

GUARDIANSHIP FOR PERSONS WITH MENTAL ILLNESS — A LEGAL AND APPROPRIATE ALTERNATIVE?

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INTRODUCTION

In the United States, when the state determines that an individual lacks the “capacity” to make some or all decisions, the state removes the individual’s legal right to make those decisions and appoints a guardian to make those decisions for that individual. Guardianship implicates the difficult question of when—and if—it is appropriate for the State to remove an individual’s legal right to make decisions “for his or her own good.” It pits the individual’s rights of autonomy, self-determination, and self-definition against the state’s interest in protecting individuals from personal and financial harm when they are found to have a diminished capability to make decisions and manage their own affairs. The guardian may prevent an individual with diminished decision-making abilities from making decisions that are perceived to be unwise or contrary to the individual’s short- or long-term interests. Yet, the divestiture of decision-making rights resulting from a guardianship order comes at a significant, though unquantifiable, cost to the individual who is losing his or her rights.

This article¹ discusses why guardianship and the guardianship appointment process may be particularly ill-suited for individuals with psychosocial disabilities.² It then argues that the Americans with Disabilities

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1. This article was written for a presentation at the 2011 annual meeting of the Association of American Law Schools panel, “New Perspectives on Guardianship: Guardianship and Mental Illness.” It draws on material in a longer recent piece that has a more elaborate articulation of the basis for an ADA integration mandate claim in the guardianship context. 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 (2010).

2. I will use the terms “psychosocial impairments,” “psychosocial disabilities,” or “psychosocial conditions,” which are preferred over the more commonly used term of “mental illness.” See, e.g., Anna Lawson, *People with Psychosocial Impairments or Conditions, Reasonable Accommodation and the Convention on the Rights of Persons with Disabilities*, 26 LAW IN CONTEXT, no. 2, 2008, at 62, 81 n.2.

Act³ (ADA) and the 2006 United Nations Convention on the Rights of Persons with Disabilities⁴ (CRPD) provide legal and/or normative bases for a right to receive decision-making support as a less restrictive alternative to the substituted decision making that characterizes guardianship.

Part I of this article sets out the basic analytical framework provided by the integration mandate of Title II of the ADA and Article 12 of the CRPD. Part II discusses the inadequacies of recent guardianship reforms to address what is characterized here as the “constructive isolation of guardianship” and the particular reasons why the current guardianship model presents particular cause for concern when the subject of the proceeding is a person with a psychosocial disability. Part III describes supported decision-making models that have been implemented in other countries and explains how they differ from reformed guardianship regimes in this country. Finally, Part IV briefly outlines the basic structure of an ADA integration mandate challenge to a state’s failure to provide assistance with decision making in a less restrictive and less isolating manner than is currently provided under guardianship.

The movement to require support with decision making, now enshrined in the CRPD, requires a reconsideration of traditional notions of “legal capacity” and forces us to alter our conception of the obligation to address the needs of persons with diminished decision-making abilities.⁵ Riding the

3. Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (2006). The ADA claim is based on the integration mandate of Title II of the Act, 28 C.F.R § 35.130(d) (2009), and built on the reasoning in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), and subsequent decisions interpreting the integration mandate.

4. See Convention on the Rights of Persons with Disabilities, *opened for signature* Mar. 30, 2007, G.A. Res. 61/106, art. 12, U.N. Doc. A/RES/61/106 (Dec. 6, 2006) [hereinafter CRPD].

5. See, e.g., John Brayley, Dir. External Organisations, Div. of Mental Health, Flinders University, Supported Decision-Making in Australia 1, 10-16 (Dec. 14, 2009), available at http://www.opa.sa.gov.au/documents/08_News_&_Articles/Supported%20Decision%20Maki ng.pdf (noting that supported decision-making requires a modified definition of “capacity” as “the ability, with assistance as needed, to understand the nature and consequences of a decision within the context of the available range of choices, and to communicate that decision, with assistance as needed”). Further:

. . . [C]apacity can also mean the ability to express one’s intention and to communicate one’s personhood (wishes, vision for the future, needs, strengths, personal attachments and field of care), to a trusted group of others chosen by the individual who, in a fiduciary relationship of trust, confidence and responsibility recognize the individual as a full person, and commit to acting on and representing that person’s agency in accordance with his/her intentions and personhood.

Id. (citing Michael Bach, Exec. Vice President, Can. Ass’n for Cmty. Living, *What Does Article 12 of the CRPD Require?: Theoretical Starting Points and Questions/Implications for Law and Policy* (Jul. 2009) (slide show at 27), available at <http://www.inclusionireland.ie/Capacity RoundtableAug2009.asp>).

wave of this incipient revolution, this article concludes that as a matter of morality and policy, and possibly as a matter of law, states in this country should be expanding existing programs or developing new ones that might serve as acceptable and appropriate alternatives for the substituted decision making of guardianship. By analyzing guardianship through the lens of the integration mandate we are forced to consider whether guardianship unnecessarily isolates a person from the opportunity for crucial social, legal, and financial interactions, and whether there are appropriate and viable alternatives to guardianship that would reduce that isolation by enabling the individual to more actively participate in the decision-making process. An extension of the integration mandate to the realm of decision making should be an integral part of current efforts to expand community-based services for persons with psychosocial disabilities, leading to enhanced opportunities for persons with disabilities, and a greater respect for the inherent dignity of all persons.⁶ Ultimately, the legal standards used to determine when the state will remove an individual's decision-making rights and the way the state provides assistance to those with limitations in decision-making ability influences the way our society conceives of mental disabilities and the social obligation to fully integrate all people with disabilities into mainstream communal life.⁷

I. THE LEGAL FRAMEWORK AND NORMATIVE PRINCIPLES OF THE ADA AND THE CRPD SUPPORT A REQUIREMENT TO PROVIDE LESS RESTRICTIVE ALTERNATIVES TO GUARDIANSHIP

Both the ADA and the CRPD seek to outlaw disability-based discrimination by prohibiting both active and passive discrimination against individuals with disabilities. The ADA was enacted in 1990 to provide a clear and broad national mandate to eliminate discrimination,⁸ and to go further than prior legislation to provide equal access to goods, services, and

6. See Stanley S. Herr, *Self Determination, Autonomy, and Alternatives for Guardianship*, in THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES 429, 447-48 (Stanley S. Herr, Lawrence O. Gostin & Harold Hongju Koh eds., 2003).

7. Salzman, *supra* note 1, at 195.

8. 42 U.S.C. § 12101(b)(1) (2006); H.R. REP. NO. 101-485(III) (1990), at 26, *reprinted in* 1990 U.S.C.C.A.N. 445, 449; 134 CONG. REC. 9384 (1988). See *U.S. Airways, Inc. v. Barnett*, 535 U.S. 391, 401 (2002). See also 42 U.S.C. § 12101(b)(4) (2006) (noting that in enacting the ADA, Congress was relying on its broad authority to enforce the Fourteenth Amendment and to regulate commerce).

opportunities⁹ as a fundamental civil right.¹⁰ By explicitly recognizing the “right [of all persons with disabilities] to fully participate in all aspects of society,”¹¹ the ADA was intended to create a new future of inclusion and integration.¹²

A challenge to guardianship would fall within the proscription of Title II of the ADA. Title II prohibits public entities from engaging in disability-based discrimination in their services, programs, or activities.¹³ Under the related integration mandate, those public services, programs, and activities must be administered in “the most integrated setting appropriate to the needs of qualified individuals with disabilities,”¹⁴ i.e., one “that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”¹⁵ Public entities must make reasonable modifications in policies, practices, or procedures to avoid disability-based discrimination, unless those modifications would “fundamentally alter” the service, program, or activity at issue.¹⁶

In *Olmstead v. L.C.*, a case challenging the plaintiffs’ unjustified confinement in a state psychiatric facility, the Supreme Court relied on the ADA’s integration mandate to conclude that the unjustified segregation and isolation of people with disabilities may constitute unlawful discrimination.¹⁷ While the Court’s *Olmstead* decision is unquestionably linked to the fact of the plaintiffs’ segregation in a physical institution, the Court issued a broad holding that can be imported to other, comparable contexts: “[u]njustified

9. See 42 U.S.C.A. § 12101(a)(7) (West 2010). See, e.g., Helen L. v. DiDario, 46 F.3d 325, 331 (3rd Cir. 1995) (citing Robert L. Burgdorf, Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 430-31 (1991) (discussing limitations of Section 504’s non-discrimination mandate)).

10. See Michael A. Stein & Penelope J.S. Stein, *Beyond Disability Civil Rights*, 58 HASTINGS L.J. 1203, 1206-08 (2007) (observing that under the ADA equal access is not intended to be a “special benefit,” but rather “a basic right”).

11. 42 U.S.C.A. § 12101(a)(1).

12. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 588-89, 589 n.1 (1999) (citing 42 U.S.C. §§ 12101(a)(2), (3), (5) (1999) (noting that the ADA was unique in specifically identifying the segregation of persons with disabilities as a type of discrimination that Congress sought to eliminate)). See also H.R. REP. NO. 101-485, pt. 2, at 50 (1990), reprinted in 1990 U.S.C.C.A.N. 303, 332; H.R. REP. NO. 101-485, pt. 3, at 49-50 (1990), reprinted in 1990 U.S.C.C.A.N. 445, 472-73; 135 CONG. REC. 19803 (1989) (comments of Senator Harkin, floor manager of the ADA in the Senate).

13. 42 U.S.C. § 12132 (2006).

14. 28 C.F.R. § 35.130(d) (2009).

15. 28 C.F.R. Part 35, app. A, subpart B (2009). The Department of Justice explains the comprehensive nature of the integration mandate. See *id.* at 568-69 (discussing the integration mandate in context of the requirements of Section 35.130(b)(1)(iv)).

16. 28 C.F.R. § 35.130(b)(7).

17. *Olmstead*, 527 U.S. at 596-97.

isolation, we hold, is properly regarded as discrimination based on disability.”¹⁸

Most important and relevant for the guardianship context, in concluding that unjustified isolation might constitute disability-related discrimination, the Court in *Olmstead* expressed the concern that segregation would perpetuate demeaning stereotypes about the abilities and human value of persons with disabilities and diminish their opportunities to enjoy the pleasures and benefits of participating in significant aspects of human and social life.¹⁹ The same can be said about guardianship. And while there is a clear and obvious difference between the more severe isolation resulting from physical segregation in an institution and the isolation from the community that results from guardianship, there are inescapable parallels between these two forms of state-sanctioned isolation. Whether an individual with a guardian²⁰ resides in a community setting or an institution, guardianship stands as a barrier to an individual’s full participation in the host of every day human activities cited by the *Olmstead* court,²¹ and perpetuates assumptions that the ward is “incapable or unworthy of participating in community life.”²² The *Olmstead* decision reaffirms and reinforces the affirmative obligation created by the ADA to integrate individuals with disabilities into social, economic, and political life to the greatest extent possible, and provides a theoretical basis for a right to less restrictive and less isolating alternatives to the substituted decision making of guardianship.

Such a right is consistent with the guiding principles of, and the rights created by, the landmark 2006 Convention on the Rights of Persons with Disabilities.²³ The CRPD is predicated on the obligation to respect each

18. *Id.* at 597. *But see id.* at 587 (articulating the relevant question as whether the ADA “may require placement of persons with mental disabilities in community settings rather than in institutions”).

19. *Id.* at 596, 600-01. The Court found that:

. . . [I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. . . . [C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

Id. at 600-01 (citations omitted).

20. An “incapacitated person” for whom a guardian has been appointed will be referred to herein as a “ward.”

21. *See infra* Part II (discussing the constructive isolation of guardianship).

22. *Olmstead*, 527 U.S. at 600.

23. *See* CRPD, *supra* note 4, at art. 12. As of June 5, 2011, 148 nations have signed the treaty, and 100 have ratified it. *Convention and Optional Protocol Signatures and Ratifications*, U.N. ENABLE, <http://www.un.org/disabilities/countries.asp?id=166#U> (last

person's inherent dignity, autonomy, and independence, including the freedom to make one's own choices, and, like the ADA, the right of each individual to fully and effectively participate in all aspects of social life.²⁴ The CRPD broadly defines disability-based discrimination to protect the wide range of recognized human rights²⁵ and obligates State Parties to "take 'immediate, effective and appropriate' steps to raise awareness of the capabilities of disabled people and to counter unfounded stereotypes and prejudices against them."²⁶

Article 12 of the CRPD recognizes the right of all persons to exercise legal capacity and to receive support to exercise that capacity, if, and only to the extent that assistance is needed.²⁷ While Article 12 neither endorses nor prohibits guardianship, it provides that any measures that limit an individual's exercise of legal capacity must "respect the rights, will and preferences of the person [receiving support], [must be] free of conflict of interest and undue influence, [must be] proportional and tailored to the person's circumstances, [must] apply for the shortest time possible and [must be] subject to regular review by a competent, independent and impartial authority or judicial body."²⁸

visited June 5, 2011). While the United States signed the treaty in July 2009, it has not yet ratified it. *Id.* Nevertheless, as an international treaty it provides an appropriate source of normative guidance. See *Roper v. Simmons*, 543 U.S. 551, 575-78 (2005). In light of the possibility that this nation might ratify the convention in the future, it is appropriate to consider what modifications of existing law would be required to bring our nation into compliance with its requirements.

24. CRPD, *supra* note 4, at art. 3; 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, 408-09 (2007) [hereinafter Minkowitz, *U.N. Convention*]. See Michael Perlin, "A Change is Gonna Come": *The Implications of the United Nations Convention on the Rights of Persons with Disabilities for the Domestic Practice of Constitutional Mental Disability Law*, 29 N. ILL. U. L. REV. 483, 483-84, 490 (2009).

25. CRPD, *supra* note 4, at art. 2 (defining "discrimination on the basis of disability" as "any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.").

26. Lawson, *supra* note 2, at 77. See also CRPD, *supra* note 4, at art. 8(1).

27. See CRPD, *supra* note 4, at art. 12; Amita Dhanda, *Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities*, SUR INT'L J. ON HUM. RTS., June 2008, at 43, 47-48, available at http://www.surjournal.org/eng/conteudos/getArtigo8.php?artigo=8,artigo_dhanda.htm (characterizing the CRPD article 12 as a model of interdependence that allows for both capacity and support); Annegret Kämpf, *The Disabilities Convention and Its Consequences for Mental Health Laws in Australia*, 26 LAW IN CONTEXT, no. 2, 2008, at 10, 31.

28. CRPD, *supra* note 4, at art. 12(4).

The CRPD represents a paradigm shift; it creates a true presumption of “legal capacity”²⁹ and calls for a “more nuanced approach” towards determining decision-making status and greater reflection on how to assist an individual within the decision-making process.³⁰ Most significantly, the CRPD changes the locus of decision-making authority—from the guardian to the individual needing support.

In addition, Article 12 of the CRPD begins to address the judicial and social tendency to more readily provide accommodations needed to overcome barriers to physical disabilities than those needed to overcome barriers to mental disabilities.³¹ While all persons with disabilities continue to confront barriers to integration and participation, as a society we seem better able to grasp the barriers affecting persons with physical and sensory impairments such as impassable stairs or printed materials and the accommodations needed to overcome them, such as ramps, elevators or talking computers. We are less adept at understanding the barriers affecting individuals with mental disabilities, such as the need for assistance with decision-making, and the precise nature and appropriate contours of the support needed to overcome these barriers. Unless we are going to exclude persons with mental disabilities from many of the benefits of our disability discrimination laws, however, it is necessary to reconsider the failure to provide accommodations such as support with decision making. Just as we don’t carry a person up the stairs but provide assistance so that she can overcome that barrier on her own, we should not assign an individual with limitations in decision-making abilities a guardian to make decisions *for* her, but should provide decision-making support so that she can make her own decisions whenever possible.

Both the ADA and the CRPD are predicated on principles of human dignity, inclusion, and participation. They create norms, and may (today, or upon ratification of the CRPD) create legal rights to support for individuals with disabilities who need assistance with decision making as an alternative to the surrogate decision-making model of guardianship. Such support would provide a critically important alternative for persons with psychosocial conditions.

29. See CRPD, *supra* note 4, at art. 12; Minkowitz, *U.N. Convention*, *supra* note 24, at 408-09.

30. Kämpf, *supra* note 27, at 31 (quoting GERARD QUINN & THERESIA DEGENER, UNITED NATIONS, HUMAN RIGHTS AND DISABILITY: THE CURRENT USE AND FUTURE POTENTIAL OF UNITED NATIONS HUMAN RIGHTS INSTRUMENTS IN THE CONTEXT OF DISABILITY 16 (2002)).

31. See Lawson, *supra* note 2, at 68-69 (discussing reasons for this disparity).

II. GUARDIANSHIP UNJUSTIFIABLY ISOLATES PERSONS WITH PSYCHOSOCIAL CONDITIONS DESPITE RECENT REFORMS

A. *A Historical Perspective on the Treatment of Persons with Mental Illness*³² in the United States

The justification for guardianship rests on the historical and well-recognized obligation of the state as *parens patriae* to protect the person and property of citizens who are deemed to be unable to meet their own needs.³³ The way in which the state exercises its *parens patriae* authority, however, is greatly influenced by long-standing negative conceptions of mental illness. In order to understand the influences operating in the context of guardianship for persons with psychosocial disability, it is necessary to understand the historical conceptions of, and approaches to treatment for, mental illness.

Mental illness has long been associated with evil, divine punishment, sin, and possession by demons.³⁴ These associations helped generate the stigma of mental illness and fueled assumptions that persons with mental illness were predisposed to violence.³⁵

The nineteenth century brought with it the notion that mental illness caused global "incompetence," affecting an individual's cognitive abilities in every area of functioning, generally for the person's entire lifetime, justifying institutional segregation of "insane persons" under fairly wretched conditions.³⁶ At the same time, there were some efforts to improve the

32. The term "mental illness" is deliberately used in this historical perspective section.

33. See *Heller v. Doe*, 509 U.S. 312, 332 (1993); Jennifer L. Wright, *Protecting Who from What, and Why, and How: A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 ELDER L.J. 53, 58, 63, 66 (2004) [hereinafter Wright, *Proposal for an Integrative Approach*] (discussing adult guardianship and *parens patriae* civil commitment proceedings in the United States). See generally Joan L. O'Sullivan, *Role of the Attorney for the Alleged Incapacitated Person*, 31 STETSON L. REV. 687, 689-92. The modern state obligation as *parens patriae* to provide care and protection for vulnerable individuals with mental disabilities traces back to the obligation of the English king to protect the property of those with intermittent mental incapacity ("lunatics"). See *Heller*, 509 U.S. at 332.

34. See MICHEL FOUCAULT, *MADNESS AND CIVILIZATION: A HISTORY OF INSANITY IN THE AGE OF REASON* 15 (Random House, Inc. 1965) (1961); MICHAEL PERLIN, *THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL* 36 (2000) [hereinafter PERLIN, *HIDDEN PREJUDICE*].

35. JOHN PETRILA & JEFFREY SWANSON, *MENTAL ILLNESS, LAW, AND A PUBLIC HEALTH LAW RESEARCH AGENDA* 8 (2010), available at <http://www.publichealthlawresearch.org/theory-practice-and-evidence/law-mental-illness-and-public-health-law-research-agenda>.

36. BRUCE J. WINICK, *CIVIL COMMITMENT: A THERAPEUTIC JURISPRUDENCE MODEL* 103 (2005). See also David Braddock & Susan Parish, *Social Policy Toward Intellectual Disabilities in the Nineteenth and Twentieth Centuries*, in *THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES*, *supra* note 6, at 83, 84-86 (discussing treatment of persons with mental illness).

generally deplorable institutional conditions by providing more “benevolent” (though not necessarily less paternalistic) treatment in open asylums, often located in pastoral settings, with the goal of curing insanity through wholesome measures such as good diet and hygiene, medical care, occupational activities, and religious practice.³⁷ This goal of providing benevolent treatment to the mentally ill was short-lived; these asylums became increasingly overcrowded and their mission of treatment changed to focus on the management and control of the swelling institutional population.³⁸ As the institutional mission changed, cure rates necessarily declined, and psychiatrists began to report that mental illness could rarely be cured.³⁹ By the middle of the twentieth century, individuals with severe mental illness were confined in large, overcrowded, and understaffed institutions away from their communities where they were treated with drugs and invasive therapies, often with long-term detrimental consequences, for the primary purpose of managing their behavior.⁴⁰

In the latter part of the twentieth century, successful litigation challenging institutional conditions⁴¹ along with philosophical changes favoring treatment in the community led to large-scale deinstitutionalization and the

37. PETRILA & SWANSON, *supra* note 35. See Braddock & Parish, *supra* note 36.

38. See *id.*; Bernard E. Harcourt, *Reducing Mass Incarceration: Lessons from the Deinstitutionalization of Mental Hospitals in the 1960s* 10-11 (Univ. of Chi. L. & Econ. Olin Working Paper No. 542, 2011), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1748796 (observing that during the period from the late nineteenth century to the mid-twentieth century the overall population confined in psychiatric facilities grew exponentially from approximately 41,000 to 500,000 (a thirteen-fold increase), with a related dramatic growth in the number of persons living in individual institutions).

39. See Braddock & Parish, *supra* note 36, at 86.

40. PETRILA & SWANSON, *supra* note 35, at 8-9. See generally Thomas Szasz, *Summary Statement and Manifesto*, THOMAS S. SZASZ, M.D. CYBERCENTER FOR LIBERTY & RESPONSIBILITY (1998), <http://www.szasz.com/manifesto.html> (theorizing that “psychosocial disability” is simply a social construct that allows us to segregate those who we find offensive or threatening under the guise of medical treatment).

41. See PETRILA & SWANSON, *supra* note 35, at 9-10, 12. See also *Lessard v. Schmidt*, 349 F. Supp. 1078, 1084, 1093, 1101 (E.D. Wis. 1972), *vacated and remanded on procedural grounds*, 414 U.S. 473 (1974), *judgment reentered*, 379 F. Supp. 1376 (E.D. Wis. 1974), *vacated and remanded on procedural grounds*, 421 U.S. 957 (1975), *judgment reentered*, 413 F. Supp. 1318 (E.D. Wis. 1976) (requiring due process safeguards in the civil commitment process and requiring proof of dangerousness for civil commitment). After the initial success of litigation to constrain the state’s use of its coercive power and to impose a duty to provide care, however, courts “lately have revitalized the state’s coercive powers in the interest of identifying and ameliorating perceived risks to the public while limiting the state’s duties in the context of community care.” PETRILA & SWANSON, *supra* note 35, at 7.

closing of certain facilities.⁴² This deinstitutionalization was facilitated, in part, by the availability of new psychotropic medications and by new streams of funding for community-based care.⁴³ Despite these advances, however, community resources remained quite limited and proved insufficient to meet the increased need for services.⁴⁴ Consequently, although individuals were given the benefit of residing outside large psychiatric institutions, many were left without adequate care and treatment in the community setting.⁴⁵ This shortage of adequate mental health services in the community continues to the present time, exacerbating the stigma of mental illness and the fear and suspicion of persons with psychosocial disability.⁴⁶ It is not surprising, then, that when the ADA was being drafted and debated, a group of conservative legislators sought to exclude schizophrenia and manic depression from coverage under the Act.⁴⁷ While the effort was unsuccessful,⁴⁸ it underscores the deep-seated prejudice against persons with severe psychosocial disability and suggests that it is more entrenched than other forms of disability-related stigma.

This history helps to explain the differential treatment of persons with psychosocial disabilities within our legal system. It helps to explain why, in the context of psychosocial disabilities, many adhere to the notion that the disability rests within the individual and is an inherent and unavoidable aspect of his or her condition, i.e., the "medical model of disability."⁴⁹ As a result, despite recent research indicating that persons with severe psychosocial disability retain the capacity to make important personal

42. PETRILA & SWANSON, *supra* note 35, at 10, 12. *See also* Harcourt, *supra* note 38, at 2 (noting a seventy-five percent decline of inpatient population in mental health facilities from 1955-1980).

43. PETRILA & SWANSON, *supra* note 35, at 12.

44. *See id.* at 13 (noting that "the new medicines proved less than magical; life in the community failed to cure schizophrenia; and President Reagan effectively defunded the community mental health centers . . .").

45. THE PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, ACHIEVING THE PROMISE: TRANSFORMING MENTAL HEALTH CARE IN AMERICA 3-4 (2003), *available at* <http://www.nami.org/Template.cfm?Section=Policy&Template=/ContentManagement/ContentDisplay.cfm&ContentID=16699> (citing the lack of consistent and appropriate community-based mental health services as barriers to recovery).

46. Lawson, *supra* note 2, at 77.

47. PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 182-83 (citing Robert L. Burgdorf, Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 451-52 (1991)).

48. *See id.* at 183 (*citing* 135 CONG. REC. S10765-86 (daily ed. Sept. 7, 1989)).

49. Lawson, *supra* note 2, at 68-69 (discussing the goal of moving from this medical model of disability to a social model that focuses on what society needs to do to remove barriers to full participation by persons with disabilities).

decisions,⁵⁰ many in our society, including judges, still make assumptions about a general incapacity of persons with psychosocial disability and underestimate their abilities.⁵¹ An understanding of this historical perspective is critical when considering the legality and propriety of guardianship for persons with psychosocial conditions.

B. "The Constructive Isolation of Guardianship"

The argument in this article rests on the assumption that guardianship unnecessarily isolates individuals with psychosocial impairments. Guardianship implicates a host of decisions that define who we are as human beings—where and with whom we live and spend time, whether we can travel, marry, and how, or if, we manage our money and resources.⁵² In some states, the appointment of a guardian continues to disenfranchise the ward.⁵³ Also, guardianship laws authorize the court to empower the

50. See Thomas Grisso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study. III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 L. & HUM. BEHAV. 149, 171 (1995).

51. See, e.g., PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 156, 173; Amita Dhanda, *Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future?*, 34 SYRACUSE J. INT'L L. & COM. 429, 432 (2007) (discussing status attribution model for determining incapacity); Bruce J. Winick, *The MacArthur Treatment Competence Study: Legal and Therapeutic Implications*, 2 PSYCHOL. PUB. POL'Y & L. 137, 153 (1996).

52. See WINSOR C. SCHMIDT, JR., GUARDIANSHIP: COURT OF LAST RESORT FOR THE ELDERLY AND DISABLED 5-6 (1995). See, e.g., N.Y. MENTAL HYG. LAW § 81.22 (McKinney 2009) (providing that in New York, a guardian may be granted the power to make decisions regarding the ward's routine or major medical or dental treatment, personal care, social environment, travel, driving, access to confidential records, education, benefits, and place of abode).

53. Fourteen states still have laws or constitutional provisions limiting the right to vote based on a finding of some type of mental "incapacity" or guardianship status. *State Laws Affecting the Voting Rights of People with Mental Disabilities*, BAZELON CTR. FOR MENTAL HEALTH LAW, available at <http://www.bazelon.org/LinkClick.aspx?fileticket=1kgFTxMFHZE%3d&tabid=315>. See ALA. CONST. art. VIII, § 177(b) (West, Westlaw through Nov. 2010 amendments); ARIZ. CONST. art. VII, § 2(C); LA. CONST. art. I, § 10(A); MD. CONST. art. I, § 4; MO. CONST. art. VIII, § 2; MONT. CONST. art. IV, § 2; NEV. CONST. art. II, § 1; N.Y. ELEC. LAW § 5-106(6) (2008); S.C. CONST. art. II, § 7; S.D. CONST. art. VII, § 2; UTAH CONST. art. IV, § 6; VA. CONST. art. II, § 1; W. VA. CONST. art. IV, § 4-1; WYO. CONST. art. VI, § 6. In contrast, nineteen states specifically provide that an individual under guardianship retains the right to vote, unless such a right was specifically removed by the guardianship court. See A.B.A. COMM'N ON LAW & AGING, STATE ADULT GUARDIANSHIP LEGISLATION: DIRECTIONS OF REFORM – 2010 7 (2010), http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/2010_leg_update.authcheckdam.pdf (last updated Dec. 2010) [hereinafter STATE ADULT GUARDIANSHIP LEGISLATION]. See generally A.B.A. COMM'N ON LAW & AGING, REPORT TO THE HOUSE OF DELEGATES: RECOMMENDATION 1 (August 13, 2007), available at http://www.americanbar.org/content/dam/aba/migrated/aging/voting/pdfs/voting_rec_final_

guardian to make medical decisions, including decisions of critical importance to persons with psychosocial impairments, such as those regarding the administration of antipsychotic medications or electroconvulsive therapy.⁵⁴

Most state guardianship statutes prohibit the guardian from consenting to the ward's involuntary commitment to a psychiatric facility, and require that the guardian follow the state's involuntary commitment procedures.⁵⁵ It appears, however, that a small minority of states still permit a guardian to consent to involuntary commitment to a mental health facility at least for certain limited time periods.⁵⁶

approved.authcheckdam.pdf (urging amendment of all state laws that disenfranchise citizens in the absence of an explicit determination of incapacity to vote). Even in states that protect a citizen's right to vote despite the appointment of a guardian, individuals with mental impairments may still be denied the right to vote due to general confusion among voting officials. *See* Mo. Prot. & Advocacy Servs., Inc. v. Carnahan, 499 F.3d 803, 807, 811 (8th Cir. 2007).

54. *See, e.g.*, UNIFORM GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 315(a)(4) (1997) [hereinafter UGPPA]; N.Y. MENTAL HYG. LAW §§ 81.03(i), 81.22(a)(8); *In re* Guardianship of E.L., 911 A.2d 35, 41 (N.H. 2006) (speaking to the compulsory nature of the medical guardianship as the explanation of why the ward was compliant with a medication regime to which he objected). However, states may require that the guardian follow certain state statutory or common law procedures for authorizing the involuntary administration of psychotropic medications or electroconvulsive therapy (ECT). *See* UGPPA § 316, Comments (noting that some states may require a guardian to follow mandated state procedures for certain involuntary medical treatment such as forced administration of psychotropic medications). *See In re* Rhodanna, 823 N.Y.S.2d 497, 498 (N.Y. App. Div. 2006) (concluding, sixteen years after the new guardianship law went into effect, that an individual who objects to a guardian's decision to administer psychotropic medications or electroconvulsive therapy has a due process right to an adversarial hearing to challenge the decision that he or she lacks capacity to make treatment decisions as well as the propriety of the proposed decision). *But see* John Monahan et al., *Use of Leverage to Improve Adherence to Psychiatric Treatment in the Community*, 56 PSYCHIATRIC SERV. 37, 37-44 (2005) (noting that while in most states a guardian may not administer psychotropic medications over the ward's objections without complying with the state's general rules for involuntary administration of psychiatric medication, guardianship may be used to condition receipt of money on continued compliance with treatment).

55. Guardianship laws in nearly forty states and the UGPPA either explicitly prohibit a court from authorizing a guardian to involuntarily commit a ward to a mental health treatment facility, or do not empower the guardian to consent to involuntary institutional commitment, and appear to require guardians to follow the state's procedures for involuntary commitment. *See* A.B.A. COMM'N ON LAW & AGING, GUARDIAN AUTHORITY FOR RESIDENTIAL DECISIONS: STATE STATUTORY PROVISIONS (AS OF AUGUST 2010), available at http://new.abanet.org/aging/Public Documents/guard_auth_res_dec_8_2010.pdf (last updated 2010) [hereinafter GUARDIAN AUTHORITY FOR RESIDENTIAL DECISIONS]; UGPPA § 316(d).

56. Guardianship laws in twelve states permit a guardian to consent to involuntary commitment to a mental health facility at least for certain time periods. ARIZ. REV. STAT. ANN. § 14-5312.01(B) (2010); ARK. CODE ANN. § 28-65-303(a)(1) (LEXIS through Oct.

By limiting an individual's right to make decisions, guardianship divests the individual of the ability to make crucial self-defining decisions. In doing so, guardianship can also remove the individual from a host of interactions involved in decision making and segregate him from many critical aspects of social, economic and political life. An individual who is divested of the right to make financial decisions becomes gradually disengaged from the management of those finances as well as the interactions with others involved in that management—banking, shopping, financial planning, the sale and management of property, and even giving gifts to loved ones. The restrictions on one's ability to manage one's own finances, can also restrict the individual's ability to engage in a variety of activities that require expenditures of money. If the individual is divested of the legal right to make his own medical decisions, he may find that medical decisions are made without or around him; he may get little information about his condition or treatment options, and may, as a result, be essentially disregarded in that decision-making process. A guardianship order can also isolate the individual by explicitly depriving a ward of the right to make certain social decisions regarding how or with whom he will spend time. And if, as a result of guardianship, the ward's participation in various decisions is no longer *required*, the ward's desires and preferences may rarely be solicited, leading to further isolation.

Further, guardianship may be fairly anti-therapeutic in the case of individuals with psychosocial disability, both because of the adverse consequences of the incapacity label and because the individual may be removed from the important and beneficial process of medical decision

26, 2010); KY. REV. STAT. ANN. § 387.660 (2008); MO. REV. STAT. § 475.120(5) (2000) (a guardian can seek admission for thirty days without court order then must follow state procedures for involuntary commitment); NEV. REV. STAT. ANN. § 159.113(1)(O), (6) (West 2011) (requiring special court authorization permitting guardian to place ward in secured residential long-term care facility unless court granted such power at the time of initial appointment); N.J. STAT. ANN. § 3B:12-56(d) (2011) ("to the extent specifically ordered by the court"); N.H. REV. STAT. ANN. 464-A:25(l)(a) (2011) (permitting guardian to admit ward to a state institution with prior court approval or the certification of a psychiatrist); N.C. GEN. STAT. § 35A-1241(2) (2005) (empowering guardian to consent to placement of ward in a treatment facility when "appropriate," though providing that guardian should give preference to a community-based treatment facility); N.D. CENT. CODE § 30.1-28-12(2) (1996) (empowering guardian to place individual in a treatment facility for up to forty-five days and then requiring guardian to follow state procedures for involuntary commitment); OR. REV. STAT. § 125.320(3)(a) (2007) (a guardian can consent to involuntary commitment to a mental health facility, but must give notice to the courts); VA. CODE ANN. § 2.2-713 (2008) (guardians may authorize temporary admission to a mental health facility in certain circumstances); WIS. STAT. § 54.25(2)(d)(2)(n) (2008) (a guardian can apply for protective placement). *See also* GUARDIAN AUTHORITY FOR RESIDENTIAL DECISIONS, *supra* note 55; STATE ADULT GUARDIANSHIP LEGISLATION, *supra* note 53.

making. As a result of the incapacity determination the individual experiences a sense of helplessness and loss of control, with critical implications for psychological well-being.⁵⁷ “A finding of incapacity may accentuate a patient’s difficulties, making him or her feel even more stigmatized and lacking in control” and diminishing his or her motivation to act in the world and to test, retain, or develop competencies.⁵⁸ Thus, the loss of legal capacity may add to the challenges of re-integration into all aspects of social life after a mental health crisis.

Further, in those cases where the court transfers medical decision-making rights to the guardian—even where the individual does not overtly object to treatment—the ward may be deprived of the significant therapeutic benefits associated with meaningful participation in medical decisions. First, this participation contributes to the individual’s sense of dignity and the notion that he or she is being taken seriously in the process.⁵⁹ Second, where the clinician understands that the individual must be taken seriously in the treatment consent process, the clinician and patient are more likely to have a meaningful dialogue about treatment options, thereby strengthening the critically important clinician-patient relationship.⁶⁰ The evidence indicates that this dialogue enables the clinician and patient to assess the

57. See Salzman, *supra* note 1, at 169-70; Wright, *Proposal for an Integrative Approach*, *supra* note 33, at 77-79 (citations omitted). For an insightful and thoughtful discussion of the need to study and carefully consider whether and under what circumstances guardianship actually succeeds in maintaining and/or improving the “physical, mental and spiritual health, longevity, functional capacity, and self-reported sense of well-being” of persons subject to guardianship’s protection, see 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, 353 (2010) [hereinafter Wright, *Guardianship for Your Own Good*].

58. Mary Donnelly, *From Autonomy to Dignity: Treatment for Mental Disorders and the Focus for Patient Rights*, 26 LAW IN CONTEXT, no. 2, 2008, at 37, 49-50.

59. PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 280. See generally Tom R. Tyler, *The Psychological Consequences of Judicial Procedures: Implications for Civil Commitment Hearings*, 46 S.M.U. L. REV. 433, 433-34 (1992) (observing that in the context of civil commitment hearings, individuals with psychosocial disabilities derive therapeutic benefits from a process that is fair, permits their participation, and treats them with dignity, and that the absence of these procedural characteristics is likely to cause “social malaise and [decrease] people’s willingness to be integrated into the polity . . .”).

60. See, e.g., PRESIDENT’S NEW FREEDOM COMM’N ON MENTAL HEALTH, *supra* note 45, at 27, 29; Donnelly, *supra* note 58, at 50; Penny Weller, *Supported Decision-Making and the Achievement of Non-Discrimination: The Promise and Paradox of the Disabilities Convention*, 26 LAW IN CONTEXT, no. 2, 2008, at 85, 102 (observing in the context of the creation of psychiatric advance directives that persons with severe psychosocial disabilities find that the meaningful discussion of treatment options enhances the working alliance between patient and provider, with benefits for treatment compliance); Bruce J. Winick, *The Right to Refuse Mental Health Treatment: A Therapeutic Jurisprudence Analysis*, 17 INT’L J.L. & PSYCHIATRY 99, 111-12 (1994).

efficacy and suitability of the treatment plan, increasing compliance with the agreed-upon treatment protocol and minimizing psychiatric crises or improving their management if they do occur.⁶¹ This type of regular dialogue between treatment providers and the consumer enhances the individual's treatment and well-being.

By excluding the individual with psychosocial disabilities from the decision-making process, guardianship can exacerbate the person's marginalization and isolation from mainstream society. Allowing an individual to retain the authority to make self-defining personal decisions, while providing assistance in the process when needed, is not only more respectful of individual dignity and autonomy than guardianship, it also enables the person to remain actively engaged in the full range of life's activities and maximize his or her capacities.

C. *Guardianship Continues to be Unnecessarily Isolating Despite Reforms*

There is no question that over the last two decades, guardianship laws throughout the United States have benefitted from significant substantive and procedural reforms that are more protective of the alleged incapacitated person's rights and seek to protect and respect the individual's autonomy and self-determination.⁶² Procedurally, states have enacted important reforms addressing the mandatory contents of the guardianship petition,⁶³ enhanced service requirements,⁶⁴ the possible appointment of counsel,⁶⁵ the use of impartial court evaluators or visitors,⁶⁶ and post-appointment reporting and monitoring procedures.⁶⁷ Substantively, states

61. See PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 280; PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, *supra* note 45, at 27, 29; Jeffrey Swanson et al., *Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates*, J. AM. ACAD. PSYCHIATRY L. 43, 44 nn.10-15 (2006). See generally Brayley, *supra* note 5, at 3 (observing the therapeutic benefits of the meaningful and calm exploration of options).

62. For an excellent guide to the variations in state adult guardianship laws, see *State Guardianship Laws & Updates*, A.B.A. COMM'N ON LAW & AGING, http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html (last visited June 5, 2011).

63. See, e.g., N.Y. MENTAL HYG. LAW § 81.08 (2006); UGPPA § 303 (1997). See generally A.B.A. COMM'N ON LAW & AGING, INITIATION OF GUARDIANSHIP PROCEEDINGS, available at http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/chart_cap_initiation_08_10.authcheckdam.pdf (last visited June 5, 2011) (comparing required petition elements in all state laws).

64. See, e.g., N.Y. MENTAL HYG. LAW § 81.07; UGPPA § 308.

65. See, e.g., N.Y. MENTAL HYG. LAW § 81.10; UGPPA §§ 305(b), 406(b).

66. See, e.g., N.Y. MENTAL HYG. LAW § 81.09; UGPPA §§ 305(a), 406(a).

67. Oversight and monitoring of guardianships is critical to ensure the integrity of the process. See UGPPA § 317(a), (c) (requiring guardian reports within thirty days of

have moved from a medical to a functional definition of “incapacity,”⁶⁸ have adopted a higher “clear and convincing” burden of proof,⁶⁹ require some exploration of less restrictive existing alternatives prior to appointment,⁷⁰ and require that the guardianship order be narrowly tailored to meet the individual’s specific needs (i.e., limited guardianships).⁷¹

Together, these substantive and procedural reforms make it less likely that an unnecessary guardianship petition will be filed and less likely that a guardian will be appointed when one is not necessary. Yet problems remain—both due to the continuing failure to implement enacted reforms and because the reforms are not sufficient to address the problems inherent in the guardianship paradigm. Consequently, we routinely see overly broad or unnecessary guardianship orders for a variety of reasons including the court’s general culture of protection, the focus on the incapacity determination, and the frequent lack of available less restrictive alternatives.⁷²

appointment and annually thereafter); UGPPA §§ 418(c), 419, 420 (requiring a property guardian to file a plan and inventory property within sixty days of appointment and to file subsequent annual reports that include a recommendation as to whether guardianship or conservatorship should be continued or modified). *See generally* A.B.A. COMM’N ON LAW & AGING, MONITORING FOLLOWING GUARDIANSHIP PROCEEDINGS (AS OF DEC. 31, 2009), available at http://www.americanbar.org/content/dam/aba/migrated/aging/PublicDocuments/chart_monitoring_08_10.authcheckdam.pdf (comparing significant elements of each state’s guardianship monitoring system) (last visited June 5, 2011).

68. *See, e.g.*, N.Y. MENTAL HYG. LAW § 81.02(b) (defining “incapacity” as the inability to care for self or manage property and to adequately understand the risks and consequences of that inability, along with a likelihood of resulting harm); UGPPA § 102(5) (defining an “incapacitated person” as “an individual . . . unable to receive and evaluate information or make 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.”).

69. *See, e.g.*, N.Y. MENTAL HYG. LAW § 81.12; UGPPA §§ 311(a)(1), 401(2)(a) (requiring clear and convincing evidence of “incapacity”).

70. *See, e.g.*, N.Y. MENTAL HYG. LAW § 81.02(a)(2) (providing that guardianship order should constitute the “least restrictive form of intervention”); UGPPA § 311(a)(1)(B) (requiring determination that “respondent’s identified needs cannot be met by less restrictive means”).

71. *See, e.g.*, N.Y. MENTAL HYG. LAW §§ 81.02(a)(2), 81.29(a) (“incapacitated person” retains all powers and rights not specifically granted to the guardian); UGPPA §§ 311(b), 401 (guardianship order should remove only those rights that the “incapacitated” person can no longer exercise on her own).

72. *See Wright, Guardianship for Your Own Good, supra note 57, at 353-54* (observing that many fundamental guardianship reforms conflict with the interests of the active players in the system, while the person who should most benefit from the reforms—the subject of the proceeding—is the person with the least actual voice and role in the proceeding). Available research indicates that guardianship petitions are usually granted. *See id.* at 359 (citations omitted); *Wright, Proposal for an Integrative Approach, supra note 33, at 82-83* (citing to studies from the 1990’s that found that guardianship petitions were granted in 91% and 94%

The evidence indicates that courts do not utilize limited guardianships as often as they are warranted.⁷³ Courts may enter overly broad guardianship orders for a number of reasons, including: a judicial habit or culture of entering broad orders;⁷⁴ the additional time and effort required to conduct a meaningful assessment of the individual's different "capacities;"⁷⁵ the fact that the court first considers whether a person is "incapacitated" and then drafts the order, making it more likely that the court would enter a broadly protective order;⁷⁶ and because the entry of a broad order both avoids confusion about the scope of the guardian's authority and the need for future proceedings to expand a more limited initial order.⁷⁷ Yet, even in

of the cases, respectively) (citations omitted). It is generally difficult to draw precise conclusions about the nature of guardianship decisions, however, because most decisions are not published and the proceedings are generally closed to the general public. See Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 200 (2007) (citation omitted).

With regard to less restrictive available resources that are considered as alternatives to the appointment of a guardian, courts look to alternatives such as trusts, powers of attorney, health care advanced directives or powers or attorney/health care proxies, home health aides, or residential care facilities. See, e.g., N.Y. MENTAL HYG. LAW § 81.03(e). Many of these alternatives are not realistic options because affordable health related services are not available because the individual wishes to remain in her home, or because the individual no longer has the recognized legal capacity to execute the relevant legal instruments. PETRILA & SWANSON, *supra* note 35, at 34-35 (discussing the limited use of psychiatric advance directives) (citations omitted); Swanson et al., *supra* note 61, at 43, 55-56. But see *In re Guardianship of E.L.*, 911 A.2d 35, 39 (N.H. 2006) (discussing the court's conclusion that neither health care power of attorney nor springing guardianship would be an appropriate less restrictive alternative to guardianship under the circumstances of that case).

73. See, e.g., *In re Estate of Fallos*, 898 N.E.2d 793, 799, 802 (Ill. App. Ct. 2008). Although the appellate court did reverse the lower court's decision refusing to terminate or limit the guardianship order, the decision likely reveals a common phenomenon at the lower court level. See *id.* at 802. In fact, in one 2007 study of guardianship orders in Colorado, a state which has adopted the UGPPA, the researcher found that while approximately one-third of the guardianship orders were technically "limited" orders, they were actually "plenary orders with some specific limitations on the guardians' powers added in." See Wright, *Guardianship for Your Own Good*, *supra* note 57, at 367 n.144.

74. See Lawrence A. Frolik, *Guardianship Reform: When the Best Is the Enemy of the Good*, 9 STAN. L. & POL'Y REV. 347, 352-53 (1998) [hereinafter Frolik, *Guardianship Reform*].

75. See Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 STETSON L. REV. 735, 742 (2002) [hereinafter Frolik, *Promoting Judicial Acceptance*].

76. See Salzman, *supra* note 1, at 175.

77. See Frolik, *Guardianship Reform*, *supra* note 74, at 354 (noting that "judges know all too well the financial costs of additional court appearances as guardians with insufficient authority to deal with the needs of their wards ask the courts to expand the limits of the guardianships."). See also Frolik, *Promoting Judicial Acceptance*, *supra* note 75, at 743-44 (2002) (noting that plenary guardianship saves the time of judges and litigants by removing

those rare circumstances when the court enters a limited guardianship order, the person has been found to be incapacitated in at least some area of decision making, and as a result, may be treated as broadly incapacitated by individuals and entities within the community.

Compounding these problems is the fact that guardianship orders rarely have a definite duration and generally continue until the ward's death or order of the court.⁷⁸ Additionally, the orders are often difficult to terminate for many of the same reasons that lead courts to enter overly broad guardianship orders in the first place.⁷⁹

With regard to the ward's participation in decision making, state laws vary in the nature and amount of the guardian's contact or consultation with the ward. Many state laws now generally encourage the ward's participation in decisions and encourage guardians to make decisions consistent with the ward's desires and preferences, to the extent they are

the need to return to court to petition for expanded powers when the ward's capacity declines).

78. See, e.g., UGPPA § 318(a). While most states have a system for requiring the filing and monitoring of guardian reports, there are serious deficiencies in guardianship monitoring practices. See, e.g., Naomi Karp & Erica F. Wood, *Guardianship Monitoring: A National Survey of Court Practices*, 37 STETSON L. REV. 143, 160-75, 184-92 (2007). As a result, many guardian reports simply "fall through the cracks," and few states mandate a periodic court review to determine the continued need for a guardian. See MONITORING FOLLOWING GUARDIANSHIP PROCEEDINGS, *supra* note 67 (indicating that only a small number of states have some requirement for affirmative court review of the need for continuation of the order, i.e., CAL. PROB. CODE § 1850(a)(1), (2) (West 2010) (requiring court investigator to periodically visit conservatee and report to the court, which may take action, including conducting a hearing to determine continued propriety of conservatorship); CONN. GEN. STAT. ANN. § 45a-660(c) (West 2010) (calling for periodic court review of the need for continued conservatorship); KAN. STAT. ANN. § 59-3084(a), (b) (2010) (requiring court or designee to review the periodic guardian report and permitting the court to order a hearing to review any issue relating to the guardianship); MICH. COMP. LAWS ANN. § 700.5309 (West 2010) (calling for unspecified court "review" of guardianship order at periodic intervals); MO. ANN. STAT. § 475.082(1) (requiring annual court review for continuing need for guardianship with the review implemented based on guardian's status report filed with the court); NEV. REV. STAT. ANN. § 159.176 (West 2010) (requiring that every guardianship is subjected to an unspecified annual court "review"); N.H. REV. STAT. ANN. § 464-A:25(d) (West 2010) (providing for unspecified court "review" of guardian's annual report, including any health care decision-making authority); OHIO REV. CODE ANN. § 2111.49(A)(2) (requiring review of guardian's biennial report to determine the continued need for a guardianship)).

79. See, e.g., *In re Estate of Fallos*, 898 N.E.2d 793, 797-99 (Ill. App. Ct. 2008) (citing to trial court finding that the ward continued to need a plenary guardian due to the risk presented by his "underestimating the severity of his physical limitations and overestimating his ability to live independently"); Wright, *Guardianship for Your Own Good*, *supra* note 57, at 361. But see, e.g., *In re Penson*, 735 N.Y.S.2d 51, 52 (N.Y. App. Div. 2001) (affirming decision terminating guardianship based on individual's understanding of his limitations and a demonstration that he was capable of managing his finances).

known.⁸⁰ As a result of these guardianship reforms, and the philosophical principles that motivated these changes, some guardians do make those decisions they believe the ward would have made, some guardians may involve their ward in decisions, and some guardians may even allow the ward to make independent decisions in certain decision-making areas within the guardian's authority. Nevertheless, while some guardians may actively involve their wards in decisions about their lives, legally, the decisions are vested in the guardian and are the guardian's to make.⁸¹ State laws do not provide an enforceable right for the ward to participate in decisions or to have his or her wishes followed. While the ward or other interested person could petition the court to change or remove the current guardian, it is not clear that a court would remove a guardian for the sole reason that he or she was not encouraging the ward's participation in decisions, in the absence of some other more concrete harm to the ward.⁸² While some states require that the guardian include in the annual guardianship reports the number of visits or contacts he or she has made with the ward,⁸³ few, if any states, require that the guardian report on the nature of the contact or the extent of the ward's involvement in decision making or any efforts by the guardian to help restore the ward's "capacity."⁸⁴ Even if guardians were required to include this information in the annual reports, the change is unlikely to be particularly useful in the absence of improved state monitoring of guardianship reports.

80. See, e.g., ARIZ. REV. STAT. ANN. § 14-5312(A)(7) (2008) (requiring guardians to "encourage" ward's self-reliance and independence); COLO. REV. STAT. § 15-14-314 (2008) (providing that guardian should "encourage the ward to participate in decisions"); CONN. GEN. STAT. § 45a-656(b) (2008) (stating that a conservator "shall afford the conserved person the opportunity to participate meaningfully in decision-making in accordance with the conserved person's abilities and shall delegate to the conserved person reasonable responsibility for decisions affecting such conserved person's well-being"). See also UGPPA § 314(a) (encouraging guardians to involve their wards in decision making "to the extent possible").

81. See, e.g., ARIZ. REV. STAT. ANN. § 14-5312 (2008); COLO. REV. STAT. § 15-14-314 (2008); CONN. GEN. STAT. § 45a-656(a) (2008).

82. See generally *In re Estate of Fallos*, 898 N.E.2d at 801 (observing that the burden is on the individual seeking to modify or terminate guardianship). But see *In re Guardianship of E.L.*, 911 A.2d 35, 38 (N.H. 2006) (noting that the guardian bears the burden in proceeding to terminate).

83. See, e.g., N.Y. MENTAL HYG. LAW §§ 81.30(a), (c), 81.31(a) (setting forth the requirements for the initial and annual reports to be submitted by the guardian); UGPPA § 317(a) (requiring guardians to report within thirty days of appointment and annually thereafter).

84. See MONITORING FOLLOWING GUARDIANSHIP PROCEEDINGS, *supra* note 67 (setting forth the general contents of each state's guardian's report). The UGPPA, however, provides model language for requiring that the annual report include a summary of the ward's decision-making involvement. UGPPA § 317(a)(4).

D. The Inadequacy of Guardianship to Address the Needs of Persons with Psychosocial Disability

In addition to the general concerns about the guardianship system, there are reasons for particular concern about the imposition of guardianship for persons with psychosocial conditions, due to prevailing stereotypes and prejudices that disadvantage them in the guardianship adjudication process. Persons with psychosocial disabilities must overcome the significant stigma attached to psychosocial disability,⁸⁵ the assumptions that they are inherently different and predisposed to violence,⁸⁶ and notions that their "mental defect" precludes their ability to reason and make a whole range of personal decisions.⁸⁷

1. The Culture of Protection and Concerns about Relapse and Related Acts of Violence

Because of judicial concerns about the episodic and recurring nature of psychosocial conditions, and a concern (or presumption) that a future relapse could result in an act of violence, courts may err on the side of caution when determining whether an individual with a psychosocial disability is "incapacitated" and in need of a guardian.⁸⁸ Recent cases in New Hampshire and New York illustrate this phenomenon.

In *In re Guardianship of E.L.*,⁸⁹ the Supreme Court of New Hampshire affirmed a lower court decision refusing to terminate the ten-year guardianship of a man with bipolar disorder even though there had not been a single incident indicating "incapacity" within the two years prior to the request to terminate,⁹⁰ and state law required evidence of the inability to

85. See PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, *supra* note 45, at 19-20 (noting that because of the stigma surrounding psychosocial disability, many individuals who might benefit from treatment are reluctant to seek it).

86. Lawson, *supra* note 2, at 77 (citation omitted) ("People with psychosocial impairments are commonly regarded as unpredictable, irrational, slow, stupid, unreliable, not responsible for their actions, violent and dangerous.").

87. See PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 42-47 (describing the myths underlying the discourse about and treatment of persons with psychosocial disability). See also *Olmstead v. L.C.*, 527 U.S. 581, 610 (1998) (Kennedy, J., concurring) (referring to the "common phenomenon that a patient functions well with medication, yet, because of the mental illness itself, lacks the discipline or capacity to follow the regime the medication requires.").

88. Thomas Grisso, *Clinical Assessments for Legal Decisionmaking: Research Recommendations*, in LAW & MENTAL HEALTH: MAJOR DEVELOPMENTS AND RESEARCH NEEDS 49, 65-66 (Saleem Shah & Bruce Sales eds., 1991). See, e.g., *In re K.L.*, 806 N.E.2d 480, 482-83, 487 (N.Y. 2004) (endorsing state intervention through assisted outpatient treatment order to prevent prospective relapse of individuals with psychosocial disability).

89. *In re Guardianship of E.L.*, 911 A.2d 35 (N.H. 2006).

90. *Id.* at 37-38, 41, 43.

manage affairs within the prior six months for the initial *appointment* of the guardian.⁹¹ In reaching its decision, the Court expressed a concern that the ward would stop taking his medications and decompensate if the guardianship was terminated.⁹²

In a similar vein, in *In re Ada (John D.)*,⁹³ the court had to decide whether to appoint a guardian for Mr. D., in light of his prior psychiatric hospitalization with a subsequent episode of hypomania that resulted in “excessive and irrational spending,” and his doctor’s prediction that there was at least a thirty percent chance of a relapse in his condition.⁹⁴ Despite the court’s specific determination that John D. *was not incapacitated*⁹⁵—a finding that should have resulted in dismissal of the guardianship petition—the court appointed a “monitor” to “oversee” John’s financial activities and medical treatment “in light of the possibility of relapse.”⁹⁶

Guardianship judges are not immune from the common presumption that individuals with severe psychosocial disability are prone to violence⁹⁷ and will engage in violent behavior without the oversight of their guardians.⁹⁸ When there is doubt, judges and experts would rather be “safe than sorry.”⁹⁹ Complicating matters is the fact that while there have been

91. *Id.* at 43.

92. *Id.* at 40-42.

93. *In re Ada*, 885 N.Y.S.2d 194 (N.Y. Sup. Ct. 2009).

94. *Id.* at 194-95.

95. *Id.* at 195.

96. *Id.* at 195-96. See N.Y. MENTAL HYG. LAW § 81.16(b) (authorizing a protective arrangement, but only *if* the AIP “is found to be incapacitated,” and only when it is necessary “as a means of providing for personal needs and/or property management *for* the alleged incapacitated person”) (emphasis added).

97. See PRESIDENT’S NEW FREEDOM COMM’N ON MENTAL HEALTH, *supra* note 45, at 20 (finding that sixty-one percent of Americans surveyed believe that people with schizophrenia are likely to be violent) (citing BERNICE A. PESCOLILDO ET AL., AMERICANS’ VIEWS OF MENTAL HEALTH AND ILLNESS AT CENTURY’S END: CONTINUITY AND CHANGE 15, 16 (1996), available at <http://www.indiana.edu/~icmhsr/docs/Americans%20Views%20of%20Mental%20Health.pdf>); Henry A. Dlugacz, *Involuntary Outpatient Commitment: Some Thoughts on Promoting a Meaningful Dialogue Between Mental Health Advocates and Lawmakers*, 53 N.Y.L. SCH. L. REV. 79, 85 (2008/2009) (noting that the perceived relationship between mental disability and violence is fueled by “[m]edia portrayals of the mentally ill, as well as the tragic nature of specific cases where a person with a mental disability kills or harms another person.”).

98. See *Understanding Psychosocial Disability: Factsheet*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., http://www.samhsa.gov/MentalHealth/understanding_MentallIllness_Factsheet.aspx (last updated Sept. 24, 2008).

99. See generally Nicholas Scurich & Richard John, *The Normative Threshold for Psychiatric Civil Commitment*, 50 JURIMETRICS J. 425, 428 (2010) (discussing research finding that judges utilize a very low threshold of the probability of violence to authorize short-term civil commitment, with half of a sample of judges concluding that an eight percent chance of violence was sufficient, and some concluding that a one percent chance was sufficient).

some improvements in risk assessment techniques, experts have difficulty predicting future dangerous conduct with any reasonable degree of accuracy, and “between one-half and three-quarters of those identified as dangerous by psychiatric professionals do not, in the end, turn out to be violent.”¹⁰⁰ The reality is that decisions about whether an individual with a psychosocial disability is likely to be a danger to self or others are “inherently subjective,”¹⁰¹ and when pressed, experts have had difficulty credibly explaining the basis for an opinion about future dangerousness.¹⁰²

2. Courts Underrate the “Capacity” of Persons with Psychosocial Conditions

The validity of the court’s “capacity” determination may be undermined by at least three factors.¹⁰³ First, pervasive stereotypes lead courts and other individuals involved in the guardianship assessment process to underrate the competencies and credibility of persons with psychosocial conditions. Second, the court may blur the distinction between the rationality of an individual’s decision and the individual’s actual ability to make a decision. Third, because of the difficulty of parsing out various decision-making

100. PETER BARTLETT & RALPH SANDLAND, *MENTAL HEALTH LAW: POLICY AND PRACTICE* 147 (Oxford University Press 3d ed. 2007); PERLIN, *HIDDEN PREJUDICE*, *supra* note 34, at 44 n.188 (citations omitted). *See generally* *Heller v. Doe*, 509 U.S. 312, 322, 323-24 (1990) (“Manifestations of mental illness may be sudden, and past behavior may not be an adequate predictor of future actions.”); *Adams v. Schwartz*, No. CIV S-05-2237 JAM JFM P, 2008 U.S. Dist. LEXIS 85269, *34-35 n.10, *39 (E.D. Cal. Sept. 8, 2008) (discussing the uncertainty in predicting future violent actions); *Matter of M.M.B.*, No. 88-0984, 1988 WL 112479, at *2 (Wis. Ct. App. Aug. 25, 1988) (noting the difficulty of objectively evaluating evidence of future dangerousness of persons with psychosocial disability due to ingrained stereotypes regarding the relationship between psychosocial disability and violent behavior). In fact, studies reveal only a very small correlation between severe psychosocial disability and violence, and show significantly higher correlations between drug use, socioeconomic status, or characteristics of the individual’s neighborhood and a person’s risk of violence. *See, e.g.*, PETRILA & SWANSON, *supra* note 35, at 29-30; PRESIDENT’S NEW FREEDOM COMM’N ON MENTAL HEALTH, *supra* note 45, at 20; *Understanding Mental Illness: Factsheet*, SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., U.S. DEP’T OF HEALTH & HUMAN SERVS., http://www.samhsa.gov/MentalHealth/understanding_MentalIllness_Factsheet.aspx (last updated Sept. 24, 2008).

101. PETRILA & SWANSON, *supra* note 35, at 10-11. *See* John Petrila & Corine de Ruiter, *The Competing Faces of Mental Health Law: Recovery and Access Versus the Expanding Use of Preventive Confinement*, AMSTERDAM L. FORUM, 2011, at 59, 63 (noting the difficulty of accurate risk assessment on an individual basis and the tendency in some cases for mental health experts to exaggerate the reliability and validity of risk assessment instruments).

102. *See* Grisso, *supra* note 88, at 65-66.

103. *See generally* Wright, *Proposal for an Integrative Approach*, *supra* note 33, at 79-82 (discussing difficulties inherent in psychiatric diagnoses, assessments of “capacity,” and treatment decisions).

competencies, the guardianship court may make more global assessments of incapacity than are actually justified.

Judges, like many others, are greatly influenced by oversimplified perceptions and “misinformed opinions” regarding psychosocial disability that cause people to “imply cause-and-effect relationships that do not exist,”¹⁰⁴ and continue to equate psychosocial disability with legal incapacity.¹⁰⁵ The equation of psychosocial disability with incapacity carries over to the court’s assessment of the credibility of the individual with the psychosocial condition. Courts have a tendency to discredit the person’s testimony regarding her own needs and abilities,¹⁰⁶ increasing the burden on the individual with psychosocial disabilities to establish her ability to make decisions and manage affairs.¹⁰⁷

There is also the well-noted problem of guardianship courts making decisions about “capacity” based on the perceived rationality of the individual’s decision, rather than on the individual’s actual ability to make a decision, a problem that is particularly acute when the alleged incapacitated person has a psychosocial disability.¹⁰⁸ A court’s reliance on the perceived irrationality of an individual’s decision in reaching a determination that the individual lacks capacity is all the more problematic because the court may discredit the individual’s stated preferences and assessment of her own well-being if it does not conform to the court’s sense of what best serves the individual’s interests.¹⁰⁹

104. See PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 25.

105. See Minkowitz, *U.N. Convention*, *supra* note 24, at 408.

106. See, e.g., *Zinermon v. Burch*, 494 U.S. 113, 133 (1989) (questioning whether an individual with psychosocial disability could ever seek “voluntary” admission to a psychiatric facility, because the individual will not be able to understand the necessary information or knowingly consent to admission); PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 173 (discussing the possible impact of *Zinermon*); Deirdre M. Smith, *The Disordered and Discredited Plaintiff: Psychiatric Evidence in Civil Litigation*, 31 CARDOZO L. REV. 749, 788 (2010) (citation omitted) (noting that at common law “insanity” rendered an individual incompetent to provide testimony in a judicial proceeding).

107. See PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 155-56; Terry Carney et al., *Advocacy and Participation in Mental Health Cases: Realisable Rights or Pipe-dreams?*, 26 LAW IN CONTEXT, no. 2, 2008, at 125, 133 (citations omitted) (referring to a 2005 study of proceedings before the Australian mental health tribunal); Donnelly, *supra* note 58, at 47; Smith, *supra* note 106, at 804-05 (discussing judicial decisions that relied on or excluded psychiatric testimony regarding a witness’s psychosocial disability for purposes of evaluating credibility).

108. See Charles M. Culver, *Health Care Ethics and Mental Health Law*, in LAW & MENTAL HEALTH: MAJOR DEVELOPMENTS AND RESEARCH NEEDS, *supra* note 88.

109. Carney et al., *supra* note 107, at 131 (noting that an individual’s assessment of his or her own well-being must consider “the balance between current and future well-being; physical, psychiatric, social and psychological well-being; safety and autonomy”). The rejection of an individual’s assessment of her own mental health and the suitability of various

The guardianship court's conflation of the irrationality of a decision with the "incompetence or incapacity" of the decision maker is most obvious in the important area of health care decision making, especially when an individual is rejecting a recommended treatment.¹¹⁰ Such a decision is deemed to be irrational because the assumption is that the person is better off taking recommended medications.¹¹¹ Because of the frequent assumption that individuals with psychosocial conditions would exercise their right to make medical decisions by rejecting necessary psychiatric treatment,¹¹² and since judges and medical professionals view consistent treatment compliance as very beneficial—which it often is—courts may be willing to favor the imposition of a guardianship order as a remedy to ensure the individual's continued treatment compliance, even if the individual's condition has stabilized and the evidence does not support a finding of incapacity.¹¹³

However, the assumption that the individual with psychosocial disability (who is not dangerous) should take medication for his or her own good, conflicts with the fundamental right accepted in other contexts to refuse

treatment regimes is ironic. It is precisely as a result of "the episodic nature of incapacity in severe mental illness" that the affected individual understands the course of the condition and the most effective means of managing it in the event of a future crisis. PETRILA & SWANSON, *supra* note 35, at 23. See Adina Halpern & George Szukler, *Psychiatric Advance Directives: Reconciling Autonomy and Non-Consensual Treatment*, 21 PSYCHIATRIC BULL. 323, 323-26 (1997) (discussing the use of PADs for people with psychosocial conditions that may make them temporarily incapacitated and significant court decisions involving the determination of capacity); Aaron Levin, *Psychiatrists Often Reluctant To Encourage PADs*, PSYCHIATRIC NEWS, July 15, 2005, at 17. (describing a study demonstrating that most individuals with psychosocial conditions had clear and insightful opinions about treatment and their conditions, and that most patients were willing to consent to treatment with at least one psychotropic drug and willing to go to at least one hospital in a crisis).

110. See Donnelly, *supra* note 58, at 46, 48-49 (citing to studies indicating that in the context of proceedings in the United States to determine whether an individual had "capacity" to refuse psychiatric treatment, most such patients were found to lack capacity).

111. See PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 155-56.

112. Swanson et al., *supra* note 61, at 54. Studies indicate that this assumption is incorrect. See generally Levin, *supra* note 109 (observing that psychiatric advanced directives were not used to solidify future inappropriate treatment refusals, and rarely contained inappropriate treatment requests); Donnelly, *supra* note 58, at 50-51 (noting that participation in treatment decisions often results in patients consenting to medication other than that which was recommended by the treating psychiatrist, but ultimately leads to a resolution both can live with); Eric B. Elbogen et al., *Clinical Decision-making and Views About Psychiatric Advance Directives*, 57 PSYCHIATRIC SERV. 350, 351, 353 (2006).

113. "Judicial paternalism manifests itself either in the sense of wishing to see an individual do well, or as conservatism in judicial decision-making based upon a desire to avoid spectacular failures." Dlugacz, *supra* note 97, at 89 (observing that in the related context of renewals of outpatient commitment orders, consistent compliance with medical treatment is often viewed by the court as evidence that the order is "working" and should be extended).

medical treatment even when it is needed to save the person's life or restore his or her health.¹¹⁴ In this context, the decision to remove the individual's ability to make health care decisions, and to give the guardian the authority to consent to medical treatment, is implicitly or explicitly justified, ironically, as a means of restoring or maintaining the individual's ability to function more autonomously.¹¹⁵ This is not to minimize the goal of appropriately treating persons with psychosocial disability. Guardianship should not be imposed, however, when an individual is able to make a medical decision, but wishes to refuse a particular treatment.¹¹⁶

The prevailing assumption that persons with psychosocial disability are not competent to make medical decisions is simply not justified. The MacArthur Treatment Competence Study concluded that approximately 50% of the persons hospitalized for schizophrenia and 75% of the persons hospitalized for severe depression performed in the adequate range of decisional abilities—as good as those without psychosocial disability—and these percentages were higher when looking at a single component of the various decision-making competencies.¹¹⁷ So, even for medication decision

114. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 272-79 (1989) (reviewing state court decisions upholding the right of an individual to refuse medical treatment even when the refusal may cause the individual's death and observing that Supreme Court precedent could support a "constitutionally protected liberty interest in refusing unwanted medical treatment . . .").

115. See Donnelly, *supra* note 58, at 43-44; EXPERT COMM., REVIEW OF THE MENTAL HEALTH ACT 1983, U.K. DEP'T OF HEALTH ¶ 2.9 (Nov. 1999), available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4062614.pdf. But see Pettila & de Ruiter, *supra* note 101, at 61 (citations omitted) (noting that "[w]hile the implementation of outpatient commitment . . . has [sometimes] been hampered by a lack of adequate treatment resources and cumbersome statutory procedures," research has suggested that outpatient commitment for at least six months in conjunction with "adequate treatment" over that time period has reduced hospitalizations and criminal conduct "among some individuals with serious mental illnesses"); Tanya Wanchek & Richard J. Bonnie, *Reducing Mental Health Civil Commitments through Longer Temporary Detention Periods*, Va. Pub. L. & Legal Theory Res. Paper Series No. 2011-05, 4, 6-7, 9 (August 2010), available at http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1766047 (analyzing state court data and Medicaid claims in Virginia and concluding that temporary involuntary treatment through Temporary Detention Orders can lower the frequency and length of involuntary civil commitments).

116. If the person is dangerous as a result of psychosocial disability, that person should be hospitalized. If there is no actual safety issue, treatment should be voluntary in order to encourage "long term engagement in treatment." *Where We Stand: Outpatient and Civil Commitment*, BAZELON CTR. FOR MENTAL HEALTH LAW, <http://www.bazelon.org/Where-We-Stand/Self-Determination/Forced-Treatment/Outpatient-and-Civil-Commitment.aspx> (last visited Mar. 16, 2011).

117. Grisso & Appelbaum, *supra* note 50, at 171-72 (citing results of study assessing decision-making abilities across all decision-making measures and noting that, when examining performance on a single measure of decisional abilities, "the rate of performance

making, psychiatric patients are “not necessarily more incompetent than non-mentally ill persons to engage in independent medication decision making.”¹¹⁸ Further, in light of the well-recognized adverse side effects of anti-psychotic drugs, including “neuroleptic malignant syndrome and painful seizures,”¹¹⁹ in many cases the decision to reject certain medications might actually reflect a clear ability to understand the consequences of such treatment. Rather than drawing conclusions about medical decision-making abilities from the individual’s acceptance or rejection of proposed treatment,¹²⁰ techniques and tools, such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) should be used for assessing medical decision-making competencies in the guardianship context.¹²¹ Grisso and Appelbaum have helped demonstrate the complexity of evaluating “decision-making capacity” in the medical decision-making context. They have demonstrated that the ability of persons with serious psychosocial disability to make health care decisions improved significantly

rose to roughly 75% for patients with schizophrenia and to approximately 90% or more for patients with depression.”). See WINICK, *supra* note 36, at 104-10 (2005) (discussing the MacArthur Treatment Competence Study).

Appelbaum and Grisso identified the competencies needed to make medical decisions as: the ability to understand relevant information, the ability to appreciate the nature and significance of the decision, the ability to draw conclusions from the facts and evaluate potential consequences, and the ability to communicate choices. PERLIN, HIDDEN PREJUDICE, *supra* note 34, at 93 (citing Paul Appelbaum & Thomas Grisso, *Assessing Patients’ Capacities to Consent to Treatment*, 319 NEW ENG. J. MED. 1635, 1635-36 (1988)).

118. Michael L. Perlin, *Therapeutic Jurisprudence and Outpatient Commitment Law: Kendra’s Law as Case Study*, 9 PSYCHOL. PUB. POL’Y & L. 183, 194 (2003). See also Barry Rosenfeld, Eric Turkheimer & William Gardner, *Decision-making in a Schizophrenic Population*, 16 L. & HUMAN BEHAV. 651, 660 (1992) (controlling for differences in verbal functioning, the study revealed that persons with schizophrenia were able to weigh risks, benefits, and probabilities as well as nonpatients).

119. *Sutton v. United Air Lines*, 527 U.S. 471, 484 (1999). See *Riggins v. Nevada*, 504 U.S. 127, 142 (1992) (Kennedy, J., concurring).

120. See Norman G. Poythress, Jr. & Robert D. Miller, *The Treatment of Forensic Patients: Major Issues*, in LAW & MENTAL HEALTH: MAJOR DEVELOPMENTS AND RESEARCH NEEDS 81, 88-89, *supra* note 88 (suggesting other ways of assessing an individual’s competency to consent to medical treatment).

121. See Thomas Grisso, Paul S. Appelbaum & Carolyn Hill-Fotouhi, *The MacCAT-T: A Clinical Tool to Assess Patients’ Capacities to Make Treatment Decisions*, 48 PSYCHIATRIC SERVS. 1415, 1418 (1997) (describing the MacCAT-T and its usefulness in determining patients’ capacities to make medical treatment decisions). See generally Grisso, *supra* note 88, at 70-71 (“In summary, research must first define what people are expected to know, understand, or do in the relevant area of functioning with which the legal standard for competence is concerned . . . descriptive research must document and categorize the types of functional abilities that various environments or decisionmaking circumstances require of people . . . [and then] require the examinee to demonstrate the specific functions in question.”).

when relevant information was presented incrementally and repeated to the patient.¹²² It is not clear that guardianship courts are uniformly willing to invest the time and effort needed to engage in the difficult analysis of decision-making abilities with regard to the specific competencies involved in the range of decisions at issue in the guardianship proceeding.¹²³

3. Guardianship is not Adequately Responsive to Changes in the Individual's Condition

As noted *supra*, most guardianship orders are not time-limited and last until the ward's death or a modification or termination of the order.¹²⁴ Psychosocial conditions are often temporary or episodic, and the individual may experience significant improvement in decision-making capabilities, or even full recovery, within a reasonably short time period.¹²⁵ These fluctuations in condition are not sufficiently accounted for in either the initial decision to appoint a guardian or in the duration of the guardianship order.¹²⁶ Because mental health conditions are subject to significant changes over time, often with long periods of stability, there is cause for concern about the accuracy and integrity of the capacity determination and the propriety of the guardianship order. These concerns are particularly troubling in the context of a guardianship process in which the ability to modify or vacate the order is not so simple.

The next question to be analyzed is how supported decision-making programs avoid these deleterious effects of guardianship on persons with psychosocial conditions and thus enable individuals with limitations in decision-making abilities to remain more fully integrated in life's essential activities.

122. Grisso & Appelbaum, *supra* note 50, at 172-73.

123. *See, e.g.*, Submission from Tina Minkowitz, Center for the Human Rights of Users and Survivors of Psychiatry, to the Comm. on the Rights of Persons with Disabilities, Day of General Discussion on CRPD Article 12, available at <http://www.chrusp.org/home/publications> [hereinafter Minkowitz, Discussion on CRPD Article 12].

124. *See* UGPPA § 318(a); Wright, *Proposal for an Integrative Approach*, *supra* note 33, at 71.

125. *See* Swanson et al., *supra* note 61, at 43-44. *See generally* L.C. by Zimring v. Olmstead, 138 F.3d 893, 902-03 (11th Cir. 1998), *aff'd in part, vacated in part, and remanded*, 527 U.S. 581 (1999) (noting general fluidity of psychiatric conditions).

126. *See* Weller, *supra* note 60, at 100. *See generally* Minkowitz, Discussion on CRPD Article 12, *supra* note 123, pt. 1 (observing in the context of forced administration of medication that standards and protocols are needed for determining when immediate treatment is required for a serious mental health condition and when such treatment may be deferred in order to obtain the individual's consent).

III. SUPPORTED DECISION MAKING PROVIDES A VIABLE AND LESS RESTRICTIVE ALTERNATIVE TO GUARDIANSHIP

A formal program of decision-making support substantially limits the deleterious and segregating effects of guardianship on persons with psychosocial conditions described in Part II (B). Supported decision making moves beyond the theoretical “presumption of legal capacity” found in modern guardianship regimes, to provide each person with the legal right to make or participate in personal or financial decisions, and to receive the support that might be needed to do so. Thus, rather than suffer a loss of decision-making rights, an individual with limitations in decision-making abilities can receive support to understand relevant information, issues, and available choices, to focus attention in making decisions, to help weigh options, to ensure that decisions are based on her own preferences, and, if necessary, to interpret and/or communicate her decisions to other parties.¹²⁷

While there is no singular supported decision-making model, scholars and commentators point to several characteristics of supported decision-making programs. First, the individual’s legal right to make decisions is not compromised by the appointment of a decision-making assistant or agent.¹²⁸ Second, the individual freely enters into a support relationship and may terminate the relationship at any point in time.¹²⁹ Third, the principal must actively participate in decision making pursuant to the appointed

127. See ANDREW BYRNES ET AL., FROM EXCLUSION TO EQUALITY: REALIZING THE RIGHTS OF PERSONS WITH DISABILITIES 89-91 (United Nations 2007). See also OFF. OF THE PUB. ADVOCATE, SUPPORTED DECISION-MAKING: BACKGROUND AND DISCUSSION PAPER 8-9 (2009), available at http://www.publicadvocate.vic.gov.au/file/file/Research/Discussion/2009/Supported_Decision_Making_Nov09.pdf (noting that the hallmarks of supported-decision-making are choice, control, and responsibility).

128. See, e.g., Representation Agreement Act, R.S.B.C., ch. 405, pt. 6, § 36 (1996), available at http://www.qp.gov.bc.ca/statreg/stat/R/96405_01.htm.

129. OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 23. See Torbjorn Odlow, Swedish Guardianship Legislation—Progressive and Lagging Behind 1 (Nov. 14, 2008) (unpublished manuscript) (on file with author) (noting that in the Swedish system, the individual must consent to the appointment of a decision-making assistant); *Swedish User-Run Service with Personal Ombud (PO) for Psychiatric Patients*, PO-SKÅNE, <http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php> [hereinafter *PO-Skåne Description*] (permitting the non-bureaucratic and consensual appointment of decision-making assistant by the principal). *But see* Herr, *supra* note 6, at 435-36 (discussing the Swedish assignment of an administrator or decision-making surrogate under certain circumstances where the individual does not consent to the appointment of a decision-making assistant); Odlow, *supra*, at 2-3 (noting that, in the event that establishment of a decision-making assistant is deemed inappropriate or insufficient due to the principal’s limitations, the court may appoint an administrator to oversee the principal’s daily activities).

powers.¹³⁰ Fourth, decisions made with support are generally legally binding.¹³¹ In addition, and quite significantly, in those circumstances when a surrogate decision maker is appointed, the order of appointment is time-limited and judicial consent is required to extend the order beyond its original duration.¹³²

So how is a formal, supported decision-making relationship created? There are two general types of models: the private supported decision-making agreement and the court-appointed legal mentor or personal ombudsman (PO).¹³³ In the relatively advanced, and apparently well-received supported decision-making models being used in some Canadian provinces, an individual with disabilities has the right to enter into a private

130. See, e.g., Representation Agreement Act, pt. 3, §§ 16, 23 (1996) (creating a duty to consult the principal regarding his/her wishes "to the extent 'reasonable' and to carry out those wishes 'if it is reasonable to do so;'" making the representative liable for actions taken without "reasonable" consultation with the principal and/or contrary to the principal's "reasonable" wishes); Odlow, *supra* note 129, at 6-7 (noting that, in the Swedish system, the decision-making mentor/assistant cannot bind the individual with a disability to any transaction to which the individual had the capacity to consent but did not do so, and if the mentor acts without this consent, the mentor is liable to a third party for any resulting damages). But see BYRNES ET AL., *supra* note 127, at 89-90 (concluding that, because the Swedish mentor is authorized to make independent decisions in certain circumstances, it seems more akin to a surrogate decision-making model).

131. See Representation Agreement Act, pt. 2, §§ 7, 9, 9.1; pt. 3, §§ 19, 24 (1996); Decision-making, Support and Protection to Adults Act, S.Y.T, ch. 21, pt. 1, § 11, pt. 2, § 25 (2003). In Canada, support and representation agreements can be entered into a central registry so that third parties are aware of their existence. See, e.g., *Nidus Personal Planning Resource Centre and Registry*, NIDUS (July 2009), http://www.nidus.ca/PDFs/About%20us_Nidus%20Fact%20Sheet_July2009.pdf.

132. See, e.g., Adult Guardianship Act, R.S.B.C., ch. 6, pt. 3, § 56(7), 57 (1996) (providing that an involuntary support and assistance plan imposed on an individual deemed incapable of acting to prevent his or her abuse or neglect lasts for no longer than six months and may only be renewed upon judicial order for a period of only six months); CRPD, *supra* note 4, art. 12(4); OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 24-25. Compare UGPPA § 301 (1997) (stating that guardianship continues until terminated) with UGPPA § 318 (1997) (stating that guardianship terminates upon a ward's death or order of the court). While UGPPA § 314(b)(5) requires the guardian to immediately notify the court if the ward regains all or partial "capacity," and must also report on improvements in capacity in the annual report to be filed under § 317, a change in the guardianship order would only be effectuated by a petition to the court, or possibly the court's *sua sponte* action to modify or terminate the petition based on a problem identified in the course of guardianship monitoring. UGPPA §§ 314(b)(5), 317 (1997). Needless to say, this rarely (or never) occurs in reality.

133. Arguments exist for making the process for appointment of support more formal or less formal. A less formal process may be more accessible and less stigmatizing, while a more formal process may provide greater protection of the individual's substantive and procedural rights. See Carney et al., *supra* note 107, at 137. See also Salzman, *supra* note 1, at 235-39 (providing a more detailed discussion of the particular programmatic elements in the two models).

legal agreement with one or more agents of his choosing who will provide assistance with decision making or act as formal decision-making representative(s) for the individual.¹³⁴ The support or representation agreement, described as a “super power of attorney,” can give the agent broad powers to assist with decisions according to the instructions in the agreement and the individual’s known wishes and preferences,¹³⁵ which will then be legally binding on third parties.¹³⁶

The support or representation agreement model differs from the traditional power of attorney in two significant ways. First, these models seek to maximize the on-going and active involvement of the principal in the decision-making process.¹³⁷ Second, at least in British Columbia, an individual who would not be deemed to have the generally accepted level of legal capacity to enter into a general or health care power of attorney could create a legally binding support agreement.¹³⁸

A second model, used in Sweden and other European nations, provides for judicial appointment of a legal mentor or PO to act as a decision-making assistant for a person found incapable of making any or all

134. See Representation Agreement Act, pt. 1, § 2 (1996); Doug Surtees, *The Evolution of Co-Decision-Making in Saskatchewan*, 73 SASKATCHEWAN L. REV. 75, 84-91 (2010) (discussing co-decision-making program in Saskatchewan). The Yukon model creates two legally distinct types of supported decision-making options, one of support and one of representation. Decision-making, Support and Protection to Adults Act S.Y.T., ch. 21, pts. 1-2 (2003). In general, these support personnel serve on an uncompensated basis. For example, in the British Columbian system, the assistants are not paid for their services, unless such compensation is specifically directed in the agreement. Representation Agreement Act, pt. 3, § 26 (1996).

135. See, e.g., Representation Agreement Act, pt. 2, §§ 7, 9 (1996) (outlining the duties that the represented adult may assign to his/her representative).

136. See, e.g., Representation Agreement Act, pt. 3, §§ 19, 24 (1996). In the absence of evidence of fraud, misrepresentation, undue influence, or over-reaching, a decision made with or communicated by the support person or representatives must be legally recognized. See, e.g., Decision-making, Support and Protection to Adults Act S.Y.T., ch. 21, pt. 1, § 11, pt. 2, § 25 (2003).

137. See, e.g., Representation Agreement Act, pt. 3, §§ 16, 23 (1996). See generally Nina A. Kohn, *Elder Empowerment as a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, 46-50 (2006) (discussing the consultation requirement of the Canadian representation agreement and recommending changes to law and policy to involve the principal in decision-making pursuant to a durable power of attorney).

138. Compare Representation Agreement Act, pt. 2, §§ 7-8 (1996) (allowing adults to make a representation agreement though they are not capable of forming a contract or handling their own health care) with Decision-making, Support and Protection to Adults Act S.Y.T., ch. 21, pt. 1, § 6 (2003) (permitting an adult to enter into a support agreement only if he or she understands the nature and effect of agreement). See also Surtees, *supra* note 134, at 88-89; OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 24.

personal or financial decisions on her own.¹³⁹ In at least one innovative Swedish PO program, an individual with severe psychosocial disability can appoint his or her own PO, with the PO accountable only to the individual who is receiving assistance.¹⁴⁰

Regardless of how they are structured or funded, however, supported decision-making programs are not without their own vulnerabilities. It is admittedly difficult to meaningfully assess whether an individual understands the risks, and can foresee the consequences of a potentially risky decision, and it is also difficult to assist another individual with decision making without inappropriately influencing her final decision.¹⁴¹ Consequently, supported decision-making programs must adopt adequate safeguards to ensure that the individual's decision-making abilities are respected and that the individual receiving support is not harmed or exploited within, or as a result of, the support arrangement. Various measures have been adopted in existing supported decision-making programs or have been recommended for adoption as programs evolve and new ones are created.¹⁴² These

139. See Föräldrabalk Svensk författningssamling [SFS] [hereinafter Code of Parents, Guardians, and Children] 1949:381 11 ch. 11, § 12, § 14, § 16, § 19 (Swed.); Herr, *supra* note 6, at 433-34; Odlow, *supra* note 129, at 1-2 (describing the "informal" judicial process for appointing a mentor/PO). In the Swedish system, the decision-making assistants are paid from local or national government funds. Herr, *supra* note 6, at 434; *PO-Skåne Description*, *supra* note 129.

140. See Maths Jespersen, *PO-Skåne – Personal Ombudspersons in Skåne*, available at <http://www.peoplewho.org/documents/jesperson.decisionmaking.doc> (last visited Apr. 10, 2011) (noting that the program assists those "living entirely in a symbolic world of their own, living barricaded in their apartment or living homeless in the streets"); Minkowitz, *U.N. Convention*, *supra* note 24, at 409. See generally PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, *supra* note 45, at 35; OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 24-25 (endorsing the option of a decision-making assistant, appointed by a tribunal, with the consent of the individual with the disability, who retains control of decisions and is responsible for them, while the support person must report to and is accountable to the appointing tribunal).

141. See OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 26. Furthermore, empirical studies demonstrate the difficulty of accurately determining another person's true preferences and wishes. See Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 996-1002 (2008).

142. For example, existing laws have created built-in safeguards such as requiring the designation of more than one decision-making representative to make certain personal and financial decisions and requiring that they act unanimously when making other than routine decisions. See Decision-making, Support and Protection to Adults Act, pt. 2, §§ 15, 16, 21, 23 (2003). In addition, some models require the appointment of a monitor to oversee the actions of any agent assisting with financial arrangements. See Representation Agreement Act, pt. 2, § 12 (1996); MICHAEL BACH, EQUAL RECOGNITION BEFORE THE LAW: ARTICLE 12 CRPD, slide 16 (2010), available at http://www.lebenshilfe.de/wDeutsch/ueber_uns/weltkongress-2010/dokumentation/downloads/2010-06-16-Bach_-Michael.pdf [hereinafter BACH, EQUAL RECOGNITION] (calling for appointment of monitors for supported and surrogate

include the adoption of appropriate standards of conduct for and adequate training of support personnel, monitors, and those acting as surrogate decision-makers.¹⁴³ In addition, administrative¹⁴⁴ and judicial¹⁴⁵ oversight and enforcement mechanisms must be available to address improprieties in the support arrangement. The challenge is for supported decision-making programs to have adequate and appropriate safeguards without making the process so bureaucratic or complex that support mechanisms are not reasonably available to those who wish to use them.¹⁴⁶

This brief discussion reveals that supported decision-making models and the models contemplated by reformed guardianship laws rest on similar enunciated principles and share a number of goals *and* vulnerabilities. Reformed guardianship laws cite to the basic supported decision-making principle of the presumption of capacity, and to the supported decision-

decision making); Brayley, *supra* note 5, at 13. As an additional safeguard, some recommend that the formal registration of the support arrangements include not only the names of the parties involved, but also the major legal transactions in which they participated, and the nature of support provided. Minkowitz, Discussion on CRPD Article 12, *supra* note 123, at pt. 5.

143. *See, e.g.*, Decision-making, Support and Protection to Adults Act, pt. 1, §§ 7, 13, pt. 2, §§ 16, 23 (2003) (setting out standards of care for support persons and representatives). *See also* BACH, EQUAL RECOGNITION, *supra* note 142, at slides 15, 16, 18; Brayley, *supra* note 5, at 2, 15; Minkowitz, Discussion on CRPD Article 12, *supra* note 123.

144. In order to ensure that the remedies for improper conduct within the support relationship are reasonably accessible to the person receiving support, as well as to others who observe intentional or unintentional impropriety in the agent's actions, a number of models designate an administrative agency to investigate and hear complaints of improper conduct. *See, e.g.*, Representation Agreement Act, pt. 5, §§ 30-31 (1996) (providing that any person can report irregularities or potential undue influence or abuse to the Public Guardian and Trustee, who may conduct an investigation of the allegations). *See also* OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 25 (discussing several possibilities for oversight of the adequacy and propriety of support); BACH, EQUAL RECOGNITION, *supra* note 142, at slides 13-15, 18 (advocating for a mandated authority to rule on the duty to provide appropriate supports, and to resolve any disputes between the supporting agents); Minkowitz, Discussion on CRPD Article 12, *supra* note 123 (providing that support networks are useful in the event that problems arise between the principal and advocate).

145. *See, e.g.*, Representation Agreement Act, pt. 5, § 32 (1996) (permitting application for a court order to alter or revoke a representation agreement). *See generally* Minkowitz, Discussion on CRPD Article 12, *supra* note 123 (observing that while judicial oversight is permitted under CRPD, Art. 12(4), it may not be needed except for situations of possible abuse or exploitation or other improper activity by the support personnel).

146. OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 27 (observing the inevitable tension between upholding the individual's freedom to decide with support and implementing those measures that monitor the arrangement and hold the support persons accountable). *See, e.g.*, Minkowitz, Discussion on CRPD Article 12, *supra* note 123, at 4 (noting that the legitimate need for safeguards must be balanced with the need to ensure the availability and accessibility of support mechanisms).

making goals of limiting restrictions on the exercise of capacity, increasing the participation of the person with a disability in the decision-making process, and considering the values, wishes, and preferences of the individual with limitations in decision-making abilities, to the extent known. Further, every jurisdiction that has developed supported decision-making options still has an option for appointment of a guardian or some type of surrogate decision maker, when support is not deemed to be a viable option.¹⁴⁷ In addition, the success of both supported decision making and guardianship programs depends in large part on the availability of trusted, trustworthy, willing, and capable individuals to serve as either support agents or guardians.¹⁴⁸

Despite these shared principles, goals, and potential limitations, however, there are significant differences between supported decision-making models and the guardianship construct. First, the prevailing guardianship system has little in the way of legally recognized options between autonomous and surrogate decision making.¹⁴⁹ There are no mechanisms for allowing individuals with limitations in decision-making abilities to appoint their own decision-making agents and to have resulting decisions recognized legally.¹⁵⁰ A formal program of decision-making

147. See, e.g., Surtees, *supra* note 134, at 84-87 (discussing Saskatchewan's *The Adult Guardianship and Co-decision-making Act*, which permits the appointment of either a guardian or a co-decision-maker). In fact, in most jurisdictions, even those with formal supported decision-making programs, guardianship continues to be the predominant paradigm for providing assistance with decision making. See, e.g., *id.* at 91-92 (noting that a review of 446 applications for appointment of a guardian or co-decision-maker filed in Saskatchewan during the period from 2001-2008 revealed that approximately ninety-three percent of the applications involved guardianship while only approximately seven percent of the applications involved co-decision-making).

148. See generally OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 22-24 (highlighting that support agents are unpaid volunteers drawn largely from family members of others with whom the individual has a trusting relationship). Appropriate and committed persons may not always be available in the life of the person needing decision-making support or within the geographical location in which the individual resides. The lack of suitable individuals to serve as guardians is often cited as a significant problem within the guardianship system. See, e.g., Herr, *supra* note 6, at 434; BYRNES ET AL., *supra* note 127, at 91.

149. Existing laws in the United States do recognize that some individuals will exercise "capacity" with decision-making assistance, such as the use of "technological assistance" to make or communicate decisions, though such a person would not be deemed to be "incapacitated," and thus would be engaging in legally autonomous decision making. See, e.g., UGPPA, §102(5) (1997).

150. See, e.g., *In re Guardianship of G.S.*, 953 A.2d 414, 419 (N.H. 2008) (concluding that "when an individual has limited insight into his mental illness and has impaired judgment regarding his need for medication, we have held that the individual 'is not an appropriate candidate for a springing guardianship or a health care power of attorney'" (citing *In re Guardianship of E.L.*, 911 A.2d 35, 45 (N.H. 2006))).

support can fill the gap between the substituted decision making of guardianship and a purely informal system of support.

Second, and related to the first distinction, while most guardianship laws provide that guardianship should only be imposed as a “last resort,” and require the court to see if there are existing alternatives that might assist the individual with personal affairs or property management, the existing available alternatives are often quite limited; guardianship laws simply do not require that all practicable decision-making support be given before a person is deemed to lack the legal capacity to make decisions and is divested of the right to make those decisions.¹⁵¹ In contrast, in the Canadian representation/support agreement model, for example, a guardian may be appointed to make decisions for the individual with disabilities, but only after “alternatives, *such as the provision of support and assistance*, have been tried or carefully considered.”¹⁵² If guardianship is to be a “last resort,” however, there must be an adequate “first resort.”¹⁵³ Formal decision-making support provides a significant option to call upon prior to the assignment of a surrogate decision maker and makes it more likely that guardianship will not be imposed unless there really are no other alternatives.

Third, because a supported decision-making regime creates a right to support and the expectation that it will be provided whenever possible, the evaluation of “capacity” has a different purpose. Decision-making abilities are not evaluated to determine if the state should intervene to remove an individual’s right to make decisions, but rather to determine the type of decision-making support that is needed by the individual.¹⁵⁴ Thus, it is necessary to refine our understanding of the types of competencies required

151. Brayley, *supra* note 5, at 5 (advocating for adoption of the principle that “a person is not to be treated as unable to make a particular decision unless all practicable steps to help the person to do so have been taken without success”).

152. Decision-making, Support and Protection to Adults Act, Schedule A, § 2(d) (2003) (emphasis added). *See also* Decision-making, Support and Protection to Adults Act, Schedule A, pt. 3, § 32(1)(c); Adult Guardianship Act, ch. 6, pt. 1, § 2(c) (1996). In contrast, in the Swedish mentor model, the court will appoint a guardian-like administrator if the individual with impaired decision-making abilities objects to either the appointment of a mentor or to any decision made by the mentor, and the court determines that the individual’s interests would be “seriously jeopardized” without assistance. *See* Herr, *supra* note 6, at 435-36. The Swedish administrator resembles a limited guardian, though the ward does not lose his or her right to vote, as she might in some U.S. jurisdictions. *See, supra* note 53. This mechanism for substituted decision-making in the mentor model undermines the principle of ensuring the principal’s consent to decisions, Odlow, *supra* note 129, at 8, and obviously may have a coercive impact even when a *mentor* is assisting with decision-making.

153. OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 3.

154. *See* MICHAEL BACH & LANA KERZNER, A NEW PARADIGM FOR PROTECTING AUTONOMY AND THE RIGHT TO LEGAL CAPACITY 98-99 (2010).

in each particular area of functioning in order to assess the nature and amount of support needed by the individual to exercise his or her legal capacity as autonomously as possible.¹⁵⁵ In addition, because of the right to exercise one's own legal capacity and the fact that any restrictions on legal capacity are to be strictly time-limited and subject to regular, formal review,¹⁵⁶ the role of an appointed surrogate decision maker within a supported decision-making jurisdiction carries with it an on-going duty to help restore the ward's ability to exercise capacity, with supports if needed.¹⁵⁷

Because the guardianship system in the United States continues to rest on a false capacity-incapacity dichotomy, and fails to provide a meaningful option of decision-making support, true and complete reform may not be possible within the existing guardianship construct. Other governments have adopted legislation allowing for the provision of formal decision-making support as an alternative to the imposition of guardianship. Experiences with these support models demonstrate that they can meet the specific needs of individuals needing decision-making support, whether the individual needs intensive, ongoing support or only short-term support during a mental health crisis. With the expectation of decision-making support and participation created by these models, it is likely that more time and effort will be spent providing an individual with the information needed to make decisions about his or her own life, a process that would be extremely beneficial to individuals with psychosocial conditions in a range of contexts, including the process for consent to medical treatment and the administration of psychotropic medication.

155. See BACH, EQUAL RECOGNITION, *supra* note 142, at slides 5-6.

156. See CRPD, *supra* note 4, art. 12(4). See, e.g., Adult Guardianship Act, pt. 3, §§ 56(7), 57 (1996). Scholars and commentators criticize the lack of time limitations in the guardianship order and the lack of regular court review of the continuing need for guardianship. See, e.g., Wright, *Proposal for an Integrative Approach*, *supra* note 33, at 88-89; In the Matter of Mark C.H., 906 N.Y.S.2d 419, 431-32 (Sur. Ct. 2010) (finding that guardianship appointments under N.Y. MENT. HYG. LAW, art. 17-A, are not generally, but should be, subject to periodic reporting and review).

157. BACH & KERZNER, *supra* note 154, at 92 (observing the duty imposed on a surrogate decision maker by the CRPD to provide the support needed to maximize legal capacity). Michael Bach refers to this surrogate decision maker as a "facilitator" so as to continue to maintain the focus on the individual with the disability and to reinforce the notion that the appointment lasts for only so long as no one can determine anything about an individual's desires. BACH, EQUAL RECOGNITION, *supra* note 142, at slide 10. See generally Wright, *Guardianship for Your Own Good*, *supra* note 57, at 354 ("Who is more likely to achieve the best substituted judgment, the incapacitated ward, who generally has some direct access, albeit limited by the degree of incapacity, to his/her own history of values and decisions, or the appointed guardian, who has full judgment capacity, but at best only a limited and indirect knowledge of the elder's rich history of experience?").

While the existing models of support are not yet perfect, as legal structures they create a right to support and participation in decision making. The direct consequence is that rather than exclude persons with psychosocial disabilities from the decision-making process, the model of support enables them to more fully participate in the range of life's activities, increasing opportunities for interactions with non-disabled individuals.

IV. THE ADA ANALYTICAL FRAMEWORK SUPPORTS A CLAIM THAT GUARDIANSHIP VIOLATES TITLE II'S INTEGRATION MANDATE

Elsewhere I have endeavored to argue that Title II of the ADA and the integration mandate support the recognition of a legal right to decision-making support as a less restrictive alternative to guardianship.¹⁵⁸ While the legal argument is not without its analytic difficulties, a push for decision-making support is certainly consistent with the intent of the ADA and much of its jurisprudence. *Olmstead* and the ADA's integration mandate provide a legal framework for thinking about a right to decision-making support as an alternative for guardianship. This part will briefly explain why we should, and possibly can, extend the ADA's non-discrimination principles to the decision-making arena and conceptualize guardianship as a form of prohibited disability-related discrimination.

A. *The Prima Facie Discrimination Claim under Title II of the ADA*

As noted above, in *Olmstead v. L.C.*, the Supreme Court concluded that the unjustified isolation of persons with disabilities in institutions subjects them to unwarranted stereotypes and diminishes their opportunity to engage in important aspects of communal life in violation of the ADA's proscription against disability-based discrimination and the integration mandate.¹⁵⁹ The argument here is that by removing the individual's right to make decisions, guardianship not only perpetuates stereotypes that wards are incapable or unworthy of participating in community life, but because of the constructive isolation of guardianship,¹⁶⁰ also diminishes the ward's opportunities to participate in the host of every day social, economic, civic, and cultural activities cited by the *Olmstead* court.¹⁶¹

In order to state a prima facie claim that guardianship imposes a form of segregation that violates the ADA, it will be necessary to establish that: 1) an individual with diminished mental capabilities for whom a guardian has

158. For a more elaborate articulation of that argument, see Salzman, *supra* note 1, at 182-231.

159. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597, 607 (1999). See generally 42 U.S.C. § 12132 (2006); 28 C.F.R. § 35.130(d) (2010); 28 C.F.R. § 35.130(b)(vii) (2010).

160. See discussion *supra* Part II.B.

161. See *Olmstead*, 527 U.S. at 601.

been appointed or who is at risk of losing her right to make decisions is a “qualified individual with a disability” under the ADA; 2) guardianship is a public “service, program, or activity” within the meaning of the Act; and 3) guardianship constitutes a form of disability-based discrimination by a public entity.¹⁶² If the provision of guardianship rather than supported decision making might constitute a *prima facie* claim of disability discrimination, it will still be necessary to determine if a state could be required to provide supported decision-making options to avoid this discrimination.¹⁶³

1. An Individual Needing Assistance with Decision Making is a “Qualified Individual With a Disability”

An individual challenging an existing or proposed guardianship, or the state’s failure to provide services to assist with decision making in order to avoid appointment of a guardian, should be able to establish that he or she is a “qualified individual with a disability” within the meaning of the ADA.¹⁶⁴ Individuals with diminished mental abilities needing decision-making assistance would meet the definition of “individuals with disabilities”¹⁶⁵ based on the showing that they are “substantially limited” in the ability to perform a recognized “major life activity,” such as caring for oneself, learning, reading, concentrating, thinking, or communicating.¹⁶⁶ Consequently, individuals with psychosocial disabilities who need some assistance with decision making to adequately manage their personal or

162. *See, e.g.*, *Duvall v. County of Kitsap*, 260 F.3d 1124, 1135 (9th Cir. 2001) (citing 42 U.S.C. § 12132).

163. *See* discussion *infra* Part IV.B.

164. *See* 42 U.S.C. § 12131(2) (2006).

165. *See* 42 U.S.C. § 12102(2)(A) (2006) (defining an individual with a disability as a person with “a physical or mental impairment that substantially limits one or more of the major life activities of such individual.”).

166. *See* ADA Amendments Act of 2008, Pub. L. No. 110-325, § 4(a), 122 Stat. 3553, 3555 (2008) (to be codified at 42 U.S.C. § 12102) (providing a nonexclusive list of “major life activities”). Although taking care of finances is not specifically noted in the list, a person who is unable to manage her finances would likely be deemed to be restricted in one of the “major life activities,” such as “caring for oneself,” “thinking,” or “concentrating.” § 4(a), 122 Stat. at 3555. In addition, utilizing an interpretation of the “substantially limits” component of the disability definition that is consistent with the comprehensive remedial purpose of the ADA, these individuals should be deemed to be “substantially limited” in their abilities to perform at least one of these major life activities. *See* 28 C.F.R. § 35.104 (2010); ADA Amendments Act §§ 2(a)(8), 2(b)(1), 4(a)(4)(A)–(B), 122 Stat. 3553, 3554–55; § 4(a)(4)(C)–(E), 122 Stat. at 3556 (noting that an impairment may substantially limit a major life activity even if the individual is not impaired in other major life activities, even if the impairment is episodic, though disabling when active, and even if mitigating measures can ameliorate the condition’s impairing effects).

property affairs would be “individuals with disabilities” within the meaning of the ADA.

It will be somewhat more challenging to demonstrate that an individual with diminished decision-making abilities is a “*qualified* individual with a disability,” i.e., one who “with or without reasonable modifications . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”¹⁶⁷ While courts have liberally interpreted the standard for demonstrating that one “meets the essential eligibility requirements” of the program or service at issue,¹⁶⁸ some work may be needed to establish that an individual is “qualified” for decision-making support outside of the guardianship construct.

This is true for two reasons. First, many decision makers are unfamiliar with the “requirements” of supported decision-making programs.¹⁶⁹ Thus, it will be necessary to conduct further research in order to demonstrate that a broad range of individuals with psychosocial disabilities are able to participate in decision making with appropriate support. This effort would be similar to that needed in connection with deinstitutionalization to demonstrate that individuals with significant disabilities could live outside institutions if they had adequate support in the community.¹⁷⁰ Second, is the related problem that under the Supreme Court’s decision in *Olmstead*, courts are permitted to rely on the professional judgment of state professionals in determining whether a person with a disability is “qualified” to receive services in a less restrictive setting,¹⁷¹ and state professionals

167. 42 U.S.C. § 12131(2) (2006).

168. *See, e.g.*, McGary v. City of Portland, 386 F.3d 1259, 1264-70 (9th Cir. 2004) (finding man with AIDS needing additional time to clean his yard to comply with the city’s nuisance abatement law was a “qualified individual with a disability”); Williams v. Wasserman, 164 F. Supp. 2d 591, 629-30 (D. Md. 2001) (noting that in deinstitutionalization litigation, plaintiffs were “qualified individuals with disabilities” despite the lack of existing community placements that could meet their needs). *See* 28 C.F.R. pt. 35, app. A, subpart A, § 35.104 (2008) (noting that “essential eligibility requirements” can be quite minimal).

169. *See generally* OFF. OF THE PUB. ADVOCATE, *supra* note 127, at 8 (“Supported decision-making is presently quite loosely defined and articulated and there is very little material in literature or policy to draw upon.”).

170. The debate continues with regard to individuals with disabilities residing outside of institutions with appropriate support. *See generally* Long v. Benson, No. 4:08cv26-RH/WCS, 2008 U.S. Dist. LEXIS 109917, at *2-3 (N.D. Fla. Oct. 14, 2008), *aff’d*, 383 F. App’x 930 (11th Cir. 2010).

171. *See, e.g.*, *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587, 189, 593-94, 602-03 (1999). Needless to say, this aspect of the *Olmstead* decision has been the subject of critical commentary. *See generally* Michael L. Perlin, “*Their Promises of Paradise*”: *Will Olmstead v. L.C. Restrict the Constitutional “Least Restrictive Alternative” Principle in Mental*

assessing “capacity” in the guardianship context could be particularly resistant to the concept of supported decision making.

In integration mandate cases decided after *Olmstead*, many courts have liberally construed the “qualified individual with a disability” standard to find that plaintiffs have met the “essential eligibility requirements” of the service, program, or activity in question.¹⁷² In cases where an individual’s eligibility for integrated services has been at issue, some courts have permitted the plaintiff to submit evidence of suitability from a treating or independent professional.¹⁷³ In the guardianship context, plaintiffs’ lawyers and consumer advocates will need to identify psychiatrists and psychologists who understand the nuances of capacity and the ability of most individuals to participate in decision making with appropriate support, and to further educate other professionals on these realities. There are of course, certain circumstances where a person with diminished decision-making abilities would be so severely impaired that he or she could not meaningfully participate in any decision making, even with assistance. But in many, if not most cases, individuals with impairments affecting decision-making abilities would be able to participate in the decision-making process with appropriate assistance. By utilizing evidence regarding the ability of most individuals to make decisions with appropriate support, and educating the relevant decision makers, it will be possible to demonstrate that most individuals seeking decision-making support would meet the ADA’s relatively liberal standard for “qualified individuals with disabilities.”

Disability Law?, 37 HOUS. L. REV. 999, 1140–41 (2000); Eric Rosenthal & Arlene Kanter, *The Right to Community Integration for People with Disabilities Under United States and International Law*, in DISABILITY RIGHTS LAW AND POLICY: INTERNATIONAL AND NATIONAL PERSPECTIVES 309, 320–21, 320 n.46 (Mary Lou Breslin & Silvia Yee eds., 2002).

172. See, e.g., *Sanchez v. Johnson*, 416 F.3d 1051, 1062 (9th Cir. 2005); *Townsend v. Quasim*, 328 F.3d 511, 516 (9th Cir. 2003); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 612–13 (7th Cir. 2004); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 n.7 (10th Cir. 2003). See generally *Salzman*, *supra* note 1, at 200 n.144.

173. See authorities cited in *Salzman*, *supra* note 1, at 200 n.145. See, e.g., *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 290–91 (E.D.N.Y. 2008); *Martin v. Taft*, 222 F. Supp. 2d 940, 972 n.25 (S.D. Ohio 2002); *Frederick L. v. Dep’t of Pub. Welfare*, 157 F. Supp. 2d 509, 540 (E.D. Pa. 2001); *Kathleen S. v. Dep’t of Pub. Welfare*, 10 F. Supp. 2d 460, 474 (E.D. Pa. 1998). See also *Knowles v. Horn*, No. 3:08-CV-1492-K, 2010 U.S. Dist. LEXIS 11901, at *10-11 (N.D. Tex. 2010) (following recommendations of Plaintiff’s treating physicians over those of the State’s treatment professionals). Compare *Boyd v. Steckel*, No. 2:10-cv-688-MEF, 2010 U.S. Dist. LEXIS 120802, at *32-33 (M.D. Ala. 2010) (finding that, in the absence of conflicting medical evidence, it was appropriate for the State to rely on the opinion of the Medical Director and Deputy Commissioner of Health Systems for the Alabama Medicaid Agency that Plaintiff may not qualify for community-based services).

2. Guardianship is a Public “Service, Program, or Activity” Within the Meaning of the ADA

The relevant case law makes clear that Title II’s prohibition of discrimination in public “services, programs or activities” was intended to address a broad range of governmental activities and courts have not been willing to carve out “spheres in which public entities may discriminate on the basis of an individual’s disability.”¹⁷⁴ The numerous decisions applying Title II to a wide range of public activities provide appropriate analogues for the application of Title II to the guardianship context.¹⁷⁵

To determine whether guardianship is properly deemed a public program, activity, or service, it is necessary to consider what guardianship *is*. Guardianship laws create a legal construct for appointing a surrogate decision-maker when an individual is deemed unable to make decisions sufficient to care for his or her needs. The court assesses “incapacity,” appoints the guardian, and monitors the fiduciary relationship. In public guardianship programs, the state funds, and may also provide, the guardianship services.¹⁷⁶ In private guardianships, the state is not generally involved in the actual provision of the guardianship services. Although a public guardianship is more obviously a public program, service or activity than is a private guardianship, there is authority to support the conclusion that both types of guardianships fall within the ADA definition of a public “program, service or activity.”¹⁷⁷

174. *McGary v. City of Portland*, 386 F.3d 1259, 1268–69 (9th Cir. 2004) [citations omitted]. See 28 C.F.R. pt. 35, app. A, subpart A §35.102 (2010) (noting “title II applies to anything a public entity does”); 28 C.F.R. § 42.540(i) (2010) (defining “[b]enefit” to include the “provision of services, financial aid or disposition (i.e., treatment, handling, decision, sentencing, confinement, or other prescription of conduct)”).

175. This author has been unable to locate any decisions specifically addressing the question of whether guardianship constitutes a public “service, program or activity” under the ADA. Some ADA cases have challenged state laws placing limitations on the rights of individuals under guardianship, such as those rendering persons under guardianship unable to vote or marry, and in those cases the relevant state program or activity has been deemed to be that of voting, marrying, etc. See, e.g., *Mo. Prot. & Advocacy Servs. v. Carnahan*, 499 F.3d 803, 812 (8th Cir. 2007); *Doe v. Rowe*, 156 F. Supp. 2d 35, 58–59 (D. Me. 2001).

176. Forty-eight states have some type of public guardianship program. See Pamela B. Teaster et al., *supra* note 72, at 201, 215-16.

177. Some have suggested that the guardianship context should be analogized to the context of the termination of parental rights in which a number of state courts have concluded that the ADA was inapplicable to these proceedings. But the analogy is flawed and the case law is mixed, at best. First, there are state courts that have concluded that a termination of parental rights proceeding may be a public “service, program, or activity” within the meaning of the ADA. See *In re Doe*, 60 P.3d 285, 292-93 (Haw. 2002). The court in *In re Doe* reviewed much of the relevant case law and concluded that some courts have concluded that the proceeding to terminate parental rights may be a “service, program, or activity” under the

Guardianships, whether public or private, can be characterized as either: 1) the government's program, activity, or service for assisting those citizens who are incapable of managing their affairs due to limitations in decision-making ability; 2) the government's program or activity regulating when a citizen can or cannot make legal decisions for him- or herself or the government's deliberative process for determining the same; or 3) as a "statutorily created" assignment of decision-making rights to a guardian that is then "recognized and followed" by third parties. Courts have found that a range of analogous governmental activities are subject to Title II, including for example, zoning laws,¹⁷⁸ local code enforcement activities,¹⁷⁹ the state's mental health services program administered in private, adult homes,¹⁸⁰ the substantive decision-making process of parole proceedings,¹⁸¹ or the state's involuntary commitment or assisted outpatient treatment laws or processes.¹⁸² In addition, one case permitted a Title II challenge to a state's health care power of attorney law, where the "program, activity, or service" was characterized as the "statutorily created opportunity to execute a [durable power of attorney] for health care and the right to have it

ADA, some courts have concluded that it is not, and some courts have skirted the issue by simply finding that, under the circumstances of the particular case, the state agency had fulfilled any obligations potentially imposed by the ADA. *Id.* at 290-91. Cases that have concluded that a proceeding to terminate parental rights was not a "service, program, or activity" within the definition of the ADA for purposes of asserting a defense to the termination process on behalf of a disabled parent appear to reflect the view of those courts that "dependency proceedings are held for the benefit of the child, not the parent." *M.C. v. Dep't of Children and Families*, 750 So. 2d 705, 706 (Fla. Dist. Ct. App. 2000). *See generally In re Gabriel Truitt & James Truitt*, 2009 LEXIS 879, at *1-2 (Mich. Ct. App. 2009) (suggesting that ADA requirements may apply in this context when the state is providing reunification services).

178. *See, e.g., Wis. Cmty. Servs. v. City of Milwaukee*, 465 F.3d 737, 750 (7th Cir. 2006) (en banc) (noting that municipal zoning is a "program" or "service," and enforcement of zoning rules is an "activity" within the meaning of the ADA); *Innovative Health Sys. v. City of White Plains*, 117 F.3d 37, 44-45 (2nd Cir. 1997) (same).

179. *McGary v. City of Portland*, 386 F.3d 1259, 1268-70 (9th Cir. 2004) (a city nuisance abatement law and related code enforcement activity qualified as "a benefit of the services, programs, or activities of a public entity").

180. *See Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 316-17 (E.D.N.Y. 2009).

181. *See Thompson v. Davis*, 295 F.3d 890, 896-99 (9th Cir. 2002).

182. *See Mental Disability Law Clinic v. Hogan*, No. CV-06-6320 (CPS)(JO), 2008 U.S. Dist. LEXIS 70684, at *50-51, *54 (E.D.N.Y. 2008) (without directly addressing the issue, finding that plaintiffs stated a claim under the ADA's integration mandate challenging eligibility criteria of the state's assisted outpatient treatment law that resulted in their unnecessary commitment and institutionalization).

recognized and followed.”¹⁸³ Thus, there is a basis for arguing that guardianship constitutes a “service, program, or activity” of a public entity within the meaning of the ADA.

3. Providing Decision-Making Assistance Through Guardianship May Constitute Disability-Based Discrimination Under the ADA’s Integration Mandate

The next element to consider is whether the appointment of a guardian rather than the provision of decision-making support might violate the integration mandate in some range of cases.¹⁸⁴ The argument is that the integration mandate is properly applied outside of the institutionalization context, that guardianship is unnecessarily isolating, and that the request for decision-making support should not be seen as a request for a “new service” beyond the ADA’s reach, but simply as a request that the decision-making assistance provided through guardianship be provided in a less restrictive manner.

a. *Olmstead’s* Disability Discrimination Holding Applies Beyond the Context of Physical Isolation in an Institution

Olmstead’s holding, which clearly addressed the isolation of individuals segregated in physical institutions,¹⁸⁵ has been applied to claims brought by individuals living in the community seeking the creation or expansion of community-based services in order to continue living in that integrated setting.¹⁸⁶ Admittedly, the bulk of these cases tie the finding of

183. See *Hargrave v. Vermont*, 340 F.3d 27, 38 (2nd Cir. 2003) (quoting *Hargrave v. Vermont*, No. 2:99-CV-128, at 23 (D. Vt. Oct. 11, 2001)) (emphasis omitted). *But see* Salzman, *supra* note 1, at 203-04 n.155 (discussing the *Hargrave* court’s dicta questioning whether the ADA can be used to challenge a state civil commitment program or the procedures of the state durable power of attorney override law).

184. Salzman, *supra* note 1, at 206-09.

185. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999).

186. See, e.g., *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 610-11 (7th Cir. 2004) (challenging the denial of continuous Medicaid private duty nursing services in the community); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1177, 1181 (10th Cir. 2003) (challenging the Medicaid limitation on prescription drug coverage under community-based waiver program); *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003) (challenging the denial of Medicaid long-term care in the community); *Cota v. Maxwell-Jolly*, 688 F. Supp. 2d 980, 993-95 (N.D. Cal. 2010) (challenging state modifications of eligibility criteria for Medicaid Adult Day Care Services); *Knowles v. Horn*, No. 3:08-CV-1492-K, 2010 U.S. Dist. LEXIS 11901, at *8-15 (N.D. Tex. Feb. 10, 2010) (challenging the denial of necessary round-the-clock home health care); *Marlo M. ex rel. Parris v. Cansler*, 679 F. Supp. 2d 635, 637-38 (E.D.N.C. 2010) (challenging the discontinuance of twenty-four-hour care and supervision at home); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 187, 223 (E.D.N.Y. 2009) (challenging the provision of mental health services in “community-

discrimination to the fact that the individual would be at some risk of institutionalization if the requested community-based services were not provided.¹⁸⁷ But many of these cases, while speaking to the risk of institutionalization resulting from a challenged practice or service denial, rest their decisions on the ADA's preference for the most integrated services, programs and activities to enable those with disabilities to interact with non-disabled persons and participate in community life to the fullest extent possible.¹⁸⁸ In light of this compelling and relatively broad rationale, the cases support the application of the integration mandate beyond those contexts in which confinement in an institution is an actual or potential result of the challenged state program, activity, or service. Rather, these cases give substance to the language and purpose of the integration mandate to maximize the interactions between individuals with disabilities and those without disabilities. In this way, these decisions support the application of the integration mandate to redress the court-ordered constructive isolation of guardianship.

based" adult homes rather than in more integrated settings). *But cf.* *Buchanan v. Maine*, 469 F.3d 158, 173 (1st Cir. 2006); *Putz v. Schwarzenegger*, No. 10-00344 CW., 2010 WL 1838717, *7-8 (N.D. Cal. May 5, 2010).

187. *See, e.g., Sanchez v. Johnson*, 416 F.3d 1051, 1053-54 (9th Cir. 2005); *Radeszewski*, 383 F.3d at 600; *Fisher*, 335 F.3d at 1177-78; *Townsend*, 328 F.3d at 515; *Cota*, 688 F. Supp. 2d at 987; *Marlo*, 679 F. Supp. 2d at 637; *Paterson*, 653 F. Supp. 2d at 187; *Putz*, 2010 WL 1838717 at *3, *7-8 (dismissing ADA integration mandate challenge to law affecting personal care services where individuals were unable to demonstrate any actual threat of institutionalization in the initial period after the law's implementation); *Ball v. Rodgers*, No. CV 00-67-TUC-EHC, 2009 WL 1395423, *5 (D. Ariz. April 24, 2009).

188. *See, e.g., Arc of Wash. State, Inc. v. Braddock*, 427 F.3d 615, 618 (9th Cir. 2005); *Fisher*, 335 F.3d at 1181; *Townsend*, 328 F.3d at 517-18; *Paterson*, 653 F. Supp. 2d at 187; *Cruz v. Dudek*, 2010 U.S. Dist. LEXIS 118520, *30-31 (S.D. Fla. Oct. 12, 2010) (granting preliminary injunction to plaintiffs based on the claim that state's denial of in-home long term Medicaid services unless the individual is institutionalized for sixty days violates the ADA's integration mandate claim); *id.* at *35-39 (citing cases); Susan Stefan, *Beyond Residential Segregation: The Application of Olmstead to Segregated Employment Settings*, 26 GA. ST. U. L. REV. 875, 917-24 (2010) (arguing that *Olmstead* and subsequent case law support the application of the integration mandate outside the traditional institutional context and may prohibit the unjustified isolation of people with disabilities in segregated sheltered workshops when those people would benefit from more integrated, supported employment services).

- b. Supported Decision Making Is Not a “New Service” But Rather One That Provides the Decision-Making Assistance of Guardianship in a Less Restrictive Manner

As a result of dicta contained in a footnote in *Olmstead*,¹⁸⁹ courts analyzing a range of Title II claims have considered whether the plaintiffs were raising claims relating to an “existing public service” or were seeking the creation of a “new service,” which would not be required under the ADA or *Olmstead*.¹⁹⁰ This analysis may appear in a Title II decision either as part of the court’s consideration of the plaintiff’s prima facie claim of discrimination or may be part of the court’s consideration of the fundamental alteration defense. Thus, in order to state a prima facie claim under Title II or to overcome a fundamental alteration defense, it may be necessary to establish that a request for supported decision-making assistance in lieu of guardianship should properly be viewed as a request for the provision of existing services in a more integrated manner rather than as a request that the state create “new services or benefits.”¹⁹¹

The decisions applying the “new services” limitation in Title II *integration mandate* cases appear to be in the minority.¹⁹² Several appellate courts have rejected the “new services” defense in the integration mandate context. In these cases, rather than looking at whether the state currently provided the precise community-based or integrated services requested by plaintiffs, the courts considered whether the plaintiffs were seeking services that were essentially the more integrated form of services that the state *would* provide

189. The Court mentioned in dicta that the ADA prohibited states from discriminating with regard to services that the state actually “provides,” but did not require them to “provide a certain level of benefits to individuals with disabilities.” *Olmstead*, 527 U.S. at 603 n.14 (writing in response to Justice Thomas’s reference to *Alexander v. Choate*, 469 U.S. 287 (1985), in his dissenting opinion). Although the applicability of the *Choate* limitation to ADA cases generally, or to integration mandate claims specifically, can legitimately be questioned, see Leslie Pickering Francis & Anita Silvers, *Debilitating Alexander v. Choate: “Meaningful Access” to Health Care for People with Disabilities*, 35 FORDHAM URB. L.J. 447, 451 (2008), lower courts addressing ADA integration mandate claims continue to cite to this *Olmstead* footnote (i.e., *Choate*) language, see, e.g., *Townsend*, 328 F.3d at 518.

190. See, e.g., *Rodriguez v. City of New York*, 197 F.3d 611, 619 (2d Cir. 1999) (concluding that New York’s Medicaid personal care program was not required to provide services needed to monitor the safety of persons with mental impairments living in the community, as the program did not provide “safety monitoring” to anyone).

191. See Salzman, *supra* note 1, at 210-20, 220 n.200, for a more detailed discussion.

192. The *Rodriguez* type of “existing services” limitation is more appropriate (if at all) in a disparate treatment challenge, or even possibly one seeking a reasonable accommodation in order to access services, than it is in the context of an integration mandate challenge. See, e.g., *Mental Disability Law Clinic v. Hogan*, No. CV-06-6320 (CPS)(JO), 2008 U.S. Dist. LEXIS 70684, at *21, *52-53 (EDNY Aug. 26, 2008); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 292 n.9 (E.D.N.Y. 2008). See also Salzman, *supra* note 1, at 211-12 n.173.

to them in a more restrictive setting.¹⁹³ One court observed that some services provided in a restrictive setting might need to be adapted for the less restrictive setting.¹⁹⁴ “If variations in the [precise form of services or the] way services are delivered in different settings were enough to defeat a demand for more community-integrated care, then the integration mandate of the ADA . . . would mean very little.”¹⁹⁵ The integration mandate would be quite limited, if not relatively meaningless, if it only required the public entity to provide a Title II plaintiff with those precise services the entity had already chosen to provide.¹⁹⁶ Consistent with the broad remedial purpose of the ADA, these decisions provide an analytical basis for arguing that supported decision making should be viewed as a less restrictive form of the personal and property management assistance currently provided within the guardianship construct.

In addition, there *are* existing community-based programs that provide assistance with decision making that could be modified and/or expanded to provide less restrictive alternatives to guardianship for persons with psychosocial disability. As one commentator has observed:

193. See, e.g., *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 609-11 (7th Cir. 2004) (finding that the request for home-based twenty-four-hour private duty nursing care not available under the state’s Medicaid program should be viewed as a request for a more integrated form of the constant monitoring and skilled assistance provided in an institutional setting); *Townsend*, 328 F.3d at 516-18 (viewing the community-based services sought by plaintiffs as “long-term medical care services” provided under the Medicaid program rather than as “new” community-based services for medically needy individuals); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1178, 1182-83 (10th Cir. 2003) (noting that a request for unlimited drug coverage not available under a Medicaid community-based waiver program should be viewed as a request for a more integrated version of the unlimited drug coverage provided by Medicaid in an institutional setting). See also *Knowles v. Horn*, No. 3:08-CV-1492-K, 2010 U.S. Dist. LEXIS 11901, at *8-15 (N.D. Tex. Feb. 10, 2010); *Marlo M. ex rel. Parris v. Cansler*, 679 F. Supp. 2d 635, 638 (E.D.N.C. 2010); *Salzman*, *supra* note 1, at 212-15 (providing a more detailed analysis of these decisions). But see *Conn. Office of Prot. & Advocacy v. Connecticut*, 706 F. Supp. 2d 266, 276-78 (D. Conn. 2010) (following the *Rodriguez* reasoning in integration mandate challenge).

194. *Radaszewski*, 383 F.3d at 610-11.

195. *Id.* at 611. The state would still have the opportunity to demonstrate that adapting existing institution-based services to the community setting would “fundamentally alter” the state’s program. *Id.* at 611-12.

196. States have had to create new services in order to comply with the integration mandate. See, e.g., *Andy Miller, Justice Dept. Pushes for Services to Move Patients out of Mental Hospitals*, KAISER HEALTH NEWS, Oct. 21, 2010, <http://www.kaiserhealthnews.org/Stories/2010/October/21/Georgia-mental-health-settlement.aspx> (describing a comprehensive agreement between the State of Georgia and the Civil Rights Division of the U.S. Department of Justice that requires Georgia to commit the use of significant state funds to meet targets for increasing the availability of housing and community treatment options for individuals with mental disabilities, including community support teams and crisis intervention teams).

Application of this support model to the needs of persons with psychosocial disabilities will require innovation and should draw on existing programs that may not have been understood as support in the exercise of legal capacity. Peer support, recovery-based services, community support networks, and personal assistance may all help people with psychosocial disabilities in ways related to decision-making or the exercise of legal capacity.¹⁹⁷

For example, existing community based programs include assertive community treatment,¹⁹⁸ intentional peer support,¹⁹⁹ intensive case management,²⁰⁰ and protective counseling.²⁰¹ These types of community-based support services could be expanded or modified to provide assistance to individuals with psychosocial disabilities so that they can make decisions regarding their personal and property affairs, enabling them to remain more fully integrated in community life.²⁰²

197. Minkowitz, *U.N. Convention*, *supra* note 24, at 409.

198. Similar to the PO-Skåne model, Assertive Community Treatment (ACT) is a multi-disciplinary, community-based mental health service delivery model that provides comprehensive and individualized services to meet the medical, rehabilitation, and support needs of individuals with "severe and persistent" psychosocial disability. *Treatment and Services: Assertive Community Treatment (ACT)*, NAT'L ALLIANCE ON MENTAL ILLNESS, [http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Mental_Illness/About_Treatments_and_Supports/Assertive_Community_Treatment_\(ACT\)1.htm](http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Mental_Illness/About_Treatments_and_Supports/Assertive_Community_Treatment_(ACT)1.htm) (last visited June 5, 2011). Assertive community treatment programs have been successful in reducing psychiatric hospitalization, homelessness, and incarceration. PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, *supra* note 45, at 44, 45 fig. 2.3. *But see*, Ronald Diamond, *Coercion in the Community: Issues for Mature Treatment Systems*, 66 NEW DIRECTIONS FOR MENTAL HEALTH SERVICES 3, 16 (1995) (cautioning about the potential for coercion in ACT program).

199. Intentional peer support is a consumer-provided program of recovery-oriented, non-hierarchical psychosocial services and support focusing on mutual exploration of concerns between peers. PRESIDENT'S NEW FREEDOM COMM'N ON MENTAL HEALTH, *supra* note 45, at 37 (describing the peer support program and citing studies showing its potential to engage individuals in traditional mental health services and assist with recovery) (citation omitted). *See* Minkowitz, Discussion on CRPD Article 12, *supra* note 123, at pts. 3-4 (citing other potential models for support, including the Soteria model and Open Dialogues).

200. *See, e.g., Adult Mental Health Services*, NEW YORK CITY DEP'T OF HEALTH & MENTAL HYG., <http://www.nyc.gov/html/doh/html/dmh/oas.shtml> (last visited June 5, 2011). Intensive case management programs may be funded by Medicaid or state Mental Health Services budgets and provide regular assistance with a range of personal and financial affairs to persons with chronic psychosocial disability. *See, e.g.,* N.Y. COMP. CODES R. & REGS. tit. 14, pt. 506, 508 (2010); N.Y. COMP. CODES R. & REGS. tit. 18, § 505.16 (2010).

201. A. Frank Johns, *Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of Its Crumbling Linkage to Unprotected Older Americans in the Twenty-First Century – A March of Folly? Or Just a Mask of Virtual Reality?*, 27 STETSON L. REV. 1, 83 (2007).

202. The development of meaningful and effective alternatives for guardianship will require commitment and creativity. *See* Johns, *supra* note 201, at 81-86 (discussing some innovative

Admittedly, to the extent that this article seeks the creation of wholly new legal constructs with substantial requirements and safeguards, the 'new services' reasoning creates a certain analytical challenge. However, the supported decision-making services sought as an alternative to the substituted decision making of guardianship need not be seen as any more dramatically different or new than the appropriate, individualized community-based care and treatment that courts have required states to provide under the integration mandate to enable individuals to move to or continue living in the community. To achieve the broad, remedial purpose of the ADA, the better analysis would follow the reasoning of *Fisher*, *Townsend*, and *Radaszewski*, and conclude that the failure to provide decision-making assistance in a less restrictive manner than is provided through guardianship presumptively violates the integration mandate. Thus, the state should be required to provide assistance with decision making in the most integrated manner appropriate to the needs of individuals with psychosocial disabilities, unless doing so would fundamentally alter the state program.

*B. Less Restrictive Alternatives To Guardianship Will Not Require A Fundamental Program Alteration*²⁰³

Under the ADA and *Olmstead*, the state must provide its programs, services, and activities in the least restrictive setting unless doing so would require a fundamental program alteration.²⁰⁴ The *Olmstead* plurality opinion sets out a loose standard for the fundamental alteration defense.²⁰⁵ As a result, there have been some disappointing results in lower court decisions, where the court has denied relief, despite the court's determination that the state was not providing services in the least restrictive setting as required by the integration mandate.²⁰⁶

What guidance does *Olmstead* provide regarding the fundamental alteration defense? *Olmstead* makes clear that cost alone is not determinative.²⁰⁷ Therefore, a state will not be ordered to provide

efforts to provide personal and property management services through less restrictive models such as protective counseling and community-based support services).

203. See Salzman, *supra* note 1, at 220-31 for a more detailed discussion of this point.

204. 42 U.S.C. § 12132 (2006); 28 C.F.R. § 35.130(b)(7) (2010); *Olmstead v. L.C. ex el. Zimring*, 527 U.S. 581, 603 (1999). As noted above, the "new services" argument has been used by Title II defendants as part of their fundamental alteration defense. See *supra* text accompanying notes 189-196.

205. *Olmstead*, 527 U.S. at 603-06.

206. See Michael L. Perlin, "What's Good Is Bad, What's Bad Is Good, You'll Find Out When You Reach the Top, You're on the Bottom": Are the ADA (and *Olmstead v. L.C.*) Anything More Than "Idiot Wind?", 35 U. MICH. J.L. REFORM 235, 255-60 (2002).

207. *Olmstead*, 527 U.S. at 604.

integrated services simply because they are less costly or because the cost of the requested integrated care is small in comparison to the relevant portion of the state's budget.²⁰⁸ At the same time, however, a state cannot establish a fundamental alteration defense based exclusively on allegations that integrated services will increase program costs and place financial pressure on the state's budget.²⁰⁹

Instead, when determining whether a state should be excused from providing a program modification needed to avoid discriminatory disability-related segregation, a court must consider whether the requested relief would so burden the state's available resources that it would be unable to meet the needs of other individuals with similar disabilities or would give particular litigants an unfair advantage over other similarly situated individuals.²¹⁰ In a number of cases in which a state has asserted a fundamental alteration defense based on the additional cost of providing integrated services, courts have required the state to establish that the requested relief would interfere with the state's actual ability to provide services to individuals with disabilities.²¹¹ Thus, cost alone will not determine the success of a fundamental alteration defense in an ADA Title II action.

The *Olmstead* plurality opinion, however, also concludes that a state can meet its fundamental alteration burden by demonstrating that it has "a comprehensive, effectively working plan" for placing qualified individuals in less restrictive settings, with "a waiting list that move[s] at a reasonable pace not controlled by the State's endeavors to keep its institutions fully

208. See *id.* at 603-06; *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003).

209. See *Olmstead*, 527 U.S. at 594-95, 604-05 (1999) (implicitly rejecting the state's assertion that it was already using "all available funds" to provide community-based services to other individuals with disabilities). See also, e.g., *Pa. Prot. & Advocacy, Inc. v. Pa. Dep't of Pub. Welfare*, 402 F.3d 374, 382 (3d Cir. 2005); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 613-14 (7th Cir. 2004). But see Jennifer Mathis, *Where Are We Five Years After Olmstead?*, 38 J. POVERTY L. & POL'Y 561, 568-70 (2005) (critiquing cost analyses utilized by several courts).

210. See *Olmstead*, 527 U.S. at 603-04.

211. See, e.g., *Radaszewski*, 383 F.3d at 614; *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1182-83 (10th Cir. 2003); *Townsend*, 328 F.3d at 513-15, 519-20; *Radaszewski ex rel. Radaszewski v. Maram*, No. 01 C 9551, 2008 WL 2097382, *13, *15 (N.D. Ill. March 26, 2008); *Cruz v. Dudek*, No. 10-23048-CIV-UNGARO/SIMONTON, 2010 U.S. Dist. LEXIS 118520, at *40-44 (So. Dist. Fla. Oct. 12, 2010) (finding that, based on all the money that the state "receives, allots or spends" on services to persons with spinal cord injuries, the state failed to meet its burden of showing that the requested program modification would render the state unable to meet the needs of this population). But see *Arc of Wash. State, Inc. v. Braddock*, 427 F.3d 615, 619-22 (9th Cir. 2005); *Boyd v. Steckel*, No. 2:10-cv-688-MEF, 2010 U.S. Dist. LEXIS 120802, *37-45 (M.D. Ala. Nov. 12, 2010).

populated.”²¹² In evaluating the adequacy of certain state integration plans, courts have rejected some plans that were not sufficiently specific and concrete.²¹³ The *Olmstead* Court’s articulation of the fundamental alteration defense, however, reflects the Court’s reluctance to interfere with state integration efforts in light of the state’s obligation to care for the entire population of individuals with disabilities. Accordingly, courts have been willing to defer to those states that presented a concrete and specific plan for on-going integration, finding that the proposed program modifications would entail fundamental program alterations.²¹⁴ The fundamental alteration defense generally presents the most significant obstacle in integration mandate litigation, both because of the generous legal standard set out by the Court and the complexity of the proof that may be necessary to defeat the defense.²¹⁵

Plaintiffs seeking modification of guardianship and the provision of supported decision-making options should be prepared to show that the requested modifications would not fundamentally alter the state’s program for providing assistance with decision making to all individuals with limitations in decision-making abilities.²¹⁶ States may legitimately argue that the program modifications sought in this article actually constitute a wholly new program for assisting individuals with decision-making limitations with the management of their personal and financial affairs. But, it is not clear that any state currently has a specific, comprehensive, and effectively working plan for providing services to assist individuals needing assistance with decision making through less restrictive means than guardianship. States should not be permitted to argue that the provision of less restrictive services would necessitate a fundamental alteration of the guardianship program because the state would have to change the segregated way in which it now provides assistance with decision making.²¹⁷

212. *Olmstead*, 527 U.S. at 605-06. See also *Arc of Wash. State Inc.*, 427 F.3d at 621-22.

213. See *Frederick L. v. Dep’t of Pub. Welfare of Pa.*, 422 F.3d 151, 155, 158, 160 (3d Cir. 2005); *Pa. Prot. & Advocacy, Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 383-85 (3d Cir. 2005); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 302-05 (E.D.N.Y. 2009); *Cruz*, 2010 U.S. Dist. LEXIS 118520 at *41-43.

214. See, e.g., *Arc of Wash. State Inc.*, 427 F.3d at 621-22; *Sanchez v. Johnson*, 416 F.3d 1051, 1063-67 (9th Cir. 2005).

215. See, e.g., *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003); 653 F. Supp. 2d at 267-300.

216. See *Olmstead L.C. v. ex el. Zimring*, 527 U.S. 581, 607 (1999); Salzman, *supra* note 1, at 228-30 (discussing some comparative costs between guardianship and supported decision-making options, and observing that some costs of the guardianship system could simply be transferred to fund supported decision-making options).

217. See *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 611, 614 (7th Cir. 2004).

CONCLUSION

By creating a presumption of capacity and participation, supported decision-making models acknowledge and respect the inherent human value of persons with psychosocial disabilities. The support paradigm shifts the focus from a perceived deficiency in the individual ("incapacity") to the social responsibility to provide assistance with decision making. By respecting the individual's right and ability to make decisions, supported decision making significantly limits the stigmatization and marginalization caused by guardianship, and more fully integrates individuals with psychosocial disabilities into social, political and economic life.

No one pretends that supported decision making is any more of a science than guardianship or other types of surrogate decision making. Many of the challenges presented by supported decision making are not new, and have been considered and debated in the context of guardianship reform. But they are challenges that involve serious questions of human value and self-determination. The importance of these challenges compels us to look beyond the guardianship construct for answers. Re-conceptualizing guardianship as one lingering mechanism of disability-based exclusion prohibited by the ADA's integration mandate, forces us to think differently about the obligation to remove unnecessary barriers to integration and to facilitate the full participation of individuals with psychosocial disabilities in all of life's activities.

The question of "whether it is realistic to put such a [supported decision making] system into place will be measured through different practices of States Parties which need to aim constantly to perform better within their available resources."²¹⁸ In the movement toward reform, it will be useful to demonstrate that supported decision-making options are able to successfully meet individual needs in a manner that is less restrictive than guardianship, that they are more beneficial to the individual's well-being than assigning a guardian, and that they do not entail significantly greater financial resources than the guardianship option. Existing supported decision-making models should be studied to identify those best practices that: 1) maximize the individual's responsibility for and involvement in decisions affecting his or her life; 2) ensure that the individual's wishes and preferences are respected; 3) ensure legal recognition of decisions made with support or by the individual's appointed agent; 4) provide the most appropriate qualifications and training for support persons, and standards for carrying out support responsibilities; 5) create the most efficient and effective mechanisms for funding support programs (including the possibility of volunteer support services); 6) have the most effective mechanisms for oversight and

218. Kämpf, *supra* note 27, at 31.

monitoring to ensure that the support relationship does not result in harm to the individual and protects against conflicts of interest, undue influence, or coercion of the individual needing support; 7) create standards for appointment of a substitute decision-maker that ensure that an individual is divested of decision-making rights only to the extent and for the time period that is absolutely necessary. There may be costs attached to the expansion and development of appropriate supported decision-making options, but the benefit in human terms may justify them, and the language and spirit of the ADA and the principles enunciated in the CRPD demand their adoption.

