

USING INTEGRATED CARE TO MEET THE CHALLENGE
OF THE ADA'S INTEGRATION MANDATE: IS MANAGED
LONG-TERM CARE THE KEY TO ADDRESSING ACCESS
TO SERVICES?

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I. INTRODUCTION

The Indiana Family and Social Services Administration’s Division of Disability and Rehabilitative Services (“DDRS”) reports that over 8,000 Indiana citizens with developmental disabilities are waiting to receive services through one of Indiana’s three Home and Community Based Service (“HCBS”) waivers for individuals with developmental disabilities.¹ Brenden was one of those waiting. Diagnosed at birth with a developmental disability, Brenden and his family received critical services through Indiana’s early intervention program that assisted him in achieving important developmental goals until he turned three years old.² At that time, Brenden began receiving services through the local school corporation targeted at his academic achievement and was placed on the wait list for home and community based services.³ Now, twelve years old, Brenden just began receiving the services that permit

¹ FAMILY & SOC. SERV. ADMIN., IND. DIV. OF DISABILITY AND REHAB. SERVS.: QUARTERLY UPDATE 2 (Oct. 2012) [hereinafter *DDRS: QUARTERLY UPDATE*], available at http://www.in.gov/fssa/files/Quarterly_Report_-_Oct_2012.pdf (indicating that as a result of efforts to clean up the waiver wait list, the number of individuals waiting has decreased from over 19,000 names long in March 2012 to 8,486 as of October 1, 2012).

² *INquietCrisis.org: Brenden*, INQUIETCRISIS.ORG, <http://www.inquietcrisis.org/page.cfm?id=24> (last visited Sept. 1, 2012).

³ *Id.*

him the chance to develop the skills he needs to fully participate in his home and community – nearly ten years after being placed on the wait list.⁴

George, on the other hand, continues to wait. He currently resides in a group home with other individuals with developmental disabilities.⁵ However, George’s goal is to live in his own home in the community.⁶ Working toward this goal, “George has learned to manage his medications, money, house work and take personal responsibility for himself.”⁷ Further, by working two jobs, he has methodically saved the money he will need to move into his own apartment.⁸ Despite his hard work, George is unable to further pursue his goal because the vital support he needs to live successfully in the community is unavailable to him.⁹ Further, because he is currently receiving services through the group home, he is not considered a “priority” and can be passed over in favor others determined to be more in need of services.¹⁰

⁴ *Id.*

⁵ *INquietCrisis.org: George*, INQUIETCRISIS.ORG, <http://www.inquietcrisis.org/page.cfm?id=23> (last visited Sept. 1, 2012) [hereinafter INQUIETCRISIS.ORG, GEORGE].

⁶ *Id.*

⁷ *Id.*

⁸ *Id.*

⁹ *Id.*; THE ARC OF IND., AN INTRODUCTION TO INDIANA’S MEDICAID WAIVER PROGRAM FOR HOME AND COMMUNITY BASED SERVICES Update 2-3 (2012), available at http://www.arcind.org/upload/assets/pdfs/helpfulresources/introduction%20to%20indiana's%20medicaid%20waiver%20program_june_2012_update.pdf (describing the purpose of Medicaid Waivers, as well as the use of wait lists which limit immediate access to waiver services).

¹⁰ INQUIETCRISIS.ORG, GEORGE, *supra* note 5; *See also* ADVOCATES FOR DISABLED CLAIM FSSA IS BREAKING LAW: SUPPORTERS SAY AGENCY ISN’T PROVIDING ASSISTANCE FOR QUALIFIED HOOSIERS, WRTV 6 – TheIndyChannel.com (Oct. 5, 2011, 5:10 PM), [hereinafter *Advocates For Disabled*] <http://www.theindychannel.com/news/29398905/detail.html>; FAMILY & SOC. SERV. ADMIN., IND. DIV. OF DISABILITY AND REHAB. SERVS.: COMMUNITY INTEGRATION AND HABILITATION WAIVER Q&AS FROM WEBINAR 7-8 (2012), available at http://www.in.gov/fssa/files/CIH_Waiver_WebexQA_DDRS_06.29.12.pdf (There are two options available to individuals like George who wish to move into waiver services. The first option is to wait to access services until their

Without access to community-based services, those on the wait list have limited choices. Depending on their circumstances, they can try and manage without support, they can move into an institutional placement like a nursing home or large private Intermediate Care Facility for the Developmentally Disabled ("ICF/DD"), or if they already reside in an institutional placement, they can wait. In *Olmstead v. L.C.*, the United States Supreme Court recognized that "unjustified institutional isolation of persons with disabilities is a form of discrimination" ¹¹ Citing to regulations implementing Title II of the Americans with Disabilities Act ("ADA"), the Court found that "[a] public entity shall administer its services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." ¹² Further, the Court held that

under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. ¹³

Since that historic decision, courts have extended *Olmstead* beyond those who are institutionalized in order to

name "comes up" on the wait list for the Family Support Waiver, which is capped at \$16,250 and may not afford sufficient funding for the amount of support the individual needs. The second option is to wait until the person experiences an "emergency" which triggers the need-based criteria now in place to access the Community Integration and Habilitation Waiver, which provides comprehensive services based on individual need.).

¹¹ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999) (plurality opinion).

¹² *Id.* at 592 (quoting 28 C.F.R. § 35.130(d) (1998)).

¹³ *Id.* at 607.

reach individuals like Brenden and George.¹⁴ Often states argue that economic limitations, not an intent to discriminate, lie at the heart of their struggle to meet the need of soaring waiting lists and therefore *Olmstead's* Integration Mandate should not be applicable.¹⁵ However, this argument that economic limitations prevent states from complying with the mandate is rarely successful as evidenced by the many wait list related *Olmstead* challenges ending in settlement agreements.¹⁶ These settlement agreements memorialize the state's commitment to meaningfully address if not eliminate the waiting list for services.¹⁷

Indiana has made great strides in rebalancing services toward integrated, community-based options for those individuals with intellectual and developmental disabilities that are already in the service delivery system.¹⁸ Over nearly a decade of planning and effort, the State, with some encouragement from the United States Department of Justice ("DOJ"), moved hundreds of individuals from large,

¹⁴ See generally GARY A. SMITH, STATUS REPORT: LITIGATION CONCERNING HOME AND COMMUNITY SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES 4 (2007), available at <http://www.hsri.org/news-events/status-report-litigation-concerning-home-and-community-services-for-people/>.

¹⁵ *Id.* at 4 (discussing instances where courts rejected state arguments based on economic limitation).

¹⁶ *Id.* (indicating that sixteen of twenty-five wait list related lawsuits ended in a settlement agreement, as of May 2007).

¹⁷ *Id.* at 4-5 (describing the typical terms of wait list settlement agreements).

¹⁸ DAVID BRADDOCK & RICHARD HEMP, ESTABLISHING A TRADITION OF COMMITMENT: INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SERVICES IN INDIANA 2 - 3 (2008), available at http://www.in.gov/gpcpd/files/Braddock_Report.FINAL_10_10.pdf ("From 1977 to 1988, the I/DD institutional population in Indiana declined by an average two percent per year, half the national rate of decline. However, during 1999-2008 the I/DD institutional census decline rate in Indiana accelerated to 18% per year."); see also ROBIN COOPER, MSSW WITH DENNIS HARKINS, GOING HOME - KEYS TO SYSTEMS SUCCESS IN SUPPORTING THE RETURN OF PEOPLE TO THEIR COMMUNITIES FROM STATE FACILITIES 9 (2006), available at http://www.nc-ddc.org/publications/Going_Home_October_06.doc.

congregate institutional settings into their own homes and communities with services funded through the Medicaid HCBS Waiver, fulfilling *Olmstead's* primary charge.¹⁹ However, individuals like Brenden, George and the other 8,000 plus Indiana citizens with disabilities struggle each day to remain in their home and community choice. For those on the outside waiting to get into the service delivery system, there is more work to be done.

With a failing economy and mounting pressures to provide more services with fewer resources, Indiana's service delivery system is at a tipping point.²⁰ Using *Olmstead* as a framework, Indiana can leverage the current challenges into an opportunity to transform the service delivery system. This can be accomplished by using Medicaid Managed Long-Term Services and Supports as a tool to more effectively manage and predict cost, facilitate

¹⁹ BRADDOCK, *supra* note 18, at 6.

²⁰ *Advocates for Disabled*, *supra* note 10 (discussing concerns with the availability and cost of services); see also Maureen Hayden, *Families of Autism Face Long Wait Time: Legislator Says State Services System Is 'Broken' and 'Dysfunctional'*, KOKOMO TRIBUNE, Oct. 26, 2011, <http://kokomotribune.com/local/x1990853208/Families-of-autism-face-long-wait-time> ("Commission member and state Sen. Jean Breaux, an Indianapolis Democrat, said those numbers show a system 'so broken and so dysfunctional' that the state needs to look at dismantling the current system and creating a more effective way to make sure families with the most pressing needs are getting help."); Charles Wilson, *Ind. Group for Disabled Pushes Improved Services*, BUSINESSWEEK (Nov. 1, 2011), <http://www.businessweek.com/ap/financialnews/D9QO370G1.htm> (last visited Sept. 5, 2012) ("We've got to change some of the basic premises that we're dealing with here,' John Dickerson, executive director of The Arc, told a conference in Carmel. 'We can't just keep cutting back. If we do, we're turning our back on people and it just won't serve anyone well."); *Indiana State Workers Suggest Leaving Disabled People at Homeless Shelters*, FOXNEWS.COM (Oct. 28, 2010), <http://www.foxnews.com/us/2010/10/28/indiana-state-workers-suggest-leaving-disabled-people-homeless-shelters/> (last visited Sept. 5, 2012) ("Indiana's budget crunch has become so severe that some state workers have suggested disabled people at homeless shelters if they can't be cared for at home, parents and advocates said."); H.E.A. 1001, 117th Gen. Assemb., 1st Reg. Sess., Chap. 45 § 4(a) (Ind. 2011), available at <http://www.in.gov/legislative/bills/2011/PDF/HE/HE1001.1.pdf> (directing the development of a plan to reduce the per person and aggregate waiver spend).

community integration, and meaningfully address the wait list. In order to adequately explore the possibilities and implications of this assertion, Part II of this Note explores Indiana's historical and current approach to services for individuals with developmental disability services, and examines *Olmstead's* significance on issues related to access to services, the DOJ's current stance, and its impact on Medicaid. Part III of this Note discusses the evolution of using Medicaid Managed Care in the delivery of Long-Term Services and Supports including state examples applying managed care to services for individuals with developmental disabilities. Finally, Part IV evaluates what elements of these Medicaid Managed Long-Term Services and Supports approaches are critical for meaningfully impacting access to services, as well as making the case for how this type of approach could support Indiana in more effectively responding to the needs of its citizens with developmental disabilities.

II. BACKGROUND

A. Indiana's Approach to Developmental Disabilities Services

Historically, Indiana relied heavily on state operated, institutionally based services for individuals with intellectual and developmental disabilities. Initial efforts to reduce the state's reliance on these services began in the late 1970s through early 1990s with the development of small, community-based ICFs/DD, also known as group homes.²¹ In 1992, Indiana began offering home and community-based waiver services as an alternative option for persons with developmental disabilities.²² Coinciding

²¹ THE UNIV. OF MINN. RESEARCH AND TRAINING CTR. ON CMTY. LIVING AND THE LEWIN GRP., A REVIEW OF THE MEDICAID HOME AND COMMUNITY-BASED SERVICES PROGRAM IN INDIANA: FINAL REPORT 9-10 (2001), *available at* <http://rtc.umn.edu/docs/indiana.pdf>.

²² IND. FAMILY AND SOC. SERVS. ADMIN.: DIV. OF DISABILITY AND REHAB. SERVS., POLICY OPTIONS TO SUPPORT INDIVIDUALIZED AND

with the advent of this new option, the state began a long struggle with scathing, high-profile reports of wide spread client abuse and neglect at state-operated facilities, which ultimately resulted in DOJ involvement.²³ In 2007, the daily average census of persons with developmental disabilities in Indiana's state operated facilities was 147 persons, and Indiana was one of nine states, including the District of Columbia, without a dedicated institution for individuals with developmental disabilities.²⁴

This shift to community-based services was also precipitated by the historic "317 Plan,"²⁵ which resulted in a series of recommendations aimed at improving community-based services, including addressing the then 6,000 individuals waiting for services.²⁶ The study was the result of "a bipartisan task force of consumers, advocates, and state officials that was charged [through Senate Enrolled Act 317] with conducting a study of services for people with developmental disabilities."²⁷ As a result of both the legislature's efforts to rebalance funding toward community-based settings and the State's commitments to the DOJ to fundamentally address deficiencies in its institutional settings,²⁸ Indiana's HCBS Waiver revenue has exceeded ICFs/DD revenue since 2004 – two years ahead of projections and clear evidence of its commitment to community-based, integrated services.²⁹

Despite this progress, Indiana still has significant challenges related to ensuring the availability of appropriate community-based services. Specifically, Indiana has the fourth highest rate of nursing home utilization for

PERSON CENTERED SERVICES AND FUNDING 17 (Mar. 28, 2001), <http://www.in.gov/fssa/ddrs/2864.htm>.

²³ See generally Tim Swarens, *State of misery: Muscatatuck State Developmental Center's residents have long faced abuse and neglect*, INDIANAPOLIS STAR, Mar. 5, 2000, <http://www.dimenet.com/dpolicy/archive.php?mode=N&id=205>; COOPER, *supra* note 18, at 9.

²⁴ BRADDOCK, *supra* note 18, at 5.

²⁵ *Id.* at 6; see also COOPER, *supra* note 18, at 9.

²⁶ BRADDOCK, *supra* note 18, at 11.

²⁷ *Id.* at 11-12.

²⁸ *Id.* at 6; see also COOPER, *supra* note 18, at 9.

²⁹ BRADDOCK, *supra* note 18, at 24.

individuals with developmental disabilities.³⁰ In addition, despite serving over 13,000 people in the HCBS Waiver for individuals with developmental disabilities, the wait list for those services exceeded 8,000 for 2011.³¹

Since 2007, approximately 1,040 new individuals are brought into services each year.³² Yet, individuals still wait for approximately nine to twelve years before they are able to access services.³³ The gravity of this issue has prompted legislators to declare that Indiana's system is "broken" and "dysfunctional" and should be reconceived to "create[] a more effective way to make sure families with the most pressing needs are getting help."³⁴

These challenges are compounded by recent activities within Indiana's General Assembly. Specifically, the General Assembly directed DDRS to develop a plan to reduce both the aggregate and per person spending in Indiana's waiver programs.³⁵ This directive identified six potential approaches for achieving this outcome including "evaluating whether a group home [operated under the ICF/DD program] or a waiver home is the most appropriate use of resources" and "evaluating alternative placements for high cost individuals to ensure individuals are served in the most integrated setting appropriate to the individual's needs and within the resources available to the state."³⁶ These directives have the potential to significantly change the manner in which services are planned, funded, and delivered. Without thoughtful planning, Indiana could lose

³⁰ *Id.*

³¹ *FSSA: Reports & Statistics*, IND. FAMILY AND SOC. SERVS. ADMIN., <http://www.in.gov/fssa/ddrs/3347.htm> (last visited Aug. 29, 2012).

³² *Id.*

³³ IND. COMM'N ON DEVELOPMENTAL DISABILITIES, SECOND MEETING MINUTES, 117th Gen. Assemb., Interim Sess., at 6 (2011), *available at* <http://www.in.gov/legislative/interim/committee/minutes/MRDDE97.pdf>.

³⁴ Hayden, *supra* note 20.

³⁵ H.E.A. 1001, 117th Gen. Assemb., 1st Reg. Sess., Chap. 45 § 4(a) (Ind. 2011), *available at* <http://www.in.gov/legislative/bills/2011/PDF/HE/HE1001.1.pdf>.

³⁶ *Id.*

valuable ground in the provision of community-based services and significantly increase the risk of institutionalization for both those in community services and those waiting for services.

Adding to these pressures, there is mounting dissatisfaction among consumers and providers regarding the effectiveness of the current service delivery system.³⁷ Highlighted by reports of state agencies staff “suggest[ing] leaving severely disabled people at homeless shelters if they can’t be cared for at home,” consumer and family groups have sought intervention from the state to address limitations within the current system.³⁸ In addition, these groups have set out on their own investing significant resources in identifying systemic alternatives that focus on employment, individual strengths, family support, creativity, and judicious use of resources.³⁹ Providers have also expressed their dissatisfaction by launching a statewide public awareness campaign to highlight their concerns about the system and its impact on Indiana’s citizens with intellectual and developmental disabilities.⁴⁰

B. Olmstead’s Significance

1. Olmstead’s Integration Mandate

Using Title II of the ADA as its basis, the United States Supreme Court responded with a “qualified yes” to the question of “whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions.”⁴¹ More specifically, the Court directed that

³⁷ Wilson, *supra* note 20.

³⁸ *Indiana State Workers Suggest Leaving Disabled People at Homeless Shelters*, *supra* note 20; *see also* Hayden, *supra* note 20.

³⁹ Wilson, *supra* note 20.

⁴⁰ *INquietCrisis.org: About*, INQUIETCRISIS.ORG, <http://www.inquietcrisis.org/page.cfm?id=21> (last visited Sept. 1, 2012).

⁴¹ *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999) (plurality opinion).

[s]uch action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.⁴²

In *Olmstead*, the plaintiffs asserted claims of discrimination related to their segregation in an institutional setting for the purposes of treatment.⁴³ Both plaintiffs were dually diagnosed with mental retardation and mental illness and had been voluntarily admitted to Georgia Regional Hospital at Atlanta where they were "confined for treatment in a psychiatric unit."⁴⁴ After a period of time, their treatment teams determined that their "needs could be met appropriately in one of the community-based programs the State supported."⁴⁵ Despite this determination, both "remained institutionalized."⁴⁶

In considering whether the State's failure to transition the Plaintiffs into a community based treatment program was discriminatory, the Court looked to Title II of the ADA.⁴⁷ The Court pointed out that Title II requires that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or subjected to discrimination by any such entity."⁴⁸

Further, the Court explored the effect of regulations issued by the United States Attorney General in furtherance of Title II. Specifically, the Court noted two key portions of the regulation including the "integration

⁴² *Id.* at 587.

⁴³ *Id.* at 594.

⁴⁴ *Id.* at 593.

⁴⁵ *Id.*

⁴⁶ *Id.*

⁴⁷ *Id.* at 589-90.

⁴⁸ *Id.* (quoting 42 U.S.C. § 12132 (West 2012)).

regulation,”⁴⁹ which requires that “[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities,”⁵⁰ such that it “enables the individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”⁵¹ As well as the “reasonable-modification regulation” which “requires public entities to ‘make reasonable modifications’ to avoid ‘discrimination on the basis of disability,’ unless those modifications would entail a ‘fundamental alteration.’”⁵² Within the context of these regulations, the Court held that “[u]njustified isolation . . . is properly regarded as discrimination based on disability.”⁵³

However, the Court qualified this conclusion in a few important ways. From a patient protection perspective, the Court stated that “nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.”⁵⁴ Further, the Court advised that “the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. Nor is it the ADA’s mission to drive States to move institutionalized patients into an inappropriate setting, such as a homeless shelter”⁵⁵

From a state perspective, the Court recognized “the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand.”⁵⁶ The Court clarified that:

Sensibly construed, the fundamental-alteration component of the reasonable-modifications regulation would allow the State to show that,

⁴⁹ *Id.* at 592.

⁵⁰ *Id.* (quoting 28 C.F.R. § 35.130(d) (1998)).

⁵¹ *Id.* (citation omitted); *see also* 28 C.F.R. § 35, App. A (2011)).

⁵² *Id.* at 592.

⁵³ *Id.* at 597.

⁵⁴ *Id.* at 601-02.

⁵⁵ *Id.* at 604-05.

⁵⁶ *Id.* at 597.

in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities.⁵⁷

Importantly, the Court indicated that “[t]o maintain a range of facilities and to administer services with an even hand, the State must have more leeway than”⁵⁸ a “simple comparison show[ing] that community placements cost less than institutional confinement.”⁵⁹ Rather, the Court indicated that a State’s “fundamental-alteration defense”⁶⁰ should include “not only the cost of providing community-based care to the litigants, but also the range of services the State provides others with mental disabilities, and the State’s obligation to mete out those services equitably.”⁶¹ Furthermore,

If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met.⁶²

2. *Olmstead’s Impact for Those “At Risk of Institutionalization”*

In the years following *Olmstead*, courts have considered a variety of issues related to its ‘integration mandate.’

⁵⁷ *Id.* at 604.

⁵⁸ *Id.* at 605.

⁵⁹ *Id.* at 604.

⁶⁰ *Id.*

⁶¹ *Id.* at 597.

⁶² *Id.* at 605-606.

These issues fall into two broad categories: those causing individuals to be “at risk of institutionalization,” and those like the issues raised in *Olmstead*, that prevent individuals the opportunity to receive services in the most integrated setting.⁶³ While states continue to make strides in rebalancing their service delivery systems and reducing their use of institutional settings,⁶⁴ significant challenges remain in addressing the demand for community-based services.⁶⁵ For the states, these challenges in turn create significant exposure to waiting list dilemmas.

Generally, courts have held that *Olmstead* applies to those individuals “at risk of institutionalization.”⁶⁶ This view is also reflected in the DOJ’s current guidance to the States on *Olmstead*.⁶⁷ In support of this assertion, courts have held that “the protections of the integration mandate ‘would be meaningless if plaintiffs were re-quired to

⁶³ SMITH, *supra* note 14, at 4.

⁶⁴ KAISER COMM’N ON MEDICAID AND THE UNINSURED, MOVING AHEAD AMID FISCAL CHALLENGES: A LOOK AT MEDICAID SPENDING, COVERAGE AND POLICY TRENDS RESULTS FROM A 50-STATE MEDICAID BUDGET SURVEY FOR STATE FISCAL YEARS 2011 AND 2012 FULL REPORT 14 (2011), *available at* <http://www.kff.org/medicaid/upload/8248.pdf>. (“Over the past two decades, spending on Medicaid home and community-based services has been growing as more states attempt to reorient their long-term care programs by increasing access to home and community-based service options.”).

⁶⁵ NAT’L COUNCIL ON DISABILITY, RISING EXPECTATIONS: THE DEVELOPMENTAL DISABILITIES ACT REVISITED 30 (2011), *available at* <http://www.ncd.gov/publications/2011/Feb142011>.

⁶⁶ *M.A.C. v. Betit*, 284 F. Supp. 2d 1298, 1309 (D. Utah, 2003); *see also* *Fisher v. Oklahoma Health Care Authority*, 335 F.3d. 1175, 1182 (10th Cir. 2003) (“We agree, and conclude that *Olmstead* does not imply that disabled persons who, by reason of a change in state policy, stand imperiled with segregation, may not bring a challenge to that state policy under the ADA’s integration regulation without first submitting to institutionalization.”).

⁶⁷ U.S. DEPT OF JUSTICE, STATEMENT OF THE DEPARTMENT OF JUSTICE ON ENFORCEMENT OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT AND *OLMSTEAD V. L.C.* (2011) [hereinafter STATEMENT OF ENFORCEMENT], *available at* http://www.ada.gov/olmstead/q&a_olmstead.pdf (“[T]he ADA and the *Olmstead* decision extend to persons at serious risk of institutionalization or segregation and are not limited to individuals currently in institutional or other segregated settings.”).

segregate themselves by entering institutions before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation.”⁶⁸

“At risk of institutionalization” claims often take the form of a challenge to a state’s wait list.⁶⁹ The primary argument in these cases is that “placement . . . on the HCBS waiver waiting list threatens plaintiffs with institutionalization because it forces them to choose between staying in the community without any services or entering an institution in order to receive services.”⁷⁰ In addition, these challenges raise questions about the extent to which a state has an effective *Olmstead* plan in place that includes assurances that the wait list “moves at a reasonable pace.”⁷¹

The DOJ asserts that a “comprehensive, effectively working plan” includes “an analysis of the extent to which the public entity is providing services in the most integrated setting[,] . . . concrete and reliable commitments to expand integrated opportunities[,] . . . specific and reasonable timeframes[,] . . . measurable goals[,] . . . funding to support the plan[, and] . . . commitments for each group of persons who are unnecessarily segregated.”⁷² Further, “[t]he Department of Justice has interpreted the ADA and its implementing regulations to generally require an *Olmstead* plan as a prerequisite to raising a fundamental alteration defense, particularly in cases involving individuals currently in institutions or on waitlists for services in the community.”⁷³

“At risk of institutionalization” claims also take the form

⁶⁸ *M.A.C.*, 284 F. Supp. at 1309 (citing *Fisher*, 335 F.3d. at 1181); see also STATEMENT OF ENFORCEMENT, *supra* note 67, at 5 (“Individuals need not wait until the harm of institutionalization or segregation occurs or is imminent.”).

⁶⁹ SMITH, *supra* note 14, at 4 (indicating a number of general access cases are related to wait lists).

⁷⁰ *M.A.C.*, 284 F. Supp. 2d at 1309.

⁷¹ *Bryson v. Valias*, No. Civ. 99-558-M, 2004 WL 613027, at *3 (D.N.H. Mar. 26, 2004).

⁷² STATEMENT OF ENFORCEMENT, *supra* note 67, at 6-7.

⁷³ *Id.* at 7.

of a challenge to a state's placing limitations on the type or amount of services available in the community. A common argument for such cases is that the limitation creates "a greater risk for institutionalization for those individuals who require [services beyond the limitation]."74

Whether a challenge is raised as an "at risk of institutionalization" claim or is focused on the question of deinstitutionalization, many cases end with a settlement agreement, whereby the State agrees to modify its policies to increase the availability of community services or to remove limitations.⁷⁵ Often, these agreements are on a scale that essentially rebalances the system of care away from institutional care and toward community-based services.⁷⁶ This often addresses the fundamental alteration issue, as it "help[s] the state leverage additional federal dollars, significantly expanding the total available funds for mental health services."⁷⁷

3. *Effect on Medicaid*

Medicaid is the primary funder of long-term services and supports for individuals with developmental disabilities, regardless of whether those services are provided in an institution or in the community.⁷⁸ Recognizing Medicaid's "institutional bias", the Centers for Medicare and Medicaid Services ("CMS") has invested a significant amount of time

⁷⁴ *Pitts v. Greenstein*, No. 10-635-JJB-SR, 2011 WL 1897552, at *3 (M.D. La. May 18, 2011).

⁷⁵ See generally SMITH, *supra* note 14 at 5-25 (describing the details of settlement agreements in Connecticut, Florida, Hawaii, Kentucky, Maine, Massachusetts, Ohio, Oregon, Virginia, Tennessee, Texas, Washington, and West Virginia).

⁷⁶ See U.S. DEPT OF JUSTICE, DELAWARE ADA SETTLEMENT FACT SHEET 1 (Jul. 6, 2011), available at http://www.ada.gov/delaware_fact_sheet.htm ("The agreement will transform Delaware's mental health system from one reliant on expensive, institutional care to one focused on cost-effective community-based services.").

⁷⁷ *Id.* at 2.

⁷⁸ KAISER COMM'N ON MEDICAID AND THE UNINSURED, MEDICAID TODAY: PREPARING FOR TOMORROW A LOOK AT STATE MEDICAID PROGRAM SPENDING, ENROLLMENT, AND POLICY TRENDS 45 (2012), available at <http://www.kff.org/medicaid/upload/8380.pdf>.

and financial resources developing tools and other mechanisms to support states in rebalancing their systems toward community care.⁷⁹ These tools include a series of *Olmstead* letters issued by CMS to State Medicaid Directors, which attempt to clarify the opportunities and limitations of Medicaid in helping states respond.⁸⁰ These efforts present opportunities for states in terms of additional resources or increased federal funding.⁸¹

The *Olmstead* Court recognized Medicaid's historical institutional bias, but pointed out that more recent policy was focused on the development of community-based services.⁸² The DOJ furthered this by clarifying that “[a] state’s obligations under the ADA are independent from the requirements of the Medicaid program.”⁸³ In addition, the DOJ explained that “[p]roviding services beyond what a state currently provides under Medicaid may not cause a fundamental alteration, and the ADA may require states to provide those services, under certain circumstances.”⁸⁴

4. *Implications for Indiana*

Given the current status of Indiana’s wait list for services, it seems an “at risk of institutionalization” challenge presents the most significant liability.⁸⁵ However,

⁷⁹ KAISER COMM’N ON MEDICAID AND THE UNINSURED, POLICY BRIEF – OLMSTEAD V. L.C.: THE INTERACTION OF THE AMERICANS WITH DISABILITIES ACT AND MEDICAID 3 (2004), *available at* <http://www.kff.org/medicaid/upload/Olmstead-v-L-C-The-Interaction-of-the-Americans-with-Disabilities-Act-and-Medicaid.pdf>.

⁸⁰ *Id.*

⁸¹ *Id.*

⁸² *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 587 (1999) (plurality opinion).

⁸³ STATEMENT OF ENFORCEMENT, *supra* note 67, at 5 (citing DEP’T OF HEALTH AND HUMAN SERVICES, HEALTH CARE FINANCING ADMINISTRATION, SMDL #01-006, OLMSTEAD UPDATE NO. 4, at 7 (Jan. 10, 2011), *available at* <https://www.cms.gov/smdl/downloads/smdl011001a.pdf>).

⁸⁴ *Id.* at 5.

⁸⁵ *See FSSA Statistics*, INDIANA FAMILY AND SOCIAL SERVICES ADMINISTRATION, <http://www.in.gov/fssa/ddrs/3347.htm> (last visited Sept. 2, 2011) (indicating that the number of individuals receiving

the legislature's recent directive to address the per person and aggregate spending in the HCBS Waivers for Individuals with Developmental Disabilities may also present liability in terms of creating limitations on community services.⁸⁶ This risk is compounded by the fact that Indiana's *Olmstead* Plan has not been substantively addressed since 2005, calling into question whether the state could assert a viable fundamental alteration defense.⁸⁷

III. ANALYSIS

A. Medicaid Managed Care, Special Populations, and Long Term Services and Supports

Historically, Medicaid Managed Care was used by states as a tool to “deliver and finance care for Medicaid enrollees, with the goals of increasing access to care, improving quality, and in some cases, reducing costs.”⁸⁸ Medicaid Managed Care programs have typically not included individuals eligible by virtue of their disability, “because of their more involved needs, concerns about provider network adequacy, and limited health plan experience serving and bearing risk of this population.”⁸⁹ In addition, Medicaid Managed Care programs have primarily focused on acute care services and rarely included long term services and

services is nearly equal to the number of individuals waiting for services).

⁸⁶ H.E.A. 1001, 117th Gen. Assemb., 1st Reg. Sess., at 212 (Ind. 2011), *available at* <http://www.in.gov/legislative/bills/2011/PDF/HE/HE1001.1.pdf>.

⁸⁷ IND. COMM'N ON MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES, THIRD MEETING MINUTES, 114th Gen. Assemb., Interim Sess., at 3 (2005), *available at* <http://www.in.gov/legislative/interim/committee/2005/committees/minutes/MRDD89T.pdf>.

⁸⁸ KAISER COMM'N ON MEDICAID AND THE UNINSURED, A PROFILE OF MEDICAID MANAGED CARE PROGRAMS IN 2010: FINDINGS FROM A 50-STATE SURVEY 1 (2011) [hereinafter MEDICAID MANAGED CARE SURVEY], *available at* <http://www.kff.org/medicaid/upload/8220.pdf>.

⁸⁹ KAISER COMM'N ON MEDICAID AND THE UNINSURED, PEOPLE WITH DISABILITIES AND MEDICAID MANAGED CARE: KEY ISSUES TO CONSIDER 3 (2012) [hereinafter DISABILITIES AND MANAGED CARE], *available at* <http://www.kff.org/medicaid/upload/8278.pdf>.

supports.⁹⁰ This is largely attributable to consumer concerns, provider reluctance, and the complexity of service design.⁹¹ As applied to services for individuals with developmental disabilities, some have suggested that the incredible growth of community-based services in the 1990's "reduce[d] the] pressure to introduce managed care techniques."⁹²

Today, most states and approximately two-thirds of all Medicaid beneficiaries are involved in a comprehensive Medicaid managed care program.⁹³ Medicaid Managed Care is beginning to encompass previously exempt or excluded beneficiaries, like "children with disabilities receiving Supplemental Security Income (SSI), children with special health care needs, and seniors and people with disabilities who are not dually eligible for Medicare and Medicaid."⁹⁴ In addition, states are showing an increased interest in using Medicaid Managed Care programs to manage Long Term Services and Supports.⁹⁵ Initial experience suggests that such models reduce institutional usage and increase access to community services, however, information about cost savings and impact on consumers is limited.⁹⁶

As the adage goes, "if you've seen one state Medicaid

⁹⁰ KAISER COMM'N ON MEDICAID AND THE UNINSURED, EXAMINING MEDICAID MANAGED LONG-TERM SERVICE AND SUPPORT PROGRAMS: KEY ISSUES TO CONSIDER 4 (2011) [hereinafter MLTSS KEY ISSUES], *available at* <http://www.kff.org/medicaid/upload/8243.pdf>.

⁹¹ PAUL SAUCIER & WENDY FOX-GRAGE, ISSUE BRIEF NUMBER 79: MEDICAID MANAGED LONG-TERM CARE 7 (2005), *available at* http://assets.aarp.org/rgcenter/il/ib79_mmltc.pdf.

⁹² ROBERT M. GETTINGS, THE NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES POLICY INSIGHTS EXPANDED BULLETIN: REASSESSING THE IMPACT OF MANAGED CARE IN THE DEVELOPMENTAL DISABILITIES SECTOR 4 (2009) [hereinafter EXPANDED BULLETIN] *available at* <http://www.nlcdd.org/insights/policy-bulletinexpanded030509.pdf>.

⁹³ MEDICAID MANAGED CARE SURVEY, *supra* note 88, at 2.

⁹⁴ *Id.*

⁹⁵ MLTSS KEY ISSUES, *supra* note 90, at 1.

⁹⁶ *Id.* at 5.

program, you've seen one Medicaid program,"⁹⁷ this remains true when examining Medicaid Managed Long-Term Services and Supports (MLTSS) approaches. There are four primary Federal authorities that permit states to implement Medicaid Managed Care.⁹⁸ For the purposes of MLTSS, states primarily utilize waiver authority either under Section 1915(a), Section 1915(b), or Section 1115 of the Social Security Act.⁹⁹ Under these authorities, states are given "flexibility to not comply with the following requirements outlined in Medicaid law outlined in Section 1902[, including] [s]tatewideness . . . [c]omparability of [s]ervices . . . [or] [f]reedom of [c]hoice."¹⁰⁰ In addition, several states use the Section 1915(b) authority to limit consumer choice by "specify[ing] the providers used" in combination with Section 1915(c) authority for HCBS to "provide long-term care to specific populations, within specific geographic areas and to specify the providers used."¹⁰¹

Beyond which federal authority to utilize, additional options for states to consider are whether to make enrollment in managed care voluntary or mandatory and which model of managed care to implement.¹⁰² There are three primary models of Medicaid Managed Care including:

Managed Care Organizations (MCOs) [which are] like HMOs, . . . [and] agree to provide most Medicaid benefits to people in exchange

⁹⁷ Penelope Lemov, *Opening up Medicaid*, GOVERNING (Aug. 19, 2009), <http://www.governing.com/topics/health-human-services/Opening-Up-Medicaid.html> (last visited Sept. 5, 2012).

⁹⁸ *Managed Care*, MEDICAID.GOV, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Managed-Care/Managed-Care.html> (last visited Sept. 2, 2012) (identifying that Federal authorities permitting Managed Care include State Plan Authority under Section 1932 of the Social Security Act and Waiver Authority, as described above.)

⁹⁹ See SAUCIER & FOX-GRAGE, *supra* note 91.

¹⁰⁰ *Managed Care*, *supra* note 98.

¹⁰¹ M. KITCHENER ET AL., MEDICAID MANAGED LONG-TERM CARE: AN INTRODUCTION 3 (2006), available at http://www.pascenter.org/publications/publication_home.php?id=546&focus=PASLibrary.

¹⁰² *Managed Care*, *supra* note 98.

for a monthly payment from the state[;] [l]imited benefits plans [which] . . . may look like HMOs but only provide one or two Medicaid benefits (like mental health or dental services)[;] [and] Primary Care Case Managers [which are] . . . individual providers (or groups of providers) [that] agree to act as an individual's primary care provider, and receive a small monthly payment for helping to coordinate referrals and other medical services.¹⁰³

The factors attributed to these authorities and program design options contribute to the wide variation among state approaches to Medicaid Managed Care, in general, and MLTSS, specifically.

Other critical considerations are the goals and outcomes the state is hoping to achieve by implementing MLTSS.¹⁰⁴ States' goals often include controlling the growth of costs, increasing access to community services, reducing use of institutional services, creating funding predictability, limiting state financial risk, protection from adverse decisions, and increasing care coordination.¹⁰⁵ Specific to those approaches using the combined authority under Sections 1915(b) and 1915(c), opportunities exist in terms of improved efficiency and flexibility in resources; improved service quality; and improved opportunity for self-direction, while potential challenges include balancing costs with quality; lack of standards of practice; lack of data to use in

¹⁰³ *Id.*

¹⁰⁴ CTR. FOR HEALTH CARE STRATEGIES, INC., PROFILES OF STATE INNOVATION: ROADMAP FOR MANAGING LONG-TERM SUPPORTS AND SERVICES 11 (2010) [hereinafter PROFILES OF STATE INNOVATION], available at http://www.chcs.org/usr_doc/MLTS_Roadmap_112210.pdf.

¹⁰⁵ ROBERT L. KANE ET AL., MANAGED LONG-TERM CARE AND THE REBALANCING OF STATE LONG TERM SUPPORT SYSTEMS: TOPICS IN REPLACING STATE LONG-TERM CARE SYSTEMS, TOPIC PAPER NO. 3 7 (2007), available at http://www.sph.umn.edu/hpm/lrcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_3_Implications_of_Managed_Long_Term_Care_for_Rebalancing.pdf.

setting capitation rates; supports are not always clinical in nature; and limitation on provider choice.¹⁰⁶

In terms of the outcomes realized, states most often report “improved access to care” as a result of Medicaid Managed Care, in general.¹⁰⁷ While the impact on cost savings is mixed, most states report that “managed care offered the state improved value related to access and quality, even if savings were modest or not realized.”¹⁰⁸ Similar patterns have been noted as a result of MLTSS.¹⁰⁹ Additionally, states have indicated that even if cost savings are not realized, they “value the increased predictability of spending under [MLTSS].”¹¹⁰

1. State Example – Wisconsin’s Family Care Initiative

Since 1999, Wisconsin has implemented its Medicaid Family Care Initiative, which includes “a capitated acute care and long-term managed care program for people with [Intellectual and Developmental Disabilities] I/DD, older people, and young persons with physical disabilities.”¹¹¹ The Family Care Initiative is operated under a combined 1915(b) and 1915(c) waiver authority¹¹² through contracted managed care organizations.¹¹³ The state identifies four goals for its Family Care Initiative including improving consumer choice, improving access, improving quality, and

¹⁰⁶ JOHN AGOSTA ET AL., INFORMATION BRIEF: OPPORTUNITIES AND CHALLENGES PRESENTED BY UTILIZING A COMBINED 1915(b)/(c) WAIVER 4-5 (2010), available at <http://www.nc-ddc.org/publications/Combined-b-c-waivers-opportunities-and-challenges.pdf>.

¹⁰⁷ MEDICAID MANAGED CARE SURVEY, *supra* note 88, at 16.

¹⁰⁸ *Id.* at 17.

¹⁰⁹ SAUCIER & FOX-GRAGE, *supra* note 91, at 8-10 (recognizing that MLTSS outcomes include increased access to home and community based services, decreased use of high cost services, mixed results in terms of cost savings, and modest, yet positive, quality outcomes).

¹¹⁰ *Id.* at 9.

¹¹¹ BRADDOCK, *supra* note 18, at 37.

¹¹² HEALTH MGMT. ASSOCS., FINAL REPORT PILOT TO SERVE PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 10 (2010), available at <http://www.hhsc.state.tx.us/reports/Managed-Care-Pilot.pdf>.

¹¹³ EXPANDED BULLETIN, *supra* note 92, at 8.

achieving cost effectiveness.¹¹⁴ However, the literature suggests that improving access by reducing and/or eliminating waiting lists is the state's primary goal.¹¹⁵

Wisconsin has a variety of statutes that address the design, delivery, and funding for the Family Care Initiative.¹¹⁶ The statutes provide the state with the authority for pursuing managed care,¹¹⁷ an overall framework for the program, and important consumer protections.¹¹⁸ These protections include the creation of regional long-term care advisory committees governed by a board of directors whose members include either persons served or their families and advocates.¹¹⁹ The committees' duties include oversight, monitoring, and long-range planning for their identified region.¹²⁰ The statutes also provide for advocacy services that would provide information, technical assistance, and support in negotiations, mediations, and individual case advocacy to Family Care participants.¹²¹ A host of regulations have been published pursuant to this statutory framework. These regulations provide additional guidance and direction on standards for performance, eligibility determination, care management organizational standards and operational

¹¹⁴ *Family Care Home Page*, DHS.WISCONSIN.GOV, <http://www.dhs.wisconsin.gov/lcicare/> (last visited Sept. 3, 2011).

¹¹⁵ PROFILES OF STATE INNOVATION, *supra* note 104 at 4 (indicating that Wisconsin identified decreasing wait lists as a driver for moving to MLTSS); *see also* EXPANDED BULLETIN, *supra* note 92, at 8.

¹¹⁶ *Family Care Statutes*, WIS. DEPT OF HEALTH SERV, <http://www.dhs.wisconsin.gov/lcicare/StateFedReqs/Statutes.htm> (last visited Sept. 5, 2012).

¹¹⁷ WIS. STAT. § 46.281(1d) (West 2012) (directing the state agency to seek approval for the use of federal funds to support the Family Care Initiative).

¹¹⁸ *See* ROBERT M. GETTINGS, THE NATIONAL LEADERSHIP CONSORTIUM ON DEVELOPMENTAL DISABILITIES POLICY INSIGHTS SHORT BULLETIN: REASSESSING THE IMPACT OF MANAGED CARE IN THE DEVELOPMENTAL DISABILITIES SECTOR 4 (2009) [hereinafter SHORT BULLETIN], *available at* <http://www.nlcdd.org/insights/policy-bulletin-short030509.pdf>.

¹¹⁹ WIS. STAT. § 46.2825(1) (West 2012).

¹²⁰ WIS. STAT. § 46.2825(2) (West 2012).

¹²¹ WIS. STAT. § 16.009 (West 2012).

requirements, and client rights and protections.¹²²

Implementation of the program began on a pilot basis “in a limited number of counties and [was] evaluated before legislative authority was sought to implement the program statewide.”¹²³ The state “announced plans to implement the Family Care program statewide by 2011”¹²⁴ as a result of a program evaluation that revealed that:

Family Care had . . . (a) substantially increased participant choice and access to needed services, while improving quality by focusing on social outcomes; (b) eliminated waiting lists for services in the participating counties; (c) improved access to information concerning long-term service options among target populations; (d) achieved a high level of consumer satisfaction; and (e) saved an average of \$452 per month, per participant in four out of the five participating counties when compared to previous fee-for-service funding arrangements.¹²⁵

More recently, in the face of budget constraints and difficulty in assessing the programs cost-effectiveness, the state attempted to cap enrollment in the program.¹²⁶ As a result, waiting lists in counties covered by the Family Care program were established.¹²⁷ However, CMS has since directed the state to lift the cap and enroll those negatively impacted by its implementation, as HCBS waivers under the state’s current program design are considered an

¹²² See generally WIS. ADMIN. CODE DHS § 10.13 (West 2008) (containing detailed regulations for each of the areas identified above).

¹²³ SHORT BULLETIN, *supra* note 118, at 4.

¹²⁴ *Id.*

¹²⁵ *Id.*

¹²⁶ PATRICK MARLEY & GUY BULTON, *WALKER PLANS TO LIFT CAP ON LONG-TERM CARE*, MILWAUKEE J. SENTINEL DEC. 29, 2011, [HTTP://WWW.JSONLINE.COM/NEWS/STATEPOLITICS/WALKER-PROPOSES-TO-LIFT-CAP-ON-LONGTERM-CARE-PROGRAM-0C3JLCO-136317513.HTML](http://www.jsonline.com/news/statepolitics/walker-proposes-to-lift-cap-on-longterm-care-program-0c3jlco-136317513.html).

¹²⁷ *Id.*

entitlement and cannot be limited in such a fashion.¹²⁸

2. State Example – Michigan’s Combination 1915(b)/(c) Medicaid Prepaid Specialty Services and Supports for Persons with Developmental Disabilities

Michigan has implemented services through various forms of managed care for over twenty years.¹²⁹ During the 1990s, the State transitioned their managed long-term care program under a combined Section 1915(b) and Section 1915(c) authority.¹³⁰

Under this combined authority, Michigan provides a “comprehensive, prepaid, capitated managed care network . . . administered by local government Community Mental Health Services Programs.”¹³¹ The state’s intent for implementing a managed care approach was to provide “greater flexibility in administering state and federal funds.”¹³² As a result of this flexibility, “[t]he Michigan Waiver affords a uniform package of benefits for people with I/DD, allowing the state to remove the artificial distinctions between Medicaid state plan benefits and Medicaid HCBS Waiver benefits.”¹³³

Like Wisconsin, Michigan’s approach includes various consumer protections. From a statutory standpoint, Michigan’s Mental Health Code prescribes the process of using person-centered planning to “establish meaningful

¹²⁸ Letter from Verlon Johnson to Brett Davis (Dec. 13, 2011), Assoc. Reg’l Admin’r, Ctrs. for Medicare and Medicaid Servs., Div. of Medicaid and Children’s Health Operations, at 1, *available at* <http://www.jsonline.com/news/statepolitics/walker-proposes-to-lift-cap-on-longterm-care-program-0c3jlco-136317513.html> (then follow “Related Document” hyperlink).

¹²⁹ SHORT BULLETIN, *supra* note 118, at 4 (In addition to serving individuals with intellectual and developmental disabilities, Michigan’s program serves individuals with mental illness and individuals with substance abuse.).

¹³⁰ *Id.* at 3.

¹³¹ BRADDOCK, *supra* note 18, at 33.

¹³² SHORT BULLETIN, *supra* note 118, at 2.

¹³³ BRADDOCK, *supra* note 18, at 33.

and measurable goals with the recipient.”¹³⁴ As requested by the recipient, the plan should address the need for “food, shelter, clothing, health care, employment opportunities, educational opportunities, legal services, transportation, and recreation.”¹³⁵ In addition, through the contracting process the state “affirmatively requires that Community Mental Health Services Programs . . . ensure that individuals with I/DD can choose among service providers and that consumer service plans are developed using person-centered planning principles.”¹³⁶

From an outcome perspective, Community Mental Health Services Programs are not permitted to maintain waiting lists. Rather, they are required to identify and connect or provide the services needed by the individual.¹³⁷ As a result, Michigan serves over 39,000 individuals with intellectual and developmental disabilities through their managed care program.¹³⁸ Further, an evaluation of the program indicated that while perhaps modest, savings were achieved by transitioning to the managed care approach.¹³⁹

3. State Example – Pennsylvania’s Adult Community Autism Program

Pennsylvania has recently implemented a managed long-term care approach targeted at serving a limited number of individuals with autism within a limited geographic area.¹⁴⁰ Unlike Michigan and Wisconsin, Pennsylvania’s program is

¹³⁴ MICH. COMP. LAWS § 330.1712 (West 2012).

¹³⁵ *Id.*

¹³⁶ BRADDOCK, *supra* note 18, at 33.

¹³⁷ MICH. DEVELOPMENTAL DISABILITIES COUNCIL, DEVELOPMENTAL DISABILITIES FIVE-YEAR STRATEGIC PLAN: FISCAL YEARS 2007–2011 14 (2007), *available at* www.michigan.gov/documents/mdch/5-yrstateplan_179395_7.pdf.

¹³⁸ HEALTH MGMT. ASSOCS., *supra* note 112, at 9.

¹³⁹ *Id.*

¹⁴⁰ *ACAP General Information Questions*, PA.GOV, <http://www.dpw.state.pa.us/foradults/autismservices/adultcommunityautismprogramacap/acapgeneralinformationquestions/index.htm> (last visited Sept. 5, 2012) (stating that the program is currently limited to two hundred clients and serves only four counties).

operated under the 1915(a) waiver authority.¹⁴¹ The goals for the program include a variety of programmatic outcomes oriented at improving independence and community integration.¹⁴² Like Michigan, the program uses a Prepaid Inpatient Health Plan approach and requires capitation rates to be actuarially sound.¹⁴³ A unique feature of Pennsylvania's approach is that the managed care entity is solely responsible and services are "dis-intermediated," meaning there is no intermediary between the individual and the managed care entity/provider.¹⁴⁴ In addition to long-term services and supports, the managed care entity is responsible for "hospital, diagnostic, laboratory, and pharmacy services . . . as well as psychologists and nutritionists."¹⁴⁵

Similar to other state's approaches, the Pennsylvania approach includes a variety of consumer safeguards.¹⁴⁶ These safeguards include formal consumer oversight, annual cost reviews, and requirements for highly qualified, specially-trained staff.¹⁴⁷ Additionally, the program includes a variety of agreed upon outcomes related to ensuring a high quality experience for participants,¹⁴⁸ including ensuring "care plans are developed pursuant to comprehensive diagnostic and functional assessment of need."¹⁴⁹ In terms of outcomes, the program has realized increases in "reduced levels of behavioral challenges, increased moves to independent living, and higher levels of competitive employment."¹⁵⁰ From the state perspective, the

¹⁴¹ DANNA MAUCH ET AL., REPORT ON STATE SERVICES TO INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS (ASD): FINAL REPORT 60 (2011), available at <http://www.cms.gov/apps/files/9-State-Report.pdf>.

¹⁴² *ACAP General Information Questions*, *supra* note 140.

¹⁴³ Robert J. Baker, President/CEO, Keystone Autism Services, Presentation at ANCOR Leadership Summit 13 (Oct. 2011).

¹⁴⁴ *Id.* at 21.

¹⁴⁵ MAUCH ET AL., *supra* note 141, at 59.

¹⁴⁶ Baker, *supra* note 143, at 19-20.

¹⁴⁷ *Id.*

¹⁴⁸ *Id.* at 14-16.

¹⁴⁹ MAUCH ET AL., *supra* note 141, at 61.

¹⁵⁰ *Id.* at 62.

program provides fiscal predictability.¹⁵¹ From the provider perspective, the program has achieved a consistent level of profitability.¹⁵²

| Table Comparison: Key Features of State Examples | | | |
|--|---|--|---|
| | Wisconsin | Michigan | Pennsylvania |
| Managed Care Model | MCO | PIHP | PIHP |
| Waiver Authority | 1915(b)/(c) | 1915(b)/(c) | 1915(a) |
| Primary Goal | Reduce/eliminate waitlists | Flexibility in administering funding | Improve consumer independence and community integration |
| Populations Served | People with I/DD, older persons, and young persons with physical disabilities | People with I/DD, people with mental illness, and people experiencing substance abuse. | People with Autism |
| Scope | Acute Care | Acute Care and Long-Term Care | Acute Care and Long-Term Care |
| Waitlist | No | No | Unknown, but program is capped at 200 consumers |

¹⁵¹ Baker, *supra* note 143, at 27.

¹⁵² *Id.* at 18.

IV. LESSONS AND IMPLICATIONS FOR STATE APPROACHES TO DD SERVICES

A. General Recommendations

Olmstead continues to be a driving force in assuring the rights of individuals with disabilities in securing and receiving community-based treatment.¹⁵³ In working to meet *Olmstead's* “integration mandate” within the context of increasing fiscal pressures, states must be creative in designing meaningful and fiscally sustainable community-based supports. While not a panacea, Medicaid Managed Long-Term Services and Supports may provide states with an effective tool in meeting this challenge.¹⁵⁴

1. Stakeholder Engagement

In order to be effective, states should engage in a thoughtful re-design process that involves stakeholders and advocates in all aspects of planning, design, and implementation.¹⁵⁵ CMS identified engaging program recipients in “system planning, policy development, local

¹⁵³ See generally *Olmstead: Community Integration for Everyone*, ADA.GOV, <http://www.ada.gov/olmstead/index.htm> (last updated Jan. 12, 2012).

¹⁵⁴ CTRS. FOR MEDICARE AND MEDICAID SERVS., STATE MEDICAID DIRECTORS LETTER NO. 10-008, COMMUNITY LIVING INITIATIVE 3 (2010), available at <http://downloads.cms.gov/cmssgov/archived-downloads/SMDL/downloads/SMD10008.pdf> (“CMS continues to identify service delivery models that can be used to further the goals of the ADA. One such tool, when structured carefully, is managed care.”); see generally Nancy Thaler, Presentation at Intellectual and Developmental Disabilities HCBS Leadership Summit 28 (Nov. 29, 2011), available at <http://www.opra.org/clientuploads/Updates/News%20Articles/Old%20News%20Articles%20prior%20to%206-8-2012/CMS%20REGION%205%20Ohio%2011%2029%2011%20Nancy.pdf>.

¹⁵⁵ JEFFREY S. CROWLEY, THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS, BUILDING STRONG MEDICAID MANAGED CARE CONTRACTS: A GUIDE TO HELP CONSUMER ADVOCATES PARTICIPATE IN STRENGTHENING HIV/AIDS PROVISIONS IN MANAGED CARE CONTRACTS 13 (2000), available at <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=13516>.

program management, and quality assessment” as a promising practice in system change and reform.¹⁵⁶ In both Michigan and Wisconsin, participant involvement is an integral part of the oversight and management of their respective programs.¹⁵⁷ Additionally, it is important to engage provider organizations traditionally involved in meeting the long term services and support needs of individuals with I/DD, given their “strong ties with consumers.”¹⁵⁸

Extensive stakeholder involvement supports the development of a shared vision for system redesign. Most states indicate that establishing a clear goal or objective is crucial.¹⁵⁹ A shared vision provides “a framework for policy development and subsequent discussions with stakeholders.”¹⁶⁰ Also, a shared vision can help communicate the primary purpose for the redesign and manage expectations.¹⁶¹

2. *Memorializing the Program in Statute*

One way to ensure stakeholder input and preservation of the program’s goals is through the legislative process.¹⁶² States who have used this approach report “that the process of getting legislative approval was an important opportunity to ensure that the state’s vision for MLTS[S] was communicated and understood in a very public way.”¹⁶³

¹⁵⁶ STEVE EIKEN, PROMISING PRACTICES IN LONG TERM CARE SYSTEMS REFORM: COMMON FACTORS OF SYSTEMS CHANGE 2 (2004), available at <http://www.hcbs.org/files/56/2766/ComparativeAnalysis12-13-04.pdf>.

¹⁵⁷ *Id.* at 2-3.

¹⁵⁸ DISABILITIES AND MANAGED CARE, *supra* note 89, at 8.

¹⁵⁹ PROFILES OF STATE INNOVATION, *supra* note 104, at 11. (“By initially focusing on the end goal — e.g., providing greater choices for receiving care in the community — rather than the method for getting there, the state could build support for the overall program before having to address potential stakeholder concerns regarding managed care.”).

¹⁶⁰ EIKEN, *supra* note 156, at 3.

¹⁶¹ DISABILITIES AND MANAGED CARE, *supra* note 89, at 8.

¹⁶² PROFILES OF STATE INNOVATION, *supra* note 104, at 9.

¹⁶³ *Id.*

Additionally, having the program reflected in statute ensures that any significant changes are also made through a transparent process with ample opportunity for stakeholder input and feedback.

3. *Quality Measurement*

Given the focus on outcomes and safeguards, an effective MLTSS should include a meaningful quality measurement system.¹⁶⁴ If planned through the lens of *Olmstead*, a meaningful quality measurement system would focus on key issues related to rate of institutionalization, number of individuals living in settings of choice, number of individuals engaged in integrated community employment, and other indicators that demonstrate effective community-based supports.¹⁶⁵ Additionally, these systems should also monitor access to care and consumer satisfaction.¹⁶⁶

B. Indiana Specific Considerations

Indiana's approach to services for individuals with intellectual and developmental disabilities is unsustainable.¹⁶⁷ The current focus on delivering home and community-based services through a fee-for-service model misaligns incentives.¹⁶⁸ Specifically, such a model encourages maximizing resources on those within the service delivery system with no incentives to reach those on the outside waiting for services.¹⁶⁹ Compounding this concern, when individuals do enter services it is usually

¹⁶⁴ MLTSS KEY ISSUES, *supra* note 90, at 2.

¹⁶⁵ *See generally* STATEMENT OF ENFORCEMENT, *supra* note 67, at 5.

¹⁶⁶ Letter from Gov't Accountability Office, to Sens. Grassley and Baucus and Reps. Barton and Dingell, Medicaid Managed Care: Access and Quality Requirements Specific to Low-Income and Other Special Needs Enrollees 1 (Dec. 8, 2004), <http://www.gao.gov/new.items/d0544r.pdf>.

¹⁶⁷ *See generally* Wilson, *supra* note 20; H.E.A. 1001, 117th Gen. Assemb., 1st Reg. Sess., at 212 (Ind. 2011), <http://www.in.gov/legislative/bills/2011/PDF/HE/HE1001.1.pdf>.

¹⁶⁸ EXPANDED BULLETIN, *supra* note 92, at 34.

¹⁶⁹ *Id.*

because they are in crisis and in need of a significant amount of support,¹⁷⁰ which translates into significant financial resources.

As a result, the finite resources available for these critical services fail to meaningfully reach those not in crisis and waiting for services within a reasonable time frame. This failure significantly increases Indiana's *Olmstead* liability as it relates to an access to services challenge. Further, Indiana's *Olmstead* liability also increases proportionately to the extent that those in crisis are redirected to nursing facilities, large private ICFs/MR, and other institutional based services due to limited HCBS capacity. While MLTSS is not without its concerns, it could help to address these concerns by bringing stable, predictable, and reliable access to services.¹⁷¹

1. *Olmstead as a Framework*

As reflected in the court's opinion in *Olmstead* and in the DOJ's subsequent guidance, having an "effective *Olmstead* Plan" in place is critical in having a viable defense against an *Olmstead* challenge.¹⁷² The elements of an effective *Olmstead* plan, as identified by the DOJ, provide a useful framework for thinking about how MLTSS could be implemented.¹⁷³ Based on the experience of other states, transition to this model represents a radical transformation

¹⁷⁰ See generally DDRS: QUARTERLY UPDATE, *supra* note 1, at 2 (asserting that the only opportunity to enter the Community Integration and Habilitation Waiver is when an individual meets certain priority/emergency criteria).

¹⁷¹ See generally EXPANDED BULLETIN, *supra* note 92; SAUCIER & FOX-GRACE, *supra* note 91.

¹⁷² *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 605-06 (1999) (plurality); see also STATEMENT OF ENFORCEMENT, *supra* note 67, at 7.

¹⁷³ STATEMENT OF ENFORCEMENT, *supra* note 67, at 6-7 (finding that a "comprehensive, effectively working plan" includes "an analysis of the extent to which the public entity is providing services in the most integrated setting[;] . . . concrete and reliable commitments to expand integrated opportunities[;] . . . specific and reasonable timeframes[;] . . . measurable goals[;] . . . funding to support the plan[; and] . . . commitments for each group of persons who are unnecessarily segregated.").

of the service delivery system.¹⁷⁴ Key components of this transformation include “craft[ing] solutions that address the unique contours of the state’s needs moving forward” and ensuring the system’s values are clearly articulated.¹⁷⁵

Approaching the transformation through the lens of an *Olmstead* plan would help ensure that its focus was on promoting access to community-based, integrated services and mitigating those issues that put individuals “at risk of institutional-ization.”¹⁷⁶ Like Wisconsin, a natural extension of this activity would be to “hav[e] the program’s goals ‘carved in stone’ ”¹⁷⁷ by incorporating the system’s current guiding principles of self-advocacy and self-direction; quality integration and quality outcomes; work first and meaningful day; and dignified risk and risk management¹⁷⁸ into authorizing legislation.¹⁷⁹ Further, in recognition of the system’s limitations motivating the transition to managed care, the authorizing legislation should also incorporate a focus on statewide access to services and creating predictable and stable funding.

2. *Promoting Access to Services*

After establishing the underlying values and goals of transitioning to MLTSS, the planning focus can shift into specifically addressing access to services through program design. “[E]nhanced statewide equity in access to services . . .” was a primary motivator behind several states moving to a MLTSS approach.¹⁸⁰ At a most basic level, transitioning long-term care services from traditional fee-for-service into managed care essentially transforms them into an

¹⁷⁴ EXPANDED BULLETIN, *supra* note 92, at 39.

¹⁷⁵ *Id* at 41.

¹⁷⁶ STATEMENT OF ENFORCEMENT, *supra* note 67, at 7.

¹⁷⁷ EXPANDED BULLETIN, *supra* note 92, at 41.

¹⁷⁸ *DDRS Mission, Vision, & Guiding Principles*, IN.GOV, <http://www.in.gov/fssa/ddrs/3341.htm> (last visited Aug. 28, 2012).

¹⁷⁹ EXPANDED BULLETIN, *supra* note 92, AT 41 - 42.

¹⁸⁰ *Id* at 45.

entitlement¹⁸¹ by requiring states to take an “all-comers” approach to enrolling individuals into services.¹⁸² As a result, the approach has been relatively effective at eliminating wait lists.¹⁸³

3. *Integrated Funding*

Further, an identified success of MLTSS is that it permits the myriad of federal, state, and local funding streams to be combined into a “single, flexible benefit package” that provides “latitude to develop more individually tailored support plans.”¹⁸⁴ This flexibility shifts the systems incentives away from “overserv[ing] eligible clients” and toward “figuring out how the appropriate array of services and supports could be provided to each individual in the most economical manner given his or her needs and preferences.”¹⁸⁵ Additionally, it incentivizes “interven[tion] [before] a major life crisis occurs.”¹⁸⁶ Some states believe that this has been an important reason in their ability to “maintain . . . a low rate of institutionalization over the years.”¹⁸⁷

The ability to transform home and community-based services into an entitlement and to provide maximum flexibility in combining and deploying resources combine to make MLTSS a powerful tool for ensuring access to services. If integrated into Indiana’s *Olmstead* Plan, the State could provide compelling evidence of their “concrete and reliable commitments to expand integrated

¹⁸¹ WIS. DEPT OF HEALTH SERVS., LONG-TERM CARE IN MOTION: 2009 ANNUAL REPORT OF WISCONSIN’S LONG-TERM CARE PROGRAMS 10 (2009), available at <http://www.dhs.wisconsin.gov/ltcare/Reports/PDF/2009annualreport.pdf>.

¹⁸² EXPANDED BULLETIN, *supra* note 92, at 45 (“[A] managed care plan can be a vehicle that affords all eligible individuals reasonably prompt access to the long-term supports they need.”).

¹⁸³ MLTSS KEY ISSUES, *supra* note 90, at 1.

¹⁸⁴ EXPANDED BULLETIN, *supra* note 92, at 34.

¹⁸⁵ *Id.*

¹⁸⁶ *Id.* at 35.

¹⁸⁷ *Id.*

opportunities.”¹⁸⁸ The shift in incentives reflects the Plan’s values and focuses the system on supporting all individuals in need of service.

In addition to promoting access, the Plan should also address how the State intends to mitigate the risk of institutionalization. As previously identified, the shift in incentives to intervene prior to a crisis resulting from more integrated funding under a MLTSS model will go a long way towards achieving this outcome.¹⁸⁹ Additionally, the managed care framework provides incentives to divert individuals away from institutionally based care like nursing facilities and large private ICFs/MR and toward the creation of robust home and community-based support options.¹⁹⁰

4. *Central Point of Accountability*

Lastly, MLTSS promotes the ability to “establish[] a fixed point of accountability” relative to meeting performance expectations,¹⁹¹ including those focused on reducing reliance on institutional placements. Coupled with an integrated funding stream, this fixed point of accountability aligns financial incentives with improved consumer outcomes and quality care.¹⁹² Following the lead of all three state examples, it may be useful to fix this single point of accountability on the existing I/DD provider community by using them as the managed care entity.¹⁹³ The benefit of this approach is twofold. First, the system benefits from the I/DD provider communities’ expertise with individuals with I/DD and the types of services and supports they require.¹⁹⁴ Second, given the limited

¹⁸⁸ STATEMENT OF ENFORCEMENT, *supra* note 67, at 7.

¹⁸⁹ EXPANDED BULLETIN, *supra* note 92, at 35.

¹⁹⁰ *Id* at 34.

¹⁹¹ *Id* at 35.

¹⁹² *See generally* Baker, *supra* note 143, at 25-26.

¹⁹³ HEALTH MGMT. ASSOCS., *supra* note 112, at 13; MAUCH ET AL., *supra* note 139, at 59.

¹⁹⁴ DISABILITIES AND MEDICAID MANAGED CARE, *supra* note 87, at 8.

opportunities for cost savings,¹⁹⁵ using this “dis-intermediated” approach eliminates intermediaries between the consumer, provider, and state agency, thus reducing administrative cost in the system.¹⁹⁶

Developing an Indiana MLTSS model with reference to an effective *Olmstead* plan provides a meaningful framework to “‘think holistically’ about the changes associated with the transition to a managed care system.”¹⁹⁷ In addition to providing a viable defense against potential *Olmstead* challenges, this approach increases the likelihood that the development of managed care remains closely tied to its underlying values. Further, as recommended by states that have implemented managed care, the planning process could provide a platform for engaging stakeholders in both the development and implementation of the resulting model.¹⁹⁸ Together, the underlying values and stakeholder involvement provide reasonable assurances that many of the potential issues and pitfalls experienced by other states can be effectively considered and hopefully mitigated.¹⁹⁹

V. CONCLUSION

Having over 8,000 individuals with developmental disabilities waiting for community-based services poses a significant liability for Indiana in terms of exposure under *Olmstead’s* Integration Mandate. Further, the current pressure from Indiana’s General Assembly to reduce the per person and aggregate spending under the HCBS Waiver for Individuals with Developmental Disabilities, increases the possibility that Indiana could enact policy and funding changes that would put individuals “at risk of institutionalization.” Indiana’s exposure to a possible *Olmstead* suit increases in proportion to the increased risk of institutionalization resulting from these changes. MLTSS models have demonstrated success in increasing access to

¹⁹⁵ *Id.*

¹⁹⁶ Baker, *supra* note 143, at 21.

¹⁹⁷ EXPANDED BULLETIN, *supra* note 92, at 42.

¹⁹⁸ *Id.*

¹⁹⁹ *See generally id.*

services and effectively eliminating wait lists in the jurisdictions in which its been implemented. Further, while the evidence on cost savings associated with MLTSS is mixed, it does appear that the model brings stability and predict-ability to home and community-based services. Combined, these outcomes serve as powerful evidence of the potential for MLTSS to be an effective tool in empowering Indiana to proactively transform its system, to avoid an *Olmstead* challenge that would likely result in a court dictated program redesign, and most importantly to meaningfully provide access to services when, where, and how they are needed to support all Indiana citizens with intellectual and developmental disabilities at home, at work, and in their communities of choice. For George, Brenden, and the over 8,000 Indiana citizens waiting for services, MLTSS could be the key to provid-ing them access to the right services at the right time, so that they do not miss out on vital opportunities for personal development and can fully realize their potential.

