly those same two commissions, then with different names, convened the now eponymous Wingspread Conference that began the first round of guardianship reform in the 1980s (see my *Changing Paradigms*, *supra* note 5, at 109).

27 [Jenica Cassidy], State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship ([2013]); Restoration in Adult Guardianships (Statutes) (June 2013).

28 [Cassidy], *supra* note 27, at 1.

29 National Conference of Commissioners on Uniform State Laws, Uniform Guardianship and Protective Proceedings Act (1997). Eighteen states that have adopted the Uniform Guardianship and Protective Proceedings Act specifically so provide, as do several other nonadopting states ([Cassidy], *supra* note 27, at 2 n.7).

to prove that the need for guardianship continues. But among the states the standard varies widely and is "often unclear."[30] The best existing procedures are incorporated in the Uniform Guardianship Protection and Procedures Act and require the petitioner or person under guardianship to make out a prima facie case for termination, after which the burden shifts to the proponent of guardianship to establish the need for its continuation by clear and convincing evidence.[31]

A number of states have procedural bars to petitions for restoration. These hurdles include constraints placed on the guardian, minimum time periods before a petition for termination may be filed, and restrictions on who may file a petition.[32] The American Bar Association's report notes the many unknowns, such as the number of petitions to terminate a guardianship that are actually filed and the number of petitions granted. The report underscores the "compelling need for additional research and data collection to determine which state practices [if any] adequately protect the individual's right to restoration."[33]

As providers and advocates develop and facilitate supporters for decision making by persons with intellectual disabilities, the opportunities for, and the necessity to seek restoration for, those many persons for whom guardianship is no longer the least restrictive alternative can only grow. Their stories, too, will be an integral part of any successful effort for legislative change. Commitment to ending the deprivation of liberty imposed by guardianship is critical to moving the human right of legal capacity forward and to bringing our legal system close to the challenge and inspiration of the Convention on the Rights of Persons with Disabilities. It is a commitment for individuals, despite their disabilities, to be able, with or without support, to make the decisions that allow them to be actors in their own lives.

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30 [Cassidy], *supra* note 27, at 3. The standards range from Maine and Minnesota, which have adopted the Act's standard, to the clear and convincing evidence required by case law in New Jersey. Thirty-three states have no statutory evidentiary standard (*id.* at 3–4).

31 National Conference of Commissioners on Uniform State Laws, Uniform Guardianship and Protective Proceedings Act (1998) §§ 318(c), 431(d) (1997) (National Conference of Commissioners on Uniform State Laws drafted Act and approved and recommended it for enactment in all states).

32 [Cassidy], *supra* note 27.

33 *Id.* at 9.

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