Childhood, Interrupted: Encouraging the De-Institutionalization of Utah's State Hospital

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In the long term, institutionalization in early childhood increases the likelihood that impoverished children will grow into psychiatrically impaired and economically unproductive adults.1

This bold statement summarizes the findings reported in an article coauthored by four pediatric physicians about the detrimental and long-lasting effects of placing children in institutional care. This theory is neither contentious nor revolutionary. And it is by no means a well-kept secret, guarded by the psychiatric and medical elite against discovery by policy makers on Capitol Hill. On the contrary, advocacy groups, lawmakers, even former President George W. Bush have all been made sharply aware of the findings on institutionalized care. The former president even took steps during his presidency toward finding solutions to the problem of institutionalization.2 This attitude shift occurred largely in response3 to the Supreme Court’s decision in Olmstead v. L.C.,4 which interpreted the Americans with Disabilities Act (ADA) to include protection for mentally ill populations from unnecessary inpatient treatment, and calling it unlawful discrimination to segregate such persons from society.5

A new approach to children’s mental health care arose from this attitude shift, with policymakers implementing community-based and in-home interventions to treat children and families together. Such interventions are not only highly effective and much less degrading to the integrity of the family and child; they are also significantly more cost efficient. This is not surprising—common sense informs us that bringing the therapeutic tools of a hospital setting into the home and transferring those skills from professional caretakers to parents is,

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2 See President’s New Freedom Commission on Mental Health, Exec. Order No. 13,263, 3 C.F.R. § 233–35 (2003) (declaring the mission of the newly created Commission to be “to recommend improvements to enable . . . children with serious emotional disturbances to live, work, learn, and participate fully in their communities”).

3 See infra Part I.


5 Id. at 598–602.
metaphorically speaking, teaching a man to fish. Thus, investing in in-home programming comes with the added bonus that eventually the taxpayer no longer needs to continue providing “fish.” Successful outcomes emerging from more recent deinstitutionalization efforts around the country are proving this logic to be true. This paradigm shift has been slower to reach Utah, in part due to two particularly alarming practices that continue to find support in the state: 1) the continued funding of long-term inpatient stays at the Utah State Hospital, compounded by the extensive investment in a building construction project at the hospital that was recently approved by the Utah State Legislature, and 2) pushing parents to relinquish custody as a method of obtaining Medicaid funding for treatment.

This Note presents two possible litigation strategies advocates may utilize in an attempt to compel the state to cease these practices and to incentivize policymakers to implement systemic change more aggressively. First, Part I examines the Supreme Court decision in *Olmstead*, wherein the practice of unnecessary institutionalization in a psychiatric hospital was held to be a violation of the ADA. The decision provided strong language suggesting not only that passive allowance of such practices is unlawful discrimination, but also that a state has an affirmative obligation to take reasonable steps to find and implement alternatives to institutionalized care. Part II goes on to apply this holding and its precedent to the state’s practice of providing long-term institutionalization at the Utah State Hospital. Further, Part II also discusses the Utah State Legislature’s recent approval of $25 million in funding to be used in part to rebuild the hospital’s children’s wing—and the strong implications that allocating extensive state resources toward further institutionalization will have for the *Olmstead* analysis. This section concludes by urging that action be brought against the state for this continued unlawful practice of affirmatively investing in continued institutionalization, thus pushing the state to better allocate its funds toward implementing more community-based programs.

Next, Part III analyzes the possible due process challenge that could be brought against the state for its complacency in the practice of custody relinquishment. This section will first examine the New York decision in *Joyner v. Dumpson*, where a plaintiff’s class of nearly 5,000 children challenged New York’s custody relinquishment scheme under the due process clause. While a conclusion as to the results of such a challenge is highly fact-dependent, a number of factors put forth by the *Joyner* decision weigh heavily in favor of the right potential plaintiff who chooses to challenge the practice in Utah. A definitive conclusion in this respect is difficult to reach, but this Note argues that judicial leanings look favorable for a child or family who claims their family integrity was destroyed for want of in-home mental health services.

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6 *Id.* at 601–03.
7 *Joyner v. Dumpson*, 712 F.2d 770 (2d Cir. 1983).
8 *Id.* at 777.
Finally, this Note concludes that these two litigation strategies appear unfavorable for the state if challenges were brought against it, only strengthening an already compelling argument that progress must be made to promote more community and in-home children’s services. This long overdue paradigm shift is necessary not only to preserve our families and our children, but also to preserve and more shrewdly allocate Utah’s increasingly scarce state resources.

I. BACKGROUND

Besides the detrimental effects on the individual, institutionalized care is an affront to civil rights. Such care is a modern and less-recognizable form of segregation, separating mentally ill or disabled children and adults from the rest of the population under the guise of “rehabilitation.”

The Supreme Court endorsed as much in its 1999 decision in Olmstead v. L.C.9 Analyzing institutionalization as a form of discrimination prohibited by the ADA, the Court pointed out that unjustified institutional placement constitutes a form of discrimination10 and “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.”11 The country took heed of this new category of discrimination and so began a movement of deinstitutionalization.

Subsequent initiatives by state and federal legislation prompted the creation of various models of community-based systems of care.12 As programs sprouted and grew, so did research that demonstrated the efficacy of community-based treatment and integrated systems of care. In a report to Congress, the Center for Mental Health Services (CMHS) provided data about children in forty-five different community-based systems of care after eighteen months of receiving services.13 CMHS reported, among other benefits, a reduction in behavioral and emotional problems, an increase in clinical functioning, an improvement in school performance and attendance, less law enforcement involvement, and lower caregiver strain.14 As the rest of the nation has continued to move toward a new system of integrated and community-based mental health care, Utah has resisted

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10 Id. at 600.
11 Id.
14 Id. at 30–36.
the movement. Utah is one of only two surveyed states\(^\text{15}\) that continue to fund the most restrictive level of care available: inpatient hospitalization.\(^\text{16}\) Furthermore, Utah spent $20 million on the second-most restrictive level of care—residential treatment—during the last legislative session.\(^\text{17}\) Not only are these levels of treatment the most costly methods of treating only very limited numbers of children, they contravene current research that demonstrates improved outcomes when service providers work with children and their families together.\(^\text{18}\) Utah would benefit both in treatment outcomes and in cost efficiency by moving away from these methods of care.

A far cry from deinstitutionalization, the state of Utah has instead decided to further invest in inpatient care. In the 2009, the 2010, and the 2011 legislative sessions, the Utah State Hospital requested funding to construct two new buildings,\(^\text{19}\) one of which would house the children’s psychiatric wing.\(^\text{20}\) In February 2011, the hospital presented its request for $30,881,000 to the Infrastructure and General Government Subcommittee\(^\text{21}\) and in March was ultimately approved for a grant of $25,000,000.\(^\text{22}\) When discussing this proposal, it is also useful to discuss the subsequent cost of treating a child once the new building is completed. It was estimated in 2007 that a pediatric bed in the Utah State Hospital costs $439 per day, per child,\(^\text{23}\) accumulating over the course of a median stay of over thirteen months.\(^\text{24}\) Compare this with the estimate that the same level of care, when provided in a community-based program, can cost less
than half that of per-day institutional care\textsuperscript{25} and does not require the $25 million starting price tag. With the legislative approval of this costly project, the state is wasting valuable funds on perpetuating the unlawful and drastically inefficient tradition of inpatient treatment that breaks up families. If the state faces pressure from legal action as proposed below, the project’s demise can act as a catalyst to more effectively allocate our state dollars and evolve to a more effective, dignified, and efficient system of care that will in turn build stronger families and communities. The following proposed legal challenges can act as the incentive for policymakers to progress toward modern theories of community-based care. These proposed litigation strategies seize on the national attitude shift that has begun creating a new way of thinking about the mentally ill.

II. CHALLENGING INSTITUTIONALIZED CARE AS A VIOLATION OF TITLE II OF THE ADA

Of the most recent challenges to states’ failure to provide children and adults with alternatives to institutionalized care, the most successful have come in the form of claimed violations of Title II of the ADA. These challenges follow from the famous Supreme Court decision in \textit{Olmstead v. L.C.}, holding that, “the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions”\textsuperscript{26} when certain conditions are met. This decision prompted extensive chatter among advocacy groups at both a national and a local level.

To offer only a few examples of the response generated by the decision, the Surgeon General in September 2000 hosted The Surgeon General’s Conference on Children’s Mental Health: Developing a National Action Agenda in Washington, DC.\textsuperscript{27} Similarly, in June 1999, legal advocates of persons with physical and mental disabilities met “to discuss the implications of the ruling”\textsuperscript{28} in \textit{Olmstead}, as well as to develop recommended strategies for states to implement more community-based services to comply with the Court’s holding.\textsuperscript{29} Both of these meetings of minds reached a similar consensus: state resources—as well as local, state, and federal

\textsuperscript{26} 527 U.S. 581, 587 (1999).
\textsuperscript{28} Judge David L. Bazelon CTR. FOR MENTAL HEALTH LAW, \textsc{Under Court Order: The Supreme Court’s Ruling in Olmstead v. L.C.}, at Foreword (1999) [hereinafter \textsc{Under Court Order}], available at http://www.bazelon.org/News-Publications.aspx (follow “Publications” hyperlink; then follow “Olmstead” hyperlink).
\textsuperscript{29} Id.
policy initiatives—ought to be centered around encouraging community integration of mental health care services whenever possible.\textsuperscript{30}

The \textit{Olmstead} decision, as well as the commentary that ensued and the various challenges mental health advocates brought against states under its precedential authority, all endeavor to establish a standard by which states are able to gauge the extent of responsibility they owe to their mentally ill populations.\textsuperscript{31} This section first discusses the opinion itself, and then examines the commentary and controversies that have shed further light on the implications of this decision for state mental health care systems.

\textbf{A. The Opinion:} \textit{Olmstead} v. L.C.

\textit{Olmstead} v. L.C. began as a challenge brought by two women with intellectual disabilities against the state of Georgia.\textsuperscript{32} The women had been voluntarily admitted into care at the Georgia Regional Hospital at Atlanta and although their treatment professionals later concluded they were appropriate for further treatment in a community-based program, the women were not released—purportedly due to inadequate funding of community services.\textsuperscript{33}

The district court ordered the state to place the women in a community-based program and held that “unnecessary institutional segregation of the disabled constitutes discrimination \textit{per se}” under Title II of the ADA.\textsuperscript{34} To establish a claim under Title II, a plaintiff must show that 1) he or she is a person with a qualified disability, 2) he or she was excluded from participation or denied services, benefits, etc. of a public entity, and 3) this discrimination was the result of his or her disability.\textsuperscript{35} Further, Title II asserts that states are required to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”\textsuperscript{36} This provision is limited in that

\begin{thebibliography}{99}
\bibitem{footnote30} \textbf{Surgeon General Report}, \textit{supra} note 27; \textbf{Under Court Order}, \textit{supra} note 28, at 1.
\bibitem{footnote32} 527 U.S. 581, 593 (1999).
\bibitem{footnote33} \textit{Id.} at 593–94.
\bibitem{footnote34} \textit{Id.} at 594.
\bibitem{footnote36} 28 C.F.R. § 35.130(d) (2010).
\end{thebibliography}
states are required to make “reasonable modifications” to their policies to avoid discriminatory practices. 37 Also, a defense is available if the state can demonstrate that making such modifications would “fundamentally alter” the nature of the service or program.38

Georgia claimed in its defense that the third element of the ADA claim—that the plaintiffs had been discriminated against because of their disability—had not been met. Georgia claimed that inadequate funding of community programs had been the reason for continued hospitalization, not discrimination by reason of their disability.39 Thus, the state asserted that without adequate funding, immediate transfers to community-based services would fundamentally alter the hospital’s program.40

The district court rejected Georgia’s inadequate funding defense, finding that segregated treatment of the mentally disabled constitutes discrimination per se under the ADA and “cannot be justified by inadequate funding.”41 The court looked to the United States Court of Appeals for the Third Circuit for this proposition, which had rejected a cost-based defense in an ADA claim filed by a nursing home patient.42 The Third Circuit ruled in favor of the patient and concluded that whenever a state chooses to provide services under the ADA, it must comport with its provisions—referring in particular to the provision that prohibits unnecessary segregation as a form of discrimination.43

The district court then turned to Georgia’s claim that requiring an immediate transfer to community services would “fundamentally alter” the state’s programs. Most significantly, the court emphasized two specific facts in its analysis of the issue: first, that Georgia already had in place community services that were appropriate for the women, and second that providing care in an institutional setting is twice as costly as providing services in the community.44 The court used these facts to support its finding that Georgia would not have to fundamentally alter its program to provide community-based care in the face of its economic shortfalls.45

On appeal, the Unites States Court of Appeals for the Eleventh Circuit modified the district court’s analysis, affirming the lower court’s holding that treating the women in a segregated institution when they were appropriate for more

37 Id. § 35.130(b)(7) (requiring “reasonable modifications” to avoid discrimination, “unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity”).
38 Id.
40 Id.
41 Id. at *4.
42 Id. (citing Helen L. v. DiDario, 46 F.3d 325 (3rd Cir. 1995)).
43 Helen L., 46 F.3d at 333–39.
44 Zimring, 1997 WL 148674, at *4 & n.4.
45 Id. at *4.
integrated community-based treatment programs constituted discrimination under the ADA. The appellate court disapproved of the lower court’s broad rejection of a cost-based defense, expressing concern that the holding had essentially “ruled out” a lack of funding justification. The court did not wholly disagree with the district court’s conclusion; it instead specified that it was clear that Congress intended to permit a lack of funding defense, but only in “the most limited of circumstances.” In this way, the appellate court attempted to provide some protection for states to raise cost-based defenses.

The court concluded that the cost-based defense ought to be upheld if it could be shown that ordering the state to transfer the two women to community-based programs would so impact Georgia’s strapped budget that it would constitute a “fundamental alteration” to the state’s programming. The court then remanded the case to the district court to determine whether this “fundamental alteration” finding could be made.

The court cited three factors to be considered in determining whether a state can establish a fundamental alteration: first, whether the costs of integrated services would be unreasonable in light of the demands of the state’s mental health budget. Second, whether it would be unreasonable to require states to use available Medicaid waiver slots. And third, whether any difference in the cost of institutional versus community-based care would lessen the state’s financial burden.

The United States Supreme Court affirmed the Eleventh Circuit’s holding in substantial part. The Court agreed that unjustified institutionalization constitutes a form of unlawful discrimination prohibited under the ADA and must be remedied by states when it is reasonable in light of certain factors. The Court, however, disagreed on what factors to consider in making this reasonableness determination. Justice Ginsburg’s concurrence found the requirements for establishing a “fundamental-alteration” cost-based defense still too burdensome for a state to

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48 Zimring, 138 F.3d at 902.
49 Id. at 904–05.
50 Id.
51 Id.
52 Id. The court considered in some detail the availability of Medicaid waivers that allowed the state to spend Medicaid dollars to provide community-based care to those not eligible for institutionalized care. Id. at 904. These waivers, known as “Home and Community-based Services” (HCBS) waivers, are discussed in more detail infra Part II.B.3.
53 Zimring, 138 F.3d at 904–05.
55 Id.
meet if only considering the costs of care for two individuals against an entire state’s mental health budget. Such a showing would be virtually impossible for a state to make. Instead, Justice Ginsburg found it important to consider a state’s need to provide a multitude of services to the diverse population of mentally ill patients in its care.

Justice Ginsburg recognized that while the cost of community-based care is far lower than institutionalized care in a simple comparison of the two, the cost analysis when releasing individual patients to community programs is far more complicated. Instead—due in part to high overhead costs associated with running an inpatient program—the release of a few individual patients saves virtually no money for the state, while funding the community programs to which these patients are released actually causes additional expenditures for the state. This was essentially an attempt to protect each individual state’s right to choose how to administer its own programs, so long as reasonable efforts were made to encourage the most integrated and least discriminatory programming possible.

Justice Stevens, concurring separately, instead felt that determining reasonableness ought to be a question for the lower courts and would have preferred to simply affirm the court of appeals. This would permit courts to make a simple comparison of community-based treatment costs versus inpatient treatment costs per individual; a comparison that Justice Ginsburg recognized would leave virtually no cost-based defense to states. In this way, the standard set by Justice Ginsburg’s concurrence actually provides more protection for state budgets and leaves plaintiffs with a bigger burden to meet. For this reason, the remainder of the analysis will consider the costs of the Utah State Hospital under the more demanding Ginsburg standard.

B. Potential Liability Theories in Utah

Since the Olmstead decision, subsequent cases applying the Court’s analysis have highlighted determinative factors that may tip the scales in favor of a plaintiff, particularly when ruling on a state’s fundamental-alteration defense. For example, courts have rejected as defenses general fiscal problems faced by the state and the argument that modifying services to fit a community rather than a

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56 Id. at 605 (Ginsburg, J., concurring).
57 Id. at 605–06.
58 See id. at 606 (recognizing that limited availability and waiting lists for community programs complicate the cost analysis).
59 Id.
60 Id. at 605 (“To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow.”).
61 Id. at 607 (Stevens, J., concurring).
hospital context will fundamentally alter programming. Conversely, states are able to avoid liability if they are able to demonstrate they have a plan to reduce institutionalization and have made “sufficient efforts” to implement that plan, such as increasing the use of Medicaid waivers, budgeting for community programming, using waiting lists to transition patients, planning new facilities, or reducing institutionalization rates.

Besides lawsuits, Olmstead prompted waves of innovative programming and funding solutions across the country for both the mentally disabled and mentally ill populations alike. Children’s mental health services have been part of this movement, with cases both past and current being brought by advocacy groups against states to enforce implementation of the Supreme Court’s ruling in this unique setting. Utah has thus far avoided any major litigation over its children’s mental health inpatient services, or its lack of comprehensive community-based programming. Viewed under the standards set forth in Olmstead, as well as in subsequent cases brought under the Olmstead precedent, the state of Utah is highly vulnerable to litigation by advocacy groups or families due to its slow pace in developing a comprehensive system of community-based mental health services, as well as its continued practice of treating children at the Utah State Hospital. This section details three specific factors that would likely tip a court in favor of a plaintiff bringing an Olmstead complaint against the state of Utah.

1. Legislative Approval of a Costly New Children’s Wing at the Utah State Hospital

In 2011, the Utah Legislature approved the Utah State Hospital’s request to for $25 million in funding to build a new facility to house the children’s wing of the psychiatric hospital. This construction project modifies the analysis such that Utah may be more vulnerable to claims that it is in violation of the ADA.

Under the least restrictive construction of a state’s obligations under Title II of the ADA, a state must show that it would be an inequitable allocation of its mental health resources to expend funds providing court-ordered services for

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62 See Fisher v. Oklahoma Health Care Authority, 335 F.3d 1175 (10th Cir. 2003); Townsend v. Quasim, 328 F.3d 511 (9th Cir. 2003).
63 See ARC of Washington State Inc. v. Braddock, 427 F.3d 615 (9th Cir. 2005); Sanchez v. Johnson, 416 F.3d 1051 (9th Cir. 2005); Williams v. Wasserman, 164 F.Supp.2d 591 (D.Md. 2001).
individual plaintiffs to the detriment of services provided for other mentally
disabled persons in the state.\footnote{Olmstead, 527 U.S. at 604 (Ginsburg, J.,
concurring) ("Sensibly construed, the fundamental-alteration component of the
reasonable-modifications regulation would allow the State to show that, 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
diverse and large population of persons with mental disabilities.").} However, even with this interpretation of states’
obligations as being minimal, the Court held that segregated and highly restrictive
treatment programs ought to be minimized as much as is reasonably possible, as
such programs are nonetheless unlawful discrimination prohibited by the ADA.\footnote{Id.
at 597 (majority opinion).}

To determine whether a state has minimized undesirable programming as
much as reasonably possible, a court takes into account the resources available to
the state, and looks for state attempts to make and implement a plan to decrease
institutionalization.\footnote{See id.} Applying such a standard to the recent funds allocated to
rebuild the Utah State Hospital, one would be hard pressed to argue that Utah is
maximizing its budget to implement new community-based services or has
formulated a plan to do so. Contrary to “reasonably possible,” it seems instead
entirely unreasonable to expend $25 million to further fund programming that the
Court is demanding be minimized. And while courts recognize states’ needs to
maintain lightly populated institutions while implementing the necessary
programming, this caveat is largely inapplicable where, ten years after Olmstead,
the Hospital continues to treat a disproportionately small population of children for
such an unreasonable length of time.

While Justice Ginsburg in \textit{Olmstead} looked at calculations of overhead costs
for institutions and pointed out the high cost of running even a very lightly
populated institution, she made the case that a state need not expend additional
funds it does not have in attempting to comply with court orders, even though such
a scheme would be more cost efficient over time.\footnote{See id. at 607.} The purpose of this, however,
was \textit{not} to allow states an open-ended and indefinite lack of funding defense. Rather, when Justice Ginsburg permitted this limited defense for states, her
intention was to allow states leeway to administer services at their own discretion,
but with the caveat that states must not passively allow segregated services to
continue without making an effort to slowly implement more integrated treatment
options.\footnote{Id. at 604–06 (Ginsburg, J., concurring).} Allocating more state dollars to rebuild the inpatient facilities, rather
than using these newfound dollars to implement community-based programs,
seems to blatantly disregard the “reasonably possible” standard.

As the Bazelon Center for Mental Health Law argues, states must work at
developing comprehensive community programs to reduce unnecessary
institutionalization in order to be in compliance with the ruling.\footnote{Under Court Order, supra note 28, at 1.} As far as

\begin{itemize}
\item \footnote{See id. at 607.}
\item \footnote{Id. at 597 (majority opinion).}
\item \footnote{See id.}
\item \footnote{Id. at 604–06 (Ginsburg, J., concurring).}
\item \footnote{Under Court Order, supra note 28, at 1.}
resources go, Bazelon argues that the decision suggests that state reallocation of resources may be compelled: “states need to look both at services that are currently funded and at how community services might be funded if the state took action to maximize its budget.”72 With the State Hospital’s new grant acting to maximize the state’s budget to fund more inpatient services, the door may be open for a plaintiff to argue that these resources ought to be used to fund integrated treatment options that comply with the ADA and Olmstead. Such an extensive allocation of resources demonstrates more than a passive allowance of continued discrimination of children with mental illness.

Finally, the recently allocated funds may be generally problematic as applied to the fundamental-alteration defense factors discussed above. They demonstrate Utah’s commitment to maintaining segregated care, undermine any fiscal defense that could be offered by the state, and suggest that the state is actually doing the opposite of formulating and implementing a plan to decrease segregated care.

2. Length-of-Stay Analysis

A second factor that would potentially weigh significantly in an ADA challenge against the state of Utah is the average length of a child’s stay in the Utah State Hospital. While the Olmstead decision does not discuss the length of hospitalization in its analysis, it clearly prohibits “unnecessary” institutionalization.73 Such language may open the door for arguments criticizing the “necessity” of excessively long periods of institutionalization. If such arguments are to be successful, they will very likely succeed in a case against the state of Utah, due to very excessive lengths of stay reported for children in the Utah State Hospital.

In 2005, the Division of Substance Abuse and Mental Health (DSAMH) issued a report on public substance abuse and mental health services in Utah. In the report, DSAMH calculated the median length of stay for children aged six to thirteen in the Utah State Hospital at 419 days.74 Compare this number to the average length of stay at the only other western state facility that designates children’s psychiatric beds, Colorado.75 Colorado reported an average length of stay for children aged zero to twelve of approximately eleven days.76 This is significantly shorter than those reported in Utah. Further, the median length of stay for “youth,” or children aged thirteen to eighteen, in the Utah State Hospital was

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72 *Id.* at 3.
73 *Olmstead*, 527 U.S. at 597 (“Unjustified isolation, we hold, is properly recognized as discrimination based on disability.”).
74 *DSAMH Report, supra* note 24, at 101.
75 *Performance Audit of USH, supra* note 15, at 37.
218 days\textsuperscript{77} versus Colorado’s average of approximately ten days for adolescent children aged thirteen to seventeen.\textsuperscript{78}

These dramatically higher numbers in the state of Utah may be open to a challenge on “necessity” grounds. The ever-growing body of research demonstrating that community-based interventions—even for children who qualify for inpatient levels of care—are as effective or more effective than costly and harmful institutionalized care only strengthens these arguments.\textsuperscript{79} With such effective interventions available, it becomes less and less likely that a court will be sufficiently convinced of the necessity of a child’s thirteen-month stay in a highly segregated institution so as to dismiss an ADA challenge.

3. Lack of Use of Medicaid Waivers to Help Fund Community-Based Services

The Supreme Court noted in its decision that Georgia failed to take full advantage of the Medicaid waivers available to it to fund the provision of services in community-based programs.\textsuperscript{80} The waivers make available federal funds for children who might not otherwise qualify for certain Medicaid funds.\textsuperscript{81} The idea behind these waivers is to allow Medicaid dollars that would eventually go toward funding an institutional stay to instead go to pay for more integrated, and preventative, services.\textsuperscript{82}

The Court pointed out specifically that “by 1996, ‘HHS approved up to 2109 waiver slots for Georgia, but Georgia used only 700’” and cited this statistic in support of its assertion that the federal government encourages states to provide more community-based treatment programs.\textsuperscript{83}

When applying the Court’s language, evidence of a failure to access these funds would strongly support a plaintiff’s assertion that a state had not made reasonable modifications to its programs so as to accommodate treatment needs in the community, in compliance with the ADA. Specifically, when “taking into

\textsuperscript{77} DSAMH REPORT, supra note 24, at 96, 101.
\textsuperscript{78} COLORADO REPORT, supra note 76.
\textsuperscript{79} See SAMHSA REPORT, supra note 13 (reporting the findings of forty-five community-based systems of care and concluding that changes occurred among children with severe emotional disturbances who utilized these services); see also supra text accompanying note 13.
\textsuperscript{81} Rebecca G.W. Random, Note, Custody Relinquishment to Obtain Mental Health Services, 7 J.L. & FAM. STUD. 475, 484 (2005).
\textsuperscript{82} Id. at 484–85.
\textsuperscript{83} Olmstead, 527 U.S. at 601. “Indeed, the United States points out that the Department of Health and Human Services (HHS) ‘has a policy of encouraging States to take advantage of the waiver program, and often approves more waiver slots than a State ultimately uses.’” Id. (citing Brief for United States as Amicus Curiae Supporting Respondents, Olmstead v. L.C. ex rel. Zimring at 25–26, 527 U.S. 581 (1999) (No. 98-536), 1999 WL 149633 at *26).
account the resources available to the state,” such evidence of unused waiver slots would support a finding that valuable resources had gone ignored. Thus, ignoring resources that would be capable of supporting community treatment programs would not be in compliance with the Supreme Court’s mandate that unnecessary institutionalization must be addressed by state action to make any reasonable modifications.

To analyze Utah’s current practices with regard to Medicaid waivers, it may be best to compare and contrast with a state that has taken notable advantage of the federal waiver program available. While nearly every state has secured waivers to develop programs for the developmentally disabled, far fewer states have adopted the waiver for use in developing children’s mental health services. Only three states in 2005 had secured Medicaid waivers to support children’s mental health care programs: Kansas, New York, and Vermont. Kansas has made significant strides in its process of deinstitutionalization, in significant part through use of the Medicaid 1915(c) Home and Community-Based Services (HCBS) waiver.

Kansas first used the Medicaid HCBS waiver in 1997, after it shut down its children’s psychiatric hospital. The state has been able to successfully treat children requiring a hospital level of care through intensive home and community services, with success measured by factors such as a child’s permanent status at home, his or her school performance, and the level of involvement with juvenile justice. The state has further expanded its waiver program, and has seen the annual per-child cost of children’s mental health services decrease by more than half when compared to institutionalization costs per child.

Utah has entirely neglected to access such a waiver to alternatively fund community-based children’s mental health services, although it is eligible and would likely qualify for such a waiver. In the reasonable modifications analysis, this factor might tip a court in favor of finding Utah in violation of the ADA.

84 Id. at 607.
86 Id.
87 See Random, supra note 81, at 484–85.
89 Id.
90 NGA ISSUE BRIEF, supra note 85, at 5.
91 MEDICAID WAIVER FACT SHEET, supra note 88, at 1 (“To qualify for the waiver, a state must show that it can serve children that require a hospital level of care with intensive services at home and in the community at a cost equal to or less than a hospital level of care. Most states find it challenging to qualify because they have closed their children’s
These three factors, either alone or taken together, may push a court to uphold an ADA challenge against the state of Utah, based on the current status of its children’s mental health care services.

III. CHALLENGING THE PRACTICE OF CUSTODY RELINQUISHMENT AS AN IMPINGEMENT OF SUBSTANTIVE DUE PROCESS RIGHTS

An alternative litigation strategy to prompt state action in building community-based children’s mental health services arises from the state’s practice of requiring a parent to relinquish custody of their child to the state so their child can qualify for Medicaid services. This is a problem that nearly half of the states are currently battling or have struggled with in the past, and one that is widely affecting families who are currently accessing the mental health care system—or those who are contemplating doing so.

States have dealt with this practice in different ways. In 2003, three members of Congress requested a report from the Government Accountability Office (GAO) on the occurrence of custody relinquishment across the country. The GAO found that states widely differed on this issue. In eleven states, statutory schemes allowed for voluntary placement of children in child welfare systems to access mental health care without requiring full custody relinquishment. In six states and the District of Columbia, statutes were in place that actively prohibited the psychiatric hospitals, however Utah would qualify because the state has cost data on serving children in a hospital setting.

92 JUDGE DAVID L. BAZELON CTR. FOR MENTAL HEALTH LAW, EXECUTIVE SUMMARY, RELINQUISHING CUSTODY: THE TRAGIC RESULT OF FAILURE TO MEET CHILDREN’S MENTAL HEALTH NEEDS 1 (2000), available at http://www.bazelon.org/LinkClick.aspx?fileticket=-hWblbUX5v8%3d&tabid=104 (last visited Oct. 5, 2011) (reporting that, in 2000, in roughly half of the states, an estimated one in four families seeking mental health services for their child was forced to relinquish custody to do so).


96 Id.
practice.97 In the remaining states, there were no statutes addressing the issue at all. 98

While the GAO has issued no follow-up reports, the commissioners of the GAO report gave testimony at a Senate hearing suggesting that shortly after the report was released several more states moved to enact bans on custody relinquishment.99 Utah, however, has not addressed the issue through statute, either to prohibit the practice or to regulate it through voluntary placement schemes, and has made no future commitment to do so.100

In a similarly silent manner, Utah keeps no data on the practice.101 No state agencies currently collect or track data about how often the decision is posed to families, or how often custody relinquishment is agreed to.102 However, both the National Alliance on Mental Illness (NAMI) in Utah and the Disability Law Center have received anecdotal reports of the practice.103 Also, common sense indicates that to be financing a costly stay in either residential treatment or the Utah State Hospital without much assistance from private health insurance,104 Utah families must be finding some way to qualify their children for public funds in order to meet the demands of such burdensome costs of high levels of treatment.

Because this practice is the consequence of high costs of treatment too burdensome for most families, it is likely flourishing in the state of Utah. This is an expected result of the lengthy and costly stays in either the Utah State Hospital or residential treatment, as well as the corresponding lack of options for lower-cost community-based services. Further still, the lack of Medicaid waiver programs that would provide alternatives to some families seeking to keep their children at home narrows the choices for families faced with this dilemma. Not surprisingly, lower

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97 Id.
98 Id.
99 Christine Lehmann, Bill Seeks to Reverse Trend of Parents Ceding Custody, PSYCHIATRIC NEWS, Sept. 19, 2003, at 11, available at http://pn.psychiatryonline.org/content/38/18/11.2.full (reporting on testimony given that thirteen states had banned parental-custody relinquishment practices as of the date of the hearing).
101 See id.
102 Id.
103 Id. at 4.
104 See GRUTTADARO, supra note 93 (asserting that private health insurance policies place severe restrictions on benefits for the treatment of mental illnesses and is “not an option for families with a seriously mentally ill child”).
cost community-based options are often cited as an effective solution to the custody relinquishment problem.\textsuperscript{105}

Thus, the custody relinquishment scheme exists as a sort of subset problem of institutionalization, in tandem with other issues that are caused by the high costs of inpatient care and issues that cause custody relinquishment. As such, litigation strategies to address one may thereby address the other as a natural consequence. The following is an analysis of a potential substantive due process challenge to the practice of custody relinquishment in Utah.

\textit{A. The Opinion: Joyner v. Dumpson}

There is little precedent in the area of custody relinquishment challenges. \textit{Joyner v. Dumpson},\textsuperscript{106} arising out of the United States Court of Appeals for the Second Circuit, appears to be the leading case providing guidance in analyzing a substantive due process claim that challenges custody relinquishment practices.\textsuperscript{107} Significantly, the opinion was issued long before the aforementioned mental health movements that currently promote family and community-based treatment options.

The claim in \textit{Joyner} arose from a custody relinquishment statute in New York state that actively required parents to relinquish custody to the state “as a prerequisite to” receiving mental health services.\textsuperscript{108} The statutory scheme effectively regulated the practice of custody relinquishment, requiring the state social services agency to negotiate and draft a written voluntary transfer of custody agreement with the family.\textsuperscript{109} Additionally, a second requirement stipulated that a family court must approve any such agreement when the custody arrangement could last more than thirty days.\textsuperscript{110}

A class of plaintiffs, approximately 5,000 children, brought suit in federal court, alleging that the custody relinquishment practice constituted a violation of their substantive due process rights under the Fourteenth Amendment, both facially and as applied.\textsuperscript{111} The district court granted partial summary judgment for the plaintiffs, finding that the scheme “infringed [their] fundamental right to ‘family integrity’ . . . violating their substantive due process rights . . . ”\textsuperscript{112}

The court of appeals reversed, following a three-step substantive due process analysis, looking at: 1) whether the claimed right is fundamental under the

\begin{itemize}
\item \textsuperscript{105} See, e.g., DLC INVESTIGATION, supra note 100, at 6; Gwen Goodman, Accessing Mental Health Care for Children: Relinquishing Custody to Save the Child, 67 ALB. L. REV. 301, 308 (2003).
\item \textsuperscript{106} 712 F.2d 770 (2d Cir. 1983).
\item \textsuperscript{107} See generally id. (applying a three-step test to guide substantive due process claims).
\item \textsuperscript{108} See Goodman, supra note 105, at 310–12.
\item \textsuperscript{109} Id. (citing N.Y. SOC. SERV. LAW § 384-a (McKinney 2003)).
\item \textsuperscript{110} Id. (citing N.Y. SOC. SERV. LAW § 358-a (McKinney 2003)).
\item \textsuperscript{111} Joyner, 712 F.2d at 771–72.
\item \textsuperscript{112} Id. at 772.
\end{itemize}
Fourteenth Amendment, 2) whether the state infringed that right, and 3) whether such infringement was justified by an important state interest. 113 Significantly, the court first held that the right to family integrity, or “the right of the family to remain together without the coercive interference of the awesome power of the state”114 was a fundamental, constitutionally protected right.115 The appellate court, however, disagreed with the district court’s finding that under a facial challenge this right had been infringed, for three specific reasons. First, the court did not see the New York statute as a relinquishment of the parents’ “right to rear their children,” because the voluntary transfer agreements protected those rights by defining “custody” narrowly.116 Second, the statute on its face declared its intention to be that of restoring families, once services were rendered.117 Third, the court pointed out that the scheme, on its face, was clearly “voluntary” and the parents ultimately had the right to choose whether to relinquish custody or not.118

The court then remanded the case for further analysis of the as-applied claim, citing factual disputes to be resolved before the issue could be fully analyzed.119 The as-applied analysis remanded to the district court subsequently went unresolved.120

B. Substantive Due Process As-Applied in Utah

Several factors weigh against the state of Utah if a plaintiff were to attempt to revive substantive due process challenges today.121 First, there is an ever-expanding and newly recognized right of those with mental disabilities to live at home and participate in their communities and families, as demonstrated by former president Bush’s executive order,122 cited in the foregoing discussion. This could motivate a court to recognize an as-applied due process violation where it was hesitant to do so before. The argument from Olmstead that integrated services are necessary to protect the integrity of the mentally disabled could be used to oppose

113 Id. at 777.
114 Id. at 777–78 (quoting Duchesne v. Sugarman, 566 F.2d 817, 825 (2d Cir. 1977)).
115 Id. at 778.
116 Id.
117 Id. at 779.
118 Id. at 780–81.
119 Id. at 783.
120 Goodman, supra note 105, at 314–15.
121 See Judge David L. Bazelon Center for Mental Health Law, Litigation Strategies to Prevent Custody Relinquishment (on file with author) (speculating that, while constitutional challenges to custody relinquishment have not generally been successful, “more favorable outcomes may be possible in different courts and with very different facts”).
states that allow custody relinquishment, as this fractures the child-family relationship and by extension threatens “family integrity.”

Second, Utah’s failure to enact a statute regulating custody relinquishment could leave the state more vulnerable to an as-applied challenge. The analysis would proceed as set out above. First, the court would determine whether “family integrity” is a fundamental right under the Fourteenth Amendment, which has been held to be so.\footnote{Joyner, 712 F.2d at 778 (citing Santosky v. Kramer, 455 U.S. 745, 753 (1982)).}

Next, the court would need to determine whether the state infringed that right. The analysis here would diverge from Joyner, because a court would no longer be analyzing a statutory scheme on its face, but rather the actual practice of custody relinquishment as alleged by a potential plaintiff. The court in Joyner pointed out such facts as the narrow definition of “custody” in the statute, the fact that the facial intention of the statute was family preservation, and the facial provision that provided the custody transfer would be clearly “voluntary,” all in support of its rejection of the contention that the statute was facially invalid.\footnote{Id. at 779.}

When addressed in Utah, however, the facial argument clearly fails because there is no statute, so a court would not be able to dispose of such a claim as easily. Further, where the court in Joyner was analyzing a statute meant to protect children from the abuses of the practice, Utah has affirmatively failed to enact such a statute or ban the practice in the thirty years since Joyner and the subsequent criticisms of custody relinquishment. This would likely balance a court unfavorably against the state in such a claim.

To be sure, such an analysis would be intensely fact specific and consequently it is difficult to analyze without any specific case on hand. However, parents would theoretically need first to demonstrate that the state effectively forced them to choose between relinquishing custody or forgoing treatment. From there, one need only demonstrate that forgoing treatment is not an option, because the state would then be able to predicate a finding of neglect on the fact that the parents do not access proper mental health care for the child. With the very limited sources of community-based care currently narrowing parents’ alternative options, this lack of choice might be easy for parents to show.

In sum, because access to community-based services is limited in Utah, leaving costly and lengthy inpatient and residential treatment options as the only choice for parents of severely emotionally disturbed children, it is likely that such a case exists in the state where the parents have virtually no choice but custody relinquishment. If such facts can be established and brought before a court, there is a strong possibility that an as-applied challenge will stand.
IV. Conclusion

While boasting a culture that is rich in family and community values, Utah ought to be leading the way in developing and implementing a comprehensive and efficient system of care that protects children and families by placing tools within the home and the community to strengthen these core units of Utah society. Further, with the Utah State Hospital at the end of its physical lifespan, and a crippled economy requiring more budget pinching than ever, the timing is particularly conducive to taking these crucial steps forward. With these litigation tools, an advocacy group or family might be able to successfully gain judicial support in the push to incentivize lawmakers to join the community-based services movement.