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Table of contents

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I. Introduction

L.C. v. Olmstead[1] was brought on behalf of two individuals with psychiatric and intellectual disabilities to challenge their unnecessary segregation in a Georgia mental institution.[2] Both women were very clear about their desire to leave the institution; L.C. pleaded "on a daily, sometimes hourly, basis to be released" from the hospital into the community.[3] Both wanted to receive habilitation services in a community setting. At no point prior to the Supreme Court appeal was choice about whether to remain in or leave the institution an issue confronted by any court in this case. Thus, neither the district court nor the Court of Appeals even considered, let alone addressed, how a public entity's obligation to provide its programs, services, or activities in the most integrated setting affected persons with disabilities who did not affirmatively request integrated services.

While the *Olmstead* case, at least in the lower courts, never presented any question about the named plaintiffs' choice of where to live, the Supreme Court felt compelled to address this issue and include it in its three prong test for determining a violation of the Americans with Disabilities Act's (ADA) integration mandate,[4] in part because the Court was pressed by *amici curiae* to consider the impact of its decision on all persons in segregated facilities and in a broad range of state institutions.[5]

[1]*L.C., by Zimring v. Olmstead*, 1997 WL 148674 (N.D. Ga. Mar. 26, 1997), *aff'd and remanded*, 138 F.3d 893 (11th Cir. 1998), *aff'd in part, vacated in part, remanded sub nom. Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

[2]*L.C., by Zimring v. Olmstead,* No. CIVA1:95-CV-1210-MHS, (N.D. Ga.) (Complaint filed May 11, 1995), Complaint at 17.

[3]*Id*.

[4]*Olmstead,* 527 U.S. at 607.

[5]Brief for the Voice of the Retarded *et al*, as *Amici Curiae* in Limited Support of Affirmance, *Olmstead v. L.C.*, 527 U.S. 581 (1999), 1999 WL 65069 at 9-11 (hereafter VOR *Amici* Brief); Brief for the American Psychiatric Association *et al.*as *Amici Curaie* Supporting Respondents, *Olmstead v. L.C.*, 527 U.S. 581 (1999),1999 WL 134004 at 23 (hereafter APA *Amici* Brief); Brief of National Centers for Independent Living *et al* as *Amici Curaie* Supporting Respondents, *Olmstead v. L.C.*, 527 U.S. 581 (1999), 1999 WL 106726 at 6-10; Brief of People First of Georgia *et al.* as *Amici Curaie* Supporting Respondents, *Olmstead v. L.C.* 527 U.S. 581 (1999), 1999 WL 143932; Brief of National Mental Health Consumers' Self-Help Clearinghouse *et al.* as *Amici Curaie* Supporting

Since the Supreme Court's seminal *Olmstead* decision, only a few lower courts have addressed the "do not oppose" prong of the holding, and even fewer have relied upon this factor to deny relief.[6] Only a handful of courts have sought to describe what constitutes evidence of opposition to moving to the community, and none have defined the conditions, processes, factors, or standards for determining whether individuals with disabilities have made an informed choice to remain in the institution and/or to knowingly refuse integrated services. There appears to be virtually no discussion of the professional research and literature on how various disabilities impact decision making, and no application of such knowledge to the legal conclusion of opposition to community placement. Finally, despite the centrality of choice in all decisions concerning living, working, socializing, and receiving supports, no court has engaged in a detailed analysis of the scope of the public entity's duty, and the practical methods for fulfilling that duty, to ensure that institutionalized persons with disabilities make a knowing and informed choice whether to remain in a segregated facility.

This article provides a conceptual framework and practical guidelines for applying the do not oppose prong of the Court's *Olmstead* test. It seeks to demonstrate that both *Olmstead* and the ADA require that a decision to remain in a segregated setting must be a knowing and informed choice made by the individual, with accommodations to both the person's disability and the vestiges of institutionalization. Where the person is under guardianship, any decision to oppose integration must be subject to judicial review and approval.

II. The Emergence of Choice in the Evolution of the Olmstead Case

A. The Evolution of a Lawsuit Involving Two Individuals Who Clearly Wanted to Leave the Institution to a Supreme Court Decision Holding that the Right to Live in the Community Is Qualified by Individuals' Lack of Opposition to Community Treatment

Prior to the filing of the original complaint, L.C. and E.W. were shuffled between the state hospital and inappropriate community locations, such as homeless shelters and poorly staffed programs.[7] Since they were not

Respondents, *Olmstead v. L.C.*, 527 U.S. 581 (1999), 1999 WL 143940; Brief of 58 State Commissioners as *Amici Curaie* Supporting Respondents, *Olmstead v. L.C.*, 527 U.S. 587 (1999),1999 WL 143935; Brief of 23 States as *Amici Curaie* Supporting Petitioners, *Olmstead v. L.C.*, 527 U.S. 581 (1999), 1999 WL 60990.

[6]A Westlaw search of cases citing to *Olmstead* reported after June 1999 reveals approximately 750 federal court decisions. Of these, it appears that fewer than 25 specifically concern the "do not oppose" standard and far fewer rely upon it for its holding.

[7]*L.C., by Zimring v. Olmstead,* No. CIVA1:95-CV-1210-MHS, (N.D. Ga.) (Complaint filed May 11, 1995), Complaint at 10-12.

provided with necessary and appropriate support services or habilitation services in the community,[8] their time outside of the institution was often cut short, forcing their untimely and undesired return to the state run institution. Even though L.C.'s and E.W.'s treatment professionals determined that community treatment would be beneficial and appropriate, both waited years for their community placements.[9]

Alleging a violation of the integration mandate of title II of the Americans with Disabilities Act,[10] the two women brought suit to compel the State of Georgia, through its senior state mental health officials, to provide them needed services and supports in the most integrated setting.[11] The district court afforded relief, and the Court of Appeals affirmed, holding that Georgia's Department of Mental Health must make reasonable modifications to its community mental health program necessary to allow L.C. and E.W. to leave the institution, and that doing so would not constitute a fundamental alteration of the State's program.[12]

On appeal to the Supreme Court, a plurality decided that Georgia had discriminated against L.C. and E.W. by confining them in the state mental hospital where they were segregated from the community and forced to live only with other persons with disabilities.[13] The Court held that people with disabilities have a qualified right to receive state-provided services in the community rather than in an institutional setting if three conditions are met: 1) the individual's treatment professionals determine that community placement and support would be appropriate for the individual, 2) the individual "do[es] not oppose" community placement, and 3) providing services in the community would be a reasonable accommodation and not a fundamental alteration of the government service being provided.[14]

Although the *Olmstead* case intentionally was not framed as a class action, the Supreme Court was reluctant to view the legal issues as only concerning the two named plaintiffs. Prompted by the briefs from the appellants, the United States, and numerous *amici,* the Court recognized that there were tens of thousands of individuals who were unnecessarily institutionalized, that States operated thousands of segregated facilities, and that there were a wide range of disabilities, preferences, support services,

[8]*Id.* at 10-14.

[9]*Id.* at 17; *see also, L.C., by Zimring v. Olmstead,* No. CIVA1:95-CV-1210-MHS, 1997 WL 148674, at *3 (N.D. Ga. Mar. 26, 1997), *aff'd and remanded,* 138 F.3d 893 (11th Cir. 1998), *aff'd in part, vacated in part, remanded sub nom. Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999).

[10]42 U.S.C. § 12131.

[11]*Olmstead, supra* note 7, Complaint at 22-24.

[12]*L.C., by Zimring v. Olmstead,* No. CIVA1:95-CV-1210-MHS, 1997 WL 148674, (N.D. Ga. Mar. 26, 1997), *aff'd and remanded* 138 F.3d 893 (11th Cir. 1998).

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

[14]*Id.* at 607.

programs, and costs relevant to any analysis of reasonable modifications and fundamental alteration. As a result, the Court concluded that the lower courts' approach to these issues was unrealistically narrow, and, if applied literally to other persons with disabilities bringing other individual lawsuits, would "leave the State virtually defenseless once it is shown that the plaintiff is qualified for the service or program she seeks."[15] By effectively expanding the appeal to all similarly-situated persons, much like a class action, the Court was forced to consider both the protests of those who "do not desire" community care,[16] as well as those who arguably could not "handle and benefit" from such placement.[17]

Several *amici* and Justice Kennedy's concurrence expressed concern that individuals who did not want to leave institutions or were not capable of living safely in the community would be forced out of public institutions and end up on the street or in jail.[18] This fundamental fear, which likely reflects society's longstanding stereotypes of persons with disabilities and particularly persons with mental illness, was raised often in the oral argument and in many of the *amici curiae* briefs filed by other States, some family and advocacy groups, and some professional associations. Additionally, some of the *amici*, particularly Voice of the Retarded (VOR), which is comprised of parents and guardians of individuals with intellectual and developmental disabilities (IDD), as well as the American Psychiatric Association (APA), raised paternalistic arguments about people with severe mental illness or profound physical and cognitive disabilities for whom community placement required intensive supports, and, in their view, was not appropriate.[19] These *amici* argued that individuals with disabilities and their parents or guardians should be able to *choose* institutional care.[20] While the issue of choice was never squarely presented or confronted in any portion of the prior *Olmstead* proceedings or in the parties' briefings in any court, the Court's ultimate adoption of a "do not oppose" standard reflected three interests: 1) the integration mandate and congressional intent in enacting the ADA, which was to end the sordid legacy of institutionalizing and isolating persons with disabilities and to compel public entities to include them in to the mainstream of American society; 2) the position of respondents L.C. and E.W. that they clearly wanted to leave the state psychiatric hospital, and had a right to community placement, based

[15]*Olmstead, supra* note 13, at 603.

[16]*Id.* at 602.

[17]*Id.* at 600.

[18]*Olmstead v. L.C. ex rel. Zimring*, 1999 WL 252681 at 34 (Oral. Arg., April 21, 1999).

[19]VOR Brief *Amici Curaie* at 9-11; APA *Amici* Brief at 23.

[20]This was the origin and foundation of VOR's right to remain arguments in opposition to subsequent *Olmstead* cases challenging the closure of institutions, discussed in Section III.C, *infra.*

on their facts;[21] and 3) the argument of certain *amici* like VOR that for some people remaining in the institution was not only appropriate, but their or their parents' choice. The third interest is arguably inconsistent with the Court's "evident judgment[]" that unnecessary institutionalization "severely diminishes the everyday life activities of individuals" including the experience of making choices about almost every aspect of one's life, and even inhibits the ability to develop choice-making capabilities.[22]

B. The Evolution from a Choice to Leave the Institution to a Do Not Oppose Community Placement Standard

Only a few *amici* directly addressed the issue of choice. The brief of the National Council on Independent Living (NCIL) relied extensively on Congressional testimony from individuals who discussed the importance of choice, autonomy, and independence.[23] NCIL's brief reviewed the distorted purpose and historical abuses of the institutionalization of persons with disabilities. It pointed to federal policy, state rules, and professional literature that support the preference of virtually all individuals with disabilities to live in the community.[24] Finally, it framed the legal question before the Court as a recognition that Congress' intent in enacting the ADA was to create a mandate to provide a choice of where to receive services.[25] At its core, the NCIL brief is about the congressional and statutory mandate for States to provide service options and to allow individuals to make a choice. VOR and the APA, on the other hand, presented a litany of horror stories about failed deinstitutionalization policies, forced community placements, and what they characterized as the erroneous presumption by some professionals and advocates that the default position for all institutionalized people is to move to the community.[26]

The Court's do not oppose standard likely was a judicial compromise between these competing views, with deference to Congress' intent in enacting the ADA,[27] and to the Attorney General's

[21]As the Supreme Court notes, "there is no serious dispute concerning the status of L.C. and E.W., as individuals 'qualified' for noninstitutional care; the State's own professionals determined that community-based treatment would be appropriate for L.C. and E.W., and neither woman opposed such treatment." *Olmstead,* 527 U.S. 602-03.

[22]*Olmstead,* 527 U.S. at 600-01.

[23]NCIL *Amici* Brief at 6-10.

[24]*Id.* at 10-11.

[25]*Id.* at 11-12.

[26]*See supra* n.20.

[27]The preamble to the ADA, set forth as the Act's Purposes, includes the recognition that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2).

integration regulation.[28] The do not oppose standard encompasses the default preference for integration, but allows for an individual's affirmative opposition to community placement, in order to preserve the individual's choice even if that choice is to remain in the institution. VOR also suggested that parents and individuals together should be making the choice; however, the Court did not adopt this position.

Given the first prong of the *Olmstead* test, which determines whether community placement is appropriate for an individual, the do not oppose framework means that transition to the community – at least for the vast majority of individuals with disabilities where there is a professional consensus that community care is appropriate – will control unless the individual affirmatively opposes such placement. This approach simultaneously preserves the default of integration while avoiding compelling treatment against the person's will.

Questions asked by the Justices during oral argument suggest that they leaned toward deferring to the judgment of treatment professionals whenever they believed that the individual is able to benefit from community services.[29] It appears that the Court was far more troubled by the prospect of inappropriate community placements, which L.C. had herself experienced and which Justice Kennedy's concurrence noted,[30] than by a concern about ensuring an informed choice about where to live and receive services. Arguably, the Court was convinced by federal policy and professional judgment that few people would truly want to remain in an institution.

The Court might have recognized that the law commanded community care, at least where there was no viable argument about fundamental alteration, since the integration regulation makes clear that States must provide services in the "most integrated setting appropriate to their *needs*"[31] and makes no mention of choice as a factor in the equation. Given that the Court was not expressly concerned with the issue of choice at the oral argument, it also is possible that the do not oppose standard was mostly an effort to acknowledge VOR's position, and oddly that of NCIL and other *amici*, which emphasized the importance of choice as an expression of autonomy regardless of whether medical professionals believed an individual could benefit from community placement.

Finally, the do not oppose standard could be understood as a product of the widening of scope of the case when *Olmstead* reached the Supreme Court. As the Court's analysis correctly recognized, even though this lawsuit was only about two women from Georgia, their decision would have

[28] 28 C.F.R. 35.130(d).

[29] *Olmstead v. L.C. ex rel. Zimring*, 1999 WL 252681 (U.S.), 42-43 (U.S.Oral.Arg, 1999).

[30] *Olmstead,* 527 U.S. at 608-10.

[31] 28 CFR § 35.130(d)(2010) (emphasis supplied).

serious implications for all other persons with disabilities who were either presently confined in state institutions or who sought community care.[32] Further, the Court acknowledged, in its reframing of the fundamental alteration analysis, that its decision would have profound implications for every State's disability service system.[33] This broadening of scope prompted the Court to consider how individuals other than L.C. and E.W., who were potentially less clear about their desire to live and receive services in the community, would be impacted by their decision.

III. The Application of *Olmstead's* Do Not Oppose Standard

A. Judicial Applications of Olmstead's *Choice Standard*

Few courts have directly addressed *Olmstead's* do not oppose standard, and even fewer have relied upon the issue of choice in rendering an *Olmstead* ruling. These decisions mostly have assessed choice issues in the context of procedural disputes like class certification under Fed. R. Civ. P. 23(a) and intervention under Fed. R. Civ. P. 24, usually in response to the views of parents or guardians who prefer their family members remain in institutions. The very few courts that have relied upon choice to determine if individuals are qualified for community services have focused on the process for assessing individual preference, the information provided about community alternatives, and the impact of institutionalization on the person's choices. Unfortunately, no court has squarely discussed what constitutes informed choice or how courts should assess whether a choice is truly informed.

1. The Requirement to Assess and Evaluate Choice

Courts have been reluctant to establish or endorse any particular methodology for assessing choice.[34] Instead, they have focused either on the interplay of the choices of guardians and individuals with the assessments of treatment professionals, or the procedures for balancing competing preferences. No court has addressed the standards or criteria for determining preference.

In *Messier v. Southbury Training School*, the court considered the sequence for determining whether a person opposed community living.[35] The defendants argued that their treatment professionals' duty to determine the most integrated setting appropriate to the individual's need was not

[32] *Olmstead,* 527 U.S. at 605.

[33] *Id.* at 605-606.

[34] *Ill. League of Advocates for the Developmentally Disabled v. Ill. Dep't of Human Services,* 60 F. Supp. 3d 856, 879 (N.D. Ill. 2014) ("[W]e are not in a position to determine if whether [the] process satisfies some articulated objective level of acceptability").

[35] *Messier v. Southbury Training School,* 562 F. Supp. 2d 294 (D. Conn. 2008).

triggered until an individual affirmatively requested community placement.[36] The court held that "[s]uch an attitude is inconsistent with the integration mandate of the ADA and § 504."[37] The court went on to note that:

> There is a significant difference between, on one hand, a procedure in which a guardian's response to a somewhat misleading question on a survey determines whether or not the ward will ever be considered for community placement and, on the other hand, a process in which guardians are allowed to consider community placement during an IDT meeting at which the guardian has an opportunity to consult with professionals and with the ward. The former procedure deprives class members of their constitutional right to the exercise of professional judgment and undermines the integration mandate of the ADA and Section 504. The latter procedure appears to the court to be consistent with these laws.[38]

The *Messier* court decided that not only are treatment professionals required to make determinations about individual's appropriateness for community living regardless of their choice, but also that the process must be collaborative and include the exchange of information on the array of placement options.[39]

Significantly, another court rejected the objections of the Illinois League of Advocates to a special assessment process that was conducted by an external professional entity, that was based upon a presumption that all persons could live safely in the community, and that explicitly excluded the treatment professionals of the Murray Developmental Center which was scheduled to close.[40] As the court noted, it was not surprising that the process determined that every facility resident was qualified to live in the community, given the professional consensus about the benefits of integrated services, or that the views of facility staff were not considered, given their determined opposition to closure.[41]

Finally, in *People First of Tennessee v. Clover Bottom Developmental Center,* the court rejected the argument of the United States and the plaintiffs that decisions of treatment professionals recommending integrated services should displace the choices of individuals or their guardians.[42] In an attempt to reconcile the integration mandate, *Olmstead's* choice requirement, and a provision of the Medicaid Act[43] that grants consumers freedom of choice in regard to their preferred provider, the court stated:

[36] *Id.* at 329.

[37] *Id.*

[38] *Id.* at 338.

[39] *Id.*

[40] *Ill. League,* 60 F. Supp. 3d at 865-68.

[41] *Ill. League, supra* note 40,. at 866-67.

[42] *People First of Tenn v. Clover Bottom Developmental* Ctr., 753 F. Supp. 2d 701 (M.D. Tenn. 2010).

[43] 42 U.S.C. § 1396a(a)(23)(A) and 42 U.S.C. § 1396n(2)(C).

> As the Supreme Court recognized in *Olmstead,* there is no federal requirement under the ADA that community-based treatment must be imposed on citizens who do not desire it. There is also no express requirement in the Settlement Agreement imposing community-based treatment on citizens where they or their conservators have opted for institutional … care. Because there are no such requirements in federal law or the Settlement Agreement, there is no merit to the contention of the United States and People First that the professional judgments [of treatment teams] as to appropriate community placement of a class member must always prevail over the citizen's own choice (expressed individually or through a guardian or conservator) of a qualified provider.[44]

Thus, the court determined that the preferences of individuals – in most cases, that of their guardians – prevail, even when that choice is for a more restrictive setting.

2. The Requirement to Provide Information and Education About Options

Remarkably, few courts have addressed the State's responsibility to provide information and education to persons in or at risk of entering segregated facilities, in order to allow them to understand their options and the benefits of receiving services in integrated settings. One court endorsed the importance of "in-reach" as a strategy to educate individuals in segregated settings, to combat their experience of institutionalization, and to provide enough information to individuals, in a format that they understand, so that they can make an informed decision about whether to transition to a community placement.[45] The court concluded that, "with accurate information and a meaningful choice, many Adult Home residents would choose to live and receive services in a more integrated setting, such as supported housing."[46] The court held that, because of the effects of institutionalization and learned helplessness, education, information, and targeted strategies like in-reach are needed to allow institutionalized persons to make informed decisions about whether to oppose a transition to the community. Several other courts have agreed and ruled that educational efforts must be undertaken to ensure informed choices are made by individuals with disabilities.[47]

[44]*People First of Tenn,* 753 F. Supp. 2d at 713-714 (internal citation omitted).

[45]*Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 214-15 (E.D.N.Y. 2009), *vacated on other grounds sub nom. Disability Advocates, Inc. v. New York Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149, 215, n 293 (2d Cir. 2012).

[46]*Id.* at 267.

[47]*Lane v. Kitzhaber*, 283 F.R.D. 587, 600 (D. Or. 2012) (in defining class, court refuses to exclude individuals who did not request Competitive Integrated Employment because they were not informed of the options of Competitive Integrated Employment); *Day v. District of Columbia*, 894 F. Supp. 2d 1, 20, 29-30 (D.D.C. 2012) (court denies summary judgment because defendants failed to provide information on housing options to individuals in nursing facilities); *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 240 (D. Mass. 1999) (defendants have an affirmative duty to inform individuals as to the options for community placement).

3. The Impact of Institutionalization on Choice

When individuals are institutionalized, particularly for extended periods of time, they often become passive, dependent, accustomed to institutional routines, and conditioned to believe that they can only live safely in a segregated facility. This phenomenon is commonly referred to as either institutionalization or learned helplessness.[48] Since learned helplessness results in institutionalized persons becoming "highly reluctant to move on, even if they are capable of living independently,"[49] additional education and deinstitutionalization efforts are needed to effectuate any community placement plan and ensure an informed choice. Moreover, their guardians or family members often become convinced that the person needs the institution's level of care and supervision, which, they believe, is not available outside of a segregated setting.

The court in *Disability Advocates Inc. v. Paterson* described the nature of this educational program as:

> Comprehensive education about supported housing [which] must consist of more than merely providing factual information to adult home residents. Crucially, the process must include efforts to build trust, to emphasize strengths, and to encourage the exercise of informed choices in order to adequately address the court's findings concerning the learned helplessness and fears instilled in many [adult home residents], the homes' discouragement of residents from leaving, and residents' lack of awareness of housing alternatives and the availability of services in supported housing.[50]

The court stated that "Adult home residents will likely require multiple meetings or discussions, and perhaps even trips to see what supported housing apartments look like, in order to address their specific concerns and help them to overcome their fear of leaving the institution."[51]

[48] *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d at 214-15 (E.D.N.Y. 2009) (explaining that "when individuals are "treated as if they're completely helpless, the helplessness becomes a learned phenomenon.") Even the State's senior official conceded that "the skills of community living are eroded by the routines of institutional life." The district court went on to note, speaking about institutions called Adult Homes, that:

> The Adult Homes discourage—and some outright prohibit—residents from cooking, cleaning, doing their own laundry, and administering their own medication. The Adult Homes also generally manage residents' personal needs allowances, distributing cash to residents on specified dates and times. The result is that Adult Home residents lose skills that they had prior to living in the Adult Home—such as medication management—because they are forbidden from practicing those skills in the Adult Home.

(citations omitted).

[49] *Disability Advocates, Inc*, 653 F. Supp. at 215-16.

[50] *Disability Advocates, Inc. v. Paterson*, No. 03-CV-3209, 2010 WL 786657, at *3 (E.D.N.Y. Mar. 1, 2010*), vacated sub nom. Disability Advocates, Inc. v. New York Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012) (internal citations omitted).

[51] *Id.* In rejecting the defendants' proposed remedial plan, the court held that "Defendants' proposal for a once-a-year 'educational opportunity' cannot hope to address the significant barriers to change found by the court." *Id.* at 3.

4. Procedural Applications of Choice

Class members' expressed choices, and more frequently the expressed opposition of guardians or family members, can play a key role in the definition of a class, the likelihood of class certification or decertification, and in the probability of intervention.[52] In fact, the majority of judicial decisions considering *Olmstead's* do not oppose standard are in the context of these procedural issues, and almost always are raised by guardians or family organizations that support institutions and oppose community living, both in principle and practice.

Courts have determined that the preference for community or institutional care is a relevant factor in assessing commonality and adequacy of representation under Fed. R. Civ. P. 23(a) and a single remedy under Rule 23(b).[53] For example, the state defendants in *Ball* argued that class definition lacked homogeneity of interests because:

> The definition implicates three groups of individuals with differing interests: (1) individuals who reside in a Large ICF, and after receiving options counseling, express that they are interested in integrated community-based services, (2) individuals who reside in a Large ICF, and after receiving options counseling, express that they may be interested in integrated community-based services, and (3) individuals who are at serious risk of institutionalization by placing themselves on a waiting list for community-based services, expressed an interest in receiving integrated services while continuing to live in the community.[54]

Thus, how the class is defined with respect to the choice whether to remain or leave the institutional setting often determines if an *Olmstead* class will be certified.

Courts have decertified classes when it became clear that there were antagonistic interests concerning choice within the certified class. In *Ligas*, class members who opposed community placement were deemed to be antagonistic to the interests of the rest of the class. The court decertified the class but then ultimately approved a new class definition which

[52]Some courts have rejected arguments opposing class certification in *Olmstead* cases when objectors claim that the named plaintiffs do not share common facts or claims with, or do not adequately represent, those who oppose community living. *Colbert v. Blagojevich*, No. 07 C 4737, 2008 WL 4442597, at *5 (N.D. Ill. Sept. 29, 2008); *Capitol People First v. State Dept. of Developmental Services*, 155 Cal. App. 4th 676, 693 (2007) ("The overarching theme is that there is a pattern and practice of failure to meet constitutional, statutory and regulatory mandates to provide services and place class members in less restrictive settings, and the systemic effect of this failure is to impinge plaintiffs' rights under state and federal law, thus, creating common questions").

[53]*See Ligas v. Blagojevich*, 2006 U.S. Dist. LEXIS 10856, at *12 ("While defendants argue that the different medical issues, treatment options, and placement histories affecting each plaintiff prevent the court from finding a common answer to these questions, the factual variations identified relate to the level of injury suffered and not [to] whether the defendants' conduct was sufficient[ly] standardized."); *see also Ball v. Kasich*, 307 F. Supp. 3d 701, 713-714 (S.D. Ohio 2018) ("The Ohio Defendants respond that Plaintiffs cannot meet their burden to show an appropriate 23(b)(2) class because their proposed class is not cohesive with homogenous interests. . . . If a court is going to give the same answer for everyone, it needs to be confident everyone wants the same thing.") (internal quotations omitted).

[54]*Ball*, 307 F. Supp. 3d at 714.

explicitly excluded those individuals.[55] Other courts have required class definitions to consider the issue of choice and explicitly exclude those who oppose community placement. Significantly, courts have not developed an explicit definition of informed choice for the purpose of assessing if individuals are or are not members of the class.

In cases that involve the restructuring of services systems, guardians and parent organizations may seek to intervene in order to protect their interests in the preservation of institutional settings, either during the merits or remedial phases of the litigation. These intervenors often have interests that are contrary to the interests of class members, but courts are split on whether their wishes justify intervention.[56]

B. The Dilemma of No Expressed Preference

When individuals have no preference concerning integrated services, lack the ability to readily communicate a preference, or remain silent when asked about their preferences, a default is needed to determine where the individual should receive services. Consistent with *Olmstead's* do not oppose standard, some courts have endorsed the default of community placement, at least in the settlement context. In *Benjamin*, the Third Circuit noted that "the annual and mandatory assessment procedure appears to involve a kind of default rule" for some residents.[57] The court determined that the settlement expressly stated that "[i]f the state ICF/MR resident does not express opposition to considering community placement, the resident will be placed on the State ICF/MR Planning List [unless their guardian opposes community placement]."[58] The court interpreted the state's Assessment Protocol to regard silence as an indication of no preference,[59] reasoning that:

[55]*Ligas v. Maram*, 2009 WL 9057733 at *2 (N.D. Ill. July 7, 2009).

[56]*See Benjamin ex rel. Yock v. Dep't of Pub. Welfare of Pennsylvania*, 701 F.3d 938, 952 (3d Cir. 2012) ("Just like the actual class members, [intervenors] may be affected by the Settlement Agreement and, among other things, appear to be in "the best position to apprise the court of any unforeseen or undisclosed impact that the class definition may have on its evaluation of [a settlement agreement]."") (internal citations omitted); *but see Capitol People First v. State Dep't of Developmental Servs.*, 155 Cal. App. 4th 676, 698–99 (2007) ("The organizational interests of these groups, while contributing an important voice, cannot in themselves conjure up a conflict within the class. . . . No matter how well intentioned parents and conservators may be, they cannot exert their influence to curtail or deny the due process rights of persons with developmental disabilities.") (internal citations omitted); *see also Ligas ex rel. Foster v. Maram*, 478 F.3d 771 (7th Cir. 2007) intervention was improper because case did not impair the interests of individuals with disabilities who did not wish to move to the community.); *but see Ball v. Kasich*, No. 2:16-CV-282, 2017 WL 3172778, at *12 (S.D. Ohio July 25, 2017) (allowing intervention of guardians in order to protect the interests of those who do not desire community placement.); *see also Benjamin v. Dep't of Pub. Welfare of Cmwlth.*, 267 F.R.D. 456, 461 (M.D. Pa. 2010), *aff'd sub nom. Benjamin v. Dep't of Pub. Welfare of Pennsylvania*, 432 F. App'x 94 (3d Cir. 2011) (residents of ICFs/MR who oppose forced placement in community care properly were denied intervention for failing to allege interests that was significantly protectable in action).

[57]*Benjamin ex rel. Yock v. Dep't of Pub. Welfare of Pa.*, 701 F.3d 938, 954 (3d Cir. 2012).

[58]*Id.*

[59]*Id.*

> It appears that a resident whose disabilities are so severe that he or she is incapable of expressing, in some fashion, where he or she wishes to live—and who otherwise lacks a guardian or involved family member or his or her guardian or involved family member fails to express *opposition* to community placement—must be placed on the Planning List [for community placement].[60]

Thus, the court decided that the default for an individual who either has no preference or remains silent, and does not have a guardian who opposes community placement, must be for community placement.

In the only case that cites to *Benjamin* for a choice-related proposition, *Williams v. Quinn*,[61] the court decided, consistent with *Benjamin* and *Olmstead,* that the default must be to place individuals who have no preference or who remain silent in the community, because they have not *opposed* community placement.[62] In *Quinn*, objectors contended that "only those who affirmatively choose to be evaluated for community placements should be evaluated."[63] However, the court disagreed and decided that:

> The language of the Decree [] is consistent with *Olmstead,* 527 U.S. at 607, 119 S.Ct. 2176, which provides that community placement that can be accommodated should be provided as long as it is not opposed by the recipient. *See also Ligas ex rel. Foster v. Maram,* 478 F.3d 771, 775 (7th Cir.2007); *Omega Healthcare Investors, Inc. v. Res–Care, Inc.,* 475 F.3d 853, 864 (7th Cir.2007); *Colbert* [*v. Blagojevich*], 2008 WL 4442597 at *1; *Benjamin v. Dep't of Pub. Welfare of Commonwealth.,* 267 F.R.D. 456, 461–62 (M.D.Pa.2010); *DAI,* 653 F.Supp.2d at 267. The language of the Decree is also consistent with federal ADA regulations. *See* 29 C.F.R. § 35.130(e)(1) ("Nothing in this part shall be construed to require an individual with a disability to accept an accommodation, aid, service, opportunity, or benefit provided under the ADA or this part *which such individual chooses not to accept."*) (emphasis added). The opt-out nature of the evaluation procedure is consistent with applicable law.[64]

Thus, the court ruled that a default of community placement – in the absence of an expressed preference or in the presence of silence – is consistent with the do not oppose standard of *Olmstead*, as well as underlying federal law and relevant judicial precedents.

C. The Consequences of Expressed Opposition

Seizing on the language in Justice Kennedy's concurrence that institutional settings are appropriate for some individuals,[65] and Justice Ginsburg's

[60] *Id.*

[61] *Williams v. Quinn*, 748 F. Supp. 2d 892 (N.D. Ill. 2010).

[62] *Quinn*, 748 F. Supp. 2d at 902.

[63] *Id.*

[64] *Quinn, supra* note 62 (emphasis in original).

[65] *Olmstead,* 527 U.S. at 610.

admonition that the ADA does not "condone[] the termination of institutional settings for those unable to handle or benefit from community settings,"[66] parents and guardians of individuals with IDD have brought several cases arguing that the ADA and *Olmstead* prohibits the phasedown or closure of institutional settings if individuals or their guardians opposes the resultant transfer. Some cases have even argued that the facility cannot close unless every individual agrees to leave the facility. This distortion of *Olmstead's* do not oppose standard – often termed the "obverse *Olmstead* argument" – has been rejected by virtually every court that has considered it.[67] Courts have noted that neither the ADA nor other federal law create "a right to remain" in the facility of one's choosing, or a restriction on a state's discretion to allocate local resources or close public facilities.[68] Put simply, requiring individuals to leave a segregated setting when the State elects to shutter the institution is not discrimination prohibited by the ADA, regardless of whether the guardian or family representative opposes the transfer.[69]

IV. The Professional Research and Literature on the Impact of Disability on Decision Making

As reflected in professional standards,[70] informed choice is not merely an expression of preference – informed choice must ensure, to the maximum extent possible, that persons with disabilities fully understand the available options, have had experiences that could lead to the development of preferences about those options, and recognize that they have the ability to choose other options. Further, those responsible for implementing these decisions must be able to understand the person's communicated preference and then must respect their expressed preference.

The professional research and literature on decision making by persons with disabilities identifies a multitude of factors, disability-related and otherwise, that can be barriers to informed choice, including the nature

[66] *Olmstead,* 527 U.S. at 601-02, 605.

[67] *Lane v. Kitzhaber,* 2014 WL 2807701, at *3 (D. Or., June 20, 2014); *Ill. League of Advocates for the Developmentally Disabled v. Quinn,* 2013 WL 3168758, at *5 (N.D. Ill., June 20, 2013); *Sciarrillo ex rel. St. Amand v. Christie,* 2013 WL 6585569, at *3-4 (D.N.J., Dec. 13, 2013); *Richard S. v. Dep't of Developmental Servs. of Cal.,* 2000 WL 35944246, at *3 (C.D. Cal., March 27, 2000); *Richard C. ex rel. Kathy B. v. Houstoun,* 196 F.R.D. 288, 293 (W.D. Pa. 1999).

[68] *Ricci v. Patrick,* 544 F.3d 8, 21 (1st Cir. 2014); *Sciarrillo,* 2013 WL 6585569, at *3.

[69] *Ill. League of Advocates for the Developmentally Disabled v. Ill. Dept. of Human Servs.,* 803 F.3d 872, 876 (7th Cir. 2015); *Black v. Dep't of Mental Health,* 83 Cal. App.4th 739, 754-55 (2001).

[70] *Autonomy, Decision-Making Supports, and Guardianship:* Joint Position Statement of AAIDD and The Arc, American Association on Intellectual and Developmental Disabilities (2016), http://aaidd.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship; Self-Determination: Joint Position Statement of AAIDD and The Arc, American Association on Intellectual and Developmental Disabilities (2018), https://aaidd.org/news-policy/policy/position-statements/self-determination.

and severity of the disability; the impact of the disability on decision making; the lack of experience and understanding of various options; environmental and other restrictions on opportunities to exercise choice; hearing, speech, language, or vision impairments that affect the perception and communication of preferences; and past experiences and participation in various alternatives. That same research and literature demonstrate that despite these barriers, with individualized support tailored to the specific needs of each person, people with disabilities can make informed choices.

A. The Impact of Intellectual and Cognitive Disabilities on Decision Making

People with an intellectual disability[71] may experience difficultly with some aspects of decision making due to limitations in language acquisition and comprehension,[72] working memory,[73] reasoning and idea production,[74] perceptual abilities and social cognition,[75] learning and knowledge acquisition,[76] and abstract thinking. These limitations directly impact every aspect of higher order cognitive functioning, including decision making.[77] For instance, challenges in language comprehension may restrict the understanding about options; memory difficulties may affect the ability to rely on past experiences to form preferences; challenges in abstract thinking may impact the ability to conceptualize a choice based on written or verbal explanation; non-traditional methods of communication, and the inability of others to understand, often complicate the communication of preferences; differences in cognitive speed and problem solving may impact the ability to quickly understand information about options and decide which alternative is best. Despite these known challenges, there frequently is a failure to provide information in formats and ways that ensure that individuals with an intellectual disability can understand and act upon.[78]

[71]Intellectual disability is the term referring to a state of functioning in which Central Nervous System (CNS) impairments lead to global limitations in intellectual and cognitive functioning. Schalock et al., *Intellectual disability: Definition, Classification, and Systems of Support,* American Association on Intellectual and Developmental Disabilities (2010).

[72]Leonard Abbeduto, *Development of Verbal Communication Persons with Moderate to Mild Mental Retardation,* 17 Int'l Rev. of Res. in Mental Retardation 91, 92 (1991).

[73]James E. Turnure, *Long-term Memory and Mental Retardation,* 17 Int'l Rev. of Res. in Mental Retardation 193 (1991).

[74]J. H. McConaghy, *Mental Retardation, Analogical Reasoning, and the Componential Method*, 15 Int'l Rev. of Res. in Mental Retardation 125 (1988).

[75]Daniela Plesa Skwerer, *Social Cognition in Individuals with Intellectual and Developmental Disabilities: Recent Advances and Trends in Research*, 53 Int'l Rev. of Res. in Developmental Disabilities 91 (2017).

[76]Stefano Vicari, et al., *Memory and Learning in Intellectual Disability*, 50 Int'l Rev. of Res. in Developmental Disabilities 119 (2016).

[77]Linda Hickson & Ishita Khemka, *Problem Solving and Decision Making*, The Oxford Handbook of Positive Psychol. & Disability 198 (2013).

[78]Jill Bradshaw, *Complexity of Staff Communication and Reported Levels of Understanding in Adults with Intellectual Disability*. 45 J. Intell. Disability Res. 233 (2001).

Because many people with an intellectual disability "have a hard time conceptualizing things they have no direct experience of, it is unlikely that they will express a desire for something if they haven't tried it."[79] For these individuals, providing a written or visual description of a choice is insufficient in providing meaningful understanding. If there are limitations to memory, individuals may not be able to draw upon historic experiences when exploring their preferences.

People with an intellectual disability may appear to express a preference when they are instead being agreeable or participating in a social exchange and, in fact, do not understand the available options, have not developed a preference, and are not expressing a choice. Suggestibility and a desire to please also are common characteristics of intellectual disability.[80] People with an intellectual disability are highly susceptible to leading questions, and have a strong desire to please or give the answer they think is being sought.[81] They often base behavior on cues provided by others[82] or exhibit outer-directedness – i.e. relying "on external cues rather than on their internal cognitive abilities to solve a task or problem."[83] A closely-related phenomenon involves acquiescence or the tendency to respond favorably when asked a question.[84] This tendency is attributed to the characteristics of outer-directedness and prompt dependency, as well as difficulty in understanding and processing verbal and written content. Despite these challenges, research has documented that people with an intellectual disability can improve decision making and problem-solving skills if given the opportunity.[85]

B. The Impact of Other Disabilities on Decision Making

Though much research on decision making in people with disabilities focuses on intellectual disability – which may impact or co-occur with other disabilities – there are some characteristics unique to other disabilities, including autism, mental illness, and neurological degenerative

[79]Little Friends, Inc., *Teaching Choices: A Curriculum for Persons with Developmental Disabilities,* 2 (1992).

[80]Martha E. Snell, et al., *Characteristics and Needs of People with Intellectual Disability Who Have Higher IQs*, 47 Intell. & Developmental Disabilities 220, 225-227 (2009).

[81]Isabel C. H. Clare & Gisli Hannes Gudjonsson, *Interrogative Suggestibility, Confabulation, and Acquiescence in People with Mild Learning Disabilities (Mental Handicap): Implications for Reliability During Police Interrogations,* 32 Brit. J. Clinical Psychol. 295 (1993).

[82]Stephen Greenspan, et al., *Credulity and Gullibility in People with Developmental Disorders: A Framework for Future Research*, 24 Int'l Rev. of Res. in Mental Retardation 101 (2001).

[83]Jane Bybee & Edward Zigler, *Outer Directedness in Individuals With and Without Mental Retardation: A Review,* Handbook of Mental Retardation and Dev. 434 (1998).

[84]W.M. L. Finlay & E. Lyons, *Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation*, 13 Psychol. Assessment 319- 335 (2001).

[85]Ishita Khemka & Linda Hickson, *The Role of Positive Psychology in Interpersonal Decision Making*, Handbook of Positive Psychol. in Intell. and Developmental Disabilities, 145-46 (2017).

conditions. Persons with autism often exhibit decision making exhaustion and avoidance of decision making. These challenges are often amplified when decisions need to be made quickly, involve a change, or require talking to others.[86]

For many individuals with mental illness, research suggests that correlations between the side-effects of psychiatric medication, behavior challenges, and paternalistic perceptions that individuals with mental illness cannot be trusted to make "correct" decisions may be responsible for apparent or real difficulties decision making.[87]

C. The Impact of Institutionalization and Other Environmental Facts on Decision Making

Because of presumed incapacity and incapability, people with cognitive and other disabilities frequently are not provided instruction, supports, and opportunities to learn and engage in more cognitively complex activities such as decision making or problem solving. They often have limited opportunities to make even basic decisions. People with an intellectual disability make fewer choices than their non-disabled peers, in large measure due to the environments in which they live and work.[88] Segregated institutions offer significantly fewer opportunities to practice decision making and self-determination, because of factors related to staff density, the presence of multiple people with disabilities, and rules impacting freedom and choice associated with running larger settings.[89] Increased levels of maladaptive behavior, diminished daily living skills, physical decline, and the absence of self-determination training further increase segregation, restrict freedom, and diminish opportunities to express preferences. Fundamentally, institutionalization leads to a decline of skills and a lack of a variety of experiences.[90]

[86]Lydia Luke et al., *Decision-Making Difficulties Experienced by Adults with Autism Spectrum Conditions,* 16 Autism 612 (2011).

[87]Filardi da Rocha et al., *Decision-Making Impairment is Related to Serotonin Rransporter Promoter Polymorphism in a Sample of Patients with Obsessive–Compulsive Disorder*, 195 Behav. Brain Res. 159 (2008).

[88]Roger J. Stancliffe, *Living with Supports in the Community: Predictors of Choice and Self- Determination,* 7 Mental Retardation & Developmental Disabilities Res. Rev. 91 (2001).

[89]There are negative consequences in multiple developmental and performance domains associated with long term institutionalization that further limit decision making abilities, including high levels of apathy and dependency; increased passivity and submissiveness; decreased levels of adaptive behavior; increased levels of maladaptive behavior; limited acquisition of and decline in self-help and daily living skills; limited language acquisition and decline in communication skills and abilities; decreased attention to tasks; poor health outcomes; and poor psychosocial adjustment. Ellis M. Craig & Ronald B. McCarver, *Community Placement and Adjustment of Deinstitutionalization Clients: Issues and Findings,* 12 Int'l Rev. of Res. in Mental Retardation 95 (1984). C. W. Greenbaum & J.G. Auerbach, *The Environment of the Child with Mental Retardation: Risk, Vulnerability, and Resilience, in* Handbook of Mental Retardation and Development 583 (J.A. Burack et al., eds., 1998). Grace Iarocci & Jacob A. Burack, *Understanding the Development of Attention in Persons with Mental Retardation: Challenging the Myths, in* Handbook of Mental Retardation and Development 583 (J.A. Burack et al., eds., 1998).

[90]Erving Goffman, Asylums: Essays on the Social Situation of Mental Patients and Other Inmates (1961). Wolf Wolfensberger, et al., The Principle of Normalization in Human Services (1972).

When people with disabilities lack opportunities to practice decision making and lack experience to base their preferences, they are often assumed to be incapable of making decisions. This leads to further diminished opportunities and experiences, perpetuating the cycle of assumed incompetence.[91]

D. Supports and Related Actions to Enhance Decision Making

There is a vast amount of research and professional practices related to decision making supports for individuals with a wide variety of disabilities. A few proven assumptions should guide the use of needed supports and other actions. First, supports must be tailored to the unique strengths and needs of the individual. Second, information must be provided in a manner that the individual can understand, and presented in a manner that the individual can appreciate. Third, comprehension must be evaluated and should not be assumed. Fourth, the person's capacity and challenges in reaching and communicating preferences must be considered. Finally, conscious, systematic, and extensive efforts must be made to address all of the potential barriers to enabling persons with disabilities to make meaningful, informed choices.

Determining what decision making supports are appropriate should begin with person centered planning and assessments. An individualized communication assessment of both receptive and expressive language is widely agreed to be necessary. This assessment should include non-verbal communication with both familiar and unfamiliar staff.

After an individual's functional skills have been assessed, people who know the individual best, aided by professionals, should implement a variety of individualized supports to ensure informed choice. The supports should focus on two important considerations: (1) information must be presented in a way that is accessible to the person, which may include breaking down the information into small pieces,[92] providing audio, video, or graphic aids, or having the individual talk to a peer who had a similar experience;[93] and (2) for individuals who have not had direct and recent experience of the choice options, opportunities to participate in the option. Professionals and academics agree that real world experiences are essential for many individuals to develop preferences and make an informed choice. Virtually all of the professional literature about the

[91]Elizabeth J. Short & Steven W. Evans, *Individual differences in cognitive and social problem-solving as a function of intelligence,* 16 Int'l Rev. of Res. in Mental Retardation 93 (1990).

[92]Irene Tuffrey-Wijne, How to Break Bad News to People with Intellectual Disabilities: A Guide for Carers and Professionals (2012).

[93]Daniel K. Davies & Steven E. Stock, *Technology Use and People with Mental Retardation,* 29 Int'l Rev. of Res. in Mental Retardation 293-337 (2004).

development of preferences (interests) emphasize that interest "always originates in some form of person-environment interaction".[94]

The use of decision making tools can help guide the decision process for both the individual and the supporters by defining the necessary information, recording concrete options, and exploring preferences.[95] However, these tools are not a replacement for real experience from which an individual can form preferences. If someone has not lived in a home or apartment, with or without roommates, that person will not know the answer to these questions. If the person has difficulty processing verbal information, he will not be able to understand either the options or the benefits and risks associated with each option. Being provided a picture of these options likely will not be enough. If preferences evolve from interactions between persons and environments, the only way to know if one has a preference for the number of bedrooms or proximity to certain services is to actually experience these options and have a direct and concrete interaction with these alternatives. While some aspects of what is preferred can be known from prior experience, for many individuals, preferences cannot be determined and ultimately selected unless and until there is a direct experience with that alternative. Moreover, because people with intellectual and other cognitive disabilities may experience difficulty processing, remembering, synthesizing, and comprehending information, information needs to be provided in multiple, concrete, discrete, and structured modalities, often over an extended period of time. Additional actions recommended by academics and professionals include providing sufficient time to reach a choice, teaching decision making skills, practicing decision making in a variety of contexts, offering encouragement and reassurance, addressing general issues around anxiety and prior negative experiences, minimizing irrelevant information, gradually introducing new ideas and experiences, repeating assessments, asking open-ended questions, engaging staff and others who know the individual, and ensuring direct experiences of various options so the individual can appreciate and visualize alternatives.

Expressive communication limitations can be a barrier to communicating preferences for some people with disabilities. But, like other barriers to successful functioning, supports can be provided that enable people to more

[94]Andreas Krapp et al., Interest, Learning, and Development: The Role of Interest in Learning and Development 5 (1992).

[95]For instance, to assist in the process of determining preferences where people with intellectual disability might want to live, Davis and Faw developed a 30-item preference assessment that asks about some of the following issues: a) how many other people would the person want to live with; b) what wake/sleeping schedule is preferred, and how does the living option facilitate/hinder that schedule (e.g., noisy, lots of light); c) what transportation options does the person need to get to work or spend time with friends; d) does the home need to be located near important services (e.g. health care, restaurants); e) how many bedrooms does the person prefer; f) what accessibility features does the home need (e.g. ramps, accessible toilet), and g) does the location allow pets. P. Davis & G. Faw, *Residential Preferences in Person-Centered Planning: Empowerment Through the Self-Identification of Preferences and Their Availability, in* Person-centered Planning: Research, Practice, and Future Directions 203-221 (Steve Holburn & Peter Vietze eds., 2002).

effectively communicate their preferences and interests. If someone communicates in a non-traditional way, devices such as augmentative or alternative communication systems—from voice synthesized systems to pictorial systems—are available.[96] Symbolic forms of communication (sign language, gestures) also can be effective.[97] People can be taught to use micro-switches, communication boards, and other forms of assistive technology to indicate preferences.[98] When the individual's disability is more related to cognitive limitations that impact the ability to communicate thoughts and ideas, there are multiple supports available to enable effective communication.

The research is clear that to ensure that persons with disabilities can make choices and express preferences, they must have ongoing, individually-designed, intensive supports to learn about options and engage in self-determined actions. This is particularly true for nearly all people who have lived in restrictive settings, either for a long or even a short time.

V. Conceptualizing Opposition to Community Living as a Waiver of the Right to Receive Services in the Most Integrated Setting

As Congress noted in its Findings, a central purpose of the ADA is to redress the historical isolation and segregation of individuals with disabilities and to prevent their unnecessary institutionalization.[99] Congress also found that this history rendered persons with disabilities a "discrete and insular minority," entitled to the same deferential analysis of federally-protected rights as other, similar minorities.[100] To achieve this purpose and redress this historical segregation, Congress enacted title II of the ADA, which included a federal right to be free of unnecessary institutionalization and to live in the most integrated setting possible.[101] The Department of Justice then elucidated that right through regulations[102] and guidance.[103]

[96]Nancy C. Brady et al., *Communication Services and Supports for Individuals with Severe Disabilities for Assessment and Intervention,* 121 Am. J. Intell. Developmental Disability 138 (2016).

[97]Walton O. Schalick et al., *Communication with Individuals with Intellectual Disabilities and Psychiatric Disabilities: A Summary of the Literature,* Michigan Retirement Research Center (2012).

[98]Craig H. Kennedy & Thomas G. Haring, *Teaching Choice Making During Social Interactions to Students with Profound Multiple Disabilities,* 26 J. of Applied Behav. Analysis 63 (1993).

[99]42 U.S.C. § 12101(a)(2)-(3).

[100]*Id.* at § 12101(a)(7).

[101]*Olmstead*, 527 U.S. at 592.

[102]28 CFR pt. 35, App. A, p. 450 (1998) ("The preamble to the Attorney General's Title II regulations defines "the most integrated setting appropriate to the needs of qualified individuals with disabilities" to mean "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.").

[103]U.S. Dep't of Justice, *Statement of the Department of Justice on the Integration Mandate of Title II of the ADA and Olmstead v. L.C.* (June 22, 2011) (clarifying that "[i]ntegrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; afford individuals choice in

The ADA's right to live and receive services in the community and to interact with non-disabled peers also implicates liberty interests in freedom of association, freedom of movement, and freedom of travel.[104] Courts have held that the confinement of individuals in institutions for persons with disabilities curtails the fundamental rights of association and movement.[105]

Olmstead's do not oppose standard is grounded in the same principles of informed consent as is the constitutional right to refuse medical treatment.[106] Accepting or opposing integrated services, like consenting to or refusing care, "carries with it a concomitant right to such information as a reasonable patient would deem necessary to make an informed decision regarding medical treatment,"[107] which includes "knowledge of the risks or consequences that a particular treatment entails[.]"[108]

As discussed above, the Supreme Court held that the ADA creates an obligation to provide services in the most integrated setting unless the individual expressly opposes leaving a segregated institution.[109] The Court's conceptual framework only relieves the public entity from its duty under the ADA's integration mandate if and when individuals with disabilities affirmatively and knowingly forfeit their right to leave the institution. This construct parallels long-established principles on waiver of constitutional and other federal law rights.

While *Olmstead* acknowledges that individuals may choose to remain in a segregated setting,[110] such a decision effectively constitutes a waiver of the statutory right to live in the community and the constitutional rights of freedom of association, movement, and refusal of treatment. In order to

their daily life activities; and, provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible").

[104]*See Attorney General of New York v. Soto-Lopez*, 476 U.S. 898 (1986) (freedom of movement); *NAACP v. Clairborne Hardware Co.*, 458 U.S. 886, 907-09, 932-33 (1982) (freedom of association); *Cf., Sawyer v. Sandstorm*, 615 F.2d 311, 316 (5th Cir. 1980) citing *Griswold v. Connecticut*, 381 U.S. 479, 483 (1965) ("The right to freely associate is not limited to those associations which are 'political in the customary sense' but includes those which 'pertain to the social, legal, and economic interests of the members."); *Bykofsky v. Borough of Middletown*, 401 F. Supp. 1242, 1254 (M.D. Pa. 1975), aff'd 535 F.2d 1245, cert den., 429 U.S. 964 (1976) ("The rights of locomotion, freedom of movement, to go where one pleases, and to use the public streets in a way that does not interfere with the personal liberty of others" are implicit in the first and fourteenth amendments); *Kent v. Dulles*, 357 U.S. 116, 125-126 (1958) ("the right to travel is basic in our scheme of values").

[105]*Thomas S. by Brooks v. Flaherty,* 699 Supp. 1178, 1203-04 (W.D.N.C. 1988) (holding that the right to freedom of association of institutionalized individuals with IDD were violated where they were denied opportunities to associate with non-institutionalized persons as a result of being confined to a segregated institution.).

[106]*Olmstead,* 527 U.S. at 604-05.

[107]*Pabon v. Wright*, 459 F.3d 241, 246 (2d Cir. 2006); *see Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 278 (1990); *see also White v. Napoleon*, 897 F.3d 103, 113 (3d Cir. 1990) (prisoner had right to make an informed choice whether to accept medical treatment and to receive information about any available viable treatment alternatives).

[108]*Pabon,* 459 F.3d at 249 (quoting *White*, 897 F.2d at 113).

[109]*Olmstead,* 527 U.S. at 607.

[110]*Id.* at 604-05.

have been deemed to have relinquished a federal right, like the rights under the ADA to live and receive services in the most integrated setting, such a relinquishment must be "knowing" and "voluntary."[111] A finding of a waiver must be based upon more than just silence.[112] And it must be supported by evidence that the individual knew what rights were implicated and consciously decided to forego them.[113] Courts have held that the standard for finding a waiver of a basic right is strict and searching, and requires conclusive evidence that the individual is fully aware of relevant options and appreciates the consequences of such a waiver.[114] To meet this test, the person must be provided adequate and individualized information, tailored to the individual's ability to understand the nature and consequences of foregoing the exercise of that right.

In ADA cases involving prisoners with intellectual disabilities, courts have found that a state has an affirmative duty to provide reasonable accommodations to ensure that these prisoners do not improperly or unknowingly waive their federal rights and provide them an equal opportunity to participate in services and procedures.[115] For people with intellectual disabilities or similar cognitive limitations, whose needs place them at heightened risk of unintentionally waiving their rights, reasonable accommodations include going beyond simply telling them that a service is available. Such accommodations require providing appropriate assistance to access that service, using effective communication, and otherwise ensuring that individuals with disabilities understand what the services and processes

[111]*See* United States v. Stout, 415 F.2d 1190, 1192–93 (4th Cir. 1969) ("[F]ederal law is well-settled that waiver is the voluntary and intentional relinquishment of a known right, and courts have been disinclined lightly to presume that valuable rights have been conceded in the absence of clear evidence to the contrary."); *see, e.g., Brady v. United States,* 397 U.S. 742, 748 (1970); *Adams v. United States,* 317 U.S. 269, 275 (1942); *U.S. v. Correa-Torres,* 326 F.3d 18, 22 (1st Cir. 2003); *United States v. LeBlanc,* 175 F.3d 511, 515 (7th Cir.1999); *United States v. Pelensky,* 129 F.3d 63, 68 n. 9 (2d Cir.1997). *Freedom From Religion Foundation, Inc. v. Abbott*, 2017 WL 4582804 *4 (federal rights may be waived only if done so "voluntarily, knowingly, and intelligently," i.e., with full awareness of the legal consequences).

[112]*Correa-Torres,* 326 F.3d at 24. As the Supreme Court held in *Carnley v. Cochran*, 369 U.S. 506 (1962): "Presuming waiver from a silent record is impermissible. The record must show, or there must be an allegation and evidence which show, that an accused was offered counsel but intelligently and understandably rejected the offer. Anything less is not waiver." *Id.*, at 516.

[113]*Correa-Torres,* 326 F.3d at 24.

[114]The Supreme Court has defined waiver as "an intentional relinquishment or abandonment of a known right or privilege." *Johnson v. Zerbst*, 304 U.S. 458, 464 (1938). It has required that the lower courts should "indulge every reasonable presumption against waiver," *Aetna Ins. Co. v. Kennedy*, 301 U.S. 389, 393 (1937), and they should "not presume acquiescence in the loss of fundamental rights." *Ohio Bell Tel. Co. v. Public Utilities Comm'n,* 301 U.S. 292, 307 (1937).

[115]*Clark v. California*, 739 F. Supp. 2d 1168, 1185-1186 (N.D. Cal. 2010) ("[m]any developmentally disabled prisoners have impaired communication skills" and "are unable to read and write .... They have difficulty understanding instructions, especially multi-step instructions, and difficulty with any task that requires writing, such as filling out requests for medical or mental health care and grievances .... It is difficult for them to express themselves, and they often need assistance choosing words to make their point .... As a result, developmentally disabled prisoners often have difficulty communicating, self-advocating, and understanding what takes place during prison administrative proceedings and grievance processes. They are therefore at risk for unintentionally waiving their rights.") (citations omitted; emphasis added).

entail, before any knowing waiver could occur.[116] Similarly, the State must affirmatively provide individuals with cognitive disabilities in all segregated facilities with individualized information and concrete opportunities to experience community services, in order to ensure they understand the services available to them and to avoid "unintentionally waiving" their right to receive services in an integrated setting.

A waiver of a fundamental right may be revoked.[117] Similarly, a waiver of the ADA right to live in the community, and the concomitant constitutional rights, may be reconsidered at any time. Under professional service planning standards as well as underlying constitutional principles, the issue of what services are needed and where they should be provided must be periodically reviewed, at least on an annual basis.[118] Thus, if a person makes an informed and voluntary decision to remain in a segregated facility, thereby waiving the right to live in the community, such decision must be reconsidered at each annual service planning meeting.

In order to determine if an individual temporarily relinquishes or "improperly or unknowingly waives" a right, courts consider the "totality of the circumstances," including: whether the individual has an intellectual or mental disability, their education background, and relevant experience.[119] For a public entity to demonstrate that an institutionalized individual with

[116]*Id.* at 1179 (holding that, because many individuals with intellectual disabilities have impaired communications skills, difficulty understanding instructions, expressing themselves, and self-advocating, "[i]t is not enough simply to say the books are there, when plaintiffs contend that they do not have the assistance necessary to use the books properly" and that, with respect to disciplinary proceedings, "[o]nly through effective communication can defendants guarantee that developmentally disabled prisoners have meaningful access to these proceedings") (*quoting Cruz v. Hauck*, 627 F.2d 710, 720 (5th Cir. 1980)); *accord Armstrong v. Davis*, No. C 94-02307-CW, 1999 WL 35799705, at *7 (N.D. Cal. Dec. 22, 1999) ("Individuals with [intellectual disabilities] often are passive and dependent, and may easily acquiesce to authority"); *see also Folkerts v. City of Waverly*, 707 F.3d 975, 983-984 (8th Cir. 2013) (police officer fulfilled duty under ADA to accommodate suspect with intellectual disability).

[117]*Barker v. Wingo*, 407 U.S. 514, 525 (1972).

[118]*Parham v. J.R.,* 442 U.S. 584, 606-07 (1979); *Secretary of Public Welfare v. Institutionalized Juveniles,* 442 U.S. 640, 646, 650 (1979); 42 C.F.R. § 440(f)(2) (annual review of service plans in Intermediate Care Facilities); 42 C.F.R. § 483.20(c) & (k)(2) (quarterly review of assessments and care plans in nursing facilities).

[119]*See, e.g., Gonzalez v. Hidalgo Cty., Texas*, 489 F.2d 1043, 1047 (5th Cir. 1973) (remanding due process case where migrant worker sued housing authority where record was not clear that uneducated master tenant spoke little English and who signed adhesion contract "was 'actually aware or made aware of the significance of the fine print now relied on as a waiver of constitutional rights'"); *U.S. v. Klat*, 180 F.3d 264 (1999) (5th Cir. 1999) (per curiam) (holding magistrate judge did not err in refusing to dismiss plaintiffs' court appointed counsel in commitment hearing where plaintiffs' mental condition and competency was directly at issue in determining if waiver of right to counsel was knowing and intelligent); *RDO Fin. Servs. Co. v. Powell,* 191 F. Supp. 2d 811, 813-14 (N.D. Tex. 2002); *compare Pelayo v. U.S. Border Patrol Agent No. 1*, 82 Fed. Appx. 986 (5th Cir. 2003) (affirming denial of motion to dismiss where person deported was alleged to have lacked the capacity to choose voluntary departure and waive his rights as evidenced by being disoriented, mumbling and unable to answer questions from border patrol agent) *with Nose v. Attorney General of the United States,* 993 F.2d 75, 79 (5th Cir.1993) ("Undisputed summary judgment evidence established that alien participating in Visa Waiver Pilot Program (VWPP) knowingly waived her right to deportation hearing where alien was highly educated person who, in addition to receiving her nursing degree, studied English for over two years at major United States university and later passed state English proficiency exam, all six VWPP forms alien signed stated alien was waiving right to hearing before an immigration judge to determine admissibility or deportability, and alien consulted with attorney about VWPP before she entered United States under VWPP").

disabilities opposes community placement, and thereby relinquishes her right to live in the most integrated setting, the entity must prove that this right was knowingly and intentionally forfeited after providing adequate and individualized information and accommodations tailored to the individual's ability to understand their options. While the standard for waivers of fundamental constitutional rights of criminal defendants may be somewhat more rigorous than for other federal rights, they are both analogous and relevant for the purpose of assessing whether an individual waived her right to receive services in the most integrated setting. Conceptualizing the decision to remain in a segregated facility as a waiver of the right under the ADA and *Olmstead* to live in an integrated setting has several advantages. First, it posits, as the predicate to the analysis, that there must be an intentional relinquishment of a federal right, which implicates fundamental liberty interests. Second, it subjects that choice to the well-established and rigorous standard for a waiver of a basic right. Third, it precludes a waiver based on silence. Fourth, it requires searching judicial scrutiny of the claimed waiver, applying conventional due process considerations and balancing of interests. Finally, given the evidence necessary to demonstrate a knowing and voluntary waiver, it demands intentional and individualized accommodations to the person's disability and choice making capacity.

VI. The Public Entity's Obligation to Make Reasonable Accommodations to the Impact of Disability and Institutionalization on Informed Choice

A. The Public Entity's Duty to Reasonably Accommodate the Individual's Disability

Under Title II of the ADA, a public entity must provide reasonable accommodations to the individual's disability in order to allow the person to meaningfully participate in its program or services.[120] An accommodation is necessary if it will "affirmatively enhance a disabled plaintiff's quality of life by ameliorating the effects of the disability."[121] Those accommodations may differ depending on the specific nature and consequences of the individual's disability on the person's decision making capacity and process.[122] In the

[120]*See Wisconsin Comm. Serv., Inc. v. City of Milwaukee,* 465 F.3d 737, 746 (6th Cir. 2006)(en banc); *Clark v. California,* 739 F. Supp. 2d 1168, 1179 (N.D. Cal. 2010).

[121]*Oconomowoc v. Residential Prog. v. City of Milwaukee,* 300 F.3d 775, 784 (7th Cir. 2002). "In other words, the plaintiffs must show that without the required accommodation, they will be denied the equal opportunity to live in a residential neighborhood." *Id.* And "'Equal opportunity' means the 'opportunity to choose to live in a residential neighborhood." *Id.*

[122]*See* 28 C.F.R. § 35.160 (communication and auxiliary aids); *Taylor v. City of Mason,* 970 F. Supp. 2d 776 (S.D. Ohio. 2013) (requiring special accommodations to deaf arrestee in order to allow him to communicate); *Hahn ex rel. Barta v. Linn County, IA*, 130 F.Supp.2d 1036 (N.D. La. 2001) (denying County's motion for summary judgment where plaintiff with developmental disability sought facilitated communication as a reasonable accommodation to participate in County's developmental disability services).

context of *Olmstead's* do not oppose standard, a compelling basis for determining what accommodations are required is the professional research on the impact of the disability on decision making capacity, and the way in which the person learns, processes information, considers options, communicates preferences and interests, and reaches an informed decision.[123] Ultimately, because different disabilities differently impact individual functioning and the life activities of thinking, learning, and communicating, the scope of the accommodation is likely to differ depending on the nature, severity, and effect of the disability. The common thread, however, is that the accommodation must be sufficient to allow the individual with a disability to enjoy equal access to the public entity's benefit, services, or program.

Public entities also have a duty to make reasonable modifications to their programs, policies, and procedures to ensure that individuals with disabilities receive effective communications, in order to have an equal opportunity to participate in the benefits, services, and programs provided by the public entity. Beyond these disability-specific, professionally-based accommodations, public entities must make additional accommodations to reflect the unique abilities, challenges, conditions, experiences, and interests of each institutionalized person. In the context of institutionalization, this obligation entails the provision of information, supports, assistance, and opportunities that are needed to allow an individual to make an informed choice about whether to remain in a segregated setting or transition to an integrated one. While there is no published list of accommodations necessary to allow institutionalized persons to make an informed choice, federal guidance, state practices, professional research, and well-accepted methods for successfully reducing unnecessary institutionalization suggest there are at least six core elements that – to a greater or lesser degree depending on the nature and severity of the disability and its impact on decision making – are required as reasonable accommodations for individuals with disabilities to make an informed choice of whether to remain institutionalized.

First, the public entity must develop a wide range of accessible, available, and effective community residential alternatives and other supports that can meet the most significant needs or conditions of institutionalized persons; that address a range of individualized preferences and interests; that allow individuals to participate in integrated activities; and that are geographically dispersed throughout the State. Absent this range of services and supports, there can be no meaningful options of integrated settings, and thus no informed choice by the individual.

Second, the public entity must have a professionally-appropriate service and transition planning process that begins with the presumption that the

[123] *See* Section IV, *supra*.

individual would prefer to live in an integrated setting; that describes the general type, intensity, and frequency of services and supports that would allow the person to have their needs met effectively in the community; that then identifies specific options and locations that directly address the person's interests, preferences, and backgrounds; and that includes and makes targeted efforts to engage family members, support persons, and guardians.

Third, the public entity must ensure the regular provision of individualized information about living and working options that is presented in a manner which the person can understand and meaningfully consider. It is often most effective when provided through peer-to-peer or family-to-family programs that offer the benefits of lived experience and personal success stories. For persons with certain disabilities, such information may need to be adjusted to the individual's learning, processing, and communication style, including, for example, visual depictions and assistance from interpreters.[124]

Fourth, there must be periodic opportunities to observe, visit, and participate in residential and vocational alternatives, so that the individual can visualize and experience these options. For many individuals with disabilities, particularly those whose cognitive impairments limit their ability to conceptualize abstract possibilities or imagine future situations, no amount of written or pictorial information would be sufficient to allow them to appreciate and understand what living or working in another setting or location would be like, and thus, not allow them to make an informed choice whether or not to do so.

Fifth, individuals must be provided a range of community services and supports while they are institutionalized that allow them to leave the facility, participate in community activities, and experience community living on a regular basis. These community supports, which must include transportation from the institution to community activities, should be provided with sufficient frequency and intensity to allow all individuals to spend much of their day outside of the segregated facility and fully engage in a range of community activities.

Sixth, there must be a qualified professional who is knowledgeable about community options, well-versed in the benefits of community living, and regularly available to assist the individual in considering and experiencing those options. This professional should be expected to develop a personal relationship with the institutionalized individual, to appreciate and skillfully address the individual's concerns and hesitations about transition, to effectively resolve those concerns, and then to support the individual during the transition process.

[124]In providing "notice concerning benefits or services or written material concerning waivers of rights or consent to treatment," states are required to "take such steps as are necessary to ensure that qualified handicapped persons, including those with impaired sensory or speaking skills, are not denied *effective* notice because of their handicap." *Messier*, 562 F. Supp. 2d 294, 338 (D. Conn. 2008).

Ensuring that individuals with disabilities and their guardians[125] can make an informed choice whether to remain in a segregated facility includes more than merely offering abstract community alternatives, like a home and community-based waiver "slot." It must encompass appropriate opportunities to understand and actually experience what community living and activities involve; to regularly participate in community activities and events; and to resolve specific concerns or avoid prior negative experiences in the community, before a determination can be made that such individuals "oppose" that option and knowingly choose to remain in a segregated facility. These requirements are heightened when individuals have disabilities that require additional accommodations which are necessary to make an informed choice — particularly cognitive disabilities like brain injuries, intellectual and developmental disabiltiies, autism, and neuropsychiatric conditions that impact both the ability to understand and to make choices —and do not have guardians. Absent these accommodations and actions, individuals with disabilities cannot be found to oppose community placement.[126] And where the State fails to make adequate and appropriate community services available, a person's or guardian's alleged "choice" to remain in a segregated facility can never constitute a knowing opposition to community services under *Olmstead*.[127]

B. The Public Entity's Duty to Reasonably Accommodate the Effects of Unnecessary Institutionalization

As the Supreme Court noted in *Olmstead*, the very fact of institutionalization "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."[128] In addition, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational

[125]As noted in Sec. III.A.4, *supra*, courts have afforded deference to the views of guardians or other substitute decision makers in the procedural contexts of class certification and intervention. Similarly, there often is a rather rote assumption that these substitute decision makers automatically are entitled to make the decision whether to oppose community living, despite *Olmstead's* explicit focus on the individual. *See* Section II.D., *supra*. For a detailed analysis of the role of guardians and other authorized decision makers in the choice process and a proposal for reconciling various interests, *see* Sec. VII, *infra*.

[126]45 C.F.R. § 84.52(b) (emphasis added).

[127]*Olmstead*, 527 U.S. at 593, 602 (plaintiff E.W. refused inappropriate discharge from institutional setting to a homeless shelter, and remained institutionalized, and the Court held that E.W. did not oppose community integration).

[128]*Id.* at 600-01, citing *Allen v. Wright,* 468 U.S. 737, 755 (1984) ("There can be no doubt that [stigmatizing injury often caused by racial discrimination] is one of the most serious consequences of discriminatory government action."); *Los Angeles Dept. of Water and Power v. Manhart,* 435 U.S. 702, 707, n. 13 (1978) ("'In forbidding employers to discriminate against individuals because of their sex, Congress intended to strike at the entire spectrum of disparate treatment of men and women resulting from sex stereotypes.'") (quoting *Sprogis v. United Air Lines, Inc.,* 444 F.2d 1194, 1198 (C.A.7 1971)).

advancement, and cultural enrichment."[129] The Court explicitly held that unnecessary institutionalization is a form of discrimination,[130] and noted that:

> Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.[131]

For individuals with disabilities who have been subject to institutionalization – often for years and even decades – the lingering impact of segregation usually is profound. It results in not only a lack of opportunities to participate in integrated activities and to interact with individuals who do not have disabilities, but a forfeiture of all engagement with the ordinary rhythms of community life and with any contact with peers without disabilities, other than paid staff. More insidiously, institutionalization, by its very nature, requires a pre-determined schedule of living, eating, and sleeping; a regimented and unwavering structure of activities; a hierarchal level of control by staff and administrators; and a wholesale denial of choice at every juncture. As a result, institutionalization results in a pattern of learned helplessness that demands conformity, obedience, and passivity. As one court found:

> [O]ne of the harms of long-term institutionalization is that it instills "learned helplessness," making it difficult for some who have been institutionalized to move to more independent settings. … [P]eople with mental illness who have spent much of their lives in an institutional setting tend to be highly reluctant to move on, even if they are capable of living independently.[132]

Thus, the very nature of segregation, and the most immediate and obvious impact of unnecessary institutionalization, is the sacrifice of the very experience of discerning preferences and exercising choice.

To cure the vestiges of this past discrimination, States affirmatively must eliminate the consequences of unnecessary institutionalization and provide accommodations necessary to re-teach facility residents the skills and methods for making independent choices. To do so, special accommodations are demanded by the ADA, so that persons confined in segregated facilities can understand and appreciate alternatives to institutionalization, experience and then weigh community options, recall what community living entails, address understandable fears and concerns about transition, and then make

[129] *Id.* at 601 citing Brief of American Psychiatric Association et al. as *Amici Curiae* 20-22.

[130] *Olmstead, supra* note 127, at 596.

[131] *Id.* at 601, citing Brief for United States as *Amicus Curiae* 6-7, 17.

[132] *Disability Advocates, Inc*, 653 F. Supp. at 265 (describing effects on long-term institutionalization on individuals with disabilities who expressed ambivalence or reluctance to leave the segregated facility.

an informed choice from a meaningful set of options about whether to oppose being in the community and knowingly decide to remain in a segregated facility.[133]

The State's obligation to cure the vestiges of discrimination and to provide these special accommodations is founded on several principles. First, if the individual was not provided sufficient supports and meaningful accommodations to remain in the community prior to being institutionalized, it is impossible to conclude that the individual made a knowing and informed choice to be admitted to a segregated facility.[134] The resultant institutionalization can never be characterized as a knowing relinquishment of the right to live in the community or an informed choice to remain in the facility. Thus, the State is obligated to eliminate the causes that led to the unnecessary institutionalization and address the consequences of such past failures, including the concerns and fears that these failures will be repeated.

Second, in determining whether an institutionalized individual with disabilities who does not affirmatively request community placement actually opposes integrated services, it is relevant whether the individual has ongoing opportunities to make an informed and meaningful decision to remain in the segregated setting, which includes, at a minimum, periodic information about community service options; opportunities to visit and experience such options; opportunities to hear from peers, families, and providers; and participation in community activities and services that facilitate access to such activities.[135] Where an individual with disabilities cannot – or where she or her guardian does not – knowingly express opposition to community placement, the default should be a transition to an integrated setting, not continued institutionalization.[136]

Third, in order to determine whether an individual knowingly prefers to remain in a segregated setting, a State must do more than wait for the person to affirmatively request community placement. It must offer "concrete and believable alternatives" that reflect the individual's

[133]*Disability Advocates, supra* note 132, at 266 (describing programs and efforts to overcome the effects of institutionalization by gradually re-introducing facility residents to the community, supporting them in making an informed choice, and then facilitating their transition to a community setting).

[134]*Id.* at 260.

[135]*Disability Advocates, supra* note 132, at 261; *see also Messier*, 562 F. Supp. 2d at 337-39 (rejecting the state's use of responses to a general and ambiguous survey question to exclude residents of a large institution from consideration for a community placement where responses were given without the benefit of adequate information about community placement).

[136]*Olmstead*, 527 U.S. at 597, 602 (citing 28 C.F.R. 35.130(e)(1) (1998) and 28 C.F.R. Pt. 35, App. A, p. 450 (1998), regulations that indicate that to stay in an institutional setting, a person who could be served in a community setting must "choose[] not to accept" or must "declin[e] to accept" the option of community-based treatment); *Pennsylvania Prot. & Advocacy, Inc v. Pennsylvania Dept. of Pub. Welfare.*, 402 F.3d 374, 379 (3d Cir. 2005); *Messier*, 562 F. Supp. 2d at 337.

preferences and adequately address the individual's needs.[137] The failure to educate individuals with disabilities and their guardians about community placement options and provide a "concrete option for placement" rather than "an abstract possibility that [the individual] could live in an integrated setting," deprives institutionalized persons, and particularly those suffering from the vestiges of discrimination, of the opportunity to be placed in more integrated settings.[138]

Fourth, while an individual with disabilities may knowingly decline community services,[139] the State must offer an array of appropriate community living and employment options, with supports as needed, that reasonably address the individual's preferences, concerns, and experiences.[140] Absent such an offer, there can be no informed choice to oppose community services.[141]

Fifth, where the State fails to periodically give institutionalized persons and their guardians sufficient, individualized information and the opportunity to actually experience community services, a prior or current indication that they prefer to remain in the facility does not necessarily mean they knowingly oppose community placement.[142]

Finally, where individuals with disabilities, their family members, or their guardians express any level of interest in exploring the possibility of transitioning to community settings, they can never be said to oppose placement in community settings. Evidence that individuals likely would not oppose community services if provided adequate, individualized information about community services also demonstrates non-opposition to community-based services.[143]

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[137]*Disability Advocates Inc.,* 653 F.Supp.2d at 263.

[138]*Messier*, 562 F. Supp. 2d at 333-34; 42 U.S.C. § 12201(d); 28 C.F.R. § 35.130(d), (e)(1); *see Frederick L. v. Dep't of Pub. Welfare*, 157 F. Supp. 2d 509, 540 (E.D. Pa. 2001) (finding that states cannot avoid the integration mandate by failing to make recommendations for community placement).

[139]*See Olmstead*, 527 U.S. at 602.

[140]*See Kenneth R. v. Hassan*, 293 F.R.D. 254, 269 n.6 (D.N.H. 2013) ("[T]he *meaningful* exercise of a preference will be possible only *if* an adequate array of community services are available to those who do not need institutionalization[, . . .] and preferences may be conditioned by availability, limited by information, and are likely to evolve in a system that complies with the ADA.") (emphases in original) (quoting plaintiffs' brief with approval in certifying class); *In re District of Columbia*, 792 F.3d 96, 100 (D.C. Cir. 2015) (lack of transition services, including information regarding community alternatives to institutionalization, could form basis for Olmstead claim). *See, e.g., Messier*, 562 F. Supp. 2d at 338 (failure to request community placement is not evidence of opposition to such placement).

[141]*See, e.g., Messier*, 562 F. Supp. 2d at 329, 337-39 (finding that defendants should have given individuals and their guardians opportunity to consider community placement prior to determining they had declined transition to the community).

[142]*See Disability Advocates, Inc.*, 653 F. Supp. 2d at 267 (relying on evidence of lack of choice in moving into an Adult Care home and lack of information about alternative housing options to determine that plaintiffs satisfied *Olmstead*'s do not oppose prong and to conclude that "with accurate information and a meaningful choice, many Adult Home residents would choose to live and receive services in a more integrated setting, such as supported housing.").

[143]*See, e.g., Olmstead*, 527 U.S. at 602-03 (plaintiffs desired a community placement); *Disability Advocates, Inc.*, 653 F. Supp. 2d at 262, 267.

VII. Decision Making Alternatives for Individuals with Disabilities Who Lack Legal Capacity

There is a strong and widely accepted presumption in democratic societies, recognized in fundamental constitutional principles, state statutes, and international law, that adults are capable of making their own decisions – even bad decisions – about important matters in their lives.[144] This presumption is a central tenet of the framework of individual autonomy and societal relations as well as legal decision making. It supports important legal rights like those to enter into contracts,[145] to consent to medical care,[146] to marry,[147] and to choose where and with whom to live.[148] This presumption should apply with equal force to all citizens, regardless of race, gender, or disability, so that individuals with disabilities are permitted to make their own decisions, with such supports as are necessary. But, in practice, the societal presumption weakens for people with disabilities in general and for people in institutions in particular. Indeed, rather than a presumption of capacity, the presumption is often just the opposite – notwithstanding evidence to the contrary.[149] Accordingly, guardians and

[144]"[T]he law will presume competency rather than incompetency; [and] that every man is sane and fully competent until satisfactory proof to the contrary is presented," 41 Am.Jur.2d, *Incompetent Persons,* § 129, p. 665 (1968), cited in *United States v. Charters*, 829 F.2d 479, 495 (4th Cir. 1987), on reh'g, 863 F.2d 302 (4th Cir. 1988); *See also, Howe v. Howe,* 99 Mass. 88 (1868) (competence is presumed unless proven otherwise); *Matter of Guardianship of Roe*, 383 Mass. 415, 442 (1981) ("a person is presumed to be competent unless shown by evidence not to be competent"); Title 7, Tex. Health & Safety Code § 576.002(b) ("There is a rebuttable presumption that a person is mentally competent unless a judicial finding to the contrary is made under the Texas Probate Code").

[145]"One tenet of contract law holds that a person is presumed to be competent when she enters into a contract." *John Knox Vill. of Tampa Bay, Inc. v. Perry*, 94 So. 3d 715, 716–17 (Fla. Dist. Ct. App. 2012).

[146]"[T]he presumption intrinsic to a modern democracy is that the vast majority of persons are capable to make their own decisions." Paul S. Applebaum, *Assessment of Patients' Competency to Consent to Treatment*, 357 N.E. J. of Med. 1834, 836 (2007).

[147]In most states marriages are presumed to be valid. For instance, Kentucky "has a strong public policy in favor of upholding marriage. The law presumes validity, and a party to the marriage must overcome that presumption before contesting it." *Marshall v. Marshall*, 559 S.W.3d 381, 384 (Ky. Ct. App. 2018).

[148]More than a century ago the Rhode Island Supreme Court grounded the choice of where to live it in a constitutional right to liberty. *Henry v. Cherry & Webb*, 30 R.I. 13, 73 A. 97 (1909) ("'Personal liberty' is the power of locomotion, of changing situation, of removing one's person to whatever place one's inclination may direct, without imprisonment or restraint, except by course of law. It includes, not only the right to go where one pleases, but to maintain himself in a lawful manner while there, [and] to live and work where he chooses."). *See also*, *Acosta v. Gaffney,* 558 F.2d 1153, 1157 (3d Cir. 1977) (holding in a deportation case that "It is the fundamental right of an American citizen to reside wherever he wishes, whether in the United States or abroad, and to engage in the consequent travel.")

[149]One need look no further than the Justice Holmes' now infamous opinion in *Buck v. Bell,* 274 U.S. 200 (1927), affirming Carrie Buck's sterilization without so much as a nod to her competence or her own preferences. Indeed, "Carrie Buck was probably not the 'imbecile' that Justice Holmes charged she was; she was an avid reader, and her child (the 'third generation' of imbecility) won a place on her school's honor roll before her death at the age of eight. It has also been brought to light that Carrie Buck's child was the result of her rape while in foster care, and her institutionalization arose from the embarrassment to the foster family engendered by her rape." Susan Stefan, *Whose Egg Is It Anyway? Reproductive Rights of Incarcerated, Institutionalized and Incompetent Women,* 13 Nova L. Rev. 405, 456 n. 35 (1989) *citing* Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.y.u. L. Rev. 30, 61 (1985).

other substituted decision-makers may be assumed or appointed to have the authority to make decisions on behalf of a person with disabilities.[150]

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that all people regardless of disability or the extent of disability have "legal capacity."[151] Since the clear directive of the CRPD is that people have the right to make their own decisions, rather than having someone else make it for them, it has provided an incentive for developing alternatives in other countries and, indirectly, in the United States.[152] Consequently, alternatives to substituted decision making are increasingly being recognized by families, providers, legislatures, government agencies, and courts, as well as being promoted by scholars and advocates.[153]

Similarly, disability professionals have encouraged the empowerment of individuals through person centered planning (PCP) and similar approaches designed to maximize individuals' participation in decision making about their lives, their services, and their futures.[154] Federal agencies have incorporated PCP in rules and service planning requirements, as the preferred process for determining the scope, type, and location of supports that should be provided to individuals with disabilities.[155] When properly implemented, PCP affords individuals a voice in their life decisions and respects that voice. It represents the most effective and coherent method for identifying and implementing interests, preferences, and autonomy for service recipients with disabilities.

Building on the CRPD and incorporating some of principles of PCP, some States have adopted Supported Decision Making (SDM) as an alternative to guardianship.[156] SDM could be used in institutions to assist

[150]"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." Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As A Violation of the Integration Mandate of Title II of the Americans with Disabilities Act,* 81 U. Colo. L. Rev. 157, 165–66 (2010).

[151]Art. 12, Convention on the Rights of Persons with Disabilities, Gen. A. Res. 61/106, U.N. Doc. A/RES/6/106 (Dec. 13, 2006), available at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/optional-protocol-to-the-convention-on-the-rights-of-persons-with-disabilities.html#ar12.

[152]The United States has signed but not ratified the CRPD. For a description of efforts in the U.S. and internationally, *see* Kristin Booth Glen, *Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond,* 44 Colum. Hum. Rts. L. Rev. 93 (2012).

[153]Glen, *Changing Paradigms, supra.*

[154]For an explanation and historical perspective of person centered planning, see, Connie Lyle O'Brien and John O'Brien, *Origins of Person-Centered Planning: A Community of Practice Perspective (1999),* https://files.eric.ed.gov/fulltext/ED456599.pdf.

[155]The Administration for Community Living, part of the Department of Health and Human Services, promotes person centered planning. *See*, for example, https://acl.gov/programs/consumer-control/person-centered-planning and CMS' Home and Community Based Settings Rule, 42 C.F.R. § 441.725, https://www.medicaid.gov/medicaid/hcbs/downloads/final-rule-fact-sheet.pdf.

[156]SDM statutes had been enacted in at least seven states and the District of Columbia. See, e.g., Alaska (13 Alaska Stat., ch. 56, § 13.56.010); Delaware (16 Del. Code Ann. 9401A et seq.); and, Texas (Tex. Estates Code Ann. §§ 1357.001 et seq.).

the person with a disability in deciding whether to intentionally and knowingly forego the right to live in the community.

Proponents of the CRPD argue that nearly all individuals, regardless of the extent of their service needs, can make their own decisions with appropriate, individualized supports.[157] For those individuals who, even with assistance and accommodations, still lack capacity to make an informed choice about remaining in an institution, some sort of substituted decision making may be required. Laws and customs usually provide that substituted decision makers may include state sanctioned arrangements like appointed guardians, conservators[158] or representative payees;[159] surrogates authorized by action of law in the absence of government appointed, substitute decision makers; [160] administrative rules empowering program staff to make certain decisions;[161] and informal arrangements where third parties seeking a decision from an apparently incompetent person turn to the person's family or next of kin. Under certain conditions, individuals may also appoint substituted decision makers for themselves through legal documents like health care advance directives (health care proxies) or powers of attorney for financial or other affairs.[162]

In most jurisdictions, residence in an institution does not, in itself, mean that a person is not capable of making basic decisions.[163] Simply put,

[157]*See, e.g.,* Arlene Kanter & Yotam Tolub, *The Fight for Personhood, Legal Capacity, and Equal Recognition Under Law, for People with Disabilities in Israel and Beyond,* 39 Cardozo L. Rev. 557, 571-72 (2017).

[158]Guardians (who typically have authority over the personal affairs of the person under guardianship) and conservators (with financial authority) are appointed by courts. Many states have modelled their guardianship laws on the model laws drafted by the Uniform Law Commission. The most recent version is the Uniform Guardianship, Conservatorship and other Protective Arrangements Act ("UGCOPAA"), adopted in 2018. It has been adopted in Maine. *Guardianship Conservatorship and Other Protective Arrangements Act,* Uniform Law Commission (2019), https://www.uniformlaws.org/viewdocument/enactment-kit-25.

[159]Representative payees are appointed by administrative agencies, particularly by the Social Security Administration, to receive and manage benefit payments for persons the agency determines to be incapable to handle their own financial affairs. 42 U.S.C § 1007.

[160]*See, e.g.*, Texas Medical Consent Act, Title 4 Tex. Health & Safety Code, Section 313.004(a)(establishing a hierarchy of surrogates for some heath care decisions); Shana Wynn, *Decisions by Surrogates: An Overview of Surrogate Consent Laws in the United States*, 36 Bifocal 10 (2014), https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALSeptember-October2014.pdf.

[161]*See, e.g.*, regulations of the Massachusetts Department of Developmental Services delegate decision making for some routine medical care to a program director if the individual receiving the treatment is not competent to consent and there is no court appointed guardian. 115 Code Mass. Regs. 5.15(12)(b)2.

[162]Most advance directive and power of attorney laws provide that adults may execute a directive appointing another individual to make decisions for them when they are unable to make decisions for themselves. Robert D. Fleischner, *Advance Directives for Mental Health Care: An Analysis of State Statutes*, 4 Psychol. Pub. Pol'y & L. 788, 791 (1998).

[163]*See, e.g.*, New Mexico St. 43-1-5 ("Neither the fact that a person has been accepted at or admitted to a hospital or institutional facility, nor the receiving of mental health or developmental disability treatment services, shall constitute a sufficient basis for a finding of incompetence or the denial of any right or benefit of whatever nature which he would have otherwise); Mass. Gen. Laws ch. 123, § 25("No person shall be deemed to be incompetent to manage his affairs, to contract, to hold professional or occupational or vehicle operators licenses or to make a will solely by reason of his admission or commitment in any capacity to the treatment or care of the [Mental Health] department or to any public or private facility."); *Rogers v. Comm'r of Dep't of Mental Health*, 390 Mass. 489, 494–95 (1983) (discussing Massachusetts statute).

mental incapacity and the "need" (eligibility) for institutional placement are not the same thing. Although substituted decision making should be the rare exception rather than the rule, it is common practice for some form of substituted decision making to be imposed on nearly all institutionalized persons with disabilities.[164] State laws and regulations, as well as specific policies and procedures of the public entity, often define who is authorized to make decisions concerning living arrangements for individuals with disability. They may – but often do not – define the criteria for determining a lack of capacity, the responsibilities of the alternative decision maker, and the process for identifying and appointing the person authorized to act on behalf of the individual with disabilities. In light of the fundamental right to live where one chooses, and the specific right under *Olmstead* to live in the most integrated setting, any alternative decision maker should ensure that the choice of whether to remain in a segregated facility is based upon the individual's preferences and is the decision the individual would make, not the decision maker's perception of the individual's best interest.

Regardless of their protective intentions, substituted decision making schemes, by definition, deny individuals the right to make their own decisions. In practice, most deny individuals the right to even participate in decision making about their own lives. And all forms of substituted decision making are exercised largely without effective oversight.[165]

Modern guardianship law reforms have tried, in part, to increase the opportunity of the person under protection to participate in decision making. These reforms are reflected in some state law reforms and in the Uniform Law Commission's Model Uniform Guardianship Conservatorship and Other Protective Arrangements Act (UGCOPAA). For instance, state reforms and UGCOPAA have: (1) limited a guardian's authority to only those decisions that the person cannot make (limited guardianship);[166] (2) placed restrictions on or eliminated a guardian's authority – at least without court approval – to place individuals in segregated facilities, like nursing facilities, Intermediate Care Facilities for Individuals with

[164]There is no reliable national data on the number of people subject to guardianship. *Beyond Guardianship: Toward Alternatives That Promote Greater Self-determination,*Nat'l Council on Disability, 65-67 (2018). However, data supplied by several states, available from the National Core Indicators, show that on average between 64% and 75% of residents with developmental disabilities in developmental disability facilities and nursing homes are under some form of guardianship. NCI Charts (2015-16), National Core Indicators (2016), https://www.nationalcoreindicators.org/charts/2015-16/?i=137&st=undefined.

[165]As to guardianship monitoring, *see*, Naomi Karp & Erica Wood, *Guardianship Monitoring: A National Survey of Court Practices*, AARP Public Policy Institute (2006), https://assets.aarp.org/rgcenter/consume/2006_14_guardianship.pdf (Despite national reforms, court monitoring by states varies and is often lax). There is minimal oversight of representative payees, although the Social Security Administration recently contracted with the National Disabilities Rights Network to oversee complaints. Michelle Diament, *Better Oversight Sought for Representative Payees*, Disability Scoop (Dec. 8, 2017), https://www.disabilityscoop.com/2017/12/08/better-representative-payees/24507/.

[166]UGCOPAA, §§ 301 (b); 310(d).

intellectual and developmental disabilities, psychiatric hospitals, or similar institutions;[167] (3) recognized that guardians have an obligation to consult with the person and, in many situations, make decisions that are consistent with the person's expressed preferences;[168] (4) required that if the person cannot make or express a decision, the guardian's decision should reflect what the guardian believes the person would chose to do if capable to make the decision (often called "substituted judgment");[169] and, (5) required guardians to make decisions that are least restrictive of the person's liberty or infringe least on rights.[170] In fact, the widely accepted practice code for guardians – the National Guardianship Association's Standards of Practice – accepts substituted judgment as the preferred method of decision making,[171] and requires guardians to make placement decisions that are least restrictive of the person's liberty.[172] These practices apply with equal force whether the substituted decision maker is a duly appointed guardian, conservator, authorized representative, family member, a friend or neighbor, an organization, or the state.[173]

Modern concepts concerning the authority of all substituted decision makers with respect to the exercise of basic human rights should mirror the tenants of guardianship alternatives and reform. Therefore, in the context of decisions about whether the person will remain in a segregated setting, courts should apply several principles to ensure that, for individuals who lack legal capacity, their preferences and choices concerning where to live and receive services from a public entity are respected.

First, since the right to live in the community, as guaranteed by the ADA, implicates liberty and associational rights, substituted decision makers cannot have unfettered freedom to make the decision for the person. Rather, like other basic rights, if the person cannot make the decision, the substitute decision maker must make the decision based upon what the individual would choose if the individual was capable of exercising his or her own independent choice – so called "substituted judgment."[174] In

[167]UGCOPAA, *supra* note 166, at § 315(b).

[168]*Id.,* §§ 313(b), 314(a)(5).

[169]*Id.,* §§ 313(d) & 314(d).

[170]*Id.,* § 314(e).

[171]Standards of Practice, National Guardianship Ass'n, 8 (2017), available at https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf.

[172]*Id.* at 8-9.

[173]For an argument that state funded public guardianship programs, if held to proper standards, can help states meet the mandates of the ADA and *Olmstead, see* Eleanor B. Cashmore, *Guarding the Golden Years: How Public Guardianship for Elders Can Help States Meet the Mandates of* Olmstead, 55 B.C.L. Rev. 1217, 1217 (2014).

[174]The concept and application of substituted judgment has been described in several important appellate court opinions. Perhaps the most comprehensive discussion is in *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 431-34 (1977). The holdings in *Saikewicz* have been codified in Massachusetts' probate code. Mass. Gen. L. ch. 190B, § 5-306A.

determining substituted judgment, the person's expressed wishes – even if expressed when incompetent – are given the most weight.[175]

Second, given the Supreme Court's findings in *Olmstead* on the consequences of living in a segregated setting, that substituted judgment is likely to be, and should by default be, the choice to live in an integrated setting.[176]

Third, the default of community living can only be overridden by clear and convincing evidence that the individual's substituted judgment would be to remain in a segregated facility.[177]

Finally, if the substituted judgment decision is to remain in a segregated facility, in light of the lost liberty, the decision may only be made by a court, and not by a substituted decision maker without judicial oversight and approval. As is the case in some States, like those concerning sterilization or other highly intrusive interventions, decisions to keep a person institutionalized must be reviewed and approved by a judge.[178]

VIII. Conclusion

Over the past two decades, courts have rarely addressed *Olmstead's* do not oppose standard, except in response to the procedural protests of parents and guardians. For the hundreds of thousands of individuals with disabilities who remain unnecessarily institutionalized, or at risk of being institutionalized, courts should adopt a waiver paradigm that only respects knowing and informed decisions to remain in a segregated setting, that demand more than silence, and that fully understand and appreciate the consequences of segregation. Such decisions can only be knowing and

[175]*See*, NGA Standard 7; *Matter of Guardianship of Roe*, 421 N.E.2d 40, 57 (1981) (expressed preference is entitled to "great weight" in determining substituted judgment).

[176]Anne M. Donnellan proposed a similar approach to supporting the choice of integrated education of students with disabilities in 1984. Anne M. Donnellan, *The Criterion of the Least Dangerous Assumption*, 9 Behavioral Disorders 141 (1984) (when conclusive data are absent, educational decisions should be based on assumption which, if incorrect, will have the least dangerous effect on the likelihood that the student will be able to function independently as an adult). The UGCOPAA grants guardians significant authority to decide where the person under guardianship resides. However, the discretion is hardly unfettered. For example, "in selecting among residential settings, give priority to a residential setting in a location that will allow the adult to interact with persons important to the adult and meet the adult's needs in the least restrictive manner reasonably feasible unless to do so would be inconsistent with the decision-making standards [in other sections]." § 314(e)(2).

[177]The Supreme Court has held that a petition to commit an individual to a mental hospital must be proven by clear and convincing evidence. *Addington v. Texas,* 441 U.S. 418 (1979). The Court has also upheld a Missouri requirement that clear and convincing evidence is necessary in cases involving withdrawal of life-sustaining treatment. *Cruzan v. Director of Mo., Dep't of Health*, 497 U.S. 261, 110 S. Ct. 2841 (1990). The same evidentiary standard should apply if a guardian chooses to keep an individual in an institution.

[178]In requiring judicial oversight, the Massachusetts Supreme Judicial Court explained in *Saikewicz,* that "questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created." 370 N.E.2d 434-35. The court subsequently expended the rule to require guardians to obtain court authorization for other intrusive treatments like antipsychotic medications, sterilization, and abortion. The UGCOPAA does not mandate court approval but recognizes that some states may. Comment to § 315(f).

informed if the public entity provides necessary accommodations both to the impact of the disability as well as to the consequences of institutionalization on the choice process, including accessible information, interactions, actual experiences, and opportunities to participate in community programs and activities. If individuals nevertheless lack capacity to make an informed choice, a decision to enter or remain in a segregated facility must be approved by a court, pursuant to the substituted judgment doctrine and with a presumption favoring integration. Courts should adopt and apply these principles in order to realize the promise of *Olmstead* to redress the vestiges of discrimination for individuals with disabilities.