

**ATTACHMENT**



The Arc of the United States, The Arc of Ohio, and the Judge David L. Bazelon Center for Mental Health Law submit this brief as Amici Curiae in support of Plaintiffs’ Motion for Class Certification.

### **INTEREST OF THE AMICI CURIAE**

Amici curiae are organizations that advocate for the rights of individuals with intellectual and developmental disabilities (I/DD).<sup>1</sup> They have a wealth of knowledge regarding best practices in the supports and services individuals with such disabilities require to live successfully in community-based settings, and they believe that the Court’s consideration of Plaintiffs’ Motion for Class Certification would be informed by a brief presenting pertinent information within their expertise.

**The Arc of the United States** is the largest national community-based organization advocating for and serving persons with I/DD and their families. Founded in 1950, The Arc has over 650 state and local chapters. The Arc seeks to promote and protect the civil and human rights of people with intellectual and developmental disabilities and to actively support their full inclusion and participation in the community.

**The Arc of Ohio** is the state affiliate of The Arc of the United States and serves people with I/DD throughout Ohio through its eleven local chapters. It is made up of people with I/DD, their families, friends, interested citizens, and professionals in the disability field. Together with its individual members and local chapters, The Arc of Ohio represents more than 330,000 Ohioans with I/DD and their families. Its mission is to

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<sup>1</sup> Amici use the term “intellectual disability” in place of “mental retardation” except when directly quoting others or referencing names of organizations. Although the latter term appears in some evidence and case law, it is offensive to many persons and has been replaced by more sensitive and appropriate terminology. *See Rosa’s Law*, 124 Stat. 2643 (changing entries in the U.S. Code from “mental retardation” to “intellectual disability”); R. Schalock *et al.*, “The Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability,” 45 *Intellectual & Developmental Disabilities* 116 (2007).

advocate for human rights, personal dignity, and community participation of individuals with I/DD, through legislative and social action, information and education, local chapter support, and family involvement. The Arc of Ohio's values are based on the concept that all people, regardless of ability, have the right to be productive, interdependent members of their respective communities and the society at large. The Arc of Ohio believes in self-determination, by empowering people with the supports needed to make informed decisions and choices. The Arc of Ohio works towards and believes in the community imperative: that all people have the fundamental moral, civil and constitutional rights to live, learn, work, play, and worship in safe and healthy communities of their choosing.

**The Judge David L. Bazelon Center for Mental Health Law** is a national non-profit advocacy organization founded in 1972 that provides legal and other advocacy assistance to people with mental illness and intellectual disabilities. Through litigation, public policy advocacy, education, and training, the Bazelon Center works to advance the rights and dignity of people with disabilities in all aspects of their lives, including community living, employment, education, health care, housing, voting, parental rights, and other areas. A primary focus of the Bazelon Center's work involves efforts to remedy disability-based discrimination through enforcement of the Americans with Disabilities Act.

In this lawsuit, Plaintiffs seek to enable sufficient access for Ohio residents to integrated, community-based services. Plaintiffs maintain that this goal must be achieved through systemic relief that can be awarded only through the vehicle of class-based relief in a class action. Based on their expertise regarding community-based services and supports for individuals with intellectual and developmental disabilities, Amici believe that

this lawsuit's goal of decreasing reliance on institutions and assuring access to community-based services for those interested in seeking such options is consistent with the requirements of federal disability rights laws. Accordingly, in order to assist the Court in considering the Motion for Class Certification, Amici submit this brief to provide relevant information concerning the professional consensus regarding the benefits of transitioning individuals with such disabilities from large institutions to community-based supports and services and the positive experiences of other states in making such transitions.

### **ARGUMENT**

Plaintiffs' Motion for Class Certification argues that the injuries Plaintiffs seek to redress flow from systemic policies of the State of Ohio that deprive proposed class members "of integrated, community-based service alternatives" and cause their "discriminatory segregation." Pls.' Motion for Class Certification at 43. These policies are embedded in the structure of the Ohio system through Defendants' decision to license, fund, and maintain an excessive number of segregated institutional placements, while failing to provide adequate funding for and provision of home and community-based alternatives. Only class-wide relief can remedy these structural defects.

Similar to other states that have successfully shifted their funding scheme to favor community-based options rather than institutional placements, the changes sought to Ohio's system for the provision of community-based services and supports to individuals with intellectual and developmental disabilities (I/DD) are both readily achievable and critically important. Such structural and systemic changes, however, simply cannot be achieved through individual lawsuits. As Plaintiffs note, Ohio's institutional footprint is one of the largest in the United States. In 2013, more than 22,000 Ohioans with immediate needs were on waiting lists for

community-based services at the time, with a median wait time of over 13 years. Pls.’ Motion for Class Certification at 7-8 (internal citations omitted). These numbers are unacceptably high and reflect a systemic problem that cannot adequately be addressed through individual litigation. Systemic relief is needed to ensure that proposed class members have sufficient access to a process that will allow informed choices – including, among other elements, information about and visits to available alternatives and discussions with peers already benefiting from such alternatives – and lead to integrated, community-based residential, employment, and other services for those seeking such options. Without a class, such relief will not be achievable.

As Plaintiffs explain more fully, class certification is appropriate here because Plaintiffs’ injury arises out of and presents common questions regarding a core of salient facts and a common course of conduct by Defendants. Individual plaintiffs and thousands of similarly situated others have experienced a common injury (discriminatory segregation) as a result of Defendants’ actions. The ability to resolve these common legal claims and systemic defects with a single injunctive order makes class treatment appropriate here. It is notable that both before and after *Wal-Mart Stores, Inc. v. Dukes*, 564 U.S. 338 (2011), courts have consistently certified class actions challenging government officials’ non-compliance with Title II of the ADA, particularly in cases such as these involving the ADA’s “integration mandate.” Pls. Motion for Class Certification at 19.

While the Court need not explore the merits in depth at this stage of the case, it is important in connection with the motion for class certification that the Court fully understand the relief Plaintiffs seek on behalf of Ohioans with disabilities who are currently unnecessarily institutionalized or at risk of such institutionalization. The research supporting community-based services and supports for people with disabilities as well as evidence from other states that have

made this transition successfully clearly demonstrates that people with significant disabilities who require regular, intensive supports greatly benefit from living in community settings. Experience shows that states can effectively shift their focus and funding priorities from institutional to community-based services without causing undue disruption to the residents who transition from institutions. Indeed, the lesson from those experiences is that residents and families are more satisfied with integrated community alternatives — even families that had initially opposed the changes. As a recent report from the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Association of University Centers on Disability (AUCD) noted:

Over the past half-century we have learned that large institutions do not promote positive outcomes for people with IDD and limit community interaction and involvement for some of our most vulnerable citizens. These settings have negative outcomes for their health, well-being, quality of life, independence, and overall happiness. As a society we have moved from providing residential supports for people with intellectual and other developmental disabilities in the large, segregated, isolated institutions of the first half of the 20th century . . . to smaller group homes, shared apartments, and individually-owned or rented houses or apartments.

*Community Living and Participation for People with Intellectual and Developmental Disabilities:*

*What the Research Tells Us* (July 24, 2015) (hereafter *AAIDD/AUCD Report*), at 2, available

at [http://www.aucd.org/docs/publications/2015\\_0723\\_aucd\\_aaidd\\_community\\_living3.pdf](http://www.aucd.org/docs/publications/2015_0723_aucd_aaidd_community_living3.pdf). The

need to maximize the availability of these community-based services for the benefit of people

with I/DD strongly counsels in favor of granting Plaintiffs' Motion for Class Certification.

**I. The Professional Literature Establishes That Former Residents of Institutions Greatly Benefit from Living in the Community**

The professional literature conclusively demonstrates the overwhelming benefits former residents of institutions receive when they move to integrated community alternatives. These benefits have been proven in a variety of community settings, and for individuals with varying degrees of disability, including severe disabilities. Importantly, gains from community living

include improvements in adaptive skills, reductions of challenging behaviors, and an increase in independence, self-care, social interactions, and vocational skills. As the AAIDD/AUCD report notes:

People who live in inclusive community settings have more opportunities to control . . . their lives than those who live in segregated community living in institutional settings . . . the benefits of living in smaller, community settings include increased choice and self-determination, larger social networks and more friends, increased access to mainstream community facilities, greater participation in community life, more chances to develop and maintain skills that foster independence, a better material standard of living, increased acceptance from other members of the community, and greater overall satisfaction with their lives as expressed by people with IDD themselves and their families.

*AAIDD/AUCD Report*, at 4-5 (internal citations omitted).

Although there may be an initial adjustment period, transition to the community, when accompanied by needed supports and services, is generally successful for individuals with I/DD. This is particularly true when, during the transition process, the individual and family are able to meet with the new provider, visit the new home, and gradually adjust to the new environment. Community living also provides individuals with I/DD opportunities not generally available in large institutions, including regular interactions with individuals without disabilities and greater freedom to experience day-to-day community life, such as grocery shopping, participating in religious services, going to the movies, and visiting friends. Community living allows individuals with I/DD to develop fuller, more autonomous lives and to enjoy the freedoms, benefits, and experiences that those without I/DD may take for granted. The advantages of community living are powerfully and convincingly supported by a large body of professional literature measuring outcomes over the last several decades.

The *Pennhurst Longitudinal Study* was a seminal study launched in connection with a landmark class action lawsuit, which provided researchers the opportunity to follow over 1,100

individuals as they moved into the community. Research and analysis were conducted for five years following the court-ordered phase-down of the Pennhurst State School and Hospital in Pennsylvania. The study found that people who moved into the community were more independent and showed significant improvements in adaptive skills, while their counterparts who remained institutionalized showed no similar growth. *See The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis* at 56-63 (1985) (hereafter *Pennhurst Study*) (available at <http://aspe.hhs.gov/daltcp/reports/5yrpenn.pdf>).

Numerous other studies have corroborated the *Pennhurst* results, finding statistically significant gains in adaptive behavior skills associated with community living. A 1989 survey analyzed 18 studies of changes in adaptive behavior for formerly institutionalized individuals who had transitioned to the community. *See* S.A. Larson & K.C. Lakin, *Deinstitutionalization of Persons with Mental Retardation: Behavioral Outcomes*, 14 J. of the Ass'n for Persons with Severe Handicaps, 324-32 (1989). The studies involved 1,358 subjects from all regions of the country, including both individuals who consented to the transitions and individuals who opposed them. The review found that institutions were “consistently less effective than community-based settings in promoting growth,” particularly among individuals with intellectual disability. *Id.* at 330. The authors found that, “based on a substantial and remarkably consistent body of research, placing people from institutions into small, community-based facilities is a predictable way of increasing their capacity to adapt to the community and culture.” *Id.* at 331.

A follow-up survey in 1999 reviewed 33 more studies and found that the literature continued to support the conclusion that individuals who moved from large institutions to smaller homes in the community saw significant gains in adaptive skills as well as a decrease in challenging behaviors. *See* S. Kim, S.A. Larson & K.C. Lakin, *Behavioral Outcomes of Deinsti-*

*tutionalization for People with Intellectual Disabilities: A Review of Studies Conducted Between 1980 and 1999* at 6 (2001) (available at <https://ici.umn.edu/index.php?products/view/83>) (hereafter “S. Kim, *et al. Behavioral Outcomes: 1980-1999*”). Among the areas of improvement noted by researchers were skills relating to self-care, domestic needs, academics, communication, community living, socializing, and vocation. *Id.* at 8. The authors updated their work in 2011 and again confirmed that individuals who move from institutions to the community experience significant gains in adaptive skills. *Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies, 1977-2010* at 8 (2011) (available at <http://ici.umn.edu/products/prb/212/212.pdf>). See also E.A. Eastwood & G.A. Fisher, *Skills Acquisition Among Matched Samples of Institutionalized and Community-Based Persons with Mental Retardation*, 93 *Am. J. on Mental Retardation* 75, 80 (1988) (hereafter “Eastwood *et al., Skills Acquisition*”); J.W. Conroy, J. Garrow, *et al., Initial Outcomes of Community Placement for the People Who Moved from Stockley Center* at 47-48 (2003) (available at <http://www.dhss.delaware.gov/ddds/files/conroyrep.pdf>) (hereafter “J.W. Conroy, *et al. Stockley Study*”); S. Kim, *et al., Behavioral Outcomes: 1980-1999*, at 6-8.

A study of more than 2,000 individuals with I/DD who moved from institutions to the community in California from 1993 to 2001 yielded similar results. See M. Brown, A. Fullerton, J.W. Conroy & M.F. Hayden, *Eight Years Later: The Lives of People Who Moved from Institutions to Communities in California* (2001) (hereafter *California Study*) (available at <http://www.eoutcome.org/Uploads/COAUploads/PdfUpload/ca2r4.pdf>). This study analyzed over 700 items of information for each of the over 2,000 individuals. The results showed that individuals who left institutions “benefited considerably from community living.” *Id.* at 2. The study found improvements in several quality of life dimensions, including

progress in personal goals, individualized treatment, integration, challenging behavior and choice-making. *Id.* at 26. Significantly, researchers also concluded that families were “unexpectedly and overwhelmingly happy with community living, even those who formerly opposed the change.” *Id.* at 3. The *California Study* also found that those who entered the community were, on average, involved in an additional 13.3 community events per month and that this almost doubling of integrative activities was statistically significant. *California Study* at 31. The *Stockley Study* showed increases in 15 of 16 types of integrative activities, six of which were significant. J.W. Conroy, *et al.*, *Stockley Study* at 35. Individuals who left institutions, thus, greatly increased their opportunities to interact with citizens without disabilities. *Id.*

Although studies in the 1980s suggested that community living may lead to some deterioration in challenging behaviors, all of the studies from 1990 onward have shown conclusively that behavior actually improves upon moving to the community. S. Kim, *et al.*, *Behavioral Outcomes: 1980-1999*, at 6, 8 (ascribing this shift to improvements in community integration services and supports that have developed strategies not only to enhance adaptive behaviors, but also to decrease maladaptive behaviors). The *California Study* identified the largest improvements ever documented in research on behavior, finding for 191 persons who moved to the community a substantial increase in their ability to address challenging behaviors. *California Study* at 40-43. This result is particularly significant, since many individuals with I/DD initially were placed in institutions precisely because of such behaviors. As community providers have developed services, supports, and strategies to deal with these challenges, it is inappropriate to continue to isolate and segregate these individuals.

Most recently, the 2015 AAIDD/AUCD report found that “smaller settings, on average, continue to produce better quality of life outcomes for people with IDD.”

AAIDD/AUCD Report, at 3; see also D. Nord, Y. Kang, R. Ticha, K. Hamre, M. Fay & C. Mosley, *Policy Research Brief: Residential Size and Individual Outcomes: An Assessment of Existing National Core Indicators Research*, Vol. 24 No. 2, Univ. of Minn. (July 2014).

Notably, even where families initially opposed the transfer, the great majority ultimately become supporters of community living. See D. Braddock, *Closing the North Dakota Developmental Center: Issues, Implications, Guidelines*, at 11 (2006) (available at <https://www.researchgate.net/publication/237751414>).<sup>2</sup> Preferences to stay in institutions are often “based on lack of experience with other alternatives and fear of something new and different.” B. Shoultz, P. Walker *et al.*, *Status of Institutional Closure Efforts in 2005* at 3 (2005) (available at <http://ici.umn.edu/products/prb/161/161.pdf>). Interestingly, family members are often surprised by their own change in feelings and report “unexpected changes for the better in their lives, and in the lives of their relatives [with disabilities], especially with regard to the happiness of their relatives.” *Pennhurst Study*, at 109. Concerns of both the individual and family members can be mitigated by involving them in the process and enabling them to visit their new home, meet the provider, and assist in selecting potential house mates. Clinical judgment, a critical aspect of the relocation process, utilizes professional standards to ensure best practices and enhanced accuracy, precision and integrity in decision-making.

As study after study has shown, when done in accord with professional standards, transitions from institutional settings result in significant growth and increased quality of life for people with disabilities. Indeed, the overwhelming consensus of these studies was recently highlighted by the National Council on Disability, an entity composed of a majority of people with disabilities and charged with making recommendations to the President and Congress. In

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<sup>2</sup> See also, e.g., *Pennhurst Study*, at 79-80, 108-09; *California Study* at 124; D. Braddock & T. Heller, *The Closure of Mental Retardation Institutions; Trends and Implications (a Working Paper)* at 20-21 (1984) (available at <https://mn.gov/mnddc/parallels2/pdf/80s/84/84-PPM-UOI.pdf>).

a 2015 report, the Council called for more small-scale, community residential supports for people with disabilities. See National Council on Disability, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community* (2015) (available at <https://ncd.gov/publications/2015/02242015>). The Council explained that the “preponderance of research . . . supports the conclusion that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities.” *Id.* at 7. And the Council specifically recommended that states “[r]evis[e] or restructure existing funding and support policies to limit the size of residential settings for people with disabilities to home and living arrangements that are of individual and family scale,” and thereby “expand access to . . . integrated community settings” while prohibiting “campus-style housing where people with disabilities are segregated from the rest of society.” *Id.* at 60. Ohio residents are entitled to benefit from the experience and wisdom behind these recommendations just as residents of other states have.

As the professional literature overwhelmingly demonstrates, “[i]t is clear from decades of studies that people with IDD have happier, healthier, and more independent lives when they live in smaller community-based residences than in larger institutional settings.” *AAIDD/AUCD Report*, at 4.

## **II. Many States Have Significantly Expanded Community-Based Services and Successfully Transitioned People with Disabilities from Institutions to the Community**

States are increasingly shifting from expensive and outmoded institutional facilities for people with disabilities to a more effective community-based system of providing necessary services and supports. In the last 30 years, states have successfully transitioned people with disabilities from more than 190 public institutions or special units of 16 or more persons with

I/DD to community-based placements. K.C. Lakin, S. Larson, P. Salmi *et al.*, *Residential Services For Persons With Developmental Disabilities: Status And Trends Through 2009* at iv, 18 (2010) (available at <https://rtc.umn.edu/docs/RISP2009.pdf>). All 50 states and the District of Columbia have reduced their reliance on state-operated institutions. *Id.* at 5 (noting that population of large state-operated residential facilities for people with I/DD declined by more than 70 percent from 1980-2009). Eleven states and the District of Columbia now exclusively provide community-based services for people with I/DD without any institutional option. *See id.* at iii.<sup>3</sup>

As discussed below, the successful experience of states in transitioning their public service systems from reliance on institutions to systems that generally provide most services in the community demonstrates that the relief sought by Plaintiffs here is consistent with national experience and professional standards. In transforming their service systems for persons with I/DD, states have maximized funding, minimized per person costs, and vastly expanded the number of individuals served. While system transformation is challenging, and may cause concerns from families who are understandably anxious about change and resource allocation, numerous states have successfully addressed these concerns and safely transitioned thousands of persons with I/DD from institutions to new community homes.

The experience of states that have shifted from institutional to community-based systems demonstrates that, with proper planning, sensitivity, and funding, people with disabilities of any age and service needs can successfully move into dramatically different – and better – environments. Amici focus here on the experiences in Pennsylvania, Indiana and Massachusetts, where the ultimately successful shifts from institutional to community-based

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<sup>3</sup> The states listed by Lakin are Alaska, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont and West Virginia. In addition, Indiana has closed its large institutions. *See infra* at pp. 15-16.

services posed challenges that were comparable to, if not greater than, those that may be faced in Ohio. These examples demonstrate the importance of the systemic changes Plaintiffs seek to ensure such a transition is meaningfully implemented, which would allow all of Ohio's residents with I/DD to access community-based supports and services should they choose to do so.

**A. Pennsylvania**

Over the past three decades, the Commonwealth of Pennsylvania has successfully shifted to a community-based system and has closed 11 state-operated institutions and special units, including three large facilities that were the subject of litigation: Pennhurst Center in 1987, Embreeville Center in 1997, and Western Center in 2000. These institutions served thousands of residents, many of whom had been institutionalized since childhood. The Commonwealth's Office of Mental Retardation<sup>4</sup> established transition teams that oversaw the entire planning process, assured the availability of adequate funding to develop community-based services before the facilities were closed, and completed follow-up visits to monitor services, health care, therapies and behavioral services, and to obtain feedback from former residents and their families. These teams worked closely with families throughout the entire process to ensure they were apprised of changes and the benefits of transitioning to community-based services. Nancy Thaler, Review of the Tennessee State Arlington Developmental Center Closure and Community Transition Plan, *United States of America v. State of Tennessee*, Civ. No. 92-2062 (W.D. Tenn. 2006) at 7 (*Thaler Report*). Despite opposition from some guardians and families who initially opposed any change in residential settings, Pennsylvania's transition from institutional to community-based services has been

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<sup>4</sup> Consistent with the changes in disability-related terminology in recent years, *see* footnote 1, *supra*, this entity is now known as the Office of Developmental Programs.

heralded as an unqualified success by public officials, legislators, involved professionals, and, most importantly, the people with disabilities themselves.<sup>5</sup>

Opposition to closing Western Center was probably the most strident that the Commonwealth encountered. The families and guardians of Western Center residents litigated to prevent people from moving to the community. The courts, however, declined to interfere with state officials' policy choices and refused to dictate which specific facilities and programs should be maintained. *See, e.g., Richard C. v. Houston*, 196 F.R.D. 288, 289 (W.D. Pa. 1999), *aff'd*, 229 F.3d 1139 (3d Cir. 2000) (denying parents' motion to intervene to stop community placement).<sup>6</sup> Despite their initial opposition, the families of all but 56 out of 380 residents actively participated in the development of individual transition plans. Perhaps most significantly, after the institution was closed, even those 56 families who did not participate were largely pleased with their sons' and daughters' community living arrangements, with only one family having sought to have a former resident returned to the institution. *Thaler Report*, at 8.

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<sup>5</sup> *See, e.g.,* "Independent Monitoring for Quality: What Consumers in Pennsylvania Say About Their Services," and "What Families, Friends and Guardians Say About Services," Dep't of Public Welfare, Office of Mental Retardation, *Report of Independent Monitoring for Quality in the Pennsylvania Mental Retardation System* at 7, 10 (2002); Pennsylvania Dep't of Public Welfare, Office of Mental Retardation, *Everyday Lives: Making it Happen* (2001); S. Kim, *et al. Behavioral Outcomes: 1980-1999*, at 3, 5 (studies of deinstitutionalization in Pennsylvania consistently show growth and development after community placement); *Pennhurst Study*, at 192 (results are "conclusive" that "the people deinstitutionalized under the *Pennhurst* court order *are* better off in *every* way measured") (emphasis in original).

<sup>6</sup> *See also* M. Bucsko, "Western Center Moves Delayed," *Pittsburgh Post-Gazette*, February 1, 2000, <http://www.post-gazette.com/regionstate/20000201western1.asp>; J. Ackerman, "Judge won't hear Western Center parents' petition," *Pittsburgh Post-Gazette*, March 31, 2000, <http://www.post-gazette.com/regionstate/20000331western6.asp>; J. Ackerman, "State closing home for mentally retarded amid continued appeals, protests," *Pittsburgh Post-Gazette*, April 12, 2000, <http://www.postgazette.com/regionstate/20000412western1.asp>.

## **B. Indiana**

Since 2007, Indiana has successfully transitioned to a primarily community-based service system. With the closure of its last large institution, the Fort Worth State Developmental Center, in April 2007, Indiana sought to promote more effective and less wasteful community-based services. The State had successfully transferred individuals with disabilities from other institutions, such as New Castle and Northern Indiana State Developmental Centers, after longitudinal studies showed that after a year in the community, former residents demonstrated statistically significant and meaningful gains in skills, and professionals and involved families stated that residents were far better off in their new homes. J. Conroy and J. Seiders, *Outcomes of Community Placement at One Year for the People Who Moved from New Castle and Northern Indiana State Developmental Centers, Report Number 6 of the Indiana Community Placement Quality Tracking Project* at 23 (2000). Nevertheless, the State's decision in January 2005 to provide almost all residents with community-based services was particularly controversial because the 239 Fort Worth residents had complex needs, were considered difficult to serve, and, indeed, were regarded as having some of the most severe disabilities in the State's public service system.

Eight of the 239 residents were transitioned to smaller mental health facilities, while the remaining 231 individuals moved into the community. Peter Bisbecos, *Closing Institutions and Opening Doors to the Community*, 14 *Community Services Rptr.* 6 (2007). Although critics predicted that many of these residents with severe disabilities would not be successful in the community, careful planning and appropriate funding helped ensure an effective and successful transition into integrated community-based services. Specifically, the State formed a special team to follow former Fort Worth residents for one year after placement and to monitor their

situations. The State also enlisted community providers to build “extensive support needs” homes for people with the most significant behavioral challenges. By transitioning to a largely community-based system, the State freed up substantial funds that it then reinvested to develop additional services to provide much needed supports to hundreds of other non-institutionalized persons on waiting lists. *Id.*

### **C. Massachusetts**

Massachusetts’ successful shift from an institutional to a community-based system similarly demonstrates that these transitions are beneficial even for those residents with the most significant disabilities. Strong planning and sensitivity to residents’ and family members’ concerns during the closures of the Belchertown and Dever State Schools in 1992 and 2001, respectively, and the more recent phase-down of the Fernald Developmental Center, resulted in a better quality of life for residents who moved to the community and, despite initial reservations, positive feedback from families.

#### **1. *Belchertown State School***

To plan for the downsizing of Belchertown, the facility superintendent and the Department of Mental Health’s community service system managers created a collaborative process to systematically develop community services for Belchertown residents. As a result, the Commonwealth created a comprehensive array of community services to respond to the identified needs of each individual resident. Residents and families were engaged in the transition process, and they were encouraged and assisted to visit new homes and to express preferences about roommates and staff. When new residences were constructed, families were asked to participate in their design. As the service system grew, so did supervision, oversight, and quality assurance.

In the early phases of the transition, residents were given the option of returning to Belchertown, but that option was rarely invoked. The great majority of Belchertown residents chose a new home in the community.<sup>7</sup> When the decision was ultimately made to close the institution, most of the remaining residents and families — including those who had lived at Belchertown for many decades — chose community living. The few who preferred to continue living in an institution were offered a transfer to another ICF for persons with I/DD.

Shortly after the plan to close Belchertown was announced, a follow-on project began to measure family satisfaction and family and resident perceptions of the quality of life – both for those who had moved from Belchertown to the community and for those who had remained at the facility. Of the residents who left, 78 percent were reported to have severe or profound intellectual disability, and their level of disability was “not at all different” from those who remained. Nevertheless, 89 percent of the families of residents who moved were satisfied or very satisfied with the move and only two percent expressed any dissatisfaction. *Belchertown Follow Study, supra* n.7, at 17. The researchers found that, “[w]hen comparing Belchertown families to community families, the community families were happier overall, perceived their relatives to be happier, [and] believed that their relatives were continuing to learn new things.” *Id.*

## **2. Dever Developmental Center**

An even more sophisticated transition planning process was initiated several years later when Massachusetts decided to move residents at the Dever Developmental Center into the

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<sup>7</sup> Eastwood *et al.*, *Skills Acquisition* (indicating that the group of Belchertown residents who transferred to the community had significantly greater level of cognitive and social skills after placement than the matched group that remained in the institution); *see also* V.J. Bradley, C.S. Feinstein, *et al.*, *Results of the Survey of Current and Former Belchertown Residents and their Families: The Belchertown Follow-Project 20* (Dec. 1992) (reporting results of Eastwood & Fisher study) (hereafter “*Belchertown Follow Study*”), available at [http://www.hsri.org/files/uploads/publications/378\\_Results\\_of\\_the\\_Survey\\_of\\_Current\\_and\\_Former\\_Belchertown\\_Residents\\_and\\_Their\\_Families.pdf](http://www.hsri.org/files/uploads/publications/378_Results_of_the_Survey_of_Current_and_Former_Belchertown_Residents_and_Their_Families.pdf).

community. At first, this policy decision was strongly opposed by family members and guardians. Eventually, through careful planning, engaged participation, and an emerging history of successful placements, the opposition waned. Over several years, hundreds of residents with severe disabilities were carefully transitioned to other settings — the vast majority to the community. All were offered, and a few requested, placements in other institutions. E.G. Enbar *et al.*, *A Nationwide Study of Deinstitutionalization and Community Integration: Massachusetts*, 67-69 (2004), available at <https://www.equipforequality.org/wp-content/uploads/2016/05/A-Nationwide-Study-of-Deinstitutionalization-Community-Integration.pdf>.

The Dever transitions were facilitated through Massachusetts’ use of person-centered planning — a systematic individual planning process characterized by searching actively for a person’s gifts and capacities in the context of community life and by strengthening the voices of the person and those who know her best to define desirable changes in her life. C.L. O’Brien and J. O’Brien, *The Origins of Person Centered Planning: A Community of Practice Perspective* at 3 (2000), available at <http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.502.8388>.

Massachusetts ultimately developed the concept of building “social units” as part of the transition planning for each resident, giving the consumer and family/guardian the opportunity to identify staff who would remain with the client through the transition and into the community.

E.G. Enbar *et al.*, at 67-69 (2004).

### **3. Fernald Developmental Center**

In 2003, based on the Commonwealth’s prior success shifting from institutional to community-based services, then-Governor Mitt Romney announced the phase-down of several additional ICFs, including the oldest institution in the country, Fernald Developmental Center. Family members adamantly opposed the plan and went to court seeking to enjoin

implementation of the decision. Although the district court granted the requested injunction, the First Circuit reversed and allowed the plan to proceed. *Ricci v. Patrick*, 544 F.3d 8, 20-21 (1st Cir. 2008). Thereafter, as with Belchertown and Dever, the Commonwealth successfully transitioned most residents to the community, while also offering the option of other ICF placements for those who chose facility-based services. *See P.S. v. Department of Developmental Disability*, 84 Mass. App. Ct. 822 (2014).

As the above examples demonstrate, a variety of states have had great success in implementing large-scale, systemic shifts from institutional to community-based services for even those with the most significant disabilities and complex needs. States have made these changes without compromising the health, safety, or continuing development of the individual. Indeed, as discussed in Section I, despite skepticism or outright opposition by family members, study after study demonstrates that when the moves are based upon a person-centered discharge planning process, with support provided to assist the individual and family with the transition, transfers to the community are both safe and beneficial. The transfers result in improvements in many areas of the individual's life, particularly individuals with the most significant disabilities, resulting in increased satisfaction by both the person with I/DD and the family. *See, e.g., Pennhurst Study*, Executive Summary at 7 (“the people with the most severe impairments turn out to be among those who benefit the most from community placement”).

Notably, researchers evaluating the experiences of people currently receiving integrated, community-based services in Ohio itself have also recognized the value of those services for people with I/DD. According to a 2016 study prepared by The Ohio Colleges of Medicine Government Resource Center, people who moved from ICFs to the community experienced high

rates of satisfaction, greater independence, greater outcomes, and improved quality of life. *See Ohio Community Transition Study* (February 29, 2016) (attached to Plaintiffs' Reply and Supplemental Evidence in Support of Motion for Class Certification as Exhibit 4). According to the study, more than 90 percent of respondents described their lives as being better since moving from an institution. *Id.* at 20. *See also* Plaintiffs' Reply and Supplemental Evidence in Support of Motion for Class Certification at 10-14.

Accordingly, there is every reason to expect that Ohio, if ordered to provide the class-wide relief requested in this case, will be as successful (and perhaps more successful given the benefits of others states' experiences) as Pennsylvania, Indiana, Massachusetts, and other states that have reduced their reliance on institutions and moved to a community-based system.

### **CONCLUSION**

The evidence clearly demonstrates that people with significant disabilities who require regular, intensive supports greatly benefit from placement in community settings. States have repeatedly shown that they can effectively shift their focus and funding priorities from institutional to community-based services without causing harm or undue disruption to the residents who transition from institutions. And numerous studies that have reviewed states' decisions to move such persons to the community have found that individuals do better, and they and their families are more satisfied, after leaving institutional placement. Accordingly, the Court should recognize the benefits achieved when people – even those with the most significant disabilities – transition from institutional to community-based services, and it should grant Plaintiffs' Motion for Class Certification.

Dated: November 9, 2017

Respectfully submitted,

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