

RETHINKING GUARDIANSHIP (AGAIN): SUBSTITUTED DECISION MAKING AS A VIOLATION OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT

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In every state, when an adult has a diminished capacity to make decisions about personal affairs or property management, a court may transfer the individual's right to make decisions to a guardian. This Article argues that, in most cases, it would be preferable to support decision making rather than supplant it through guardianship, and then seeks to locate a right to receive such support as a less restrictive alternative to the substituted decision making that characterizes guardianship.

*Building on the reasoning in *Olmstead v. L.C.* and subsequent decisions interpreting the Americans with Disabilities Act's integration mandate, this Article argues that by limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the Act's mandate to provide services in the most integrated and least restrictive manner. After discussing why recent reforms of state guardianship laws have proven inadequate, this Article conceptualizes guardianship as a form of disability-based discrimination and argues that *Olmstead* and the integration mandate are legitimately applied to the guardianship context. This Article then argues that states should be required to modify their current guardianship systems to provide decision-making support as a less restrictive form of assistance and suggests that such a modification would not necessitate a "fundamental program alteration." Finally, this Article points to supported decision-making models that have been developed in other countries as less restrictive alternatives to guardianship that enhance the in-*

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dependence, autonomy, and inclusion of individuals with limitations in decision-making abilities. The hope is that this re-conceptualization of guardianship will further the development of a range of meaningful and effective alternatives for guardianship.

INTRODUCTION

Ms. G lived alone in an apartment in New York City. In her seventies, Ms. G was starting to show signs of physical frailty, impaired vision, and forgetfulness. She was also beginning to manifest some eccentric behaviors.

After attending the city's most prestigious public high school for girls in the 1940s, Ms. G went to work as a clerk for the city—a position she held until her retirement in the early 1990s. She was bright, funny, self-reflective, sharp-witted, proud, and fiercely independent. Ms. G managed to care for her basic personal needs, purchase food for herself and her cat, and pay her rent and other bills. At the same time, she lacked the physical ability to perform housekeeping tasks and could not see well enough to adequately maintain her apartment, including her cat's litter box. It was not clear, however, that she viewed her inability to maintain her apartment as a serious (or even notable) problem.

Ms. G first sought legal assistance after New York City's Adult Protective Services agency, acting to prevent her threatened eviction, conducted a heavy duty cleaning of her apartment by tossing virtually all of her apartment's contents out her window into a dumpster below. After this event, Ms. G's lawyer helped her obtain funds from the city to replace her furniture and clothing, and her legal case was closed.

A year or two later, Ms. G again contacted her lawyer when her landlord formally sought her eviction based on allegations that the conditions in her apartment were creating a health hazard. In order to prevent her eviction, Ms. G agreed to have someone come for a day to clean her apartment, but rejected any formal or ongoing housekeeping assistance. Following this event, she continued to live her life without assistance of any kind.

One year later, Ms. G's landlord again called Adult Protective Services to address the conditions in Ms. G's apartment. After the agency's unsuccessful effort to have Ms. G involuntarily committed for psychiatric treatment, she returned home but reluctantly agreed to the agency's demand that she move to

a nursing home. Within two months of arriving at the institution, Ms. G died from cardiac failure.

The case of Ms. G presents the difficult question of when the State should be permitted to intervene to take care of an adult “for her own good.” Ms. G presented a true dilemma. While Ms. G was able to manage many aspects of her life, she was unable to maintain her apartment in a minimally habitable condition, jeopardizing her own health and safety and that of her neighbors. If a guardianship petition had been filed based on Ms. G’s significant inability to maintain her apartment and to appreciate the consequences of failing to do so, it is likely that a court would have appointed a guardian to control many, if not all, aspects of Ms. G’s life. A guardianship might have addressed Ms. G’s housekeeping problem, but it might also have had devastating consequences. For Ms. G it was crucial that she remain in control of her person and her property; the appointment of a guardian to make decisions about the governance of her affairs would have represented an unacceptable intrusion into her life and an assault on her dignity. Without any assistance, however, Ms. G was forced to leave her apartment and died shortly after entering the nursing home.¹

As a legal matter, the case of Ms. G raises fundamental questions, two of which are explored in this Article. First, does guardianship, by limiting an individual’s right to make decisions, impose a form of segregation that potentially violates the non-discrimination mandate of the Americans with Disabilities Act (“ADA”)?² Second, if so, are there acceptable alternatives for guardianship that states should develop in order to comply with the ADA’s requirement that state services, programs, and

1. While there is some controversy regarding the exact health consequences of an involuntary institutional relocation (such as Ms. G’s), there is general agreement that such a major life change is a stressful event with some adverse health consequences, particularly in the period immediately after the relocation. *See, e.g.*, Nancy Hodgson, Vicki A. Freedman, Douglas Granger, & Amy Erno, *Biobehavioral Correlates of Relocation in the Frail Elderly: Salivary Cortisol, Affect, and Cognitive Function*, 52 J. AM. GERIATRIC SOC’Y. 1856, 1856–62 (2004).

2. 42 U.S.C. §§ 12101–12213 (2006). Congress enacted the ADA in 1990 to address the continuing exclusion and isolation of individuals with disabilities, and thus created a comprehensive mandate to end disability-based discrimination in employment, public accommodations, public services, benefits, and programs. *See infra* Part II.A.

activities be provided in the most integrated and least restrictive manner?³

When an individual has a diminished ability to meet personal needs or manage property, a court may authorize a guardian to make crucial decisions on the individual's behalf. The guardian may be authorized to make decisions regarding where and with whom the person will live or spend time, what type of medical treatment he or she will receive, and how (or if) the individual will spend his or her money.⁴ By limiting an individual's right to make decisions, guardianship not only divests the individual of the important right to self-determination but also marginalizes that person and removes him or her from a host of interactions involved in decision making. In this way, guardianship segregates a person from many critical aspects of social, economic, and civic life.

The integration mandate of Title II of the ADA requires that states provide services, activities, and programs in the most integrated and least restrictive setting appropriate to the needs of qualified persons with disabilities.⁵ This Article argues that by limiting an individual's right to make decisions, guardianship imposes a form of segregation that is not only bad policy, but, in given circumstances, is also a violation of the integration mandate of the ADA. This argument, in large part, relies on the United States Supreme Court's groundbreaking decision in *Olmstead v. L.C. ex rel. Zimring* to suggest that states must provide less isolating alternatives to guardianship.⁶

In *Olmstead*, women with intellectual disabilities residing in a state psychiatric institution challenged the state's failure to move them into community-based treatment programs after their physicians determined that such placement was appropriate. The Supreme Court held that the unjustified segregation and isolation of people with disabilities may constitute unlawful discrimination in violation of Title II of the ADA and the integration mandate.⁷ The Court concluded that the state was

3. See 28 C.F.R. § 35.130(d) (2009); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597–99 (1999).

4. See, e.g., Winsor C. Schmidt, Jr., *Guardianship of the Elderly in Florida: Social Bankruptcy and the Need for Reform*, in *GUARDIANSHIP: THE COURT OF THE LAST RESORT FOR THE ELDERLY AND DISABLED* 3, 5–6 (Winsor C. Schmidt, Jr. ed., 1995).

5. See 28 C.F.R. § 35.130(d) (2009); *Olmstead*, 527 U.S. at 597–99.

6. See *infra* Parts II and III.

7. *Olmstead*, 527 U.S. at 597–601.

required to provide community-based care and treatment services to persons with mental disabilities unless it could establish that the provision of such care would cause a “fundamental alteration” of the state’s overall services and programs for individuals with mental disabilities.⁸ The decision has provided states with some incentive to engage in comprehensive integration planning and, in some subsequent cases, the decision has provided the legal authority for courts to require states to continue to provide or to expand community-based services.⁹

This Article argues that the *Olmstead* integration mandate provides a basis to oppose the imposition of guardianship as a form of unlawful segregation. *Olmstead* also provides a basis to require states to provide “supported decision-making services” to assist an individual in making his or her own decisions as a less restrictive alternative to the substituted decision making provided in guardianship arrangements. In contrast to guardianship, a supported decision-making model generally allows the disabled individual to retain the legal right to make decisions, and provides assistance to the disabled person to make or communicate those decisions.¹⁰ In this way, supported decision making is less isolating than guardianship and provides greater opportunities for a person with a disability to interact with others—the principal goal of the integration mandate.¹¹ Moreover, a move to a supported decision-making paradigm is consistent with the ADA, as well as with the recently adopted U.N. Convention on the Rights of People with Disabilities (“CRPD”).¹²

This Article begins with a discussion of recent changes to state guardianship laws and seeks to explain why such reforms do not ensure that persons needing assistance with decision

8. *Id.* at 587, 592, 603, 607 (citing 28 C.F.R. § 35.130(b)(7) (1998)).

9. See Jennifer Mathis, *Where Are We Five Years After Olmstead?*, 38 CLEARINGHOUSE REV. 561 (2005) [hereinafter *Five Years After Olmstead*]; Jennifer Mathis, *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 CLEARINGHOUSE REV. 395, 405–10 (2001) [hereinafter *Community Integration*]. See generally Ira Burnim & Jennifer Mathis, *After Olmstead v. L.C.: Enforcing the Integration Mandate of the ADA*, 33 CLEARINGHOUSE REV. 633 (2000) (discussing *Olmstead*’s potential as a tool for integration).

10. See *infra* Part V.

11. See *Olmstead*, 527 U.S. at 592, 597 (citing 28 C.F.R. pt. 35, app. A., 450 (1998)).

12. See Convention on the Rights of Persons with Disabilities, G.A. Res. 61/611, U.N. Doc. A/RES/61/611, art. 12 (Dec. 6, 2006) [hereinafter CRPD], available at <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.

making¹³ have the maximum opportunity to participate in the full range of life's activities. In Parts II and III, this Article endeavors to conceptualize guardianship as a form of disability-based discrimination under the ADA in order to locate a legal basis for requiring formal alternatives for guardianship as part of a state's program for providing decision-making assistance to individuals with diminished abilities. In Part IV, assuming that current guardianship regimes presumptively violate the ADA's integration mandate, this Article considers the extent of the state's obligation to modify existing mechanisms for providing decision-making assistance to persons with limitations in decision-making abilities. Finally, Part V briefly discusses supported decision-making models that have been developed in other countries and identifies some of the practical challenges presented by the creation or expansion of services designed to support (rather than supplant) an individual's exercise of his or her own capacity.

In light of the national policy enshrined in the ADA—to eliminate the exclusion and isolation of people with disabilities—it seems worthwhile to ask whether guardianship is the least isolating and most integrative means of providing assis-

13. The argument presented in this Article would apply to individuals with limitations in decision-making abilities that might result from a range of conditions such as developmental disability, intellectual disability, traumatic brain injury, mental illness, or dementia. The type of decision-making support needed by the individual may differ based on the cause and manifestation of the individual's limitation in decision-making capacity. See Lawrence A. Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 31 STETSON L. REV. 735, 745–49 (2002) (discussing the use of limited guardianship for persons with different medical bases for limitations in decision-making capacity).

This Article will refer to any person who needs assistance making decisions as a result of an identifiable medical condition as an individual with limited or diminished “mental or decision-making capacities, capabilities, or abilities.” These references should not be read to imply that there is (or should be) any limitation in the individual's legal capacity.

For a more elaborate discussion of the difficulties of defining terms such as “disability,” “mental disability,” “cognitive ability,” etc., see, for example, MARTHA C. NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* 98 n.5 (2006); Robert D. Fleischner & Dara L. Schur, *Representing Clients Who Have or May Have “Diminished Capacity”: Ethics Issues*, 41 CLEARINGHOUSE REV. 346, 346 n.1 (2007); or Anna Lawson, *The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?*, 34 SYRACUSE J. INT'L L. & COM. 563, 593–95 (2007). See also CRPD, *supra* note 12, art. 1 (without defining “disability,” CRPD extends protections to “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”).

tance with decision making.¹⁴ The hope is that the proposed theoretical shift to thinking about guardianship as an unnecessarily isolating form of providing assistance with decision making will encourage the development of a range of meaningful and effective alternatives for guardianship.

I. THE STATE OF GUARDIANSHIP AFTER RECENT REFORM EFFORTS

Over the last two decades, states have enacted many positive reforms to their guardianship laws. But problems persist, both because courts are not routinely implementing some of the most significant reforms and because further systemic reforms are needed outside of the guardianship construct. This Part briefly discusses the historical origins of guardianship and explores how these historical origins may explain why we view our obligation to provide assistance with decision making differently from our obligation to address other barriers to full participation by individuals with disabilities, such as the obligation to facilitate access to buildings and public spaces. After addressing both the demographic increase in the population likely to need some assistance with decision making and the significant benefits of exercising one's own decision-making capacity, this Part identifies the ways in which guardianship serves to isolate individuals from many routine interactions and attempts to give substance to what is referred to here as the "constructive isolation of guardianship." Next, the Part provides an overview of the more recent reforms to state guardianship laws and sets out several reasons why the reforms have not achieved their intended results. Finally, this Part introduces supported decision making and explains why such options provide assistance with decision making in a more integrated and less isolating manner than is provided through guardianship.

14. A significant though unknown number of adults in this country are under some form of guardianship. See ERICA F. WOOD, STATE-LEVEL GUARDIANSHIP DATA: AN EXPLORATORY SURVEY, AMERICAN BAR ASSOCIATION COMMISSION ON LAW AND AGING 10–11 (Aug. 2006) available at http://www.ncea.aoa.gov/NCEARoot/Main_Site/pdf/publication/GuardianshipData.pdf (noting the absence of guardianship statistics throughout the states) (citing F. Bayles & S. McCartney, *Guardians of the Elderly: An Ailing System*, ASSOCIATED PRESS, Sept. 1987, 1–26 (indicating that approximately 300,000–400,000 American adults were under guardianship in the mid-1980s)).

A. *Guardianship and Recent Reforms*

Western legal traditions have long held a deeply entrenched notion that “the State” has an obligation as *parens patriae*, or “parent of the country,” to protect the person and property of those individuals whom the State has deemed to be mentally “incompetent” or “incapacitated.”¹⁵ Originally, the king exercised the *parens patriae* power to preserve the property of those deemed mentally “incompetent” or “incapacitated.”¹⁶ Over time, this power developed into a more general authority to protect the person and property of those unable to care for themselves.¹⁷ In this country, after the American Revolution, the states assumed this authority to act on behalf of vulnerable citizens.¹⁸

The states, however, have often exercised the *parens patriae* authority with less concern about the needs of persons with disabilities, focusing instead on society’s desire to protect itself from those deemed “dangerous” or merely different. Thus, relying on *parens patriae*, states have used measures such as the adoption of eugenics laws to eliminate the population with severe mental impairments; states have also engaged in the wholesale isolation of individuals in massive state institutions.¹⁹ The history of this nation’s treatment of individuals

15. The roots of American guardianship law stretch back to at least the English Feudal System. See Hal Fliegelman & Debora C. Fliegelman, *Giving Guardians the Power to Do Medicaid Planning*, 32 WAKE FOREST L. REV. 341, 343–44 (1997); Nora von Stange & Gary von Stange, Note, *Guardianship Reform In New York: The Evolution of Article 81*, 21 HOFSTRA L. REV. 755, 757 (1993).

16. See *Heller v. Doe*, 509 U.S. 312, 326 (1993) (noting that at English common law the king had a duty to protect the estates of mentally incapacitated subjects); 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 (2004).

17. See Joan L. O’Sullivan, *Role of the Attorney for the Alleged Incapacitated Person*, 31 STETSON L. REV. 687, 689–91 (discussing the king’s obligations to care for “idiots” (those deemed incapacitated from birth) and “lunatics” (those with intermittent mental incapacity)).

18. See *id.* at 691–92; *Hawaii v. Standard Oil Co.*, 405 U.S. 251, 257–58 (1972); *Late Corp. of the Church of Jesus Christ of the Latter Day Saints v. United States*, 136 U.S. 1, 56 (1889).

19. See, e.g., *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432, 454 (1985) (Stevens, J., concurring) (noting the history of “unfair and often grotesque mistreatment” of persons with mental retardation) (citation omitted); *id.* at 461–63 (Marshall, J., concurring in part and dissenting in part) (concluding that the “state-mandated segregation and degradation” of persons with mental retardation through eugenics laws and lifetime warehousing of individuals in huge custodial institutions, “in its virulence and bigotry rivaled, and indeed paralleled, the worst

with disabilities is checked, at best, particularly for those with mental conditions.

Over the last several decades, however, Congress and state legislatures have enacted laws designed to dignify, integrate, and empower people with physical and mental disabilities.²⁰ Although these lawmakers have clearly acted with a mixed commitment of energy and resources, as a society we purport to recognize three basic principles relating to the treatment of persons with disabilities: 1) discrimination against people with disabilities is unlawful; 2) discrimination against people with disabilities often results from social attitudes and structural barriers to participation; and 3) some affirmative measures are needed to “level the playing field” so that individuals with disabilities have a fair opportunity to live in the community, work, travel, access housing and public accommodations, obtain the benefits of public services, and participate in civic and communal life.²¹ Thus, we recognize legal obligations, such as the obligation to provide special education services to enable children with any sort of disability to obtain an education, to make modifications to the physical environment to enable people with disabilities to access public services and accommodations and to provide translation services and assistive devices to enable individuals with speech or hearing limitations to communicate with others in order to access public services and government benefits.²²

When it comes to the obligation to assist persons with a diminished ability to make decisions, however, we generally accept the notion of supplanting, rather than assisting, the decision-making process. But just as we recognize that the law—and common principles of human decency—generally require that we build a ramp so that an individual with a physical impairment can enter a building without being carried up the steps, we should also recognize a legal obligation to provide de-

excesses of Jim Crow”); *Buck v. Bell*, 274 U.S. 200, 206–07 (1927) (upholding state eugenics law as a legitimate measure to protect public welfare).

20. See, e.g., Individuals with Disabilities Education Act (formerly the Education for All Handicapped Children Act of 1975), 20 U.S.C. §§ 1400–31 (2006); Rehabilitation Act of 1973, 29 U.S.C. §§ 701–96, 791–94 (2006); Fair Housing Act Amendments of 1988, 42 U.S.C. §§ 3601–31, 3604–05 (2006); ADA, 42 U.S.C. §§ 12101, 12112, 12132, 12182–84 (2006). Many states also have laws that prohibit disability-based discrimination. See, e.g., N.Y. EXEC. LAW § 296(1)(a) (McKinney 2009).

21. See, e.g., statutes cited *supra* note 20.

22. See, e.g., statutes cited *supra* note 20.

cision-making support to an individual with limitations in mental capabilities rather than assign a guardian to make decisions *for* that person.²³ The need to preserve the rights of persons with diminished decision-making abilities to make decisions for themselves to the greatest extent possible and to identify ways of providing support to enable them to do so assumes increasing importance as the population of adults with limitations in mental capabilities continues to grow, both in number and as a percentage of the overall national population.²⁴

Our legal system continues to recognize the state's power and obligation to take appropriate action to preserve human life and protect vulnerable citizens from abuse, neglect, and mistakes.²⁵ Guardianship is viewed as one such necessary and legitimate mechanism for protecting vulnerable citizens from harm. The legitimacy of state-sanctioned surrogate decision making for a citizen deemed vulnerable or "mentally deficient" is entirely consistent with the historical exercise of *parens patriae* to control and protect the affairs of the "incapacitated" or

23. See CANADIAN ASS'N FOR CMTY. LIVING, REPORT OF THE C.A.C.L. TASK FORCE ON ALTERNATIVES TO GUARDIANSHIP (Aug. 1992), http://www.worldenable.net/rights/adhoc3meet_guardianship.htm (referring to supported decision making as "the ramp" to access "a wider scope of human experience").

24. As of 2005, approximately 16.1 million people over the age of fifteen had some type of reported mental, cognitive, or emotional disability. MATTHEW W. BRAULT, U.S. CENSUS BUREAU, AMERICANS WITH DISABILITIES: 2005, CURRENT POPULATION REPORTS 7 (Dec. 2008), available at <http://www.census.gov/prod/2008pubs/p70-117.pdf>. Within this group, 8.4 million persons reported having one or more symptoms that interfered with the ability to manage day-to-day activities, and 5.1 million had difficulty keeping track of money and bills. *Id.*

As the number of older individuals in the population continues to rise, see Toby Golick, *Demographics, Trends, and a Call to Action*, 42 CLEARINGHOUSE REV. 205 (2008), the number of persons with mental impairments will also continue to rise. See BRAULT at 4, fig. 2 (displaying the positive correlation between disability and age). In addition, as the number of individuals with disabilities who live to older ages increases over time, so does the overall population of individuals with mental disabilities. See Mark C. Weber, *Ageing, Rights, and Quality of Life: Prospects for Older People with Disabilities*, 31 LOY. U. CHI. L.J. 485, 488 (2000) (reviewing STANLEY S. HERR & GERMAINE WEBER, *AGING, RIGHTS, AND QUALITY OF LIFE* (1999)) (noting that life expectancies for people with developmental disabilities are now similar to those of the general population and that the number of people with developmental disabilities aged sixty-five and older is expected to increase from 526,000 to 1,065,000 by 2030).

25. See, e.g., *Heller v. Doe*, 509 U.S. 312, 332 (1993) (recognizing a state's "legitimate interest under its *parens patriae* power in providing care to its citizens who are unable because of emotional disorders to care for themselves") (citing *Adington v. Texas*, 441 U.S. 418, 426 (1978)); *Washington v. Glucksberg*, 521 U.S. 702, 728–30 (1997) (recognizing a state's "unqualified interest in the preservation of human life").

“incompetent” subject. While guardianship may address certain needs of individuals who are unable to manage their personal and property affairs on their own, the question is the manner in which guardianship provides this assistance and its impact on individuals with disabilities.

1. The Constructive Isolation of Guardianship and Its Impact on the “Ward”²⁶

Guardianship laws potentially impact many decisions that define who we are as human beings: where and with whom we live; whether we can travel, marry, engage in certain social activities or interactions; whether we accept or reject medical treatment; and whether and how we manage our income and resources.²⁷ When a guardianship order transfers an individual’s right to make some or all of these decisions, the resulting guardianship can have a significant impact on an individual’s daily life, and it may do so in ways we may not fully consider when thinking about guardianship.

This is not to suggest that the possibility of being subjected to an overly paternalistic—and arguably unlawful—guardianship process is the most pressing problem facing individuals with mental disabilities. It is but one problem—and perhaps not the most significant or most acute problem—in the life of a person with a chronic mental disability.²⁸ This is par-

26. This Article will use the term “ward” to refer to a person who has been deemed “incompetent” or “incapacitated” in a guardianship proceeding.

27. See, e.g., N.Y. MENTAL HYG. LAW § 81.22 (McKinney 2009) [hereinafter N.Y. MENTAL HYG.] (noting 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).

28. At present, a large segment of this population still needs many basic resources such as affordable and flexible community-based housing options, meaningful choices of work and leisure activities, and appropriate and affordable health care—including necessary assistive devices, personal care services, and support and respite services for caregivers. See Henry Korman, *Clash of the Integrationists: The Mismatch of Civil Rights Imperatives in Supportive Housing for People with Disabilities*, 26 ST. LOUIS U. PUB. L. REV. 3, 9–12 (2007).

Furthermore, scholars have argued that in light of these continuing unmet needs, social welfare and economic policies may be as important or even more effective than anti-discrimination laws (such as the ADA) in achieving true integration of persons with disabilities in the workforce and the community. See, e.g., Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1 (2004); Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 2000 U. ILL. L. REV. 889 (2000) (discussing the need to move beyond an integrationist model, such as that underlying the ADA, to a model that effectuates policy

ticularly true in light of the more recent judicial and legislative recognition that guardianship involves the potential loss of individual freedom and the invasion of important personal liberty interests, warranting significant procedural protections.²⁹ But for those who are subjected to proceedings to remove their decision-making authority, the process raises exceptionally important questions of human dignity and the right and ability to govern one's own affairs.

With the loss of decision-making rights, the individual may be deprived of opportunities to engage in a range of activities that enable him or her to interact with others. The individual without the right to make financial decisions becomes gradually disengaged from the management of his or her finances and then loses opportunities for interactions with others involved in that management. This might mean that the person stops banking because he cannot make withdrawals; stops shopping or going to restaurants because he is unable to make his own purchases; or stops purchasing gifts for, or giving monetary gifts to, loved ones because he is unable to do so without a guardian's intervention. As a result, the individual is less likely to interact with shopkeepers, store patrons, vendors, bankers, and even friends. Similarly, if this individual loses the right to make medical decisions, the providers of medical or health-related services will likely seek guidance from the guardian rather than from the individual. The individual may get little information about his or her condition or treatment options, eventually becoming disregarded as a participant in the decision-making process and losing opportunities for important interactions with health professionals and others working in the healthcare system. Restrictions on an individual's abili-

changes needed to ensure greater social and economic equality for persons with disabilities). *See also*, Matthew Diller, *Judicial Backlash, the ADA, and the Civil Rights Model*, 21 BERKELEY J. EMP & LAB. L. 19 (2000) (noting the ADA's profound impact on institutional responses to disability-related issues, yet identifying limits of the civil rights model to address claims of disability-based discrimination—particularly in the employment context).

29. *See, e.g.*, *Hedin v. Gonzalez*, 528 N.W.2d 567, 575 (Iowa 1995) (finding that guardianship involves the stigmatization of an incompetence finding and "such a significant loss of liberty" that "the ward is entitled to the full panoply of procedural due process rights comparable to those present in civil commitment") (citations omitted); *Sabrosky v. Denver Dep't Soc. Servs.*, 781 P.2d 106, 107 (Colo. App. 1989) (explaining that guardianship's potential restriction of personal liberties "raises constitutional concerns"); Fliegelman & Fliegelman, *supra* note 15, at 344–45 (noting the "increased recognition that the imposition of guardianship can significantly deprive a person of fundamental rights guaranteed by the United States Constitution"). *See also infra* Part I.A.2.

ty to travel freely or engage in social interactions and activities will also have a direct impact on the individual's ability to interact with others. In all of these ways, the loss of decision-making rights can have an isolating effect on the individual with the disability.

The loss of the right to make one's own decisions also has a negative impact on the individual's functional abilities and general well-being—an impact which itself has further isolating effects. As the individual is deprived of the right to make decisions, he or she experiences a loss of control and a feeling of helplessness that has critical implications for his or her psychological well-being; the label of “incapacity” alone may have a negative psychological effect on an individual's sense of competency to act in the world.³⁰ As a result of this “incapacity” label, the individual is marginalized, presumed to be incapable of performing a range of tasks or activities, and given few opportunities to test and develop expertise in those areas of functioning.³¹ Once the individual is deemed to be “incapacitated” and

30. See, e.g., 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, 437 n.30 (2007) (discussing innate psychological needs of competence, autonomy, and relatedness); Nina A. Kohn, *Elder Empowerment As a Strategy for Curbing the Hidden Abuses of Durable Powers of Attorney*, 59 RUTGERS L. REV. 1, 27–30 (2006) (reviewing the psychological literature regarding individuals' perceived lack of control over their lives and affairs including the classic study by Judith Rodin and Ellen J. Langer demonstrating that a sense of control can have significant positive impact on the physical and psychological health of older individuals); Wright, *supra* note 16, at 77–78 (discussing studies and articles indicating the negative health consequences and anti-therapeutic effects of adult protective proceedings and the resulting loss of the ability to make one's own decisions); Bruce Winick, *The Side Effects of Incompetency Labeling and the Implications for Mental Health*, 1 PSYCHOL. PUB. POL'Y & L. 6, 16–17, 20–22, 42 (1995) (discussing experiments with learned helplessness in animals and the self-fulfilling consequences of the incapacity determination); A.B.A. COMM'N ON MENTALLY DISABLED, COMM'N ON LEGAL PROBLEMS OF THE ELDERLY, GUARDIANSHIP: AN AGENDA FOR REFORM 20 (1989) (“Allowing the allegedly incompetent person to retain as much autonomy as possible seems consistent with gerontological findings indicating that the maintenance of opportunity for choice and control are important to the [physical and] mental health of the elderly Indeed, complete loss of status as an adult member of society could act as a self-fulfilling prophecy and exacerbate any existing disability.”); J. GARBER & M.E. SELIGMAN, HUMAN HELPLESSNESS: THEORY AND APPLICATIONS (1980) (concluding that helplessness experienced by humans was aggravated when the individual believed that the helplessness was due to an internal deficiency such as lack of intelligence, lack of problem solving skills, or brain damage).

31. See Dhanda, *supra* note 30, at 436 n.25; Winick, *supra* note 30, at 10–11; Bruce Winick, *A Therapeutic Jurisprudence Approach to Dealing with Coercion in the Mental Health System*, 15 PSYCHIATRY, PSYCHOL. & L. 25, 18, 20–21 (2008), available at <http://ssrn.com/abstract=1157510> (“When decisions that significantly

incapable of making most decisions, her desires and preferences are rarely solicited and often ignored.³² As a result, the individual experiences a further loss of control over his or her life and the related losses of sense of self and self-esteem which cause further withdrawal from participation in life's activities.³³ This begins a vicious cycle: the incapacity determination and the resulting inability to manage one's affairs diminish the individual's opportunities to test his or her abilities. The "disuse of decision-making powers" may lead to further decline in the individual's capabilities and sense of competence to act in the world, leading to further isolation and loss of abilities.³⁴

In this way, guardianship can isolate an individual and limit his or her ability to interact with others, particularly those without disabilities. This isolation from the community is clearly different from the largely inescapable—and significantly more severe—isolation that results from placement in a highly regimented and physically segregated institutional setting.³⁵ There are, nevertheless, inescapable parallels between these two forms of state-sanctioned isolation. Allowing an individual to retain the authority to make self-defining personal decisions while providing any necessary assistance is both more respectful of individual dignity and autonomy than guardianship and provides the individual with greater opportunities to interact with others.³⁶

affect the individual . . . are made by others without the individual's participation, the resulting disuse of decision-making powers may lead to further degeneration of existing capabilities and behaviors.") (citations omitted). *See also*, Winsor C. Schmidt, Jr., *Guardianship of the Elderly in Florida*, 55 FLA. BAR J. 189, 190 (1981) ("In their landmark study of over 400 guardianships, Alexander and Lewin found that wards ended up worse in every case.") (discussing G. ALEXANDER & T. LEWIN, *THE AGED AND THE NEED FOR SURROGATE MANAGEMENT* 136 (1972)).

32. Dhanda, *supra* note 30, at 436.

33. *Id.* at 436–37 (noting "the basic human need to be . . . self-actualizing"); Edward L. Deci & R.M. Ryan, *The Empirical Exploration of Intrinsic Motivational Processes*, in 13 *ADVANCES IN EXPERIMENTAL SOCIAL PSYCHOLOGY* 39 (L. Berkowitz ed., 1980); MARTIN E. SELIGMAN, *HELPLESSNESS: ON DEVELOPMENT, DEPRESSION, AND DEATH* 21–74, 99, 166–88 (1992). *See generally*, AMARTYA SEN, *DEVELOPMENT AS CAPABILITY EXPANSION*, in *READINGS IN HUMAN DEVELOPMENT* 3–16, 4–5 (Sakiko Fukada-Parr & A.K. Shiva Kumar eds., 2003) (discussing essential value of actively "achieving self-respect, taking part in the life of the community, and appearing in public without shame."); NUSSBAUM, *supra* note 13, at 155–223 (developing a conception of well-being that is measured in part by exercising one's capability to function and engage in life's activities).

34. *See* Winick, *supra* note 31, at 18, 20–21; Winick, *supra* note 30, at 10–11.

35. *See infra* note 125.

36. *See* *Disability Advocates v. Paterson*, 598 F. Supp. 2d 289, 320–21 (E.D.N.Y. 2009) (observing that the relevant inquiry in integration mandate chal-

2. Recent Guardianship Reforms

The long-standing view of guardianship as a necessary, legitimate, and beneficent mechanism for protecting “incapacitated persons” has had at least two significant consequences. First, when confronted with vulnerable individuals, courts may tend to err on the side of appointing a guardian when there is a question about the individual’s ability to manage his or her affairs.³⁷ Second, historically, the procedures for appointing guardians have been fairly relaxed, and the resulting court orders have typically vested guardians with broad, plenary powers.³⁸

Over the last two decades, however, many states have enacted procedural and substantive reforms to their guardianship laws in an effort to more appropriately balance the autonomy and self-determination of persons with diminished mental capacity against a state’s legitimate concerns that its vulnerable citizens not be physically or mentally abused, exploited, or otherwise victimized.³⁹ Generally, the reforms have shifted the guardianship paradigm from a medical model that determines “incompetence” or “incapacity” based on an individual’s diagnosis, to a model that assesses an individual’s functional abilities.⁴⁰ Many state laws now impose a heightened burden of

lenge is not just whether the plaintiffs have *some* opportunities to interact with non-disabled individuals, but whether they have the opportunity to do so “to the fullest extent possible”); *Disability Advocates v. Paterson*, No. 03-CV-3209, 2009 U.S. Dist. LEXIS 80975, *116–19 (E.D.N.Y. Sept. 8, 2009) (discussing evidence that adult homes do not enable interactions with non-disabled individuals to the greatest extent possible).

37. See Frolik, *supra* note 13, at 736–37, 742 (recognizing that judicial concern with the welfare of the alleged incapacitated person may result in the imposition of a broad guardianship order to effectively address the person’s needs).

38. See Wright, *supra* note 16, at 59–60; Fliegelman & Fliegelman, *supra* note 15, at 344.

39. Guardianship is a matter of state law. While there have been clear national trends in reform, state laws have variations in both substantive and procedural provisions. For an excellent guide to the variations in state adult guardianship laws, see A.B.A. COMM’N ON LAW AND AGING, *State Adult Guardianship Legislation: Directions of Reform—2008* (2008) [hereinafter *ABA State Adult Guardianship Legislation*], (updated through December 31, 2008), available at <http://www.abanet.org/aging/guardianship/lawandpractice/home.shtml>.

40. See, e.g., UNIF. GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 102(5) (1998) [hereinafter UGPPA] (defining an “incapacitated person” as “an individual . . . unable to receive and evaluate information or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance”); N.Y. MENTAL HYG. § 81.02(b) (defining “incapacity” as the inability to care for self or manage property and to adequately understand the risks and

proof of “incapacity,”⁴¹ require the exploration of less restrictive existing alternatives to guardianship,⁴² and provide that the guardianship order be narrowly tailored to meet the individual’s specific needs.⁴³ Further, state statutes require comprehensive, comprehensible, and meaningful notice and pleadings, and numerous statutes have enhanced service requirements.⁴⁴ Many state laws call for the appointment of a neutral court evaluator with defined responsibilities. These include the following obligations: to explain the proceeding to the alleged incapacitated person (AIP); to determine AIP’s limitations, preferences, and available resources; and to report these findings to the court, along with conclusions about the need for a guardian and the least restrictive dispositional alternative.⁴⁵ In addition, some state laws now allow courts to appoint counsel for the AIP under certain circumstances.⁴⁶ And, to counteract the tendency of written information to “underrate capacity,”⁴⁷

consequences of that inability, along with a likelihood of resulting harm). *See generally* ABA State Adult Guardianship Legislation, *supra* note 39, at Initiation of Guardianship Proceedings, (comparing state definitions of incapacity).

41. *See, e.g.*, UGPPA §§ 311, 401 (requiring clear and convincing evidence of “incapacity”); N.Y. MENTAL HYG. § 81.12 (same).

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

43. *See* UGPPA §§ 311(b), 401 (guardianship order should remove only those rights that the “incapacitated” person can no longer exercise on her own); N.Y. MENTAL HYG. §§ 81.02(a)(2), 81.21(a), 81.22(a), 81.16, 81.29(a) (“incapacitated person” retains all powers and rights not specifically granted to the guardian). *See generally* ABA State Adult Guardianship Legislation, *supra* note 39, at Limited Guardianship of the Person (identifying states with stated preference for limited guardianship, as well as states, such as Delaware, that do not appear to provide for limited guardianships).

Under the UGPPA, if the petitioner requests an unlimited guardianship or conservatorship, the petition must state why a limited guardianship or conservatorship is not being sought. *See* UGPPA §§ 304(b)(8), 403(c)(3). This is not required in all states. *See generally*, ABA State Adult Guardianship Legislation, *supra* note 39, at Initiation of Guardianship Proceedings (comparing required petition elements in all state laws).

44. *See, e.g.*, UGPPA §§ 304, 309; N.Y. MENTAL HYG. §§ 81.07, 81.08. *See also* VT. STAT. ANN. tit. 14, § 3063 (2002 & Supp. 2008) (recent amendment requiring that guardianship petition specify the alternatives to guardianship that have been considered and explain why they will not work). *See generally*, ABA State Adult Guardianship Legislation, *supra* note 39, at Initiation of Guardianship Proceedings (comparing required petition elements in all state laws).

45. *See, e.g.*, UGPPA §§ 305(a), 406(a); N.Y. MENTAL HYG. § 81.09; ABA State Adult Guardianship Legislation, *supra* note 39, at Representation and Investigation in Guardianship Proceedings.

46. UGPPA §§ 305(b), 406(b); N.Y. MENTAL HYG. § 81.10.

47. *See* N.Y. MENTAL HYG. § 81.11, cmts. at 148.

many state laws create a general presumption that the AIP will be present at any hearing that would determine incapacity.⁴⁸ Many state laws now also require greater monitoring and oversight of the guardianship after appointment.⁴⁹

Thus, most states have amended their guardianship laws to provide greater procedural and substantive protections to individuals with the diminished ability to make decisions. The question to be explored in Subpart B is whether these changes have been sufficient to ensure that decision-making assistance is provided in the least restrictive and most integrated manner.

B. *The Limitations of Recent Guardianship Reforms*

There is little doubt that the reforms to state guardianship laws have brought improvements to the guardianship system. In particular, these reforms have made it less likely that a party will file an unnecessary guardianship petition or that a court will appoint a guardian in circumstances when it is not necessary. The mandates to deny a guardianship petition when less

48. See UGPPA § 308(a) (presence required unless excused by court); N.Y. MENTAL HYG. § 81.11 (setting forth general presumption that AIP will be present to enable court to assess functional abilities, but allowing court to dispense with AIP's presence when the AIP "is completely unable to participate in the hearing" or cannot "meaningfully participate" in the hearing).

49. Oversight and monitoring of guardianships is critical to ensure the integrity of the process. See UGPPA § 317 (requiring guardian reports within thirty days of appointment and annually thereafter); UGPPA §§ 418(c), 419, 420 (requiring property guardian to file a plan and property inventory within sixty days of appointment and subsequent annual reports that include a recommendation as to whether guardianship or conservatorship should be continued or modified). See generally, *ABA State Adult Guardianship Legislation*, supra note 39, at Monitoring Following Guardianship Proceedings (comparing significant elements of each state's guardianship monitoring system).

For a discussion of the effectiveness of various monitoring systems, see Naomi Karp & Erica F. Wood, *Guardianship Monitoring: A National Survey of Court Practices*, 37 STETSON L. REV. 143, 151–55 (2007); SALLY BALCH HURME, A.B.A., STEPS TO ENHANCE GUARDIANSHIP MONITORING (1991). See also, e.g., N.Y. MENTAL HYG. § 81.30(b) (setting forth requirements for service and filing of an initial report that includes, as appropriate under the circumstances, an inventory of property and financial resources, a report of the guardian's visits with ward, the steps the guardian has taken to comply with the court's order, "the guardian's plan" for provision of personal needs, and the need for any changes in the guardianship order); N.Y. MENTAL HYG. § 81.31(b)(1)–(10) (setting forth the requirements for serving and filing an annual report that includes information regarding the incapacitated person's residence and suitability of current living situation, health and functional abilities based on recent medical evaluation, past and planned medical treatment, the individual's social needs, social skills and social and personal services, an annual financial accounting, and the need for any changes to the guardianship order).

restrictive alternatives are available and to narrowly tailor the guardianship order to meet the needs of the ward are quite significant. Despite the adoption of these critically important reforms, problems persist in guardianship both because of a continuing failure to fully implement the enacted reforms and because the reforms themselves are not sufficient to address the problems inherent in the guardianship paradigm. As a result, guardianship continues to provide assistance in a manner that is more isolating than necessary in many cases. Subpart B seeks to explain why this is so, and briefly introduces supported decision-making options as less isolating mechanisms for providing assistance with decision making.

Legislative reform requiring courts to limit a guardian's authority to only those realms of decision making with which the individual needs assistance have not proven sufficient.⁵⁰ First, empirical studies indicate that courts simply do not take advantage of the limited guardianship option and rarely limit the guardian's authority.⁵¹ Rather, courts continue to vest guardians with unnecessarily broad powers over the individual's person and property for several possible reasons: courts habitually err on the side of protection; courts find it difficult to ascertain the precise areas of decision making with which the individual needs assistance; courts deem it necessary to avoid

50. See Fliegelman & Fliegelman, *supra* note 15, at 345–46; Lawrence A. Frolik, *Guardianship Reform: When the Best is the Enemy of the Good*, 9 STAN. L. & POL'Y REV. 347, 354 (1998) (“To date, limited guardianship has not been a success.”).

51. See Pamela B. Teaster et al., *Wards of the State: A National Study of Public Guardianship*, 37 STETSON L. REV. 193, 219, 219 n.177 (2007) (noting that a 2005 national study of public guardianship programs revealed court orders were limited in only zero to seven percent of the guardianships). A 1994 national study of guardianship proceedings by The Center for Social Gerontology found that guardianship orders were limited in only 13 percent of the cases. *Id.* at 199 (citing LAUREN GARITT LISI, ANNE BURNS & KATHLEEN LUSSENDEN, NATIONAL STUDY OF GUARDIANSHIP SYSTEMS: FINDINGS AND RECOMMENDATIONS 3 (1994)). While the 1994 study was completed at a point in time when the concept of limited guardianships was still relatively new and arguably underutilized, the evidence indicates that courts still rarely limit the guardian's authority. See Frolik, *supra* note 13, at 740–44.

The UGPPA and various state laws also specifically provide courts with significant discretion to authorize limited protective arrangements and single transactions in lieu of appointing a guardian of the property. See UGPPA § 412; N.Y. MENTAL HYG. § 81.16(b). It would be very useful to ascertain how often courts choose to use these less restrictive alternatives to property guardianship in those states that have adopted such provisions. There do not appear to be comparable provisions pertaining to guardianship of the person other than to recognize an existing alternative arrangement that is meeting the individual's personal needs.

confusion about the scope of the guardian's authority; or courts wish to avoid the need for additional future proceedings to expand the scope of a more limited initial order.⁵²

There may also be a structural explanation for the general judicial tendency to enter broad guardianship orders. Despite the availability of limited guardianships, the primary focus of the guardianship process continues to rest on the determination of "incapacity." Most state guardianship laws are structured so that the court first determines whether the individual is "incapacitated" and subsequently considers whether to limit the guardian's power when crafting the guardianship order.⁵³ It is not surprising that once a court has determined that the individual is "incapacitated," there is a tendency to transfer decision-making authority, and to do so in an order that grants the guardian a broad range of decision-making powers.

Second, the limited guardianship reform is inadequate because even when the court limits the scope of the order, the order nevertheless transfers the individual's right to make some range of decisions to a substitute decision maker despite the fact that the individual might be capable of making those decisions if he or she had assistance to do so. And, although many state statutes now provide that the ward's wishes should be considered and honored when possible,⁵⁴ the ward has no en-

52. See generally Frolik, *supra* note 50, at 352–53 (noting that for reasons of custom and human nature, courts tend to utilize plenary guardianships rather than limited guardianships); Frolik, *supra* note 13, at 741–44 (suggesting that judges may not be concerned that a plenary guardianship order would be overturned on appeal, as appeals in these cases generally challenge the determination of incapacity, not the scope of the order).

53. See, e.g., UGPPA § 311(a), (b); N.Y. MENTAL HYG. §§ 81.02(a)(2) (providing for determination of "incapacity" and then providing that guardianship order should be limited to powers that constitute the least restrictive form of intervention), 81.03(d) (defining "least restrictive form of intervention" as "the powers granted by the court to the guardian with respect to the incapacitated person"), 81.15(a)(3)–(4), 81.15(b)(4)–(5), 81.15(c)(2)–(7) (mandating separate judicial findings regarding the "necessity of the appointment" to meet needs or avoid harm and the guardianship powers that represent the least restrictive form of intervention).

54. See N.Y. MENTAL HYG. § 81.11 (c), (e); COLO. REV. STAT. § 15-14-314 (2008) (guardian should "encourage" ward to participate in decisions; ARIZ. REV. STAT. § 14-5312(A)(7) (2008) (guardian shall "encourage" ward's self-reliance and independence). See generally UGPPA §§ 314(a), 418(b) (guardian is "encouraged" to involve the ward in decision making "to the extent possible"). *But see* CONN. GEN. STAT. § 45a-656(b) (2008) (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"). Compliance with provisions "encouraging" the ward's involvement may be limited as

forceable “right” to participate in the decision-making process, and there is generally no formal mechanism for ensuring that the ward’s wishes have been solicited and seriously considered other than by raising the failure to solicit those wishes in a motion to remove or replace the guardian.⁵⁵

Third, even when the guardianship order is limited, members of the community may nevertheless treat the individual as if she were “incapacitated” in more areas of decision making than are covered by the actual order.⁵⁶ Fourth, whether the court ultimately enters a plenary or limited guardianship order or dismisses the petition, the individual may have been subjected to a proceeding that is, by its nature, uncomfortable, embarrassing, and stigmatizing.

the guardian has the ultimate authority to make decisions and may view the requirement as unnecessary, time-consuming, and difficult.

55. Many state guardianship statutes only require limited contact with the ward. See Karp & Wood, *supra* note 49, at 172 (citing results of 2005 survey indicating that the guardian did not visit the ward in 40 percent of the jurisdictions responding to the survey). The UGPPA provides that the guardian should “maintain sufficient contact with the ward to know of the ward’s capacities, limitations, needs, opportunities, and physical and mental health,” but does not set any specific requirements for doing so. UGPPA § 314(b)(1). *But see* N.Y. MENTAL HYG. § 81.20(a)(5) (requiring guardian to visit “incapacitated individual” at least four times per year).

Some state laws require that the annual report include some information on “the extent to which the ward has participated in decision making.” See, e.g., CONN. GEN. STAT. § 45a-656(c) (2008) (requiring conservator of person to report annually regarding efforts to encourage the independence of the conserved person); UGPPA § 317(a)(4). However, the problems with reporting of guardian activities and the lack of adequate state oversight are notorious. See Karp & Wood, *supra* note 49, at 184–92. Furthermore, while some states may require documentation of periodic visits to the ward, there is no requirement that the report document the extent of the ward’s participation in the decision-making process. See, e.g., N.Y. Mental Hygiene Law §§ 81.30–31; *ABA State Adult Guardianship Legislation*, *supra* note 39, at Monitoring Following Guardianship Proceedings.

56. See, e.g., *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 334–35, 335 n.26 (D. Conn. 2008) (observing that in some cases a state institution honored the guardian’s wishes that the ward not be moved to a community placement even though the guardians had limited powers that did not include the authority to make place-of-residence decisions).

In addition, there can be collateral legal impacts of a determination of incapacity even in those cases where the court limits the scope of the guardianship order. For example, approximately fifteen states and the District of Columbia still have laws that prohibit individuals from voting based on a finding of “incapacity” or guardianship status. See Jennifer Mathis, *Voting Rights of Older Adults with Cognitive Impairments*, 42 CLEARINGHOUSE REV. 292, 293 (2008). Thus, in some states, if a limited guardianship order was entered, but did not specifically provide that the person retained the right to vote, that individual could be disenfranchised even though he or she had the ability to understand the voting process. See *id.*

Additionally, while many state reforms now rightly require courts to consider less restrictive alternatives to guardianship prior to any appointment, the new laws generally require courts to consider only “available” alternatives that are brought to the court’s attention.⁵⁷ Frequently, however, alternatives for assisting individuals with decisions regarding personal needs and property management simply are not readily “available.” Many individuals fail to make the necessary advanced legal arrangements (such as appointing an attorney-in-fact or health care agent) prior to their “incapacity” and real alternatives to guardianship (such as supportive intensive case management services or protective counseling) are in short supply.⁵⁸ Furthermore, as in the case of the court’s consideration of whether to limit the scope of the guardianship order, the court often first determines whether the individual is “incapacitated” and then considers the sufficiency and reliability of available resources.⁵⁹ As a result, the court may tend to err on the side of appointing a guardian despite the availability of less restric-

57. See, e.g., N.Y. MENTAL HYG. §§ 81.02(a)(2), 81.03(e) (indicating that a petition should include “available resources” that have been explored prior to filing; available resources include “visiting nurses, homemakers, home health aides, adult day care and multipurpose senior citizen centers, powers of attorney, health care proxies, trusts, representative and protective payees, and residential facilities”).

58. See *Wingspan—The Second National Guardianship Conference: Recommendations*, 31 STETSON L. REV. 595, 575, 600 (2002) (noting the lack of adequate available alternatives and recommending multi-disciplinary education and advocacy efforts to increase general public awareness of the “risks and benefits of guardianship and planning alternatives”). In addition, the call for mediation prior to guardianship suggests that guardianship courts are not currently exhausting potential alternatives prior to entering guardianship orders. See A. Frank Johns & Charles P. Sabatino, *Wingspan—The Second National Guardianship Conference: Introduction*, 31 STETSON L. REV. 573, 581–83 (2002). For a discussion of some existing services that might serve as supported decision-making alternatives to guardianship (with or without some modifications), see 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, 82–87 (1997) (discussing some innovative efforts to provide personal and property management services through less restrictive models such as protective counseling and home-based support services) and *infra* note 197.

59. See, e.g., N.Y. MENTAL HYG. §§ 81.02(a)(1), (2); GA. CODE ANN. §§ 29-4-1 (a), (f) (2008) (court determines that the “adult lacks sufficient capacity to make or communicate significant responsible decisions concerning his or her health or safety,” then may enter a guardianship order “after a determination that less restrictive alternatives to the guardianship are not available or appropriate”). *But see*, e.g., UGPPA § 311(a)(1) (specifically providing that order cannot be entered without a determination that person is incapacitated *and* there are no less restrictive alternatives to guardianship).

tive options.⁶⁰ For these reasons, while the guardianship laws that require consideration of the availability of less restrictive alternatives are certainly much better than those that do not, the presence of such a provision does not ensure that a guardian will not be appointed in those circumstances where an individual could manage her person and property with a less restrictive form of assistance than guardianship.

The significant reforms in state guardianship laws reflect the sincere and long-term efforts of many scholars and advocates to ensure that these laws respect the rights of people with disabilities and strike a better balance between the concerns of autonomy and protection that arise in this context. Despite these important reforms, many courts continue to hold deeply embedded tendencies toward protection over autonomy, and courts continue to issue guardianship orders that are not necessary and are overly broad in scope.⁶¹ In addition, the system still lacks readily available and acceptable alternatives. As a result, guardianship laws continue to subject individuals to guardianships that are insufficiently respectful of their decision-making abilities and that unnecessarily isolate them from the daily life of their respective communities.

The story of Ms. G at the beginning of this Article is not unique. Rather, it presents the very real and classic dilemma

60. See, e.g., *Cruver v. Mitchell*, 656 S.E.2d 269, 272 (Ga. Ct. App. 2008) (reversing the decision of probate court that declined to appoint a guardian where AIP's daughters had "taken care of their mother's health and safety affairs thus far without a formal guardianship" and remanding for a determination of whether the alleged incapacitated person lacked capacity to make "responsible decisions"); The tendency for courts to appoint a guardian after making an initial "incapacity" determination may explain why it has been necessary for appellate courts to reverse trial court decisions appointing a guardian despite available alternatives to guardianship. See, e.g., *In re Isadora R.*, 5 A.D.3d 494 (N.Y. App. Div. 2004) (reversing the appointment of a guardian where the individual had previously appointed her long-time friend as health care proxy and power of attorney); *In re Albert S.*, 286 A.D.2d 684 (N.Y. App. Div. 2001) (concluding that guardianship was not warranted where a man had executed a living will, health care proxy, durable power of attorney, and created a trust).

61. See generally Frolik, *supra* note 13, at 740–45; Frolik, *supra* note 50, at 354 ("In order for judges to enthusiastically support limited guardianship and other recent reforms, they must appreciate why the underlying values of personal autonomy and independence trump the need for protection."); Johns & Sabatino, *supra* note 58, at 593 (noting that some guardianship experts suggest that guardianship practice has not followed the reforms in guardianship law); Jan Ellen Rein, *Preserving Dignity and Self-Determination of the Elderly in the Face of Competing Interests and Grim Alternatives: A Proposal for Statutory Refocus and Reform*, 60 GEO. WASH. L. REV. 1818, 1878 (1992) (concluding that guardianship reforms have not proven to be effective and proposing additional reforms).

inherent in the effort to balance the interests of self-determination and avoidance of harm raised in this context. Even assuming the good faith of all involved, these cases present difficult challenges affecting important interests. There is the individual's right of self-determination and the human desire to make one's own decisions and control one's own life. There is the related interest of those involved in the life of an individual with diminished decision-making ability to respect that person's desire for autonomy and to do all that is possible to help that person maximize his or her abilities and independence. At the same time, there is the legitimate concern that the person not make decisions that are harmful or difficult to correct. There is also the strong desire to ensure that the individual is not exploited or abused by others. In the case of Ms. G, those who knew her were moved to respect her desire to control her own life and to honor her right to live with the "dignity of risk."⁶²

The question is whether the type of reformed guardianship regime described above could adequately address the dilemma presented by Ms. G's situation. It is possible to argue that Ms. G's case is actually ideal for the appointment of a limited guardian for the singular purpose of authorizing homecare or housekeeping assistance and that persons like Ms. G could be assisted humanely and effectively if guardianship reforms could be fully and reliably implemented. Or is there something inherently problematic about guardianship and substituted decision making that calls for a more radical solution? Do we

62. See generally JOSEPH SHAPIRO, NO PITY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT 162 (1994) (observing that as individuals with disabilities began to live independently and to fully participate in life's activities, they were entitled to the corresponding "dignity of risk"). Whether (and if so at what point) Ms. G's former lawyer *could* or *should* have attempted to take protective action consistent with her ethical obligations is quite complex and beyond the scope of this article. See, e.g., MODEL RULES OF PROF'L CONDUCT, R. 1.14(b) (2009) ("When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial or other harm unless action is taken and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action, including consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, conservator or guardian."). There is a significant body of literature on the ethical issues that arise in the representation of persons with "diminished capacity." See, e.g., Fleischer & Schur, *supra* note 13; Stanley S. Herr, *Representation of Clients with Disabilities: Issues of Ethics and Control*, 17 N.Y.U. REV. L. & SOC. CHANGE 609 (1989-1990); Paul R. Tremblay, *On Persuasion and Paternalism: Lawyer Decisionmaking and the Questionably Competent Client*, 1987 UTAH L. REV. 515 (1987).

need to develop supported decision-making options to achieve more fundamental reforms?

While supported decision making is discussed more fully in Part V, a word about this option is needed here for purposes of comparison. The concept of supported decision making is predicated on the basic principle that all people are autonomous beings who develop and maintain capacity as they engage in the process of their own decision making, even if some level of support is needed to do so.⁶³ In a supported decision-making paradigm, the individual receives support from a trusted individual, network of individuals, or entity to make personal, financial, and legal decisions that must be followed by third parties (such as financial institutions, businesses, health professionals, and service providers).⁶⁴ Other nations have implemented supported decision-making models, including the judicially appointed “legal mentor” and the privately created “representation agreement.”⁶⁵

Described in its most basic and general terms, a legal mentor acts as the individual’s agent, with the individual’s consent, pursuant to specified powers similar to those that might be given pursuant to a power of attorney. The legal mentor is usually appointed through a simple local court procedure with the consent of the individual needing assistance. In contrast, under the private representation agreement model of supported decision making, an individual who might not be able to demonstrate that she has “legal capacity” in the traditional sense may enter into an agreement with an individual or support network to provide her with assistance making or communicating decisions which will then be legally binding.⁶⁶

63. See Dhanda, *supra* note 30, at 458 (characterizing supported decision making as a system “premised on the universal presence of competence,” while guardianship is a system based on “the selective presence of competence”).

64. See Andrew Byrnes et al., *From Exclusion to Equality: Realizing the Rights of People with Disabilities* (2007), <http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf>; Michael Bach, *Legal Capacity, Personhood, and Supported Decision Making*, (Jan. 2006), <http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii3.ppt>, at slides 13, 15.

65. As explained in Part V, Sweden and various Canadian provinces, among other governments, have adopted these supported decision-making models.

66. See Bach, *supra* note 64, at slide 13 (defining supported decision making as “an accommodation in legally-regulated decision-making processes to exercise the right to self-determination . . . [that] [p]rovides legal recognition and status to trusted others to assist in any aspect of . . . decision making, reflective capacity, and personal identity”); Byrnes et al., *supra* note 64; OPEN SOCIETY MENTAL HEALTH INITIATIVE, SUPPORTED DECISION MAKING, <http://www.osmhi.org/>

The value of supported decision making was starkly illustrated in testimony presented to the Ad Hoc Committee that drafted the CRPD regarding individuals who previously had been divested of the right to make their own decisions:

For years, even people who knew them well believed they were not able to make any decisions for themselves. We started to talk to them as real people in a safe environment and the results have been amazing. People who were in the institution . . . and who I know have never made their own decisions are now talking about the things they like. They are also talking about the things that they don't like. They have found their voice even though many do not use the spoken word to communicate.⁶⁷

In this way, supported decision making and its recognition of universal (or near universal) capacity helps correct for the frequent underestimation of the abilities of persons with intellectual, psychosocial, and other conditions affecting mental functioning. Accordingly, supported decision making enables each individual to realize his or her fullest capabilities.⁶⁸

It is indisputable that elements of supported decision-making models can be found in the language of those reformed guardianship laws that speak to the need to recognize capacity, limit restrictions on the exercise of that capacity, and encourage the ward's participation in the decision-making process. It is also undeniable that the laws in those countries that have developed supported decision-making alternatives still provide for guardianship or the appointment of a surrogate decision

page=266 (defining supported decision making as an alternative to guardianship and providing citations to resources regarding supported decision making).

67. Tina Minkowitz, *The Paradigm of Supported Decision Making*, at slide 20, http://www.barcsi.hu/letoltesek/neveseloadoink/Minkowitz_presentation.pdf (citing to Expert Paper for the Special Rapporteur, <http://www.un.org/esa/socdev/enable/rights/ahc7docs/ahc7ii2.doc>).

68. When given the opportunity to act independently, individuals with such mental disabilities have demonstrated significant capabilities. *See generally* Dhanda, *supra* note 30, at 448 (noting the significant numbers of individuals with various, severe impairments that arguably affect decision-making abilities who effectively testified before the U.N. Committee and demonstrated that they "were capable of reasoning, expressing opinions, voicing aspirations and making decisions"). *See also* PRAMILA BALASUNDARAM, *SUNNY'S STORY* (2005) (chronicling a year in the life of an individual with an intellectual disability who lived independently) (cited in Dhanda, *supra* note 30, at 459 n.143).

maker under certain circumstances.⁶⁹ However, the differences between the two paradigms are real.

In the guardianship paradigm, the norm is one of substituted decision making with exceptions for persons who had previously made private arrangements or for those deemed to be “OK on their own.” In contrast to guardianship’s focus on the determination of capacity and the individual’s need for another to step into those areas of decision making with which he or she needs assistance, supported decision-making models presume the existence of capacity. These models focus on the creation of relationships of trust and agency to assist the individual with the identification and effectuation of his or her own decisions to the fullest extent possible. In so doing, supported decision making underscores each individual’s right and ability to participate in the decision making that affects his or her life to an extent that may not be possible within the current substituted decision-making paradigm that characterizes guardianship.

Therefore, despite the many positive reforms that have been implemented in the guardianship context, it seems that it could be both beneficial and appropriate to take the next step to provide assistance with decision making through the creation of supported decision-making options. This Article now explores the question of whether there is a “right” to such assistance under the ADA.

II. CONCEPTUALIZING GUARDIANSHIP AS A FORM OF DISABILITY-BASED DISCRIMINATION UNDER THE ADA

Having endeavored in Part I to suggest that existing state guardianship laws continue to provide assistance with decision making in a manner that is unnecessarily isolating, Part II of this Article addresses whether this isolation falls within the reach of the ADA’s integration mandate. This section argues that the language and legislative history of the ADA justify the application of the statute to the guardianship context, as does the Supreme Court’s determination in *Olmstead*.⁷⁰ that the un-

69. See, e.g., *infra* notes 244 (discussing appointment of a guardian-like “administrator” under certain circumstances); 257 (discussing provision of the Yukon Decision-Making Support Act permitting appointment of a guardian in those instances where support alternatives have been “tried or carefully considered”).

70. 527 U.S. 581 (1999).

justified isolation of persons with disabilities constitutes a form of unlawful discrimination under the Act.

A. *The ADA and the Integration Mandate*⁷¹

Beginning in 1973, Congress enacted a number of laws to address the problems and barriers facing individuals with disabilities in a range of areas.⁷² Concerned that disability-based discrimination was persisting despite these legislative efforts, in 1984, Congress mandated that the National Council on Disability (“The Council”) formally evaluate the effectiveness of existing federal laws and programs in achieving the integration of people with disabilities.⁷³ The Council concluded that unnecessary, external barriers prevented the full participation of people with disabilities in significant aspects of economic and social life. The Council called on Congress to enact a comprehensive law “requiring equal opportunity for individuals with disabilities . . . and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap.”⁷⁴ In 1988, therefore, Congress introduced federal legislation that formed the basis of the ADA.⁷⁵

71. 42 U.S.C. §§ 12101–213 (2006); 28 C.F.R. § 35.130(d) (2008).

72. The Rehabilitation Act of 1973 sought to achieve the integration and inclusion of people with disabilities through the creation and funding of vocational rehabilitation services programs, employment demonstration projects, independent living centers, and services. See 29 U.S.C. §§ 701–96 (2006); S. REP. NO. 93-318 (1973), *reprinted in* 1973 U.S.C.C.A.N. 2076 (tracing the history of the Rehabilitation Act of 1973, including the original post-World War II rehabilitation legislation); 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* 309, 312 (S. Yee & M. Breslin eds., 2002). The statute also provided for affirmative action in the hiring, placement, and advancement of people with disabilities by federal agencies and federal contractors and prohibited discrimination based on disability by those entities. See 29 U.S.C. §§ 701, 720, 791–794 (2006). *But see* SHAPIRO, *supra* note 62, at 65 (noting that “[s]ection 504 of the Rehabilitation Act of 1973 was no more than a legislative afterthought”). Over the next fifteen years, Congress enacted additional legislation to address the needs of persons with disabilities and to prohibit disability-based discrimination in the provision of institutional services, education, housing, voting, and public accommodations and transportation. See, e.g., federal statutes cited, *supra* note 20.

73. See Pub. L. No. 98-221, Sec. 142(a) (1984).

74. NATIONAL COUNCIL ON DISABILITY, *TOWARD INDEPENDENCE* 11 (1986), available at <http://www.ncd.gov/newsroom/publications/1986/pdf/toward.pdf>. See also Kathleen S. v. Dep’t of Pub. Welfare, 10 F. Supp. 2d 460, 467–68 (E.D. Pa. 1998); H.R. REP. NO. 101-485, pt. 3, at 25 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 447–48 (citing to Louis Harris & Associates, *The ICD (International Center for the Disabled) Survey of Disabled Americans: Bringing Disabled Americans in-*

The legislative history of the ADA indicates that Congress intended to provide broad protections to address not only intentional discrimination but also the “benign neglect” and continuing “invisibility” of persons with disabilities.⁷⁶ The comments of Senator Paul Simon were typical in explaining the need for enhanced civil rights legislation to eradicate disability-based discrimination:

In spite of progress resulting from laws such as . . . the Rehabilitation Act, this sizeable part of our population remains substantially hidden. They are hidden in institutions. They are hidden in nursing homes. They are hidden in the homes of their families Because they are hidden, we too easily ignore the problem and the need for change.⁷⁷

Some members of Congress analogized this segregation of persons with disabilities to the historic, unjustified segregation of African Americans, expressing concerns that this segregation could “affect [the] hearts and minds [of persons with disabilities] in a way unlikely ever to be undone.”⁷⁸

To create a new future of inclusion and integration,⁷⁹ in 1990 Congress enacted the ADA to “provide a clear and com-

to the Mainstream (1986) (survey finding that people with disabilities were socially, economically, and educationally disadvantaged)); S. REP. NO. 101-116, at 20 (1989) (noting compelling need for a clear national mandate to provide for “the integration of persons with disabilities into the economic and social mainstream of American life”). There was general agreement that section 504, the anti-discrimination provision of the Rehabilitation Act, was ineffective in addressing disability-based discrimination. *See, e.g.*, *Helen L. v. DiDario*, 46 F.3d 325, 331 (3d 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, 431 (1991) (discussing limitations of section 504’s non-discrimination mandate)).

75. H.R. 4498, 100th Cong. (1988) (introduced by Rep. Coelho); S. 2345, 100th Cong. (1988) (introduced by Sen. Weicker).

76. *See, e.g.*, *U.S. Airways, Inc. v. Barnett*, 535 U.S. 391, 401 (2002) (“The statute seeks to diminish or to eliminate the stereotypical thought processes, the thoughtless actions, and the hostile reactions that far too often bar those with disabilities from participating fully in the Nation’s life”); *Helen L.*, 46 F.3d at 335.

77. 134 Cong. Rec. 9384 (1988).

78. *See* H.R. REP. NO. 101-485, pt. 3, at 26 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 449.

79. H.R. REP. NO. 101-485, pt. 3, at 29 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 451–52; H.R. REP. NO. 101-485, pt. 2, at 50 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 332. *See* *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 675 (2001) (noting that with its focus on integration, the ADA is “a milestone on the path to a more decent, tolerant, progressive society.”) (citation omitted); H.R. REP. NO. 101-485, pt. 3, at 49–50 (1990) (“The purpose of Title II is to continue to break down

prehensive national mandate for the elimination of discrimination against individuals with disabilities.”⁸⁰ The Act is founded on the explicit Congressional recognition that while individuals with disabilities have the ability, and should have the right, to fully participate in all aspects of social life,⁸¹ often they are precluded from doing so because of discrimination in various forms, including “outright intentional exclusion, [and] the discriminatory effects of . . . communication barriers, overprotective rules and policies . . .”⁸² The ADA also explicitly recognizes that the historical isolation and segregation of people with disabilities is a “serious and pervasive social problem.”⁸³ In this way, the ADA differs from preceding legislation by clearly identifying the isolation and segregation of persons with disabilities as a type of discrimination that Congress sought to eliminate.⁸⁴

Congress set forth a national goal “to assure equality of opportunity, full participation, independent living, and economic self-sufficiency” for people with disabilities.⁸⁵ To meet this goal the ADA prohibits disability-based discrimination in employment (Title I); public activities, services, and programs

barriers to the integrated participation of people with disabilities in all aspects of community life.”); 135 CONG. REC. 19803 (1989) (comments of Senator Harkin, floor manager of the ADA in the Senate) (“[The ADA] guarantees individuals with disabilities the right to be integrated into the economic and social mainstream of society; segregation and isolation will no longer be tolerated.”).

80. 42 U.S.C. § 12101(b)(1) (2006). In enacting the ADA, Congress invoked the “sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce.” 42 U.S.C. § 12101(b)(4) (2006). *See generally* *Wis. Cmty. Servs., Inc. v. City of Milwaukee*, 465 F.3d 737, 750 (7th Cir. 2006) (en banc) (noting that the ADA substantially extends the reach of the Rehabilitation Act of 1973).

81. 42 U.S.C.A. § 12101(a)(1) (West 2009). The ADA Amendments Act of 2008 [hereinafter ADA Amendments Act], effective January 1, 2009, was enacted to address a series of Supreme Court decisions that narrowed the scope of the ADA. This Act replaced the original findings of § 12101(a)(1) and (a)(7) with a reformulated finding that “physical or mental disabilities in no way diminish a person’s right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination.” ADA Amendments Act, Pub. L. No. 110-325, § 3, 122 Stat. 3553 (2008).

82. 42 U.S.C.A. §§ 12101(a)(5) (West 2009).

83. 42 U.S.C. § 12101(a)(2) (2006).

84. *See* *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 589, 589 n.1 (1999) (citing 42 U.S.C. §§ 12101(a)(2), (3), (5) (1999)); *Martin v. Taft*, 222 F. Supp. 2d 940, 967 (S.D. Ohio 2002); Rosenthal & Kanter, *supra* note 72, at 309–395, 313–17. *But see* *Olmstead*, 527 U.S. at 614 (Kennedy, J., concurring in the judgment) (specifically concluding that the congressional findings do not establish that segregation and institutionalization are always discriminatory or would always constitute a type of prohibited discrimination).

85. 42 U.S.C.A. § 12101(a)(7) (West 2009).

(Title II); and in public accommodations and services operated by private entities (Title III).⁸⁶

A challenge to guardianship would fall within the ambit of Title II of the ADA. Title II provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”⁸⁷ Acting pursuant to a specifically delegated authority,⁸⁸ the Attorney General has issued regulations implementing Title II of the ADA.⁸⁹ Among these is the regulation, referred to as the “integration mandate,” which requires that public entities “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”⁹⁰ The Attorney General has defined the “most integrated setting” as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent poss-

86. See Title I, 42 U.S.C. §§ 12111–17 (2006) (discrimination in employment); Title II, 42 U.S.C. §§ 12131–65 (2008) (discrimination by public entities, including public transportation services); Title III, 42 U.S.C. §§ 12181–89 (2006) (discrimination by private entities in public accommodations and services).

87. 42 U.S.C. § 12132 (2006).

88. See 42 U.S.C. § 12134(a) (2006).

89. 28 C.F.R. § 35.101–190 (2008) (“Nondiscrimination on the Basis of Disability in State and Local Government Services”).

90. 28 C.F.R. § 35.130(d) (2008). The Supreme Court has not specifically determined the validity of the Attorney General’s Title II regulations. See *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 591–92 (1999) (citing to the Attorney General’s regulations, including the integration regulation, but noting that because the parties had not directly challenged the ADA regulations, the Court would not determine their validity); *id.* at 598 (concluding that as the agency vested with authority to implement Title II, the Attorney General’s “well-reasoned views” regarding the scope of the statute are entitled to “respect [and] ‘constitute a body of experience and informed judgment to which courts and litigants may properly resort for guidance’”) (quoting *Bragdon v. Abbott*, 524 U.S. 624, 642 (1998)); *Skidmore v. Swift & Co.*, 323 U.S. 134, 139–40 (1944).

The ADA specifically provides that the Attorney General’s regulations should be consistent with the coordination regulations under 28 C.F.R. § 41.504. 42 U.S.C. § 12134(b) (2006). In light of this congressional approval of the coordination regulations, including section 504’s integration regulation, 28 C.F.R. § 41.51(d), on which the ADA’s integration mandate, 28 C.F.R. §35.130(d) (2008) is based, lower courts have concluded that the ADA’s integration regulation should be deemed to have the “force of law.” See *Helen L. v. DiDario*, 46 F.3d 325, 332 (3d Cir. 1995). Other lower courts have concluded that the Attorney General’s regulations implementing Title II should be given controlling weight unless they are arbitrary, capricious, or manifestly contrary to the statute. See, e.g., *McGary v. City of Portland*, 386 F.3d 1259, 1269 n.6 (9th Cir. 2004) (quoting *Chevron U.S.A., Inc. v. Natural Resources Defense Council, Inc.*, 467 U.S. 837, 844 (1984)); *Yeskey v. Pa. Dep’t Of Corrs.*, 118 F.3d 168, 171 (3d Cir. 1997), *aff’d*, 524 U.S. 206 (1998); *Blatch v. Hernandez*, 360 F. Supp. 2d 595, 629, n.29 (S.D.N.Y. 2005).

ible”⁹¹ 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.⁹²

B. *The Supreme Court’s Olmstead Decision*

In *Olmstead*, the Supreme Court was asked to define the contours of a state’s obligation under the ADA to address the isolation and segregation of individuals with disabilities.⁹³ The plaintiffs in *Olmstead*, L.C. and E.W., were two women with intellectual disabilities who had been voluntarily admitted to a state psychiatric hospital for treatment of mental illness. When their treating doctors concluded that L.C. and E.W. no longer required institutional treatment, the state was unable to discharge them due to the lack of appropriate care and treatment options in the community. L.C. and E.W. sued the state under Title II of the ADA, alleging that the state’s failure to place them in a community-based treatment program deemed medically appropriate by their treating physicians violated the anti-discrimination and integration mandates of the ADA.⁹⁴

91. 28 C.F.R. pt. 35, app. A, subsec. B (2008). The Department of Justice explains the comprehensive nature of the integration mandate:

Integration is fundamental to the purposes of the Americans with Disabilities Act. Provision of segregated accommodations and services relegates persons with disabilities to second-class status. For example, it would be a violation of this provision to require persons with disabilities to eat in the back room of a government cafeteria or to refuse to allow a person with a disability the full use of recreation or exercise facilities because of stereotypes about the person’s ability to participate The Department recognizes that promoting integration of individuals with disabilities into the mainstream of society is an important objective.

Id., Commentary on Section 35.130 (2008) (discussion of integration mandate in context of the requirements of section 35.130(b)(1)(iv)).

92. 28 C.F.R. § 35.130(b)(7) (2008). Congress provided that the remedies, procedures, and rights of Section 504 of the Rehabilitation Act, 29 U.S.C. § 794a (2006), should apply to discrimination claims under Title II of the ADA. *See* 42 U.S.C. §§ 12133, 12201(a) (2006); 28 C.F.R. § 35.103(a) (2008); Cary LaCheen, *Using Title II of the ADA on Behalf of Clients in TANF Programs*, 8 GEO. J. ON POVERTY L. & POL’Y 1, 38 (2001). While there are subtle distinctions between the ADA and Section 504, in general, courts analyze claims under the two statutes and their related regulations identically. *See, e.g.*, *Henrietta D. v. Bloomberg*, 331 F.3d 261, 272 (2d Cir. 2003); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 607 (7th Cir. 2004).

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

94. *See id.* at 593–94.

The case presented the Supreme Court with the question of “whether the [ADA’s] proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.”⁹⁵ The *Olmstead* Court concluded that unjustified isolation of people with disabilities in institutions constitutes disability-based discrimination.⁹⁶ Accordingly, under Title II of the ADA, a state must make reasonable program modifications to avoid discriminatory isolation, unless doing so would “fundamentally alter” the state services provided to other persons with mental disabilities.⁹⁷

While the *Olmstead* decision addresses the specific factual context of unjustified institutionalization, three aspects of the Supreme Court’s decision are particularly relevant to the guardianship context.⁹⁸ First, a majority of the Court concluded that the ADA’s proscription against discrimination “by reason of disability” prohibits unjustified segregation and isolation because of the resulting damage to people with disabilities. 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.⁹⁹

95. *Id.* at 587.

96. *Id.* at 597–98 (noting the long-standing Department of Justice position that unjustified segregation of persons with disabilities in institutions constitutes a form of prohibited disability-based discrimination) (citing to Brief for United States at 27, 45, *Halderman v. Pennhurst State Sch. & Hosp.*, 673 F.2d 647 (3d Cir. 1978) (Nos. 78-1490, 78-1564, 78-1602) and Brief for United States as Amici Curiae at 7–16, *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1994) (No. 94-1243)).

97. *Id.* at 603–07.

98. See generally Michael Perlin, “*Their Promises of Paradise*”: Will *Olmstead* v. L.C. Resuscitate the Constitutional ‘Least Restrictive Alternative’ Principle in Mental Disability Law?, 37 HOUS. L. REV. 999, 1040–44 (2000) (arguing that *Olmstead* should serve to revitalize the concept of least restrictive alternative in the involuntary civil commitment context and discussing *Olmstead*’s significance, including the Court’s qualifiers, in that context).

99. *Olmstead*, 527 U.S. at 600–01 (citing Brief for the Am. Psych. Ass’n and the Nat’l Alliance for the Mentally Ill as Amici Curiae Supporting Respondents, *Olmstead v. L.C., ex rel. Zimring* 527 U.S. 581 (1999) (No. 98-536), 1999 WL 134004, at *20–*22). See *id.* at 596 (noting Attorney General’s determination that

Similarly, guardianship “perpetuates unwarranted assumptions” that persons with guardians “are incapable or unworthy of participating in community life” and diminishes their life activities.¹⁰⁰

The second aspect of the *Olmstead* decision relevant to the guardianship context is the Court’s explicit recognition of the ADA’s “comprehensive view of the concept of discrimination.”¹⁰¹ The majority’s conclusion that an individual can assert a claim of discrimination under the ADA based on his or her own unjustified isolation in a state mental health facility, without the need to identify a comparison group of similarly situated non-disabled individuals given preferential treatment, has direct applicability to an ADA challenge in the guardianship context.¹⁰²

Third, the *Olmstead* Court attempted to define what constitutes a fundamental alteration of a state’s services, programs, or activities.¹⁰³ Having found that plaintiffs’ unjustified isolation constituted disability-based discrimination, the Court had to determine how far the state would be required to go in order to avoid or correct the identified discrimination. The Court’s analysis provides guidance for understanding the potential scope of the state’s obligation to avoid discrimination in a Title II challenge to guardianship.¹⁰⁴

According to the *Olmstead* plurality, both lower courts utilized incorrect standards for analyzing the state’s fundamental alteration defense.¹⁰⁵ The plurality concluded that the district court erred when it compared the costs of treating plaintiffs in the community with the costs of treating them in an institution because that analysis did not account for the costs associated with the state’s continuing operation of institutions still needed

unjustified placement or retention in institutions severely limits exposure to the outside community); *id.* at 600–01 (citing cases recognizing deleterious and stigmatizing impact of discriminatory stereotyping).

100. *Id.* at 600–01. See discussion *supra* Part I.A.1.

101. *Olmstead*, 527 U.S. at 598.

102. *Id.* at 598 n.10; see *id.* at 611–12 (Kennedy, J., concurring).

103. See *id.* at 597–98, 603, 607.

104. It is appropriate to follow the interpretation of the fundamental alteration defense contained in *Olmstead*’s plurality opinion, even though it commanded only four votes, because it rested on narrower grounds than the concurring opinions of Justices Stevens and Kennedy. See *Townsend v. Quasim*, 328 F.3d 511, 519 n.3 (9th Cir. 2003); *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 619 n.3 (9th Cir. 2005).

105. See *Olmstead*, 527 U.S. at 603–06.

by others with disabilities.¹⁰⁶ The plurality also concluded that the Court of Appeals erred when it compared the cost of the plaintiffs' care in the community to the state's entire mental health budget because such analysis would almost always result in an order to provide services to the particular plaintiffs.¹⁰⁷

The Court rejected both methods of analysis, finding that both made it extremely difficult for the state to ever put forward a successful defense and tended to place the plaintiffs at an unfair advantage over other disabled individuals in obtaining integrated services.¹⁰⁸ Ultimately, the *Olmstead* plurality concluded that:

In evaluating a State's fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State's obligation to mete out those services equitably.¹⁰⁹

The plurality posited that a State could establish a fundamental alteration defense by demonstrating that it has a "comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."¹¹⁰

The plurality opinion was likely influenced by at least two significant factors. First, it reflects the Court's reluctance to mandate specific requirements for state compliance in an area that necessarily requires the exercise of substantial administrative expertise and judgment and involves serious questions of resource allocation. In addition, the decision reflects the plurality's concern that the particular plaintiffs in an integration mandate challenge not be unfairly preferred over the substantial group of other individuals with equally legitimate demands for a range of state mental health services.¹¹¹ In the

106. *Id.* at 604 n.15.

107. *Id.* at 603–04.

108. *Id.*

109. *Id.* at 597.

110. *Id.* at 605–06.

111. *See id.* at 597, 605–07 (recognizing a state's obligation to maintain a range of facilities for the care of a substantial population with diverse mental conditions and the need to fairly distribute state mental health resources).

final analysis, however, the Court may have acted with an excess of caution. Out of deference to the state's administration of its mental health programs, the Court provided the state with a generous opportunity to establish a fundamental alteration defense and, as a result, placed an exceptionally high burden on plaintiffs seeking services in a more integrated setting.

Despite its limitations, however, the *Olmstead* decision represents a tremendous step forward in the recognition of the rights of people with disabilities. The decision has been viewed by some scholars and commentators as the promise of a new dawn for individuals with disabilities.¹¹² Courts have been moved by the tragedy of institutionalization and the converse benefits of integrated living and have required concrete efforts at deinstitutionalization based on *Olmstead*.¹¹³ In other cases following *Olmstead*, courts have taken seriously the Court's endorsement of the integration mandate, applying its reasoning to challenges by individuals living in the community and seeking expanded community-based housing and health-related services that would provide an alternative to institutional care.¹¹⁴

To be sure, however, the significant leeway provided by *Olmstead's* formulation of the fundamental alteration defense—viewed by some as a lack of substance in the articulated right—has led to a number of disappointing results in the lower courts, raising questions about *Olmstead's* importance as a vehicle for truly integrating people with disabilities into mainstream civic life.¹¹⁵ Furthermore, the broad, articulated scope of the state's fundamental alteration defense also makes *Olmstead*-type litigation complex, time-consuming, and diffi-

112. See Mary C. Cerreto, *Olmstead: The Brown v. Board of Education for Disability Rights: Promises, Limits, and Issues*, 3 LOY J. PUB. INT. L. 47, 67 (2001); Rosenthal & Kanter, *supra* note 72, at 321–22; Perlin, *supra* note 98.

113. See discussion *infra* Part III.C.

114. See *id.*

115. See, e.g., 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). See generally Bagenstos, *supra* note 28, at 6–24, 83 (arguing that the ADA's anti-discrimination model alone is inadequate to achieve the long-term goals of community integration and employment of people with disabilities and that social welfare interventions may be needed to effectively achieve these long-term goals).

cult for plaintiffs to win¹¹⁶—all issues that may account for the limited amount of litigation based on the integration mandate.¹¹⁷

But while progress in realizing the full potential of *Olmstead* has been slow, *Olmstead* has served as an impetus to states to engage in concrete planning to reduce institutional populations and to increase community-based services as an alternative to segregated institutional care.¹¹⁸ Even in those post-*Olmstead* cases in which courts have found that the state has established a fundamental alteration defense based on its “comprehensive and effectively working” integration plan, the court has required the state to demonstrate that it has a reasonable and concrete plan with a range of available, community-based treatment options.¹¹⁹ Thus, to a certain degree, states have been motivated to develop integration plans both in order to comply with the ADA and to be able to defend against a future integration mandate challenge.¹²⁰

116. See *Five Years After Olmstead*, *supra* note 9, at 562. Scholars have also raised concerns that *Olmstead*'s deference to the judgment of state professionals in determining whether an individual is capable of residing in the community may ultimately serve to limit the reach of its holding. See *infra* note 142.

117. See Perlin, *supra* note 115, at 258.

118. See *Five Years After Olmstead*, *supra* note 9 (reviewing litigation and state and federal compliance efforts, and finding that progress of de-institutionalization has generally been slow, with the most significant achievements obtained through litigation relying on *Olmstead*); CTR. FOR PERS. ASSISTANCE SERVICES, *Olmstead Plans and Lawsuits* (Aug. 2009), <http://www.pascenter.org/olmstead> (select “Find Olmstead Information for a Specific State”) (providing state-by-state information on *Olmstead* litigation and state compliance plans).

Not every state has developed a formal *Olmstead* compliance plan. See CTR. FOR PERS. ASSISTANCE SERVICES, *A Table of State Olmstead Plans and Related State Activity* (Aug. 2009), <http://www.pascenter.org/olmstead> (select “Table 1—Olmstead Plans”) (providing information on *Olmstead* compliance efforts in all fifty states). For example, New York does not have a formal *Olmstead* compliance plan, but in 2002, the state adopted a law requiring the formation of the “Most Integrated Setting Coordinating Council” (“MISCC”) to develop a comprehensive, effectively working integration plan. N.Y. EXEC. LAW §§ 700–03 (McKinney 2002). In 2008, the MISCC issued a report on state agency efforts to remove barriers to the maximum integration of individuals with disabilities in community living. See MOST INTEGRATED SETTING COORDINATING COUNCIL, *ANNUAL REPORT* (2008), available at http://www.omr.state.ny.us/MISCC/images/hp_miscc_annualreport.pdf.

119. See *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 621 (9th Cir. 2005); *Sanchez v. Johnson*, 416 F.3d 1051, 1063 (9th Cir. 2005); *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 364 F.3d 487, 500–01 (3d Cir. 2004).

120. *But see Five Years After Olmstead*, *supra* note 9, at 579–82 (discussing disappointing results of state *Olmstead*-planning efforts which tend to focus on past efforts rather than concrete, detailed, and time-specific plans for achieving integration; also observing that state planning efforts are greatly affected by state

In the end, despite *Olmstead*, rates of institutionalization of persons with mental disabilities remain higher than necessary and there continue to be insufficient opportunities and services to facilitate integrated, community living. Despite its failure thus far to transform the landscape for people with mental disabilities, *Olmstead* has provided a legal basis both to require states to move individuals out of institutions and to maintain or expand a range of community-based services for persons with mental disabilities. In addition, the decision has motivated states to do something they were not required to do before—to systematically evaluate existing programs and services for people with disabilities and develop plans to provide public programs and services in the most integrated setting. Thus, in spite of its limitations, *Olmstead* still holds real potential to make a difference in the lives of people with disabilities. This Article seeks to build on that potential.

C. *Applying Olmstead and the ADA to the Guardianship Context*

While the Court's decision in *Olmstead* directly addressed the specific issue of institutional confinement, it was not the institutional conditions that were the focus of the Court's concerns.¹²¹ Rather, the Court focused on the harms flowing from the individual's segregation from society—namely the perpetuation of demeaning stereotypes and lost opportunities for engagement in significant aspects of community life.¹²² The decision therefore speaks to the affirmative obligation created by the ADA to integrate individuals with disabilities into social, economic and political life, to the greatest extent possible. Thus, while the *Olmstead* decision is unquestionably linked to plaintiffs' institutionalization, the Court issued a broad holding that can be imported to other, comparable contexts: "Unjustified isolation, we hold, is properly regarded as discrimination

budget limitations and concerns over immediate costs without adequate consideration of long-term savings that could be achieved by care in the community).

121. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 588 (1999) (demonstrating that the Court was not presented with the question of whether defendants had violated plaintiffs' constitutional rights to minimally adequate care and freedom from undue restraint).

122. *Id.* at 600–01.

based on disability.”¹²³ This principle applies as well to guardianship.

As discussed above,¹²⁴ when the state appoints a guardian and restricts an individual from making his or her own decisions, the individual loses crucial opportunities for interacting with others. Although wards often reside in the community and are not physically segregated by the walls of an institution, guardianship creates a legal construct that parallels the isolation of institutional confinement.¹²⁵ Just as most individuals residing in institutions would benefit from living and receiving care in a less restrictive community setting, many individuals with guardians could successfully manage their personal and property affairs through the less isolating mechanism of supported decision making. Thus, drawing on the principles enunciated in *Olmstead*, an argument can be made that guardianships violate the integration mandate because they fail to provide assistance with decision making in the least restrictive “setting.”

Before proceeding further, it is worth addressing two preliminary questions. First, does it make sense to try to extend the integration mandate beyond the context of deinstitutionalization to that of guardianship when there is still a lack of basic services to enable individuals with mental disabilities to live in the community rather than in institutions? Second, is it useful—or any more useful than current efforts to reform state guardianship laws and processes—to re-conceptualize guardianship as a failure to provide services in the most integrated

123. *Id.* at 597. *But see id.* at 587 (tying the Court’s holding more closely to the question of whether the ADA “may require placement of persons with mental disabilities in community settings rather than in institutions”).

124. *See* discussion *supra* Part I.A.2.

125. “[Q]uestions of institutionalization and deinstitutionalization are far broader than simply inquiries into whether a patient is ‘behind the wall’ . . . [but] touch on virtually every aspect of interpersonal interaction.” Perlin, *supra* note 115, at 255. As previously noted, in drawing this analogy between the isolation resulting from guardianship and the isolation caused by institutionalization, there is no intent to minimize the physical isolation and stigmatization of institutionalization, nor to ignore the well-documented reality that living conditions in institutions are generally much worse than the basic living conditions of those individuals with guardians who are living in the community. *See supra* Part I.A.1 and text accompanying note 35. *See generally* Michael L. Perlin, *International Human Rights Law and the Comparative Mental Disability Law: The Universal Factors*, 34 SYRACUSE J. INT’L L. & COM. 333, 335–36 (2007) (discussing abusive institutional conditions in other countries and noting severe institutional conditions in this country as recently as the early 1980s).

manner, and will this re-conceptualization lead to a model that is more respectful of autonomy and self-determination?

As to the first question, it does not seem inappropriate to try to extend *Olmstead* beyond the context of deinstitutionalization and the creation of community-based services needed to make deinstitutionalization a reality. Clearly, deinstitutionalization and the creation of community-based services is a priority. We still have far to go until those who neither need nor want to be in institutions have been moved to the community; and much work remains to be done to expand or improve the basic community treatment, living, and work options available to individuals with mental disabilities.¹²⁶ Extending the *Olmstead* precedent should not detract from current efforts at deinstitutionalization and the expansion of community-based services, but should be an integral part of those efforts. Moreover, an extension of *Olmstead* would lead to enhanced opportunities for persons with disabilities and greater respect for the inherent dignity of all persons, not least those with diminished mental capabilities.¹²⁷ For, even assuming that we as a society were fully committed to maintaining virtually all individuals with disabilities in their chosen communities and ensuring that they have the ability to meet at least their basic needs, we fall short if we do not also maximize their ability to make decisions for themselves. The legal standards we utilize for determining decision-making “capacity” and the way we provide assistance to those with limitations in decision-making ability, influence the way our society conceives of mental disabilities and the social obligation to fully integrate all people with disabilities into mainstream communal life.

As to the second question, there are at least two benefits of re-conceptualizing guardianship as a form of disability-based discrimination. First, and perhaps principally, the integration mandate and the ADA’s requirement to make necessary program modifications to avoid discrimination provide a theoretical framework for requiring states to provide options to support individuals with the exercise of their capacity outside of a guardianship system. The possibility of required program mod-

126. See, e.g., *Five Years After Olmstead*, *supra* note 9, at 561 n.5.

127. See Stanley S. Herr, *Self Determination, Autonomy, and Alternatives for Guardianship*, in *THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES* 429, 447 (Stanley S. Herr et al. eds., 2003) (“As cases such as the U.S. Supreme Court’s *Olmstead v. L.C.* decision fuel the drive for deinstitutionalization, and consumers face the prospect of more self-determined personal decisions and options, the urgency of reform is ever more apparent.”).

ifications to address the discriminatory isolation of guardianship could spur more immediate state action than has been achieved by guardianship reforms to date.

Second, the re-conceptualization could alter the way society views its obligation to persons with diminished decision-making capacity. When, as now, guardianship is viewed as a process that seeks to determine whether a person is able to make decisions on his or her own or needs someone else to make decisions *for* him or her, the inquiry focuses on whether the State should or should not divest the person of the right to make decisions.¹²⁸ However, if guardianship is seen as a mechanism that serves to isolate a person from the opportunity for crucial social, medical, legal, and financial interactions, then the inquiry might focus on ways of reducing the individual's isolation by enabling him or her to more actively participate in the decision-making process.¹²⁹ As a result, the extension of the integration mandate to the guardianship context could require states to engage in a continuing process of increasing the available options for providing support with decision making.

III. GUARDIANSHIP PRESUMPTIVELY VIOLATES TITLE II OF THE ADA

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 been appointed or who is at risk of losing his or her right to make decisions is a "qualified individual with a disability" under the ADA; 2) the "guardianship system" 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.¹³⁰ After establishing in this Part that the provision of

128. See Dhanda, *supra* note 30, at 457–58 (discussing the foundational role of legal capacity and distinguishing our current guardianship system and its selective recognition of capacity from a system that recognizes universal capacity with individual differences in ability to exercise that capacity).

129. See *supra* notes 54–55 (discussing state statutory provisions that call for the ward's participation in the decision-making process and explaining how the extent of the ward's involvement remains largely a matter of the guardian's discretion).

130. *Duvall v. County of Kitsap*, 260 F.3d 1124, 1135 (9th Cir. 2001) (citing 42 U.S.C. § 12132). See generally LaCheen, *supra* note 92, at 37–54, 70–88, 91–94,

guardianship, rather than supported decision making, can constitute a prima facie claim of disability discrimination, it will be crucial to determine in the next Part what remedy might be required by the ADA to address the unlawful discrimination inherent in the guardianship system.¹³¹

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

An ADA Title II claim might be brought by an individual who wished to challenge an existing or proposed guardianship or by an individual who needed services to assist with decision making in order to avoid appointment of a guardian. The question is therefore whether such an individual would meet the definition of a “qualified individual with a disability” within the meaning of the ADA.

The ADA defines an individual with a disability as a person with “a physical or mental impairment that substantially limits one or more major life activities.”¹³² Thus, in determining whether an individual would be covered under the Act, it is necessary to consider whether the individual’s impairment limits her performance of a “major life activity,” and whether the resulting limitation is appropriately deemed to be “substantial.”¹³³

After a series of Supreme Court decisions significantly narrowed the scope of the “disability” definition under the ADA,¹³⁴ Congress passed the ADA Amendments Act and clari-

95–115 (providing comprehensive discussion of then-current ADA Title II jurisprudence).

131. See discussion *infra* Part IV.

132. See 42 U.S.C. § 12102(2)(A) (2006). While an individual with a “record of” a disabling impairment or who is “regarded as having” a disabling impairment, would qualify as a disabled individual under 42 U.S.C. §§ 12102(1)(B) or (C), such a person would not need either a guardian or supported decision-making assistance.

133. See § 12102(2)(A).

134. First, the Supreme Court began considering the ameliorative impact of any mitigating measures used by the individual to compensate for the impairment in determining whether the individual was substantially limited in a major life activity. See *Albertson’s Inc. v. Kirkingburg*, 527 U.S. 555, 563–67 (1999) (unconscious compensation for monocular vision caused by amblyopia); *Murphy v. UPS*, 527 U.S. 516, 518–521 (1999) (mechanic who controlled high blood pressure with medication). Second, the Court began to require the plaintiff to establish that his or her impairment restricted the ability to function across a wide range of activities. See *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184, 197–98 (2002) (woman with carpal tunnel syndrome, myotendonitis, and thoracic outlet compression was not substantially limited in a major life activity because she was

fied the legislative intent to provide broad coverage under the law.¹³⁵ Congress made clear that “the question of whether an individual’s impairment is a disability under the ADA should not demand extensive analysis.”¹³⁶

In light of these amendments, individuals with diminished mental abilities needing decision-making assistance should be able to establish that they are “substantially limited” in the ability to perform a “major life activity.” These individuals would likely be restricted in at least one of the major life activities now identified in the ADA Amendments Act such as caring for oneself, learning, reading, concentrating, thinking, or communicating.¹³⁷ 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 major life activity.¹³⁸ Consequently, individuals needing some assis-

restricted in some, but not all, manual tasks). Third, the Court applied an extremely strict standard under the “regarded as” prong of the disability definition. *See Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 493–94 (1999) (finding employer regarded plaintiff as ineligible for single job as commercial pilot, not for a “broad range of jobs”). These rulings allowed for the absurd result that individuals who were able to work despite their impairments, but were terminated from or denied employment *because of* their impairments, might not be “disabled” under the ADA. *See generally id.* at 482–89.

135. *See* ADA Amendments Act, Pub. L. No. 110-325, § 2, 122 Stat. 3553, 3553–55 (2009) (reinforcing congressional intent to provide broad coverage under the ADA, and explicitly rejecting several aspects of the Supreme Court’s decisions).

136. *Id.* § 2(b)(5) (2009).

137. *See id.* § 4(a) (2009) (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.” *See* 28 C.F.R. § 35.104 (2008) (providing a slightly less comprehensive, non-exclusive list of “major life activities”).

138. *See* ADA Amendments Act, Pub. L. No. 110-325, § 2(a)(8), 122 Stat. 3553, 3554 (2009) (noting that “substantially limit[ed]” should not be read as “significantly restricted”); *id.* § 2(b)(1) at 3554 (expressing congressional intent to reinstate “a broad scope of protection” under the ADA); *id.* § 4(a)(4)(A)–(B) at 3555 (noting congressional intent to provide broad coverage under the Act and to interpret the “substantially limit[ed]” standard “consistent with the findings and purposes of the ADA Amendments Act”). The ADA Amendments Act further clarifies that an impairment is a “disability” if: 1) it “substantially limits” the performance of one major life activity, even if the individual is able to perform all other activities; 2) it is episodic or in remission but “would substantially limit a major life activity when active;” or 3) it “substantially limits” a major life activity without consideration of the ameliorative effects of mitigating measures (except for those of ordinary eyeglasses or contact lenses). *Id.* § 4(a)(4)(C)–(E) at 3556.

tance with decision making due to a limitation in mental or neurological functioning should be able to establish that they are “individuals with disabilities” within the meaning of the ADA.

The next step in the legal analysis is to demonstrate that an individual with diminished decision-making abilities is a “qualified individual with a disability,” more specifically, “an individual with a disability who, with or without reasonable modifications to rules, policies, or practices . . . meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”¹³⁹ Courts have liberally interpreted the standard for demonstrating that one “meets the essential eligibility requirements” of the program or service at issue.¹⁴⁰ In the context of institutionalization, to which this Article seeks to draw an analogy, the courts have determined that an individual is a “qualified individual with a disability” for purposes of an integration mandate challenge where the treating professional has determined that the individual can safely reside in the community with appropriate care and services.¹⁴¹ In *Olmstead*, the Court determined that there was “no dispute” that the plaintiffs were “qualified individuals with disabilities” because the state’s own professionals had determined that the plaintiffs were eligible for treatment in the community—assuming appropriate services were available and the plaintiffs were not opposed to such care.¹⁴² While the Court concluded that the

139. 42 U.S.C. § 12131(2) (2006) (emphasis added). The “essential eligibility requirements” can be quite minimal. See 28 C.F.R. pt. 35, app. A, subpart A (2008) (defining “qualified individual with a disability,” and explaining in a cited example of a public entity service providing information about governmental operations that the only “essential eligibility requirement” is to make a request for information).

140. See, e.g., *McGary v. City of Portland*, 386 F.3d 1259, 1264–70 (9th Cir. 2004) (man with AIDS needing additional time to clean yard in order to comply with city’s nuisance abatement law was a qualified individual with a disability who could assert ADA claim); *Williams v. Wasserman*, 164 F. Supp. 2d 591, 629–30 (D. Md. 2001) (in deinstitutionalization litigation, the fact that existing community placements often were not sufficient to meet the plaintiffs’ needs did not negate plaintiffs’ status as “qualified individuals with disabilities”).

141. See, e.g., *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999).

142. *Id.* at 589, 593–94, 602–03. For this reason, plaintiffs in deinstitutionalization cases may be able to establish that they are “qualified individuals with disabilities” based on a determination by a state medical professional that they can be appropriately treated in the community. However, in some cases, a medical professional employed by the state in an institutional setting might resist deinstitutionalization, making her judgment of questionable value. Several scholars are critical of the *Olmstead* Court’s reliance on the judgments of state professionals in

state could rely on the “reasonable assessments of its own professionals” in determining an individual’s suitability for community treatment, the Court did not answer the question of how to determine whether the assessments of the state professionals are “reasonable” in any given case.¹⁴³

In integration mandate cases decided after *Olmstead*, many courts have liberally construed the “qualified individual with a disability” standard to find that the plaintiffs have met the “essential eligibility requirements” of the service, program, or activity in question.¹⁴⁴ 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 an independent professional.¹⁴⁵ In the guardianship con-

determining eligibility for community treatment. *See, e.g.*, Perlin, *supra* note 98, at 1140–41 (implicitly criticizing the Court’s reliance on the judgments of state professionals in determining eligibility for community treatment); Rosenthal & Kanter, *supra* note 72, at 320–21, 320 n.46. *See also* Frederick L. v. Dep’t of Pub. Welfare, 157 F. Supp. 2d 509, 539–41 (E.D. Pa. 2001) (noting that professional assessment under *Olmstead* must be based on the individual’s needs rather than the medical professional’s determination that there is no available community placement).

143. *See Olmstead*, 527 U.S. at 602–03. In *Wasserman*, 164 F. Supp. 2d at 629, the court found that the plaintiffs were “otherwise qualified” for community-based treatment based on the recommendations of treating professionals and the plaintiffs’ eventually successful community placements.

144. *See, e.g.*, *Sanchez v. Johnson*, 416 F.3d 1051, 1062 (9th Cir. 2005) (finding individuals with disabilities who were living in, or at risk of living in, state institutions and seeking community-based services were “qualified individuals” under the ADA); *Townsend v. Quasim*, 328 F.3d 511, 516 (9th Cir. 2003) (finding plaintiff was a “qualified individual with a disability” who could challenge the lack of community-based long-term-care services under the medically needy Medicaid program because he was eligible to receive other services through the state’s Medicaid program); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 612–13 (7th Cir. 2004) (finding plaintiff was a “qualified individual with a disability” for purposes of challenging the state’s failure to provide private duty nursing services in the home under its community-based Medicaid waiver program because he was eligible for Medicaid, had severe, long-term disabilities, was at risk of institutionalization, and had demonstrated his ability to safely live at home *with appropriate supportive nursing services*); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 n.7 (10th Cir. 2003) (finding no dispute as to whether community placement is appropriate for the plaintiffs who were successfully living in the community and receiving Medicaid waiver services).

145. *See Frederick L.*, 157 F. Supp. 2d at 540 (concluding that “a treatment professional” must determine that an individual can be cared for appropriately in the community) (emphasis added); *Kathleen S. v. Dep’t of Pub. Welfare*, 10 F. Supp. 2d 460, 474 (E.D. Pa. 1998) (in a dispute between parties over whether the residents of a state psychiatric facility could be appropriately treated in the community, the court ordered independent psychological evaluations by a psychiatrist or psychologist acceptable to both plaintiffs and the state agency, with the cost of the evaluations to be borne by the state); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 290–91 (E.D.N.Y. 2008) (concluding that an individual’s treating physician may

text, there could be some exceptional circumstances where a person with diminished decision-making abilities would be so severely impaired that she could not meaningfully participate in any decision making, even with assistance. Such an individual might require the assistance of a substituted decision maker and would not meet the essential eligibility requirements of a supported decision-making program. However, in many cases, if not most, individuals with impairments affecting decision-making abilities would be able to participate in the decision-making process with appropriate assistance, and should therefore be considered “qualified” individuals with disabilities within the meaning of the ADA.¹⁴⁶

B. Guardianship is a State “Service, Program, or Activity”

The next question that must be answered is whether “guardianship” is properly regarded as a public “service, program, or activity” within the meaning of the ADA. In *Olmstead*, the plaintiffs challenged the clear state activity of providing care and treatment to persons with mental illness in state facilities. Plaintiffs in subsequent integration mandate cases have challenged both state institutional services and community-based services provided under the state’s medical assistance, mental health, or developmental disabilities programs.¹⁴⁷ In the guardianship context, a “public guardianship program” directly administered or funded by the state presents a similarly identifiable public “service, program, or activity.”¹⁴⁸

In the vast majority of guardianships, however, the state creates the legal construct, appoints the guardian, and monitors the relationship. Yet, the state neither funds nor directly provides guardianship services; rather, the court appoints a private individual to provide those services, and most costs are

determine whether the individual’s needs can be met in a more integrated setting); *Martin v. Taft*, 222 F. Supp. 2d 940, 972 n.25 (S.D. Ohio 2002) (giving due deference to the reasonable assessment of the state’s own professionals as to plaintiffs’ suitability for community placement, unless plaintiffs demonstrate that those assessments are “manifestly unreasonable”). See also Rosenthal & Kanter, *supra* note 72, at 402.

146. One of the challenges in the development of comprehensive programs to provide decision-making support will be to educate relevant professionals about the ability of individuals with impairments in decision-making capabilities to make decisions with appropriate support.

147. See generally cases cited *supra* notes 144–145.

148. See generally Teaster et. al, *supra* note 51, at 201 (defining public guardianship programs).

paid from the ward's estate. Although the public "service, program, or activity" at issue in the context of private guardianship may not be as obvious as the "services" at issue in *Olmstead* and its progeny, it is still identifiable.¹⁴⁹

In the context of the private guardianship appointment, the state exercises its authority as *parens patriae* to "protect" an individual with "diminished capacity" by entering a court order that divests the individual of crucial decision-making rights and appoints a surrogate to make decisions for the individual. Thus, the relevant state "program or activity" could either be characterized as "the state program established to assist individuals incapable of making decisions and managing their affairs" or "the statutorily created transfer of decision-making rights to a guardian which is then legally recognized by third parties." In this way, the state's guardianship program and the divestiture of individual decision-making authority can be appropriately viewed as a state "program or activity" within the meaning of the ADA.

This position is supported by numerous court decisions as well as the conclusions of the Attorney General. The Supreme Court has determined that Title II covers all programs, services, and activities of governmental entities "*without* any exception,"¹⁵⁰ and courts have been unwilling to carve out "spheres in which public entities may discriminate on the basis of an individual's disability."¹⁵¹ The Attorney General has similarly

149. *But cf.* *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1292 (11th Cir. 2005) (finding a court-appointed guardian is not a public entity under Title II of the ADA). In contrast to the situation in *Schiavo*, where an ADA claim was brought to challenge the actions of a private guardian, in the scenario contemplated by this Article, the ADA claim would be brought against the state to challenge the application of the state's guardianship law or the failure of the state to provide alternative forms of assistance with decision making.

150. *See* *Pa. Dep't of Corr. v. Yeskey*, 524 U.S. 206, 209–10 (1998) (noting that the ADA covers all state activities including the administration of state prisons, and includes "services" provided "involuntarily" to prisoners and pre-trial detainees) (emphasis in original).

151. *McGary v. City of Portland*, 386 F.3d 1259, 1268–69 (9th Cir. 2004) (citations omitted) (noting that the ADA covers municipal code enforcement activities even though compliance is compelled rather than voluntary). *See also, e.g.,* *Oconomowoc Residential Programs, Inc. v. City of Milwaukee*, 300 F.3d 775, 782 (7th Cir. 2002) (citation omitted) (noting that the ADA regulations provide that "[T]itle II applies to anything a public entity does"). This language in Title II's anti-discrimination provision should be seen as "a catch-all phrase that prohibits all discrimination by a public entity, regardless of the context, and that should avoid the very type of hair-splitting arguments the [government] attempts to make here." *Innovative Health Sys., Inc. v. City of White Plains*, 117 F.3d 37, 44–45 (2d Cir. 1997), *superseded by statute* 42 U.S.C. § 12188(a) (2006). *See also* Thompson

concluded that the ADA is intended to address a broad range of governmental activities in order to eliminate disability-based discrimination.¹⁵² The ADA cases, therefore, broadly construe those activities deemed to be covered “services, programs, and activities,” and provide appropriate analogues to the guardianship context.¹⁵³

The Second Circuit’s analysis of the “state activity” involved in the power of attorney context provides a compelling analogy to the guardianship context.¹⁵⁴ In *Hargrave*, plaintiffs brought an ADA action challenging an amendment to state law that permitted the override of validly executed durable powers of attorney upon the civil commitment of persons with mental illness. The Second Circuit endorsed the district court’s unchallenged determination that the relevant state program or activity was properly characterized as “ ‘the statutorily created opportunity to execute a [durable power of attorney] for health care and the right to have it recognized and followed.’ ”¹⁵⁵ In

v. Davis, 295 F.3d 890, 896–99 (9th Cir. 2002) (finding that “substantive decision-making process” of parole proceedings constitutes a public entity activity within the ADA’s reach and rejecting defendants’ argument that the ADA applies “only to logistical matters of prison administration, including access to parole hearings, but not to substantive decision-making processes”).

152. See 28 C.F.R. pt. 35, app. A, subpart A (2008) (“[T]itle II applies to anything a public entity does,” and applies to all governmental activities of executive agencies, as well as those of the legislative and judicial branches of state and local governments, “even if they are carried out by contractors.”); 28 C.F.R. § 42.540(j) (2008) (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”).

153. Courts have found that the ADA reaches discrimination in the context of state laws that regulate private conduct, such as zoning regulations and local code enforcement activities. See, e.g., *Wis. Cmty. Servs. v. City of Milwaukee*, 465 F.3d 737, 750 (7th Cir. 2006) (en banc) (municipal zoning is a “program” or “service” and enforcement of zoning rules is an “activity” within the meaning of ADA); *Innovative Health Sys., Inc.*, 117 F.3d at 44–45 (same); *McGary*, 386 F.3d at 1268–70 (citing 28 C.F.R. § 42.540(j) and DEPARTMENT OF JUSTICE, THE AMERICAN WITH DISABILITIES ACT: TITLE II TECHNICAL ASSISTANCE MANUAL § II-3.6100, illus. 1 (1993) (TA Manual), and concluding that city nuisance abatement law and related code enforcement activity is a public “benefit, program, or activity” within the meaning of the ADA).

154. *Hargrave v. Vermont*, 340 F.3d 27, 37–38 (2d Cir. 2003).

155. See *id.* at 38 (quoting *Hargrave v. State of Vermont*, No. 2:99-CV-128, at *23 (D. Vt. Oct. 11, 2001)) (emphasis omitted) (affirming district court injunction against the implementation and enforcement of the amendment). Although the *Hargrave* court acknowledged that there was no dispute as to the “relevant service, program, or activity” for purposes of the ADA claim, the court states in dicta without explanation that “the specific language of [28 C.F.R.] section 35.130(b)(7) makes clear that the ‘service, program, or activity’ at issue is neither Vermont’s entire civil commitment program nor the specific procedures set forth in [Vermont’s durable power of attorney override law], but rather Vermont’s program of

the same vein, guardianship may be characterized as a “statutorily created” assignment of decision-making rights to a guardian which is then “recognized and followed” by third parties. In both the power of attorney and private guardianship contexts, the state does not itself act as the “attorney” or guardian, but instead creates a legally cognizable relationship pursuant to which one person is given the authority to make certain decisions for another person—the principal or “incapacitated person.”¹⁵⁶

A further analogy can be drawn to other cases where courts have been willing to find a state “service, program, or activity” subject to the ADA when the “state uses private entities to deliver services to people with disabilities.”¹⁵⁷ For example, in *Disability Advocates, Inc. v. Paterson*, a challenge to the state’s placement of thousands of individuals with mental illness in adult homes, the state argued that no state “service, program, or activity” could be identified for ADA Title II purposes where the adult homes are privately operated and the state’s only involvement was in licensure and inspection of those facilities.¹⁵⁸ The court correctly determined that the plaintiffs were not challenging the conduct of any particular

permitting its citizens to execute” durable powers of attorney. *Id.* The language of section 35.130(b)(7), however, does not provide the clarity suggested by the court. This assertion also conflicts with the significant authority concluding that the ADA reaches an extremely broad scope of governmental activities. *See supra*, notes 150–51. Nevertheless, the *Hargrave* court’s description and recognition of the “service, program, or activity” involved in that case and the parallels between the power of attorney and guardianship contexts, support the conclusion that guardianship is a “service, program, or activity” under the ADA.

156. Although there have been ADA challenges in the guardianship context, to the author’s knowledge, those cases have not challenged the institution of guardianship. Rather, they have challenged the legal ramifications of guardianship under particular state laws, such as the inability to vote. The courts in those cases have viewed the relevant state program or activity as voting, marrying, etc. *See, e.g.*, *Mo. Prot. & Advocacy Servs. v. Carnahan*, 499 F.3d 803, 812 (8th Cir. 2007) (finding in challenge to voting laws that disenfranchise individuals with “full guardianship” that state program or activity is that of “voting”); *Doe v. Rowe*, 156 F. Supp. 2d 35, 58–59 (D. Me. 2001) (ADA challenge to state constitutional provision that prohibits voting by persons “under guardianship by reason of mental illness” addresses discrimination within state activity of voting).

157. *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 316 (E.D.N.Y. 2009) (citing *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 601–02. (7th Cir. 2004) (Medicaid nursing services provided by hospital and home health agency)); *Martin v. Taft*, 222 F. Supp. 2d 940, 946, 981 (S.D. Ohio 2002) (Medicaid services provided in privately owned and operated group homes); *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 237 (D. Mass. 1999) (integration mandate claim brought by plaintiffs living in private rather than government-operated nursing facility).

158. *Disability Advocates, Inc.*, 598 F. Supp. 2d at 317–18.

adult home, but rather were challenging “the [s]tate’s choice to plan and administer its mental health services in a manner that results in thousands of individuals with mental illness living and receiving services in allegedly segregated settings.”¹⁵⁹ Similarly, the Title II challenge to guardianship proposed in this Article is not a challenge to the actions of a particular guardian, but is rather a general challenge to the state’s choice to plan and administer its program for providing assistance to individuals with limitations in decision-making abilities such that the individuals are assisted through the more restrictive guardianship mechanism.

The Supreme Court has determined that Title II of the ADA is intended to reach any state programs, activities, or benefits, without exception, and the lower courts have heeded this instruction. Courts have found that Title II reaches state statutes and ordinances that govern private conduct, state-administered programs involving services administered by private entities, as well as a state’s “statutorily created opportunity to execute a [durable power of attorney] for health care and the right to have it recognized and followed.”¹⁶⁰ Because the relevant state program or activity in the guardianship context can be characterized either as “the state program established to assist individuals incapable of making decisions and managing their affairs” or “the statutorily created transfer of decision-making rights to a guardian which is then legally recognized by third parties,” guardianship is properly characterized as a public entity “service, program or activity” within the meaning of the ADA.

159. *Id.* at 318. The court observed that this was a challenge to the state’s “administration” of its program to house individuals with mental illness, and determined that the state had created a statutory and regulatory framework and had made choices about the allocation of state resources for the funding of these housing services; these decisions could be challenged under the ADA to determine if they resulted in the unjustified segregation of individuals with disabilities. *Id.* at 317–19.

160. *See Hargrave*, 340 F.3d at 38 (quoting *Hargrave v. Vermont*, No. 2:99-CV-128, at *23 (D. Vt. Oct. 11, 2001) (emphasis omitted)).

C. The State's Provision of Decision-Making Assistance through the Guardianship Model Constitutes Disability-Based Discrimination under the ADA's Integration Mandate

Once a relevant class of individuals is deemed protected by the ADA and guardianship is properly viewed as a public “service, program, or activity” covered by Title II, the question 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. This next section will address the application of the integration mandate outside of the institutional context and will argue that the request for decision-making support is not a request for a new service that arguably goes beyond the scope of the ADA, but is simply a request that the decision-making assistance provided in guardianship be provided in a less restrictive manner. Such an argument is supported by the ADA’s preference for integrated services and treatment as a mechanism for maximizing the opportunities for persons with disabilities to interact with non-disabled individuals.

1. The Integration Mandate is Properly Applied Outside the Institutional Context

Since issuing its decision in *Olmstead*, the Supreme Court has not further delineated the scope or nature of the “unjustified isolation” that is impermissible under the ADA. Lower court decisions have uniformly followed *Olmstead* in concluding that unjustified isolation in institutions presumptively violates the ADA’s integration mandate.¹⁶¹ In the bulk of these cases, as in *Olmstead*, the courts have cited to the ADA’s preference for community-based treatment over institutionalization so that individuals with disabilities are able to interact with non-disabled persons to the fullest extent possible.¹⁶²

161. See, e.g., *Pa. Prot. & Advocacy, Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 379 (3d Cir. 2005); *Frederick L. v. Dep’t of Pub. Welfare of Pa.*, 422 F.3d 151, 156–57 (3d Cir. 2005); *Disability Advocates, Inc. v. Paterson*, 2009 U.S. Dist. LEXIS 80975, *116-119, *366 (E.D.N.Y. 2009); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 290 (E.D.N.Y. 2008); *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 337–38, 342 (D. Conn. 2008); *Williams v. Wasserman*, 164 F. Supp. 2d 591, 629–30 (D. Md. 2001).

162. See, e.g., *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 618 (9th Cir. 2005) (stating that one of the ADA’s purposes is “ending the isolation and segrega-

The analysis in the integration mandate cases involving individuals in institutions is fairly straightforward. The care and treatment services are being provided in the unquestionably isolating institutional setting, the individuals wish to move to the community, and a professional has determined that the institutionalized individuals could be appropriately treated with adequate services in a less restrictive community setting. Under the ADA, therefore, the state must provide these services in the more integrated community setting, unless a fundamental program alteration would be required.¹⁶³

As a general theoretical proposition, it makes sense to draw an analogy between the diminished opportunities for interactions with others resulting from institutional segregation and the diminished opportunities for interactions with others that results from the lost ability to manage one's personal and financial affairs as a result of guardianship. The question is whether the *Olmstead* precedent can legitimately be extended beyond the context of physical isolation in an institution or the risk of institutionalization.¹⁶⁴

Courts presented with integration mandate claims have not limited *Olmstead's* holding to challenges by institutiona-

tion of disabled persons"); *Pa. Prot. & Advocacy, Inc.*, 402 F.3d at 379; *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 364 F.3d 487, 491–92 (3d Cir. 2004); *Disability Advocates, Inc. v. Paterson*, 2009 U.S. Dist. LEXIS at *116–19 (observing that supported housing may provide greater opportunities for interactions with non-disabled persons than adult homes and thus may be a more integrated setting); *Messier*, 562 F. Supp. 2d at 320–21, 326; *Wasserman*, 164 F. Supp. 2d at 630; *Joseph S.*, 561 F. Supp. 2d at 292. See generally *Ligas ex rel. Foster v. Maram*, 478 F.3d 771, 773 (7th Cir. 2007) (noting ADA's preference for deinstitutionalization enables individuals with developmental disabilities to "live more fully integrated into society at large"); *Bruggeman ex rel. Bruggeman v. Blagojevich*, 324 F.3d 906, 913 (7th Cir. 2003) (noting purpose of integration mandate to prevent isolation or segregation of people with disabilities).

163. See *Olmstead*, 527 U.S. 581, 603; cases cited *supra* notes 161–62.

164. Based on anecdotal evidence, it might be possible to argue that guardianship increases the risk of institutionalization. For example, in the well-documented situation at the infamous Southbury Training School—a state institution housing persons with moderate, severe, or profound mental retardation—the court noted that there were "class members who had expressed a desire to be placed in the community and who had not been placed because their guardians withheld consent." *Messier*, 562 F. Supp. 2d at 327. See generally *Rein*, *supra* note 61, at 1871–72, 1871 n.256 (noting frequency with which "wards" are placed in institutional settings); U.N. Enable, Comments, Proposals and Amendments Submitted Electronically, <http://www.un.org/esa/socdev/enable/rights/ahcstata13fiscoment.htm#idc> (last visited Sept. 5, 2009) (concluding that "guardianship facilitates institutionalization"). For the reasons discussed below, it should not be legally necessary to establish a direct link between guardianship and frequency of institutionalization.

lized individuals seeking discharge to the community. Instead, they have extended *Olmstead's* reach to challenges by individuals living in the community who were seeking services needed to continue living in that integrated setting.¹⁶⁵ In some of these cases, courts have required the non-institutionalized plaintiffs to establish that they are actually at some demonstrable risk of institutionalization if the requested community-based services are not provided.¹⁶⁶ In a significant number of these cases, however, the courts have not required a showing of actual risk of institutionalization. Instead, the courts have focused on whether the state was failing to provide the same types of services in the community that it would provide to disabled residents in an institutional setting.¹⁶⁷

165. See, e.g., *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003) (“[T]here is nothing in the plain language of the regulations that limits protection to persons who are currently institutionalized . . . nothing in the *Olmstead* decision supports a conclusion that institutionalization is a prerequisite to enforcement of the ADA’s integration requirements.”). See generally *Disability Advocates, Inc. v. Paterson*, 2009 U.S. Dist. LEXIS at *115–19 (reviewing evidence and concluding that “community-based” adult homes do not constitute the “most integrated setting”). But cf. *Buchanan v. Maine*, 469 F.3d 158, 173 (1st Cir. 2006) (in case challenging adequacy of services provided after plaintiff’s discharge from state mental facility in which plaintiff did not raise an integration mandate claim, court noted in dicta that the case did not raise “the special category of claims about deinstitutionalization” because plaintiff was residing in a community setting) (citations omitted).

166. See, e.g., *Sanchez v. Johnson*, 416 F.3d 1051, 1053–54 (9th Cir. 2005) (class included individuals “at risk” of living in state institutions because of inadequate funding for community-based services). See generally *Colbert v. Blagojevich*, No. 07 C 4737, 2008 WL 4442597, at *2 (N.D. Ill. Sept. 29, 2008) (certifying a class of “all Medicaid-eligible adults with disabilities in Cook County, Illinois, who are being, or may in the future be, unnecessarily confined to nursing facilities and who, with appropriate supports and services, may be able to live in a community setting”). For a discussion of the applicability of the ADA’s integration mandate in cases involving individuals at risk of institutionalization, see *Five Years After Olmstead*, *supra* note 9, at 562–64. At least at one point in time, the federal government had concluded that *Olmstead* reaches individuals who are not currently institutionalized but who are at risk of institutionalization if adequate community-based services are not provided to them. See *id.* at 562–63 (detailing letter from Centers for Medicare and Medicaid Services).

167. See, e.g., *Fisher*, 335 F.3d at 1178, 1181–82 (concluding that plaintiffs need not demonstrate an actual risk of institutionalization, only whether they would need to enter a segregated setting to receive requested services); *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003) (concluding that plaintiffs can challenge denial of Medicaid long-term care in the community that was comparable to long-term care available in institutional setting); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 610–11 (7th Cir. 2004) (concluding that plaintiff could challenge denial of continuous private duty nursing services in community that were comparable, though not identical to, services that would be provided in institutional setting); *Michelle P. ex rel. Deisenroth v. Holsinger*, 356 F. Supp. 2d 763, 764, 769 (E.D. Ky. 2005) (finding that the *Olmstead* proscription is not limited to

Admittedly, the decisions applying the integration mandate in challenges by individuals who were not institutionalized tie the finding of discrimination to at least some possibility that the individual would be forced to enter an institutional setting to obtain necessary services. However, the language used in the ADA regarding Congress's intent to eradicate segregation is sweeping, and the language used by the courts has been expansive. The cases have often relied on *Olmstead's* language that "discrimination" may arise out of the fact that in order to receive necessary services, individuals with mental disabilities are forced to "relinquish participation in community life they could enjoy given reasonable accommodations."¹⁶⁸ As a result, *Olmstead* and subsequent integration mandate cases need not be read to require some connection, however tangential, to isolation in a physical institution as a requirement for bringing an integration mandate challenge. Rather, these cases can be read to go beyond the paradigm of physical isolation in an institution to support the general requirement of the integration mandate that public programs, services, and activities be provided in a manner that enables individuals with disabilities to interact with others to the greatest extent possible.¹⁶⁹ Thus, their holdings can be applied with equal force to the court-ordered, constructive isolation of guardianship.

the "unjustified placement or retention of persons in institutions" and applies to a challenge by a class of adults with mental disabilities living at home with aging caretakers who were waiting for appropriate community-based services) (quoting *Olmstead v. L.C. ex. rel. Zimring*, 527 U.S. 581, 596 (1999)); *Martin v. Taft*, 222 F. Supp. 2d 940, 946, 981 (S.D. Ohio 2002) (integration mandate claim could be asserted by individuals with developmental disabilities living in the community who needed long-term services that were only available in an institutional setting); *Makin ex rel. Russell v. Hawaii*, 114 F. Supp. 2d 1017, 1023, 1033-34 (D. Haw. 1999) (finding individuals with intellectual disabilities living at home on waiting list for limited community-based services are in same position as *Olmstead* plaintiffs because, although not currently institutionalized, they would be forced to enter institution to receive services under the Medicaid program).

While courts have recognized prima facie integration mandate claims in challenges brought by individuals living in the community, these plaintiffs may nevertheless have greater difficulty overcoming the state's fundamental alteration defense where the state can show that it is not currently expending any funds on these individuals and the cost of expanding community-based services could be significant. See *Five Years After Olmstead*, *supra* note 9, at 562-63.

168. See *Olmstead v. L.C. ex. rel. Zimring*, 527 U.S. 581, 601 (1999). See generally cases cited *supra* note 167.

169. See 28 C.F.R. pt. 35, app. A, subpart B, § 35.130 (2008).

2. The Request for Supported Decision-Making Assistance Is Not a Request for a New Service, but a Request that the Decision-Making Assistance Provided in Guardianship Be Provided in a Less Restrictive Manner

There is one additional theoretical hurdle to the assertion of a prima facie discrimination claim in the guardianship context, and it is perhaps the most challenging hurdle for the type of Title II claim contemplated by this Article. In *Olmstead*, the Court mentioned that while the ADA prohibited states from discriminating with regard to services that the state “in fact, provides,” states were not required to “provide a certain level of benefits to individuals with disabilities.”¹⁷⁰ As a result, courts analyzing Title II claims have considered whether plaintiffs raised claims relating to an existing public service or sought the creation of a “new service,” which would not be required under the ADA or *Olmstead*. It is necessary, therefore, to address whether a court should construe a request for supported decision making in lieu of guardianship as a request for the provision of existing services in a more integrated manner or as a request that the state create “new services or benefits.”

In *Rodriguez v. City of New York*, plaintiffs brought an ADA challenge to the failure of New York’s Medicaid personal care program to provide services needed to monitor the safety of persons with mental impairments living in the communi-

170. *Olmstead*, 527 U.S. at 603 n.14. The footnote was a response to Justice Thomas’s dissent in which he quotes from *Alexander v. Choate*, a decision that addressed a state’s obligation under Section 504 of the Rehabilitation Act to make a “reasonable modification” to a rule. *See id.* at 619 (Thomas, J., dissenting) (citing *Alexander v. Choate*, 469 U.S. 287, 304 (1985)). *Alexander v. Choate*, however, did not address a state’s obligation under the ADA to provide services in the most integrated setting. *See id.* Nevertheless, lower courts addressing ADA integration mandate claims continue to cite to this *Olmstead* footnote language. *See, e.g., Townsend*, 328 F.3d at 518–19 (noting that a state need not “guarantee that each recipient will receive that level of health care precisely tailored to his or her particular needs”) (quoting *Choate*, 469 U.S. at 303). The applicability of the *Choate* limitation to ADA cases generally, or to integration mandate claims specifically, can legitimately be questioned. *See generally* Leslie Pickering Francis & Anita Silvers, *Special Series on Health Care: Debilitating Alexander v. Choate: “Meaningful Access” to Health Care for People with Disabilities*, 35 *FORDHAM URB. L.J.* 447, 451–52 (2008) (noting that *Choate* decided the question of meaningful access to benefits through the lens of the Rehabilitation Act—a law designed principally to provide training and services to enable people with disabilities to qualify for the workforce—while the ADA is a civil rights act with a broader purpose, making the meaningful access analysis of *Choate* less appropriate for claims under Title II of the ADA).

ty.¹⁷¹ In a decision issued shortly after *Olmstead*, the Second Circuit determined that the ADA did not require the state to provide plaintiffs with a new service regardless of disability.¹⁷² A limited number of courts, the vast majority of which are in the Second Circuit, have relied on this aspect of *Rodriguez* to deny ADA Title II integration mandate claims.¹⁷³

171. *Rodriguez v. City of New York*, 197 F.3d 611, 613–14 (2d Cir. 1999).

172. *Id.* at 618–19. In reaching its decision, the Second Circuit cited to disability discrimination decisions that did not involve integration mandate challenges. *See id.* at 618 (citing *Choate*, 469 U.S. at 304 (noting that the Rehabilitation Act requires “evenhanded treatment,” but does not “guarantee equal results”) and *Doe v. Pfrommer*, 148 F.3d 73, 84 (2d Cir. 1998) (drawing distinction between the “substance of the services provided” and “illegal discrimination against the disabled”).

The *Rodriguez* plaintiffs contended that the elimination of “safety monitoring” services which had previously been provided to some of the plaintiffs would force them into institutions where they would receive the institutional equivalent of “safety monitoring.” *See Rodriguez v. DeBuono*, 44 F. Supp. 2d 601, 619–20 (S.D.N.Y. 1999). By narrowly construing the scope of the *Olmstead* decision, the circuit court in *Rodriguez* sidestepped the plaintiffs’ contention. The Second Circuit found that *Olmstead* did not require states to “provide disabled individuals with the opportunity to remain out of institutions,” and concluded that the Court was only determining “where,” not “whether,” Georgia would be required to provide services to the *Olmstead* plaintiffs. *Rodriguez*, 197 F. 3d at 619. *See Rosenthal & Kanter, supra* note 72, at 398–99 (discussing *Rodriguez*, 197 F.3d at 611, and concluding that “the *Rodriguez* analysis appears to rest on a dubious interpretation of *Olmstead*”).

173. *See, e.g., Leocata v. Leavitt*, 148 F. App’x 64, 65–66 (2d Cir. 2005), *aff’g, Leocata ex rel. Gilbride v. Wilson-Coker*, 343 F. Supp. 2d 144 (D. Conn. 2004) (summarily affirming district court decision that ADA does not require state to meet a disabled person’s particular needs by requiring Medicaid coverage of residential expenses at an assisted living facility as a means of avoiding Medicaid services in a more restrictive institutional setting, where state’s Medicaid program did not cover room and board in community-based settings); *M.K. ex rel. Mrs. K. v. Sergi*, 554 F. Supp. 2d 175, 198–99 (D. Conn. 2008) (deciding that states are not required by the ADA to provide disabled individuals with “a certain level of benefits” so that they can live in the community rather than in segregated residential institutions); *Davis v. Cal. Health & Human Serv. Agency*, No. C 00-CV-2532 SBA ADR, 2001 WL 1772763, at *1 (N.D. Cal. Aug. 21, 2001) (rare case outside the Second Circuit granting a motion to dismiss plaintiffs’ integration mandate claims to extent that they “are intended or may be interpreted as requiring San Francisco to create new programs or services”). *See Five Years After Olmstead, supra* note 9, at 576–77 (discussing settlement in *Davis* requiring assessment and discharge planning for nursing home residents and the provision of ongoing case management after discharge).

While the *Rodriguez* type of “existing services” limitation might be appropriate in a disparate treatment challenge, or even possibly one seeking a reasonable accommodation in order to access services, such reasoning makes much less sense in the context of an integration mandate challenge. *See Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 292 n.9 (E.D.N.Y. 2008) (distinguishing decisions such as those in *Rodriguez*, 197 F.3d at 618–19, *Henrietta D. v. Bloomberg*, 331 F.3d 261, 272–73 (2d Cir. 2003), *Pfrommer*, 148 F.3d at 81–83, and *CERCPAC v. Health & Hosps. Corp.*, 147 F.3d 165, 167–68 (2d Cir. 1998) on the grounds that those deci-

At the same time, a line of appellate decisions have rejected the “new services” defense in the context of integration mandate claims. In these cases, rather than looking at whether the state currently provides the precise community-based or integrated services requested by plaintiffs, the courts have taken a broader view of the integration mandate and have considered whether the plaintiffs were seeking services that were similar to those that the state *would* provide to them in a more restrictive, institutional setting.¹⁷⁴

In 2003, the Ninth and Tenth Circuits each addressed the question of whether the integration mandate required the state to provide certain community-based services to plaintiffs and whether the requested services should properly be seen as “new services” or as the integrated counterpart to the services the state was currently providing in an institutional setting. In *Fisher v. Oklahoma Health Care Authority*, plaintiffs with mental disabilities receiving Medicaid services under a community-based services waiver program¹⁷⁵ challenged a state

sions were interpreting the ADA’s reasonable accommodation and equal access requirements, not Title II’s integration mandate). In fact, courts have relied on the *Rodriguez* “new services” reasoning in cases challenging the public entity’s failure to provide reasonable accommodations needed to access government services or benefits. See, e.g., *Henrietta D.*, 331 F.3d at 279, 282–83 (2d Cir. 2003) (requiring a city to modify policies and provide reasonable accommodations to ensure disabled individuals’ access to existing government benefits, but not requiring a city to provide new substantive benefits not provided to non-disabled individuals); *Blatch ex rel. Clay v. Hernandez*, 360 F. Supp. 2d 595, 630–31, 635–36 (S.D.N.Y. 2005) (finding that the ADA does not require an agency to provide mentally disabled individuals with a legal representative prior to termination of tenancy proceedings as an accommodation—in part because the agency does not provide this type of assistance to persons without mental disabilities—but requiring other measures to ensure that persons with disabilities were not unfairly disadvantaged in the hearing process).

174. See, e.g., *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 609–11 (7th Cir. 2004); *Townsend*, 328 F.3d at 517; *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1175 (10th Cir. 2003); *Helen L. v. DiDario*, 46 F.3d 325, 333 (3rd Cir. 1995).

175. Under Medicaid law, a state can request that the federal government waive certain Medicaid requirements in order to create more innovative health care programs to serve individuals who would otherwise qualify for institutional care, including cost-effective home and community-based services, also known as “HCBS” or “waiver services.” See 42 U.S.C. § 1396n(b)–(i) (Supp. 2008); 42 C.F.R. § 430.25(d) (2008); 42 C.F.R. §§ 441.300–10 (2008); 42 C.F.R. §§ 441.350–65 (2008); 42 C.F.R. §§ 440.180–81 (2008); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 601 n.12 (1999). The federal government agrees to provide reimbursement for up to a certain number of HCBS waivers, though in many states demand exceeds availability, resulting in waiting lists of eligible individuals. See, e.g., *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 617 (9th Cir. 2005); *Makin ex rel. Russell v. Hawaii*, 114 F. Supp. 2d 1017, 1022 (D. Haw. 1999).

Medicaid policy that limited the prescription drug coverage for individuals living in the community at the same time that the general Medicaid program provided unlimited prescription drug coverage to individuals living in institutions.¹⁷⁶ The Tenth Circuit concluded that the integration mandate prohibited a policy that would require an individual to submit to institutionalization in order to obtain necessary medication.¹⁷⁷ Therefore, the state would be required to expand the services available under its waiver program to include unlimited prescription medications, unless it could establish a fundamental alteration defense.¹⁷⁸

In *Townsend v. Quasim*, the Ninth Circuit arguably took the conceptualization of an “existing service” one step further.¹⁷⁹ *Townsend* was a class-wide challenge to a state Medicaid waiver program that provided community-based long-term care services only to persons with very low incomes; Medicaid recipients with slightly higher incomes could only receive long-term care in institutional settings.¹⁸⁰ The state had argued, and the district court had agreed, that the plaintiffs were seeking the creation of a wholly new service of “long-term care in community-based settings” for medically needy individuals.¹⁸¹

The Ninth Circuit took a broader view of the services in question, characterizing them generally as long-term care services,¹⁸² rather than as the more narrowly defined package of services that the state provided under its Medicaid program for medically needy individuals.¹⁸³ Recognizing that the integration mandate would have little meaning if a state could charac-

176. *Fisher*, 335 F.3d at 1177–78.

177. *See id.* at 1182–83.

178. *Id.*

179. *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003).

180. The named plaintiff had been receiving long-term community-based waiver services as a “categorically needy” Medicaid beneficiary. When his income increased and he became eligible for Medicaid services as a “medically needy” individual, the state informed him that he was no longer eligible for community-based long-term care and would have to move to a nursing home to receive Medicaid covered long-term care. *Id.* at 513–14.

181. *Id.* at 515.

182. *Id.* at 517.

183. *See id.* at 515 (“Washington state does not provide community-based programs to the medically needy”) (citation omitted). The district court had determined that the state had properly exercised its discretion to design its Medicaid program for the medically needy and made a distinction in eligibility criteria that was based on income, not disability. Relying on *Rodriguez*, the district court had refused to require the state to develop and fund what the court deemed to be a new service program for medically needy disabled individuals.

terize a service based on the location in which it was provided, the court concluded that under *Olmstead*, a state's failure to provide the same long-term care services to medically needy individuals in the community as it would provide to them in an institutional setting constitutes disability-based discrimination under the integration mandate.¹⁸⁴ Accordingly, the state would have to expand its community-based waiver program to add the medically needy population unless such action would cause a fundamental program alteration.¹⁸⁵

In 2004, the Seventh Circuit addressed the question of whether the state violates the ADA integration mandate by failing to provide Medicaid-covered private-duty nursing services to adults living in the community.¹⁸⁶ In *Radaszewski*, an adult Medicaid recipient challenged the state's refusal to provide the extensive private duty nursing services he needed at home for his survival.¹⁸⁷ The district court dismissed the plaintiff's ADA claim because it concluded that he was seeking services that were not provided to anyone over the age of twenty-one under the state Medicaid program.¹⁸⁸

On appeal, the Court of Appeals reversed, finding a presumptive violation of the ADA's integration mandate in the state's failure to provide the plaintiff with twenty-four-hour nursing services in the community even though those services

184. *Id.* at 517–18.

185. *Id.* at 520. See *Makin ex rel. Russell v. Hawaii*, 114 F. Supp. 2d 1017, 1034 (D. Haw. 1999) (requiring expansion of waiver program unless the state could demonstrate a fundamental program alteration); *Martin v. Taft*, 222 F. Supp. 2d 940, 953–54, 971–73 (S.D. Ohio 2002) (allowing Title II integration mandate claim seeking expansion of available Medicaid HCBS waiver program to serve additional persons with disabilities). See generally *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 621 (9th Cir. 2005) (concluding that under particular circumstances court would not require state to expand its waiver program but noting “[w]e do not hold that the forced expansion of a state’s Medicaid waiver program can *never* be a reasonable modification required by the ADA”).

186. *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 600 (7th Cir. 2004).

187. *Id.* at 604–05. These nursing services had been provided to plaintiff in his youth under the state's Medicaid program for children. They were also available in limited amounts under a state waiver program. *Id.* at 608–09.

188. See *id.* at 606. The state's general Medicaid program at issue in *Radaszewski* had previously provided private-duty nursing services to individuals living in the community, but the state subsequently obtained federal approval to delete all references to private-duty nursing services in its State Medicaid Plan. *Id.* at 601, 606 n.4. While the Circuit's decision in *Radaszewski* may have been influenced by the fact that private-duty nursing had previously been provided under the state's general Medicaid program, see *id.* at 612, that is not the only reason for the court's conclusion that the requested services may not be “entirely new,” see *id.* at 610–12.

were not available under the state Medicaid program. The court observed:

Nothing in the regulations promulgated under the ADA . . . or in the Court’s decision in *Olmstead* conditions the viability of a Title II . . . claim on proof that the services a plaintiff wishes to receive in a community-integrated setting already exist in exactly the same form in the institutional setting. Although a State is not obliged to create entirely new services or to otherwise alter the substance of the care that it provides to Medicaid recipients in order to accommodate an individual’s desire to be cared for at home, the integration mandate may well require the State to make reasonable modifications to the form of existing services in order to adapt them to community-integrated settings . . . If variations in 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.¹⁸⁹

The court held that as long as the services being sought in the integrated setting were similar in substance to those provided in the institutional setting, the plaintiff could meet his prima facie burden under Title II, even though the service might “take on a different form or method if provided in a community setting.”¹⁹⁰

In large part, a court’s determination of whether or not a requested service in the community should be deemed to be a “new service” or simply a service already provided by the state in a more segregated setting generally turns on the court’s willingness to take a broad view of the substance of the services being requested and to view the content of those requested ser-

189. *Id.* at 611 (emphasis added). *See id.* at 609–11 (observing that Medicaid private duty nursing services at home appeared to be the functional equivalent of the constant monitoring and skilled assistance that state would be obligated to provide in an institutional setting).

190. *Id.* at 611–12. The court observed that while certain kinds of medical treatment such as prescription medications would be precisely the same whether provided in an institution or in the community, health-related services and treatment “might vary in format depending on whether it is provided to the individual in an institution or a community-based setting.” *Id.* at 611. The Court noted that the state would nevertheless have the opportunity to demonstrate that “adapting existing institution-based services to a community-based setting” would fundamentally alter its programs and services and would not be required by the ADA. *Id.* at 611.

vices at a “high level of generality.”¹⁹¹ If the court looks narrowly at the particular content of the community-based services sought by the plaintiff with a disability, the court is more likely to find that the plaintiff is seeking “new services” not currently provided by the public entity and not mandated by the ADA. For example, in *Rodriguez*, the court viewed the services at issue as safety monitoring under the personal care services program, rather than as the comparable custodial care and monitoring that would be provided in the more restrictive setting of a nursing home.¹⁹² As a result, the court concluded that the plaintiffs were seeking a “new service” and that the state did not discriminate by failing to provide a service that was not offered to anyone.¹⁹³

In contrast, in those cases where the court viewed the content of the services or benefits at issue at a higher level of generality, the court was more likely to conclude that the plaintiff was not requesting a “new” service, but simply a different, integrated form of the services being provided by the state in a more restrictive setting. In *Radaszewski*, for example, the court was willing to view the services at issue as the type of continuous monitoring and skilled assistance that the state would provide in an institutional setting—even if it would not be provided by a twenty-four-hour private-duty nurse—rather than as the more specific service of “private duty nursing ser-

191. See Bagenstos, *supra* note 28, at 45–50. Professor Bagenstos observes that the courts appear to have created an access/content distinction in their analysis of ADA claims seeking accommodations or program modifications but that the distinction is both false and inconsistent with the ADA’s goal of full integration. *Id.* at 3–10, 45–50. The distinction is false, Professor Bagenstos explains, because an analysis of relevant judicial opinions reveals that the particular court’s decision is often determined by whether it is willing to view the “content” of the benefit sought at a high or low “level of generality.” *Id.* at 45–50. For example, he argues that the different outcomes in *Choate* and *Olmstead* are not adequately explained by the access/content distinction but are instead largely explained by reference to the Court’s choice of “the level of generality at which to describe the ‘content’ of the relevant benefit.” *Id.* at 50. See also *id.* at 49–50 (noting that while the Court in *Olmstead* held that states could not discriminate with regard to “the services they in fact provide,” (citing *Olmstead*, 527 U.S. 581, 603 n. 14), the Court’s decision would potentially require the state to create community-based programs that did not already exist). In addition, he argues that courts undermine the purpose of the ADA by only requiring those accommodations that provide people with disabilities “access” to the same benefit received by non-disabled individuals, and refusing to require those accommodations that would alter the “content” of the benefit, even if the accommodation could be provided at reasonable cost and without undue hardship. *Id.* at 34–35, 37.

192. *Rodriguez*, 197 F.3d 611, 616–17 (2d Cir. 1999).

193. *Id.* at 618–19.

vices *at home*.”¹⁹⁴ Similarly, the *Fisher* court viewed the service at issue as the unlimited prescription medications the plaintiffs would receive if they resided in an institutional setting rather than as the more specific package of limited prescription benefits available under the state’s approved community-based waiver program.¹⁹⁵ In *Townsend*, the court viewed the service at issue as “long term care services” under the Medicaid program rather than as a request that the state create a “new” community-based waiver program for medically needy individuals.¹⁹⁶

The question of whether supported decision-making options would be deemed to be an integrated version of the decision-making assistance provided in guardianship or as a wholly “new service” will be critical in the guardianship context. This Article takes the position that a request for services to support an individual in decision making as an alternative to the substituted decision making that characterizes guardianship should not be construed as a request for “new services” for both factual and legal reasons. First, as a factual matter, most states have existing public guardianship programs that provide assistance with decision making in regard to personal affairs and property management, though generally in a more restrictive manner than supported decision-making models; there are also some limited, existing programs, such as intensive case management, protective counseling, and home-based support services that provide support with personal affairs and property management in ways that involve the individual with disabilities in the decision-making process, enabling him or her to remain more fully integrated in community life.¹⁹⁷ Hence, a

194. *Radaszewski*, 383 F.3d at 611 (emphasis added).

195. *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1178, 1181–82 (10th Cir. 2003).

196. *Townsend v. Quasim*, 328 F.3d 511, 515, 517.

197. Forty-eight states have some type of public guardianship program that provides a range of services to assist individuals with personal affairs and property management. See Teaster et al., *supra* note 51, at 201, 215–16.

There are also current service models or programs that, with some modification and expansion, could be tapped as alternatives to guardianship. For example, intensive case management programs funded by Medicaid or state Mental Health Services budgets provide some assistance with a range of personal and financial affairs to persons with chronic mental illness or developmental disabilities. See, e.g., 42 U.S.C. § 1396n(c)(5)(A) (2006) (waiver to provide habilitation services “to assist individuals [with limitations in intellectual functioning] in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings”); *Id.* at § 1396n(d)(4) (2006) (waiver to provide medical assistance to elderly individuals “for

straightforward argument could be made that the services currently provided in public guardianship programs should be provided in a more integrated manner and that existing programs and services providing assistance with personal affairs

case management services, homemaker or home health aide services and personal care services, adult day health services, respite care, and other medical and social services that can contribute to the health and well-being of individuals and their ability to reside in a community-based care setting”).

The best of these models function in a way that is similar to the supported decision-making model. They provide for the development of a trusting relationship between a trained social worker and the person with a disability that involves weekly personal visits to discuss and carry out personal and financial management decisions. *See, e.g.*, N.Y. COMP. CODES, R. & REGS. TIT. 14, Parts 506, 508; N.Y. COMP. CODES, R. & REGS. TIT. 18, § 505.16 (2008), available at <http://www.nyc.gov/html/doh/html/dmh/oas.shtml> (scroll down to “Case Management and Assertive Community Treatment Services”) (explaining that program provides individually-tailored, supportive case management service for persons enrolled in community mental health programs that includes: “1) the facilitation of service delivery, including helping individuals make and keep appointments, escorting individuals to appointments as needed, [and arranging health services]; 2) advocating and assisting individuals to gain access to entitlement[s] . . . ; 3) assisting consumers to learn how to use fiscal resources; and, 4) providing health promotion services or arranging for medication education that will help the consumer to understand the importance of taking prescribed medication”); Disability Advocates, Inc., No. 03-CV-3209, 2009 U.S. Dist. LEXIS 80975, at *105–07 (E.D.N.Y. Sept. 8, 2009) (discussing the intensive case management services provided by the Assertive Community Treatment program).

Governmental social services agencies also provide some less formal assistance with personal affairs. They also can provide financial assistance outside the guardianship context, usually as a representative or protective payee. While these latter services sometimes serve as informal alternatives to guardianship, the involvement of the person with a disability in the decision-making process is often quite minimal.

This is not to suggest that the answer to the problem presented by this Article is to replace the current guardianship system with large public agencies that will provide less formal alternatives to guardianship or to simply expand current protective services, which often simply provide financial management services with little control exercised by the individual with the disability. The development of real alternatives will require commitment and creativity. As one scholar has noted in a related context:

If public guardianship is part of the answer to the problem of serving masses of unprotected older Americans in the twenty-first century, then one safeguard should be to vest the power and control of such agencies in private nonprofit organizations that may only serve small numbers of people in small geographic areas. Additionally, the models and the operations should be grass-roots, driven from the bottom up. There is no need for top-heavy administration through state agencies that are too expensive and politically driven. The money and the process should be decentralized, with umbrella oversight for quality assurance in the form of human rights committees.

Johns, *supra* note 58, at 81; *see id.* at 82–87 (discussing some innovative efforts to provide personal and property management services through less restrictive models such as protective counseling and home-based support services).

and property management outside guardianship should be expanded.

Second, the cases cited above 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 programs currently provided within the guardianship construct.¹⁹⁸ The purpose of the ADA and the language of the integration mandate certainly suggest that the mandate should be liberally construed to achieve the true integration of people with disabilities. Consequently, when a court is addressing an integration mandate challenge, it is appropriate and consistent with the remedial purpose of the ADA for the court to consider whether the services sought by the plaintiffs are essentially an integrated form of the services that the state is already providing in a more restrictive setting, rather than to narrowly consider whether the state is already providing the precise service the plaintiffs are seeking in the more integrated setting. If the integration mandate were limited to requiring an expansion of only those specific services the state has already chosen to provide, the mandate would be quite limited, if not relatively meaningless. The integration mandate must mean more than that, especially in the Title II context.

This Article seeks the development of comprehensive state programs of supported decision-making services that may require legislative reform, and it seeks to rely on the integration mandate to force states to do so. As a result, the “new services” reasoning creates a certain analytical challenge to the position taken in this Article. 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 persons living in institutions to move into the community or to enable persons living in the community to continue doing so. 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 assis-

198. See, e.g., *Fisher*, 335 F.3d at 1178, 1181–82.

tance with decision making in the most integrated manner appropriate to the individual's needs, unless doing so would fundamentally alter the relevant state program.

IV. LESS RESTRICTIVE ALTERNATIVES TO GUARDIANSHIP WILL NOT FUNDAMENTALLY ALTER STATE PROGRAMS

Assuming then, that an individual with a limited ability to make decisions can state a prima facie claim of disability-based discrimination based on the state's failure to provide appropriate decision-making support in lieu of guardianship, this Part seeks to answer the question of whether, and to what extent, the state might be required to modify its existing program to avoid the unjustified isolation resulting from guardianship.¹⁹⁹ The goal of the argument presented in this Article is to encourage the creation of a range of effective mechanisms for supported decision making as alternatives to guardianship. However, while a public entity is required to make reasonable modifications to avoid the segregation of persons with disabilities, the entity is relieved of that obligation if it can show that such modifications would fundamentally alter the nature of the state's service, program, or activity.²⁰⁰ Thus, it is crucial to

199. Because the type of ADA Title II challenge against a state actor contemplated by this Article would most likely seek prospective injunctive relief, it seems fairly clear that under the doctrine of *Ex parte Young*, 209 U.S. 123 (1908), the Eleventh Amendment would not bar such an action. See *Bd. of Trs. of the Univ. of Ala. v. Garrett*, 531 U.S. 356, 374 n.9 (2001) (suggesting, in dicta, that the Eleventh Amendment does not bar ADA Title II claims seeking prospective injunctive relief); *Henrietta D. v. Bloomberg*, 331 F.3d 261 (2d Cir. 2003) (granting prospective injunction against state official in a Title II action); *Martin v. Taft*, 222 F. Supp. 2d 940, 957–64 (S.D. Ohio 2002) (concluding that an integration mandate claim seeking development of community-based care and treatment options for individuals with mental disabilities is not barred by the Eleventh Amendment). Whether the Eleventh Amendment would bar an ADA Title II claim for damages requires a more complicated analysis that is beyond the scope of this Article. See *Tennessee v. Lane*, 541 U.S. 509, 518, 523–24, 530–32 (2004) (requiring a claim-by-claim analysis to determine whether the challenged conduct comes within Congress's Fourteenth Amendment "prophylactic enforcement powers;" i.e., whether the Congressional action is "congruent and proportional" to the evil Congress sought to prevent or remedy); *United States v. Georgia*, 546 U.S. 151 (2006). In addition, Congress may have power under the Spending Clause to address disability discrimination in a state program that receives federal funds. See *Lovell v. Chandler*, 303 F.3d 1039, 1051 (9th Cir. 2002); *Jim C. v. United States*, 235 F.3d 1079, 1082 (8th Cir. 2000) (en banc).

200. Just as Title II defendants argue that a plaintiff cannot state a prima facie claim of disability discrimination because he or she is seeking the creation of some entirely new service, Title II defendants also raise this argument in conjunction with their fundamental alteration defense, arguing that the creation of the

understand how the courts have interpreted the scope of the fundamental alteration defense in order to determine how far a state might be required to go to avoid the unjustified isolation of substituted decision making.²⁰¹

In general, the determination of whether a proposed program modification is deemed “reasonable” or one that would result in a “fundamental program alteration” will necessarily turn on the specific relief requested, the state’s past and ongo-

program or type of service sought by the plaintiff will, by definition, require a fundamental program alteration. While, analytically this argument is more appropriately raised in the context of the fundamental alteration defense than in the context of the prima facie discrimination claim, courts have rejected the argument in both contexts for similar reasons. *See, e.g.,* *Townsend v. Quasim*, 328 F.3d 511, 516–19 (9th Cir. 2003) (while recognizing that a state need not “create new programs that provide heretofore unprovided services to assist disabled persons,” the court nevertheless concluded that “policy choices that isolate the disabled cannot be upheld solely because offering integrated services would change the segregated way in which existing services are provided Such a broad reading of fundamental alteration regulation would render the protection against isolation of the disabled substanceless”). *See also* *Pa. Protection & Advocacy, Inc. v. Pa. Dep’t of Pub. Welfare*, 402 F.3d 374, 381 (3d Cir. 2005) (requiring state to provide currently segregated services in community setting would not cause fundamental program alteration); *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 344–45 (D. Conn. 2008) (as state already had an existing and growing range of community-based programs, ordering “reasonable modifications” to state programs to facilitate community placement of additional individuals would not necessitate the “creation” of “new programs”). *See generally* *Martin v. Taft*, 222 F. Supp. 2d 940, 986–87 (S.D. Ohio 2002) (concluding that determination of whether the requested program expansion constitutes a fundamental alteration requires careful examination of the facts and circumstances and cannot be resolved at the pleadings stage of the litigation).

201. Generally, in an ADA Title II claim, the plaintiff bears the initial burden of showing that the accommodation he or she seeks is “reasonable on its face.” *See* *U.S. Airways, Inc. v. Barnett*, 535 U.S. 391, 401–03 (2002) (defining “reasonable on its face” as “ordinarily or in the run of cases,” and summarizing case law); *Oconomowoc Residential Programs, Inc. v. City of Milwaukee*, 300 F.3d 775, 783 (7th Cir. 2002). The defendant must then establish that the proposed modification is unreasonable or would cause an undue burden or fundamental alteration of the program under the particular circumstances. *See id.* at 783–84 (following decisions of the Second, Third, Eighth, Ninth, and Tenth Circuits regarding this allocation of burdens).

The decision in *Olmstead* and some subsequent decisions suggest that in integration mandate cases the court may focus less on the plaintiff’s burden of establishing that a requested modification is “reasonable,” and may focus more on whether the requested relief will result in a fundamental program alteration. *See* *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 604 (1999) (referring to “the fundamental alteration component of the reasonable-modifications regulation”); *id.* at 605–06 (suggesting that the state meets its reasonable modification burden by establishing that it has a comprehensive, effectively working deinstitutionalization plan); *Martin*, 222 F. Supp. 2d at 972 n.26; *Williams v. Wasserman*, 164 F. Supp. 2d 591, 631 n.35 (D. Md. 2001) (declining to require plaintiffs to “prove explicitly that the modification sought is reasonable”).

ing efforts at integration, and, as in most cases, the predilections of the court deciding the matter. Neither *Olmstead* nor the subsequent integration mandate cases have set forth a clear standard that can be easily applied in all contexts.²⁰² Thus, while it is difficult to confidently assert the exact parameters of the program modifications that courts might require to avoid discrimination in the guardianship context, the Title II integration mandate cases provide some guidance on the issue. These cases suggest that cost alone is not determinative; courts will require a state to demonstrate that the requested program modification actually interferes with the state's ability to provide services to other individuals with disabilities. The state can meet this burden, however, by establishing that it has a comprehensive, effectively working plan for the integration of individuals with disabilities.²⁰³

Olmstead makes clear that a state will not be ordered to provide integrated services simply because they can be provided at a lower cost or because the cost of the requested integrated care is small in comparison to the relevant portion of the state's budget.²⁰⁴ 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.²⁰⁵ The

202. See, e.g., *Ligas v. Maram*, 478 F.3d 771, 773 (7th Cir. 2007) ("*Olmstead* has left the exact route to implementing [the] integration mandate somewhat murky."). For a detailed discussion of several decisions interpreting the scope of the fundamental alteration defense in integration mandate cases, see *Five Years After Olmstead*, *supra* note 9, at 564–72. See also CTR. FOR PERS. ASSISTANCE SERVS., A Table of *Olmstead* and *Olmstead*-Related Litigation (Aug. 2009), <http://www.pascenter.org/olmstead> (select "Table 2—*Olmstead* Lawsuits") (compiling results of *Olmstead*-related litigation throughout the country).

203. See *Olmstead*, 527 U.S. at 605–06.

204. See *id.* at 603–06; *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 613–14 (7th Cir. 2004); *Townsend*, 328 F.3d at 520.

205. See *Olmstead*, 527 U.S. at 594–95, 604–05 (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. Protection & Advocacy, Inc.*, 402 F.3d at 382 (additional costs of providing community care alone do not establish fundamental alteration defense); *Radaszewski*, 383 F.3d at 613–14 (cost alone does not defeat a Title II claim); *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 364 F.3d 487, 495 (3d Cir. 2004) [hereinafter *Frederick L. I*] (unsupported assertion of insufficient resources to provide community-based mental health services does not establish fundamental alteration defense); *Messier*, 562 F. Supp. 2d at 345 ("minimal additional expense" resulting from additional community placements does not alone support fundamental alteration defense); *Wasserman*, 164 F. Supp. 2d at 638 (refusing to rely exclusively on state's assertions regarding increased costs of community placement); *Makin v. Hawaii*, 114 F. Supp. 2d 1017, 1034 (D. Haw. 1999) (fundamental alteration defense cannot be

courts generally recognize that the integration of people with disabilities carries immediate financial and administrative costs, and that those burdens must be balanced against the significant societal benefits of that integration.²⁰⁶ Thus, cost, without more, should rarely serve as an adequate defense in an ADA Title II action.²⁰⁷

Instead, when determining whether a state should be excused from providing a program modification needed to avoid discrimination, a court must consider whether the requested relief would so burden the state's available resources²⁰⁸ that it

based on assertion that State "would potentially have a problem" funding additional community-based services). *See generally* Michelle P. v. Birdwhistell, No. 3:02-23-JMH, 2008 U.S. Dist. LEXIS 16637, at *6-7 (E.D. Ky. Mar. 4, 2008) (requiring state to implement class action settlement agreement to create appropriate community-based care under a federally approved waiver program, despite state's subsequent determination that it could not afford to comply with this prior agreement). *But see Five Years After Olmstead*, *supra* note 9, at 568-70 (critiquing cost analyses utilized by the courts such as the *Frederick L. I* court's acceptance of the state's generalized assertion that any shifting of funds from institutional services to community services would necessarily harm other institutionalized individuals and refusing to consider evidence that the state would incur relatively modest cost increases from community placements for the plaintiffs even when taking into account the costs incurred in maintaining unused institutional beds).

206. *See, e.g.*, Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1182-83 (10th Cir. 2003) ("If every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the ADA's integration mandate would be hollow indeed."). *See generally* PGA Tour, Inc. v. Martin, 532 U.S. 661, 690-91 (2001) (recognizing the administrative burdens associated with modification of rules needed to enable persons with disabilities to have access to public accommodations).

207. *See* Rosenthal & Kanter, *supra* note 72, at 317 n.33 (Title II, unlike Titles I and III, does not include an "undue hardship" or "readily achievable" defense with respect to costs). *Compare* 42 U.S.C. § 12132, *with id.* at §§ 12112(b)(5)(A), 12111(10), *and id.* at §§ 12182(b)(2)(A)(iii)-(v), 12181(9).

208. *See, e.g.*, *Olmstead*, 527 U.S. at 603-04. The *Olmstead* decision does not provide clear guidance on the scope of "available resources" to consider in determining the state's fundamental alteration defense. *Compare id.* at 604 (appearing to suggest that "available resources" might be the state funds available "for the care and treatment of a large and diverse population of persons with mental disabilities"), *with id.* at 603 (suggesting that "available resources" might be the more limited state "mental health budget" that might not include funds from the state's general social services budget). *See* Disability Advocates, Inc. v. Paterson, No. 03-CV-3209, 2009 U.S. Dist. LEXIS 80975, at *249-50 (E.D.N.Y. Sept. 8, 2009) (citing *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 298, 350 (E.D.N.Y. 2009) (reviewing decisions and concluding that relevant budget for determining "available resources" is the "'mental health budget' which includes any money the State receives, allots for spending, and/or spends on mental health services and programs")); *Shepardson v. Stephen*, No. 99-CV-558 (SM), 2006 WL 2805238 at *22, 23 (D.N.H. Sept. 29, 2006); *Five Years After Olmstead*, *supra* note 9, at 567-68 (citing support for a broader interpretation of the scope of "available resources").

would be unable to meet the needs of other individuals with similar disabilities or whether the provision of this relief would give the particular litigants an unfair advantage over other similarly situated individuals.²⁰⁹ 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.

In *Fisher*, for example, the state argued that its decision to reduce, rather than eliminate, prescription drugs provided under its Medicaid community-based waiver program, was simply a reasonable response to its fiscal difficulties, and the district court agreed.²¹⁰ Rejecting the "district court's cursory fundamental alteration analysis,"²¹¹ the Tenth Circuit concluded that the state had failed to demonstrate that the requested program modification would fundamentally alter the state's program because there was no clear evidence that: 1) the state was considering the elimination of its Medicaid community-based waiver program, 2) the expense of providing unlimited prescriptions to persons receiving Medicaid waiver services in the community would necessitate cutbacks in services to other Medicaid recipients, or 3) the provision of these services to the plaintiff class would be unfair in light of the state's obligation to care for a diverse population of persons with disabilities.²¹²

Likewise, in *Townsend v. Quasim*, the Ninth Circuit rejected a state's unsupported contention that the financial burden of providing additional community-based waivers for long-

209. See *Olmstead*, 527 U.S. at 603–04. When undertaking the fundamental alteration analysis it is also not clear whether the court should be considering resources that are potentially available or only those resources actually available to the state. Compare, e.g., *Frederick L. I.*, 364 F.3d at 497 (refusing to interfere with pre-budgetary negotiations that set the annual budget for community based services), and *Bruggeman v. Blagojevich*, 219 F.R.D. 430, 435 (N.D. Ill. 2004) (finding that a court should limit its consideration to those resources actually available in the state's mental health budget), with *Helen L. v. DiDario*, 46 F.3d 325, 338–39 (3d Cir. 1995) (state might have to transfer funds from a nursing home budget to a home care budget to avoid unjustified segregation), and *Martin v. Taft*, 222 F. Supp. 2d 940, 984 (S.D. Ohio 2002) (citing to the availability of additional federal waivers that are potentially available to the state for provision of mental health services).

210. See *Fisher v. Oklahoma Health Care Auth.*, No. 02CV-762P, 2002 U.S. Dist. LEXIS 26538, at *4, *14–15 (N.D. Okla. Oct. 31, 2002); *Fisher*, 335 F.3d at 1182.

211. See *Fisher*, 335 F.3d at 1183.

212. See *id.*

term care to medically needy Medicaid beneficiaries would require significant service cuts that would fundamentally alter the state's Medicaid program. In particular, the court found inadequate evidence in the record that any additional costs of providing long-term care to the medically needy in the community would compel service reductions to other Medicaid recipients.²¹³ Similarly, in *Radaszewski*, the Seventh Circuit reversed and remanded the lower court decision because the state had not adequately demonstrated that it was unable to fund plaintiff's care at home without "fundamentally altering the care it provides to others with similar needs."²¹⁴ On remand, the state was unable to meet this burden.²¹⁵

As noted above, according to the *Olmstead* plurality, the state can meet its burden of demonstrating that the requested integrated services would fundamentally alter the relevant state program if it can show that it has "a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."²¹⁶ In light of the acknowledged daily burden of unnecessary and indefinite institutionalization, the Third Circuit has concluded that under *Olmstead*, the state cannot rest its defense on its past performance in community integration of institutionalized patients with mental disabilities.²¹⁷ Rather, the state must have a comprehensive, concrete, and viable integration plan for placing eligible patients in community-based programs by a target

213. *Townsend v. Quasim*, 328 F.3d 511, 513–15, 520 (9th Cir. 2003) (remanding to determine whether expansion of the waiver program would fundamentally alter the state's program). *But see* *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 619–21 (9th Cir. 2005) (refusing to require the state to expand Medicaid home and community-based waiver program for eligible developmentally disabled individuals in light of state's acceptable deinstitutionalization plan).

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

215. *See Radaszewski v. Maram*, No. 01 C 9551, 2008 U.S. Dist. LEXIS 24923, at *36, *41 (N.D. Ill. Mar. 26, 2008).

216. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605–06 (1999). *See* Julia Gilmore Gaughan, Comment, *Institutionalization as Discrimination: How Medicaid Waivers, the ADA, and § 1983 Fail*, 56 U. KAN. L. REV. 405, 417–18 (2008) (observing that in reality *Olmstead* provides a systemic right rather than an individual right).

217. *See Frederick L. v. Dep't of Pub. Welfare of Pa.*, 422 F.3d 151, 158 (3d Cir. 2005) [hereinafter *Frederick L. III*].

date that is sufficiently specific for a court to review the adequacy of the state's ongoing "commitment to action."²¹⁸

The integration mandate cases, however, reveal a tension between the courts' concern that the state have a sufficiently specific and effective plan to integrate persons with disabilities, and the courts' desire to avoid judicial involvement in the planning, administration, and funding of state programs and services.²¹⁹ For this reason, when the state can demonstrate that it has a well-considered and specific plan for ongoing integration, courts have been willing to defer to the state, finding that proposed modifications would entail fundamental program alterations. This dynamic is particularly apparent in the Ninth Circuit's integration mandate decisions.

For example, in *Sanchez v. Johnson*, providers of community-based mental health services and developmentally disabled Medicaid recipients living in, or at risk of living in, institutions brought an ADA Title II claim asserting that a

218. See *Pa. Prot. & Advocacy, Inc. v. Pa. Dep't of Pub. Welfare*, 402 F.3d 374, 382–83 (3d Cir. 2005) (citing *Frederick L. I*) (criticizing the district court for its acceptance of the state's budgetary constraints defense without having carefully reviewed the adequacy of the state's deinstitutionalization plan and specific state efforts to expand community-based services); *id.* at 381–85 (granting plaintiffs' motion for summary judgment with respect to the state's fundamental alteration defense because the facility in which they were institutionalized had been deliberately omitted from the state's *Olmstead*-compliance planning process, and remanding for determination whether any plaintiffs opposed community placement and whether such placement was appropriate); *Disability Advocates, Inc. v. Paterson*, No. 03-CV-3209, 2009 U.S. Dist. LEXIS 80975, at *245–46, *250, *254, *349, *365–66 (E.D.N.Y. Sept. 8, 2009) (concluding that state defendant did not meet burden of establishing that requested expansion of state's supported housing program to accommodate adult home residents seeking to move to a more integrated setting would cause fundamental program modification because the state did not have an "effective or comprehensive plan" to move residents to the most integrated setting appropriate to their needs, nor could the state show that the requested relief would increase its costs and require cutbacks in services provided to others with disabilities). See also *Frederick L. III*, 422 F.3d at 155, 160 (second remand of district court's determination that state had established fundamental alteration defense for further consideration of adequacy of state's deinstitutionalization plan, noting that "at a bare minimum [a viable integration plan] should specify the time-frame or target date for patient discharge, the approximate number of patients to be discharged each time period, the eligibility for discharge, and a general description of the [agency] collaboration required . . . to effectuate integration into the community").

219. See, e.g., *Arc of Wash. State Inc. v. Braddock*, 427 F.3d 615, 618 (9th Cir. 2005); *Bruggeman ex rel. Bruggeman v. Blagojevich*, 324 F.3d 906, 913 (7th Cir. 2003) (concluding that while ADA requires states to have comprehensive and effective plans to provide integrated services to prevent isolation or segregation of people with disabilities, federal courts should not become "the supervisors of the care and treatment of disabled persons").

Medicaid funding cap limited the availability of community-based programs in violation of the integration mandate.²²⁰ The district court rejected the plaintiffs' ADA claim.²²¹ On appeal, the Ninth Circuit affirmed that decision, concluding that regardless of the number of developmentally disabled persons who remained institutionalized, in light of the state's continuing need to maintain some institutional services, the requested relief would constitute a fundamental alteration of the state's extensive and ongoing deinstitutionalization plan which effectively provided a comprehensive array of community-based services for persons with developmental disabilities.²²²

These decisions provide some guidance for the application of the fundamental alteration defense in an integration mandate challenge in the guardianship context. We know that cost alone will not be determinative, unless the state can demonstrate—specifically and concretely—that the cost of providing supported decision-making options would prevent the state

220. *Sanchez v. Johnson*, 416 F.3d 1051, 1053–54 (9th Cir. 2005). The plaintiffs based their claim at least in part on the argument that increased funding would enable the community-based service providers to offer wages and benefits competitive with those offered to institutional employees, thereby allowing these providers to expand community-based services needed by the developmentally disabled plaintiffs. *Id.* at 1055.

221. The district court provided three bases for its conclusion: 1) there was no proof that the proposed increase in wages would remedy any “unjustified isolation” of the class, 2) the requested \$1.4 billion in additional expenditures was not a “reasonable modification” as it represented a forty percent increase in the state’s budget for developmental disabilities services, and 3) any relief would involve a fundamental alteration of California’s acceptable deinstitutionalization plan. *Id.* at 1063.

222. *Id.* at 1063–68 (noting state law mandating provision of free health services to all developmentally disabled residents, along with the state’s significant past efforts at deinstitutionalization, its annual assessments of individual needs, and its ongoing and concrete plans to develop community-based treatment programs and facilities and to close at least one large institution). *See Arc of Wash. State Inc.*, 427 F.3d at 621–22 (finding that the state established a fundamental alteration defense based on the state’s demonstrated commitment to deinstitutionalization, as evidenced by its sizeable (10,000), fully utilized, and growing community-based waiver program, its “comprehensive,” “effectively working” deinstitutionalization plan with a properly administered waiting list, significant budgetary increases for community-based disability services, and meaningful reductions in its institutional population); *id.* at 619 (observing facts in *Olmstead* were distinguishable because in that case the state had not used all its waiver slots and the Court did not need to decide whether a forced expansion of a Medicaid waiver program beyond the federally approved cap would constitute fundamental program alteration). *See also Bryson v. Stephen*, No. 99-CV-558-SM, 2006 WL 2805238, at *8–9 (D.N.H. Sept. 29, 2006) (following decisions in *Sanchez* and *Arc of Washington* and finding that, in light of the state’s acceptable deinstitutionalization program, the state would not be forced to expand a community-based waiver program).

from providing assistance with decision making to other individuals with diminished mental abilities.²²³ But the comparative cost analysis is difficult and complex. It requires calculation of the costs of the supported decision-making services and any immediate cost savings to the guardianship system when individuals move into less restrictive programs. It then requires consideration of these overall expenditures for supported services on the state's continuing ability to provide guardianship services for others who want, or arguably need, those more restrictive services.²²⁴ Consequently, it will be necessary to understand and compute the costs of the current guardianship system and to develop cost analyses of various supported decision-making options.

States currently provide some funding in connection with both public and private guardianships. The state generally incurs the expenses of operating its system for adjudicating guardianship petitions and for whatever oversight and monitoring it provides after appointment. In the private guardianship context, many of the costs, such as the costs of necessary evaluations and assessments, as well as payments for the guardian's services after appointment, are often paid from the ward's estate. In the context of public guardianship programs,

223. This would appear to be the correct inquiry, but the cases have not been entirely consistent with regard to the precise contours of the "services to other persons with similar disabilities" to be considered in the analysis of the state's fundamental alteration defense. Compare *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 607 (1999) (considering impact on state services to meet "the needs of others with mental disabilities") with *Townsend v. Quasim*, 328 F.3d 511, 518 (9th Cir. 2003) (considering impact on state service provided to "medically needy Medicaid recipients in Washington"), and *Arc of Wash. State Inc.*, 427 F.3d at 620 (considering the impact on a state's comprehensive plan for the deinstitutionalization of "disabled persons" when determining whether a state should be required to expand a state's HCBS waiver program for developmentally disabled individuals).

224. In the deinstitutionalization context, states have opposed community placement, arguing that they would not experience immediate cost savings, as they would be paying for the services in the community, while being unable to experience any concomitant cost savings due to their continuing obligation to maintain institutions still needed for the care of others with disabilities. See generally *Olmstead*, 527 U.S. at 604 (concluding that fundamental alteration defense should take into account the immediate increase in state costs for the provision of community services along with the expenses of operating state institutions still needed by other disabled individuals). States would not have a similar argument in the guardianship context where most of the expenses of "the system" are expenses associated with the particular individuals needing assistance. Thus, while the state would incur the cost of providing more integrated assistance with decision making, the guardianship system should see immediate cost reductions when individuals are diverted to supported decision-making alternatives.

the state often pays for necessary evaluations and funds the guardianship services; however, this funding is often quite limited.²²⁵

Although current state funding for private and public guardianships may be limited, a question that remains to be answered is whether the state would incur significantly greater expenses if it diverted cases from the guardianship system to supported decision-making alternatives. For example, since the process for appointment of a supported decision-making assistant would likely be less formal and less adversarial than that of guardianship, the state's adjudication costs may decrease with the implementation of a supported decision-making program. For many other state expenditures in connection with guardianship, the costs could simply be transferred to a budget for supported decision-making alternatives. The state's current expenditures within the guardianship system for evaluations and assessments, training of public and private guardians, public guardianship services, and guardianship monitoring and oversight, could be transferred to fund similar functions within the supported decision-making context. In addition, the guardianship-related expenses that are currently paid from the ward's own funds could be utilized by that same individual to pay the costs of alternative supported decision-making assistance.²²⁶ Finally, while there would be some costs associated with the initial creation and funding of supported decision-making models, they should be limited, short-term development costs.

Because supported decision making calls for intensive interaction with the individual needing assistance, it is possible that the costs of such services would be higher than those in-

225. See Teaster et al., *supra* note 51, at 221 ("The primary reported weakness of the public guardianship programs was the lack of funding.").

226. See discussion *infra* Part V. In the Swedish system, the decision-making assistants are paid from local or national government funds. Herr, *supra* note 127, at 434; PO-Skåne, Swedish User-Run Service with Personal Ombud (PO) for Psychiatric Patients, <http://www.po-skane.org> (last visited Dec. 27, 2008) (click on "In English" on left-hand side) [hereinafter PO-Skåne Description] (program is financed two-thirds by the state and one-third by the local government). In the British Columbian system, the assistants are generally not paid for their services. Representation Agreement Act, R.S.B.C., ch. 405, pt. 3, § 26 (1996) [hereinafter RAA], available at http://www.qp.gov.bc.ca/statreg/stat/R/96405_01.htm (noting that unless a Representation Agreement explicitly provides for payment of representative or monitor, there is no remuneration for performing obligations under the agreement, though reasonable expenses may be reimbursed from the individual's assets).

volved with a guardian who may make unilateral decisions without the ward's participation. In addition, state guardianship systems are notoriously underfunded. It would be important to avoid trading an underfunded guardianship system for underfunded supported decision-making services that are unable to meet the goal of maximizing the integration of individuals with limitations in decision-making abilities. Ultimately, if advocates can demonstrate that the cost of providing assistance with decision making in a support model is not significantly higher than the cost of providing such assistance in a guardianship model, a state may have difficulty arguing that the provision of supported decision-making services will substantially limit the state's ability to meet the needs of all individuals requiring assistance with decision making. Nevertheless, the cost analysis required to overcome a state's fundamental alteration defense is complex.²²⁷

At the same time, in Title II challenges, states will still need to defend their provision of assistance with decision making through guardianship rather than supported decision making. At a minimum, the state will need to explain its plan for providing more integrated services, and there is a great need to expand the limited options currently available for support. Much could be accomplished in this context, even if courts were only to require states to demonstrate that they have specific, comprehensive, and effective working plans for providing services to individuals needing assistance with decision making outside of the more restrictive guardianship model. States may well argue that this Article seeks a whole new program for individuals with conditions affecting their ability to manage their property and personal affairs. But, as explained in Part III. C.2, some support services already exist that might be expanded. In addition, we now have an elaborate guardianship system that provides assistance in an unnecessarily restrictive manner. The fundamental alteration regulation should not be used to maintain more restrictive services because the provision of less restrictive services would require the state to

227. See, e.g., *Disability Advocates, Inc. v. Paterson*, 2009 U.S. Dist. LEXIS 80975, *286–331 (E.D.N.Y. 2009) (analyzing the evidence regarding the cost of providing more integrated services to residents of the more segregated adult home setting); *Townsend*, 328 F.3d at 520 (remanding for further factual development of the State's fundamental alteration defense though also criticizing plaintiffs' analysis of the comparative costs of community-based and institutional care because it failed to account for the potential increased demand for community-based services if they were made available as an alternative to nursing-home care).

change the segregated way in which it now provides services. It is worth considering whether the costs of developing and funding less restrictive alternatives would actually prevent the state from providing necessary guardianship services.

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,²²⁸ and that they do not entail significantly greater financial resources than the guardianship option. As states consider further guardianship reforms, or consider allocating additional funds to improve public guardianship programs, it may be an appropriate time to think again about where we should be investing energy and resources.

V. SUPPORTED DECISION MAKING OFFERS A MORE INTEGRATED AND LESS ISOLATING FORM OF ASSISTANCE

The final questions to be answered are whether supported decision making is viable and does it actually provide a more integrated and less isolating form of decision-making assistance than is provided under a reformed guardianship model. The international consensus of people with disabilities and experts on disability rights, as expressed in the United Nations Convention on the Rights of Persons with Disabilities,²²⁹ is that all individuals, regardless of disability, are entitled to equal recognition before the law and have a right to exercise legal capacity, and to receive support to exercise that capacity, if needed.²³⁰ Support is the clearly preferred norm, and states

228. As discussed above, the loss of control over one's life affairs can have negative health consequences. *See supra* Part I.A.1, text accompanying notes 30–34. Permitting individuals to retain control over their personal and financial decisions to the greatest extent possible could bring savings from reduced health care expenditures.

229. The CRPD, *supra* note 12, represents the culmination of over two decades of advocacy efforts and five years of negotiation and drafting by the broadly representative Ad Hoc Committee, which included representatives of disabled people's organizations, human rights organizations, and governmental representatives. Arlene S. Kanter, *The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities*, 34 SYRACUSE J. INT'L. L. & COM. 287, 288–89 (2007); U.N. WEB SERVS. SEC., U.N. DEP'T OF PUB. INFO., WHY A CONVENTION (2006), <http://www.un.org/disabilities/convention/questions.shtml>.

230. CRPD, *supra* note 12, at art. 12(1)–(3). *See id.* at art. 12(5) (requiring measures to protect the rights of people with disabilities to own and inherit property, engage in financial transactions, and control their own financial affairs). *See*

are obligated to develop measures to support the individual's exercise of capacity when needed.²³¹ Correlatively, measures that interfere with an individual's exercise of capacity must be carefully restricted.²³²

As noted briefly in Part II, under a supported decision-making paradigm, the individual receives support from a trusted individual, network of individuals, or entity to make personal, financial, and legal decisions that must be followed by third parties, such as financial institutions, businesses, health professionals and service providers. Depending on the needs of the individual with a disability, the support person helps the individual to understand the relevant issues and information and make decisions based on his or her own preferences. If necessary, the support person interprets and communicates the individual's preferences and desires to third par-

generally Dhanda, *supra* note 30, at 438–56 (discussing genesis and implications of the Convention's provisions regarding legal capacity).

231. CRPD, *supra* note 12, at art. 12(3). The language of the CRPD does not explicitly prohibit or provide for substituted decision making, referring only to “measures relating to the exercise of legal capacity.” *Id.* at art. 12(4). The question of whether, or when, guardianship might be appropriate within a system predicated upon the provision of decision-making support, is complex and beyond the scope of this Article. See Dhanda, *supra* note 30, at 444–50, for an interesting discussion of this debate among the drafters of the CRPD.

232. The CRPD provides that measures relating to the exercise of capacity must have safeguards that “respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.” CRPD, *supra* note 12, at art. 12(4). See Dhanda, *supra* note 30, at 449–50 (observing that this provision combines some of the standards for supported decision making and the required safeguards for guardianship); International Conference on Intellectual Disability, Montreal, Can., Oct. 5–6, 2004, *Proposal: Montreal Declaration on Intellectual Disability: Wednesday October 4th 2004*, ¶ 6(b)–(c) (Oct. 6, 2004), available at http://www.inclusion-international.org/site_uploads/11190151051066068714.pdf [hereinafter International Conference on Intellectual Disability] (declaring that the decision-making rights of people with intellectual disabilities should be compromised only in the most extreme circumstances and only after compliance with strict procedural protections, including clear and convincing evidence that “*even with adequate and appropriate supports*, all less restrictive alternatives to the appointment of a surrogate decision maker have been *exhausted*”) (emphasis added); Michael Bach, Supported Decision Making Under Article 12 of the U.N. Convention on the Rights of Persons with Disabilities: Elements of a Model, 21–23 (Nov. 2007) (unpublished article, on file with author) (concluding that if substituted decision making is permitted, it must only be in cases where supported decision making is not possible, should always be limited in scope and time period, and must be subject to strict procedural protections, including necessary review).

ties so that they can be realized.²³³ For example, a person with a learning disability might receive help with reading, or support to focus attention in making a decision. A person who uses alternative forms of communication might have support to interpret those communications to others.²³⁴ A person who has no verbal communication may need others who understand his or her preferences and wishes and who can interpret and help implement those decisions.²³⁵ In these ways, the supporting entity can assist the individual with a disability with decision making, even when the individual has severe impairments.²³⁶

Once decisions are made or understood with support,²³⁷ there must be a legal structure that gives formal recognition to

233. See Byrnes, *supra* note 64; Bach, *supra* note 232, at 7–9. Supported decision making recognizes that “[e]ven people who have difficulty making choices, formulating decisions and communicating their preferences can make positive choices and decisions that further their personal development, relationships and participation in their communities.” Bach, *supra* note 64, at slide 17 (quoting International Conference on Intellectual Disability, *supra* note 232, at ¶ 6(a)). See also Rein, *supra* note 61, at 1868 (calling for the use of a decision-making assistant in cases in which the individual has a physical condition that impairs his or her ability to make decisions).

234. See INCLUSION INT’L, LEGAL CAPACITY: POSITION PAPER 1 (2006), http://www.inclusioninternational.org/site_uploads/File/amendedLegal%20Capacity%2018%2010%2006%20rev.pdf.

235. See Minkowitz, *supra* note 67, at slide 24.

236. As one family acting as a support network explained: “Even with all the tools available, Charlie still can’t express his choices independently. We don’t always know what he wants, decisions aren’t always perfect, but together we can support him to make decisions about where he wants to live or what he wants to do.” Inclusion Int’l, *People with Intellectual Disabilities & the Right to Make Decisions* 3, available at http://www.ii.tomekklas.com/site_uploads/File/Legalcap.%20bulletin.pdf.

237. One concern that is raised by individuals who are being introduced to the concept of supported decision making is that the supported decision may be too greatly influenced by the support person or persons. The concern is not illegitimate. Nevertheless, there are several responses to this concern. First, no decision-making process is perfect or free from influences, and everyone seeks assistance with decisions from others at various points in their lives. See, e.g., Winick, *supra* note 30, at 10 (noting that decisions are often influenced by a variety of social, familial, psychological, occupational, and financial pressures). Second, supported decision making is likely to get at least as close to the individual’s preferences, wishes, and values as is guardianship. See generally 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) (reviewing empirical psychological research and questioning whether surrogate decision makers in the health care context accurately predict and effectuate the patient’s wishes and substantive treatment preferences). In addition, notwithstanding the fact that there are clearly individual guardians working in good faith to involve the “incapacitated person” in the decision-making process and to ascertain his or her wishes, in general, decisions made within a support model are more likely to involve the individual and will therefore be perceived as

those decisions. Formal supported decision-making models have been developed in other countries that provide for decision making outside of a guardianship structure. Collectively, these models provide a range of options that differ in ways such as: the mechanism for requesting or appointing a support person; the individuals and entities that can serve in a support capacity; the level of “capability” required to appoint one’s own individual representative or to qualify for a decision-making assistant; the degree to, and the circumstances under, which the supporting entity can make decisions without the principal’s consent.²³⁸ Supported decision-making programs continue to evolve and new models are being created and tested.²³⁹ Two basic types of existing models—the legal mentor or friend and the Canadian supported decision-making model—will be briefly outlined here.

less coercive than are decisions made by a guardian. *See generally* Winick, *supra* note 31, at 9–10 (noting that whether a decision is perceived as coerced is heavily dependent on subjective factors). In the end, it is philosophically and empirically difficult to argue that decisions made by substitute decision makers are “better” or “purer” than those made in the supported decision-making context.

238. For a more detailed description of various supported decision-making models and other national efforts to more fully recognize individual autonomy, see, for example Herr, *supra* note 127, at 431–44; Michael Bach, Executive Vice President, Can. Ass’n for Cmty. Living, Presentation to Conference on Legal Capacity and Supported Decision Making: Supported Decision Making Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: Questions and Challenges, 6–7 (Nov. 3, 2007), *available at* <http://www.inclusionireland.ie/documents/Bach-SupportedDecisionMaking-InclusionIrelandNov07.doc> [hereinafter Questions and Challenges]; Minkowitz, *supra* note 67, at slides 21–32; Mental Capacity Act 2005 (c. 9) §§ 1–3, 35–41, *available at* http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1; Department for Constitutional Affairs and Department of Health, Mental Capacity Act Explanatory Notes, 1–35; 4–6 (discussing liberal definition of decision-making “capacity” and requirement to provide support with decision making); 20–22 (discussing appointment of independent mental capacity advocates to provide representation and support to certain vulnerable individuals when they must make significant medical or residential placement decisions) *available at* http://www.opsi.gov.uk/acts/acts2005/en/ukpgaen_20050009_en.pdf; Department for Constitutional Affairs, Mental Capacity Act 2005 Code of Practice, 1-296 23-39 (2007), *available at* <http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf>; C. Lyons et al., *The Mental Capacity Act 2005: Implications for Dietetic Practice*, 20 J. HUM. NUTRITION & DIETETICS 302, 304, 306, 308 (2007) (discussing implications of Mental Capacity Act for dietetic practice in the United Kingdom, including the provision of tube feeding).

239. *See generally* OPEN SOCIETY MENTAL HEALTH INITIATIVE, *supra* note 66 (listing select publications, reports, and useful links to additional resources regarding supported decision-making programs and options).

A. *Two Instructive Models*

1. The Legal “Mentor” or “Friend”

In the legal mentor or legal friend model, a court may appoint a person to assist an individual found incapable of managing his or her affairs by acting on the individual’s behalf, generally only with his or her consent. Thus, the mentor acts in a “sometimes ‘grey zone’ between autonomous and substitute decision making.”²⁴⁰ While the goal of the mentorship is to preserve the decision-making authority of the individual with a disability to the greatest extent possible, and to involve the individual in the decision-making process, the mentor may nevertheless have significant discretion within this model to make decisions for the individual, with or without the individual’s input.²⁴¹

In 1989, Sweden abolished its formal guardianship system for adults with disabilities and replaced it with a two-tiered system of decision-making assistance—the “god-man” (“good or fair man”) and the “administrator.”²⁴² The god-man acts as a legal mentor. The administrator acts as a surrogate decision maker similar to a guardian.

The god-man is appointed through a simple procedure before a local court that requires the consent of the individual needing assistance with personal affairs or property management.²⁴³ The god-man acts as a decision-making agent and is

240. Bach, *supra* note 232, at 6.

241. *Id.* at 7.

242. See Torbjorn Odlow, *Swedish Guardianship Legislation—Progressive and Lagging Behind* (Nov. 14, 2008) (unpublished manuscript, on file with author); Code of Parents, Guardians, and Children, *Foraldrabalken 1949*: 383, c. 11, 12, 14, 16, 19; Herr, *supra* note 127, at 432–41 (providing a detailed description of Sweden’s comprehensive national program of social and personal supports for persons with disabilities, including the supported decision-making arrangement). For a brief description of the mentor/personal ombudsman (“PO”) program in Skane, Sweden, which provides consensual supported decision-making services to persons with severe psycho-social disabilities without a bureaucratic process for the PO’s appointment, see Maths Jespersen, *PO-Skane—Personal Ombudspersons in Skane*, www.peoplewho.org/documents/jesperson.decisionmaking.doc, 1–3 (last visited Nov. 5, 2009); see also *PO-Skane Description*, *supra* note 226.

243. The individual must consent to the arrangement; the law does not require the principal’s consent to the selection of the guardian, but for practical reasons it is usually obtained. See Odlow, *supra* note 242, at 1. One notable exception to the legal requirement for consent to the appointment allows for the appointment of a god-man when an individual is completely unable to participate in the decision-making process because he or she is in the equivalent of a “persistent vegetative state” or suffers from such “grave dementia . . . that [the individual] could not

supposed to obtain the principal's consent for all non-routine transactions to the extent the individual is capable of giving such consent.²⁴⁴ Thus, the god-man cannot legally bind the individual with a disability to any transaction to which the individual had the capacity to consent but did not do so, and the god-man may be liable to a third party for any resulting damages.²⁴⁵ The individual's legal capacity is not compromised by the appointment of the god-man, and the individual may ter-

enter into any kind of agreement what so ever." *Id.* at 3, 5. The Legislature has permitted the use of the less restrictive god-man alternative in cases of severe disability based on its determination that in such cases the individual would not be able to engage in harmful transactions that might conflict with the actions of an appointed god-man. *See id.*

244. *See id.* at 1–2; Dhanda, *supra* note 30, at 434 n.16 (stating that the mentor acts with consent of the person for whom he is appointed, and acts with powers similar to those of a power of attorney). There are a couple of caveats to the general principle that the god-man must have consent of the principal for all actions regarding matters to which the principal is deemed to be able to consent. First, the god-man does not need to obtain consent from the individual for regularly recurring acts such as the payment of rent or other monthly bills. Odlow, *supra* note 242, at 5. Second, consent is not required for a god-man to act on behalf of an individual who is completely unable to participate in the decision-making process. *Id.* at 3. Third, and quite significantly, in those situations where the person with a disability objects to either the god-man's appointment or the god-man's decisions, and a determination is made by a court that the individual's personal or property interests would be "seriously jeopardized" unless the individual has some assistance, the court will appoint a "trustee" or "administrator" who is given the exclusive right to make legally binding decisions for the person with a disability in those areas of decision making in which the individual is deemed incapable of acting on his or her own. *See id.* at 2, 6; Herr, *supra* note 127, at 435–36. In this circumstance, as noted above, the Swedish administrator appears to act in a capacity that is indistinguishable from that of a guardian with potentially limited powers, although the individual for whom the administrator is appointed continues to retain the right to vote as a matter of law. *See Odlow, supra* note 242, at 6.

245. Odlow, *supra* note 242, at 6–7. In contrast, in cases where an administrator rather than a god-man is appointed, the administrator is mandated to discuss important decisions with the person with the disability, but there is no sanction if the administrator fails to do so and the only remedy for its violation would be a formal petition to dismiss or replace the administrator. *Id.* at 4. This ability of the administrator to bind the principal without his or her consent is seen as a limitation in the Swedish program. *Id.* at 8. Even when an administrator is appointed, the Swedish system attempts to limit the appointment so that the individual with the disability maintains the maximum ability to control his or her own affairs. For example, in a case where an individual with serious limitations in ability to manage finances were to get a large inheritance, an administrator might manage the money in one bank account but transfer sufficient funds to another account that is under the individual's complete control. Similarly, in a case where an individual with a compulsive disorder habitually incurred credit card debts well in excess of his or her means, an administrator could be given exclusive authority to engage in credit transactions while the individual retained the ability to engage in any cash transactions. *See id.* at 2–3.

minate the mentorship at any point in time.²⁴⁶ While the Swedish program is not without its limitations, it does appear that even when the court appoints an administrator, rather than a god-man, Sweden's national effort to focus on supported (rather than substituted) decision making has helped to limit the scope of the administrator's control over the incapacitated person's affairs. This altered focus enables the individual to be more directly involved in his or her own life's activities than he or she would under a system in which surrogate decision making is the norm.

2. The Canadian Supported Decision-Making Paradigm

With the adoption of statutes permitting individuals with disabilities to create private agreements authorizing others to assist with decision making, Canadian jurisdictions have become leaders in the legal implementation of supported decision-making models.²⁴⁷ Under British Columbia's Representation Agreement Act ("RAA"), an adult can enter into a "representation agreement" with a trusted person (or support network) who is empowered either to assist that individual in making and communicating certain decisions with which he or she needs assistance, or to make decisions for him or her.²⁴⁸ An individual can enter into a representation agreement despite an inability to demonstrate that he or she has "legal capacity" or the capacity to understand, appreciate consequences, act voluntarily, and communicate a decision independently.²⁴⁹ The Act creates a presumption that an individual is capable of entering into a representation agreement unless, based on specified criteria, the individual is specifically found "incapable of doing

246. *Id.* at 1–2; Description of PO-Skane, *supra* note 226.

247. *See* RAA, *supra* note 226, at s. 3(26); Decision-Making Support and Protection to Adults Act, S.Y. 2003, c. 21 [hereinafter YDMSA], available at <http://www.canlii.org/en/yk/laws/stat/sy-2003-c-21/latest/sy-2003-c-21.html>; Manitoba Family Services and Housing, *The Vulnerable Person Living With a Disability Act* (1993), http://www.gov.mb.ca/fs/pwd/vpact_decision.html (describing supported decision making and support networks).

248. *See* RAA, *supra* note 226, at s. 1(2), 2(4), (7), (9).

249. *Id.* at s. 2(8). *See also* Questions and Challenges, *supra* note 238, at 7 (explaining that Canada has created a decision-making status under which the state fully recognizes an individual's legal capacity if either the individual can demonstrate to others his or her "will and intent," or if the individual's "personhood" can be articulated by others who have sufficient knowledge to understand that individual's unique form of communication and his or her "life history").

so.”²⁵⁰ Significantly, the individual does not compromise any existing legal capacity by entering into a representation agreement.²⁵¹

The representation agreement can provide the representative with broad, legally binding powers to act with or for the adult, according to its terms and the individual’s known wishes and preferences.²⁵² The Act attempts to safeguard against abuse in assistance with routine financial transactions by requiring the adult/principal to appoint a trusted individual to serve as a financial monitor when the adult appoints a representative for such financial transactions.²⁵³ Any person can report irregularities, potential undue influence, or abuse to the Public Guardian and Trustee who may conduct an investigation of the allegations.²⁵⁴

The paradigm created by the RAA is predicated on a relationship of trust and creates a mechanism that bears some re-

250. See RAA, *supra* note 226, at s. 1(3), 2(8). See also Bach, *supra* note 64; Canadian Centre for Elder Law Studies and British Columbia Law Institute, *A Comparative Analysis of Adult Guardianship Laws in British Columbia, New Zealand and Ontario* (Oct. 2006), available at http://www.bcli.org/sites/default/files/Comparative_Analysis_of_Adult_Guardianship_Laws-1.pdf [hereinafter *Comparative Analysis*] (discussing RAA’s use of different levels of “capacity” or ability to enter into a representation agreement depending on the types of decisions covered by the representation agreement). Under the RAA, an individual who might be deemed “incapable” of entering into a contract, making health care decisions, etc., would be legally qualified to enter into a representation agreement for purposes of more routine decisions based on an assessment that: 1) the person can communicate a desire to have another participate in the decision-making process; 2) the individual can communicate choices and preferences, including approval or disapproval of others; 3) the individual is aware that making the agreement or modifying or revoking any provisions means that the representative may make or stop making decisions or choices affecting the individual; and 4) the individual and the representative have a relationship “that is characterized by trust.” RAA, *supra* note 226, at s. 2(8) (emphasis added). See *Comparative Analysis, supra*, at 14 (covering routine decisions such as the adult’s personal care and residence, certain healthcare services, securing legal representation). In order for an individual to enter into a representation agreement involving “higher-level” decisions such as that required for end-of-life decisions or temporary care of one’s children, the individual must “consult with a member of the Law Society” who would determine whether the individual has the ability to understand “the nature of the authority and the effect of giving it to the representative.” RAA, *supra* note 226, at s. 2(9), (10); see also *Comparative Analysis, supra*, at 15.

251. RAA, *supra* note 226, at s. 6(36).

252. *Id.* at s. 2(7), (9), 3(19), (24). The representation agreement can be entered into a central registry and the person with a disability can authorize registry access to third parties to view the agreement. See Nidus, Personal Planning Resource Center and Registry, <http://www.rarc.ca/textual/home.htm> (last visited Nov. 15, 2009).

253. RAA, *supra* note 226, at s. 2(12).

254. *Id.* at s. 5(30)–(31).

semblance to a power of attorney, though with a generous and flexible concept of the “legal capacity” required to enter into such an agreement. The RAA requires that the representative consult with the principal “to the extent reasonable” to determine the principal’s current wishes.²⁵⁵ While the language of the RAA appears to vest the representative with some discretion regarding consultation with the principal, it suggests that a representative who fails to comply with the “requirement” to consult could be personally liable for any damages resulting from that failure.²⁵⁶

The Yukon Decision-Making Support Act (“YDMSA”) creates two types of decision making support mechanisms, one for support and the other for representation, and is worthy of further study.²⁵⁷

255. *Id.* at s. 3(16). See generally Kohn, *supra* note 30, at 48–52 (providing an excellent discussion of deficiencies in laws governing durable powers of attorney and recommending that such laws be amended to require that the agent communicate and consult with the principal prior to acting and provide the principal with prior notice of certain “fundamental transactions” as a means of avoiding abuses of the appointment).

256. RAA, *supra* note 226, at s. 3(23).

257. The YDMSA, like the RAA, sets forth the presumption of universal capability and the principle that all adults should receive “the most effective, but the least restrictive and intrusive, form of support, assistance, or protection when they are unable to care for themselves or manage their affairs” YDMSA, *supra* note 247, at sec. 2(c). Accordingly, the law provides that a court should not be asked to appoint a guardian and should not appoint a guardian “unless alternatives, such as the provision of support and assistance, have been tried or carefully considered.” *Id.* at sec. 2(d); see also *id.* at Part 3, Sec. 32(1)(c).

The YDMSA creates two supported decision-making options. An individual can enter into a supported decision-making agreement with one or more trusted friends and relatives who provide assistance with, and are legally recognized participants within, the decision-making process. *Id.* at Part 1(4)–(6). Any decision made by the adult without the assistance of the appointed support person in an area covered by the support agreement is subject to legal challenge. *Id.* at Part 1(12), Part 2(25). The statute also provides that an individual can authorize *two or more* trusted representatives to make a specified range of daily personal and/or financial decisions for the individual, consistent with his or her wishes and with his or her participation, “to the extent reasonable,” but the representatives must act unanimously when making decisions for the individual. *Id.* at Part 2(15)–(16), Part 3(21), (23).

Under the YDMSA, an adult can enter into a support or representation agreement as long as he or she understands the nature and effect of the agreement, but this standard is not further defined in the statute, except by stating that the individual cannot be so impaired that he or she “need(s) a guardian.” *Id.* at Part 1(4), (6), Part 2(15). The law sets out standards of care for support persons and representatives and attempts to limit the possibility of undue influence by restricting the persons who may provide support or representation in the process. *Id.* at Part 1(7), (13), Part 2(16), (23). In the absence of evidence of fraud, misrepresentation, undue influence, or overreaching, a decision made with or

*B. Moving Toward a Supported Decision-Making Model:
Future Research*

The previous discussion of existing supported decision-making options is quite preliminary. It is included here to demonstrate that there are existing supported decision-making models that go further than guardianship reforms in this country to create a presumption of capacity and participation. These models shift the paradigm from one in which a person is divested of the right to make decisions on his or her own, to one that respects the individual's right and ability to make decisions and provides the individual with the appropriate level of support to enable him or her to make those decisions. In so doing, these models maximize the individual's opportunities for interactions with others and thus provide assistance with decision making in a more integrated manner than is provided in a guardianship model.

These formal supported decision-making models are still relatively new. They are not yet perfect, but they are gradually evolving. Further study of existing programs is needed in order to understand the optimal program features and to develop best practices. The challenge is how to best structure a system so that it: (1) ensures the centrality of the individual with a disability and maximizes his or her active involvement in the decision-making process; (2) provides assistance in a manner that is neither over-protective nor intrusive; and (3) provides sufficient support to enable the individual to meet his or her legitimate needs and to protect his or her interests.²⁵⁸

Additional study and analysis might also address the following related questions:

1. How do these supported decision-making models ensure the legal recognition of agreements made by an individual with decision-making support, and how do such models address the related issues of third party reluctance to deal with individuals with limitations in decision-making abilities and the possibility of conflicting actions by the principal and the support agent?

communicated by the support person or representatives must be legally recognized. *Id.* at Part 1(11), Part 2(25).

258. See Questions and Challenges, *supra* note 238, at 9–17 (discussing various features of supported decision-making models).

2. What are the qualifications for persons or entities serving in the support role, what resources and training are needed to ensure that they are qualified to serve in that role, and what oversight and monitoring is needed to minimize the possibility of exploitation, abuse, or corruption?
3. Who bears responsibility for the costs or expenses associated with the process and how would the costs of such an alternative system of supported decision making compare with the costs of current surrogate decision-making models?²⁵⁹
4. Finally, and perhaps most difficult, how does the system deal with individuals who need but do not want assistance with decision making or who are unable to effectively participate in the decision-making process even with support? Stated differently, when does the system allow for appointment of a surrogate decision maker and what standards are utilized for that appointment?²⁶⁰

In order to encourage the development of a range of supported decision-making options, it will be crucial to demonstrate that they are superior to and more integrative than the surrogate decision making default of guardianship.

259. "Establishing comprehensive support networks requires effort and financial commitment," but current guardianship models also involve the significant effort of many parties and significant costs, which could be shifted to create a system of supported decision making. See Byrnes et al., *supra* note 64; see also text accompanying notes 225–27.

260. One characteristic of the guardianship system is that it tends to minimize individual capabilities. Virtually everyone has the ability to participate in the decisions affecting his or her life, with the possible exceptions of persons who are comatose or in a persistent vegetative state. For example, in the context of certain medical treatment decisions, the MacArthur Treatment Competency Study III found that 50 percent of persons hospitalized for schizophrenia and 75 percent of persons hospitalized for major affective depression demonstrated an ability to make decisions regarding medical treatment that were comparable to a sample of hospitalized heart patients and "community controls." Thomas Griso & Paul S. Appelbaum, *The MacArthur Treatment Competence Study III: Abilities of Patients to Consent to Psychiatric and Medical Treatments*, 19 L. & HUM. BEHAVIOR 149, 171–72 (1995); see also Winick, *supra* note 30, at 21–22.

The question remains whether supported decision-making options might have assisted Ms. G. In Ms. G's case, there was a point in time when some housekeeping intervention might have been extremely helpful to her and could have enhanced the quality of her life and enabled her to continue to live in the community. Clearly, she was resistant to assistance. However, due to the lack of acceptable alternatives, Ms. G was caught in the void between autonomous decision making with no support and involuntary, surrogate decision making. In the final analysis, those who knew her decided that the risk to Ms. G resulting from the continued exercise of her full legal capacity was outweighed by the probable harm resulting from the guardianship process and the likely appointment of a surrogate decision maker. Some may disagree that this was the better choice. But it seems likely that had a trained legal mentor or support person been able to develop a trusting relationship with Ms. G, he or she might have been able to persuade her to agree to housekeeping services and to assist her in coping with the intrusion into her apartment that she found so traumatic. In the end, we will never know if a supported decision-making model would have been sufficient to maintain Ms. G's life in the community. Yet it remains tragic that there were not acceptable alternatives to guardianship that could have enabled Ms. G to manage her affairs without divesting her of the right to make decisions for herself.

CONCLUSION

Due to the decades of work by scholars and advocates, most state guardianship laws now reflect significantly greater concern for the autonomy and self-determination of people with disabilities. But the guardianship system is inherently flawed for two reasons. First, it "assists" individuals with limitations in decision-making capabilities by divesting and transferring the right to make some or all decisions to another entity. Second, because it focuses on the determination of whether the individual is "incapacitated" and therefore in need of a guardian, or is not "incapacitated" and entitled to dismissal of the guardianship petition, the prevailing guardianship system does not adequately provide for legally recognized options that fall somewhere between autonomous and substituted decision making. There is no mechanism for the legal recognition of de-

cisions that an individual can only make with appropriate support. Nor is there a legal mechanism that enables an individual with limitations in decision-making abilities to appoint his or her own decision-making agent to assist with personal and financial affairs and to have those decisions recognized and followed by others.

In contrast to guardianship, the supported decision-making paradigm presumes each person's capacity and ability. It shifts the focus from a perceived deficiency in the individual ("incapacity") to the social responsibility to provide assistance with decision making, significantly limiting the stigmatization and marginalization caused by guardianship. In addition, by vesting each person with a disability with the "right" to participate in all facets of the decision-making process—the big decisions (whether to have surgery, transfer ownership of a home, move to a different residence, marry), and the smaller decisions (whether to make a modest gift, which account to withdraw money from, whether to travel out of town, which friend to see)—each person remains more fully and concretely involved in the activities of his or her life and community.

No one pretends that supported decision making is any more of a science than guardianship or surrogate decision making. But, because the stakes involved in the loss of autonomy are so high, other countries have started to formally design and implement national programs of supported decision making. The programs are evolving and have imperfections, but they all operate from a position that recognizes the centrality of the individual to his or her own life's choices, regardless of disability.

Relying on *Olmstead* and the integration mandate for a theoretical construct, this Article has attempted to craft an argument under the Americans with Disabilities Act for mandating supported decision-making services as a less restrictive alternative to guardianship. The strength of such an integration mandate challenge will depend in large part on future trends in the law under Title II of the ADA. However, in order to develop this legal argument (and hopefully persuade the courts and legislatures), additional work is needed to compare and evaluate existing supported decision-making models and to demonstrate their value in human and financial terms relative to the human and financial costs of guardianship.

Just as it took years to develop the evidence and educate the necessary parties—courts, legislatures, government agencies, and health professionals—about the ability of virtually all

persons with disabilities to live outside institutions with adequate support, similar work will be needed to demonstrate the ability of virtually all individuals to make decisions and express their preferences and wishes if they have the appropriate support. As states begin to develop comprehensive supported decision-making options, it will be useful to think of ways to utilize existing service programs (such as the intensive case management programs that are currently providing support with personal and financial affairs) to determine how they might be modified and expanded. Additionally, we should think about ways of modifying other existing service programs, like independent living programs, home health care, or habilitation services, to provide legally recognized, supported decision-making assistance in a manner that is sufficiently protective of the principal's rights.

This Article raises many questions, legal and non-legal, and only begins to answer them. Many of the challenges and the promises presented by supported decision making are not new, and have been considered during the debates on guardianship reform. But those reforms do not appear to have taken us as far as we might have hoped to go. The challenges in this context involve serious questions of human value and self-determination, including the right to a life free from exploitation or abuse. The importance of these challenges compels us to look for further solutions.

In the CRPD, the international community has spoken with regard to the human right to enjoy legal capacity regardless of disability and the related right to obtain appropriate and necessary support in exercising that legal capacity. As articulated by Professor Amita Dhanda, the shift toward the recognition of universal capacity and the provision of necessary decision-making support will create:

[A regime in which] all human beings are accorded the lead role in the dramas of their lives with everyone and every thing else which assists in the effective performance of that drama being only cast in support. The support players can shore up the lead player but cannot displace or replace him or her.²⁶¹

Despite its reform, guardianship does not provide the most integrated form of assistance with decision making. If the ADA

261. Dhanda, *supra* note 30, at 459.

is to fulfill its intended purpose of eliminating the unnecessary isolation of individuals with disabilities and ensuring their full participation in life's activities, the Act must be construed to require that supported decision making be provided in lieu of guardianship under most circumstances. By re-conceptualizing guardianship as one lingering mechanism of disability-based exclusion, we can begin to look at our obligation to individuals with limitations in decision-making abilities in a different way. Rather than focusing on how to improve the guardianship process, we will consider innovative ways to integrate persons with diminished mental capabilities to the greatest extent possible into the management of their personal and property affairs. With the appropriate level of decision-making support, individuals with disabilities will be further integrated into the "theater" of human activity and guardianship will rarely be needed and will be utilized in only the most extreme circumstances. As the number of individuals living with disabilities continues to grow, there is an urgent need for further reform.