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VIA US MAIL AND ELECTRONIC MAIL

Governor Kasich and Directors Moody, Martin, and McCarthy:

We write on behalf of thousands of individuals with intellectual and developmental disabilities in Ohio who are needlessly segregated in private intermediate care facilities for individuals with intellectual disabilities (ICFs/IID) or state-operated developmental centers. As a result of the State's system, these individuals are segregated in institutions, with scarce opportunity for supported employment or integrated day services, in violation of federal law.

In recent months we conducted an extensive investigation<sup>1</sup> that included more than a dozen site visits to ICFs/IID, developmental centers, sheltered workshops and facility-based day habilitation programs. Our analysis was further informed by our collective experience. Disability Rights Ohio is the federally mandated and funded Protection and Advocacy organization for the State. The Center for Public Representation is a public interest law firm based in Northampton, Massachusetts, and one of two national technical assistance and legal support centers for the national Protection and Advocacy system. Samuel Bagenstos is a

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<sup>1</sup> Our investigation has included: (1) analyzing and studying Ohio's ICF/IID and developmental center residential programs, and its employment and day service system; (2) meeting with stakeholders, including service providers and other leaders in the field; and (3) visiting many ICFs/IID, developmental centers, sheltered workshops, and facility-based day habilitation sites, including meetings with consumers, staff, and management at each site.

Professor at University of Michigan Law School,<sup>2</sup> who previously served from 2009-2011 as the Principal Deputy Assistant Attorney General for Civil Rights in the United States Department of Justice.

Throughout our investigation, we met many individuals who are directly affected by the State's policies and practices. Their personal stories are compelling, their capabilities are impressive, and their segregation is plainly unnecessary. Nevertheless, they languish in segregated residential placements, sheltered workshops, and facility-based day programs, without any real prospect of community integration. Here are a few of their stories:

B.M. is a 28-year-old man who has lived in a 36-bed ICF/IID for the past 8 years. He wants to leave the institution because he has no freedom, no social life, and no opportunity to meet nondisabled people other than staff. He has a 10-year-old son, but he is unable to maintain a meaningful relationship from within the facility. He could enjoy a full life in the community, but instead is infantilized, isolated, and depressed by his placement in the institution.

A.B. is a 35-year-old woman who has lived in a developmental center for 8 years. Her days are highly regimented. She is required to awaken very early each day, at a time not of her choosing, and she loses privileges if she sleeps later. She is not permitted to choose, shop for, or assist in cooking any of her meals. She wants to have a pet, but none are allowed in the facility. She yearns for a home in the community where she can live with people as friends and family. And although she very much wants to work in the community, preferably at a restaurant, she is relegated to a sheltered workshop.

For the past decade, D.J., 35, has lived in a 32-bed ICF/IID, which he describes as a form of incarceration. He wants to live in the community – a choice his guardian supports. But for 12 years he has been stuck on a waiting list for a Medicaid waiver that would provide a home in the community. He also wants to work in the community and earn a pay check, but instead he is assigned to a day habilitation program on-site at the ICF/IID which offers no opportunity for wages or integrated employment.

B.M., A.B. and D.J. are among the thousands of individuals with intellectual and developmental disabilities experiencing segregation in Ohio. Segregation permeates virtually all aspects of their lives, not only where they live, but where and how they spend their days. As the Supreme Court held in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 599 (1999), segregation “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life,” and “severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, [and] economic independence.” Individuals with developmental disabilities are able to live in integrated home and community-based settings, and to work and engage in meaningful day activities in the community. Integrated services provide regular contact with peers without disabilities, foster community inclusion, promote economic independence, and enhance individuals' productivity

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<sup>2</sup> Professor Bagenstos is participating in this matter in his personal capacity; his institutional affiliation is listed for identification purposes only.

and sense of self-worth and the chance to live and work in a manner that reflects each individual's strengths and preferences.

We recognize that the State has publicly committed to shifting some aspects of its service delivery system for people with developmental disabilities toward more community integration. But the State's actions are inadequate and, in key respects, the recent actions by the State further entrench the segregation that is endemic to the Ohio developmental disabilities system. The State is constructing new ICF facilities to house individuals who leave state-operated developmental centers and other large ICFs. Moving from a large facility to a smaller facility will not mitigate the inherent segregation. Our investigation found that even smaller ICFs are highly segregated and do not provide or allow for the integration that the law requires. By committing to construct and maintain these new facilities, the State is subjecting yet another generation of Ohioans with developmental disabilities to a life of segregation.

Similarly, although the State has adopted an Employment First policy, the State has taken no meaningful steps toward ensuring that people with developmental disabilities have the supports to enable them to succeed in integrated, competitive employment. And the State has made no visible effort to ensure that day services are provided in an integrated setting. Instead, the State has left sheltered workshops and facility-based day habilitation programs as the mainstay of its system.

## **I. Background: Ohio's Residential, Employment, and Day Services System for People with Developmental Disabilities**

### ***A. Ohioans with Developmental Disabilities Experience Widespread Segregation***

The State of Ohio administers and funds a system for people with developmental disabilities that promotes segregation and relies heavily on institutional residential placements and facility-based work and day services. Presently, approximately 6,000 individuals in Ohio are institutionalized in private ICFs/IID, and almost 1,000 more in developmental centers. As of fiscal year 2011, no other state has as many beds in large (16 or more beds) private ICFs/IID. Director Martin publicly recognized in a 2014-15 budget review that the national trend over the past 10 years reflects a 33% decrease in the number of people living in large ICFs/IID. But Ohio has experienced a 6% *increase*, with a total of over 3,400 beds in large private ICFs. And under the State's current system, the people in these facilities are stuck there with little hope of community placement: Thousands of ICF/IID residents are on wait lists for waiver slots to transition to integrated residential placement with slim prospects of an opening, given that the median wait time is over 13 years.

The overreliance on institutional, segregated settings is mirrored by Ohio's system of employment and day services. The State funds 93% of its employment services in sheltered work or enclave settings; nearly 17,000 people in Ohio receive services in sheltered workshops—more than in any other state in the nation. Furthermore, nearly all state (and county) funding for day habilitation in Ohio is for congregate facility-based services, and according to the Ohio Department of Developmental Disabilities, nearly all of the roughly 14,000 people receiving adult day support are in congregate facility-based settings.

## **B. Ohio's System Design Favors Institutional Placement**

The degree of segregation in Ohio's developmental disabilities system results, in significant part, from financial incentives built into that system. Ohio funds institutional placements at state developmental centers or private ICFs/IID with a combination of federal Medicaid and matching state dollars. In contrast, the State's policies require placement in Medicaid waiver programs providing home and community-based services (HCBS) for individuals with developmental disabilities (primarily the Individual Options (IO) waiver)<sup>3</sup> to be matched with county dollars. For this reason, county boards of developmental disabilities have a strong economic disincentive to provide HCBS waivers to individuals in institutional placements or to those who are at risk of institutionalization. Indeed, the only provision of new IO waivers is in limited emergency situations, and even that varies by a county's ability to leverage local dollars.

This financial disincentive for using waiver placements poorly serves the State's individuals with developmental disabilities and leads the State to contravene its obligations under the ADA. It is also costly and fiscally inefficient. The average annual cost for the IO waiver is \$58,181 per person, while the average annual cost for institutional care is substantially higher: \$94,313 per person at an ICF/IID with 16 or more beds, \$83,688 at an ICF/IID with 15 or fewer beds, and \$186,670 at a developmental center. The State has recognized research showing that prioritizing spending on HCBS waiver placements leads to a "decline in institutional spending and long-term cost savings." (*Rebalancing Long-Term Services and Supports* (Hilltop Institute, June 14, 2011) p. 10). But the State has failed to act on this important fact.

Moreover, the State's HCBS waiver programs have arbitrary restrictions on the level and types of services that many people with developmental disabilities would need to live safely and successfully in the community. The IO waiver program, for example, does not cover nursing services or intensive behavior supports. The SELF and Level One waiver programs have strict cost caps and can only support people with minimal needs. Also, excessive administrative billing requirements for providers, inadequate rate structures, and assessment instruments that focus more on financial considerations than a person's actual needs all contribute to this flawed system.

The State's heavy reliance on ICFs/IID and developmental centers also fosters segregation in the provision of employment and day services. Individuals who live in these segregated institutions are relegated to sheltered employment and facility-based day services, either at the site of their residence or in separate facilities. The State has recognized that institutional settings restrict individual choice, whereas home and community-based settings provide individuals with "greater ability to choose where they receive employment or day services." (*The Future of the ICF-IID Program* (DoDD, August 2012) p. 5). But, once again, it has failed to act on that important knowledge.

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<sup>3</sup> The only real recent expansion of HCBS in Ohio was the creation of the Self-Empowered Life Funding (SELF) waiver in December 2011; however, its funding limitations (\$40,000 for adults, \$25,000 for children) make it infeasible as a mechanism for institutionalized persons to return or move to the community.

## **II. Federal Law Requires Ohio to Provide Services, Programs, and Activities in the Most Integrated Setting Appropriate**

When it enacted the ADA in 1990, Congress recognized that “society has tended to isolate and segregate individuals with disabilities” and that “such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” 42 U.S.C. §12101(a)(2). The ADA’s implementing regulations specifically require a state to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. §35.130(d). The United States Supreme Court has interpreted this provision, known as the “integration mandate,” to mean that unnecessary segregation of individuals with disabilities constitutes discrimination under Title II of the ADA. *Olmstead*, 527 U.S. at 601-02.<sup>4</sup>

The integration mandate speaks broadly about integration in “services, programs, and activities” that the state administers. The *Olmstead* decision specifically addressed the improper residential institutionalization of individuals who were qualified to live in the community. *Olmstead*, 527 U.S. 581. But recent cases and administrative interpretations recognize that the mandate applies as well to the provision of employment-related services and day programs. See *Lane v. Kitzhaber*, 841 F.Supp.2d 1199, 1205 (D. Or. 2012); *U.S. v. State of Rhode Island*, Consent Decree p. 2 (“[T]he integration mandate of the ADA and the *Olmstead* decision... require that the State’s day activity services, including employment and day services, for individuals with I/DD be provided in the most integrated setting appropriate to meet their needs.”); DOJ Guidance at 3 (*Olmstead* applies to “segregated day programs”).

Also, in the most recent expression of the federal government’s understanding of the scope of the mandate, the Centers for Medicare and Medicaid Services (CMS) have clarified that an integrated setting is one that “supports full access of individuals... to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community.” (42 C.F.R. § 441.301(c)(2)(i); Federal Register, Vol. 79, No. 11 (Jan. 16, 2014) p. 3030).

By continuing to fund, oversee, and rely upon segregated residential placements, sheltered workshops, and facility-based day services for thousands of individuals with developmental disabilities, the State is violating federal law. Despite its recent statements and policy initiatives, Ohio has not made any measurable progress transitioning these individuals to community-based residential settings, supported employment, and meaningful community-based day services. Under the ADA and Rehabilitation Act, the State must take measurable, effective steps to redress this violation, as delineated below.

## **III. Proposed Remedial Actions**

In an effort to promote a resolution of these issues without resort to litigation, and to more quickly address the needs of individuals with developmental disabilities in Ohio, we ask

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<sup>4</sup> Similarly, a state violates Section 504 of the Rehabilitation Act, 29 U.S.C. § 794 when, as a recipient of federal funds, it fails to “administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.” 28 C.F.R. 41.51(d).

that the State take immediate action to: (1) significantly reduce the number of persons residing in developmental centers and ICFs/IID, with a transition to small, integrated, community-based, non-ICF/IID placements; (2) reduce its reliance on segregated workshops and enhance its capacity for supported employment; and (3) reduce its reliance on facility-based day habilitation and enhance its capacity to provide integrated day supports in the community. The State should make a firm commitment to transition a substantial number of individuals from segregated residential, employment, and day services and to rebalance its system as quickly and effectively as possible.

Based upon the input of stakeholders we have consulted, and an analysis of successful strategies implemented in other states, including recent settlements reached by the Department of Justice, we propose the State initiate the following remedial actions:

1. Issue a statewide plan, with specific annual numerical targets, to substantially increase the number of persons who receive integrated, individualized home and community-based residential and nursing supports, supported employment, and community-based day services, and concomitantly decrease the number of persons in developmental centers, ICFs/IID, sheltered workshops, and facility-based day services.
2. Utilize cost savings from the reduced reliance on expensive institutional settings to reinvest in a strengthened home and community-based services system.
3. Over the course of the next 10 years, expand home and community-based residential supports to meet the needs of individuals currently in ICFs/IID or developmental centers who choose to transition to an integrated residential setting.
4. To facilitate expansion of adequate home and community-based residential supports, ensure adequate funding for the non-federal share of HCBS services (presently shouldered by the county boards of developmental disabilities), irrespective of where the individual consumer lives; ensure conflict-free assessments so that county boards are not serving a role in determining an individual's funding level for services while also coordinating his or her services; adjust rate structures to enable the development of sufficient capacity for home and community-based services; and commit to expanding the capital assistance programs for the development of housing and the creation of rental subsidy programs to achieve scattered-site housing options in residential neighborhoods.
5. Develop a diversion program to ensure that future admissions to private ICFs/IID and developmental centers occur only in exigent circumstances (an emergency or crisis, for example), that admissions be short-term only, and that discharge planning occur immediately upon admission.
6. Develop adequate safeguards to ensure the health and welfare of all individuals who transition from an institutional setting to the community. This includes the implementation of a discharge planning process at each developmental center and ICF/IID, with a presumption that, with sufficient supports and services, all individuals (including individuals with complex behavioral and/or medical needs) can live in an integrated setting. The decision of any individual not to leave an institutional

placement must be informed and consistent with that person's needs. The process must also include a system whereby discharge is followed by the identification of gaps in care to reduce the risk of re-admission, crisis, or other negative outcomes.

7. Make supported employment in integrated work settings the priority service option for individuals currently placed in developmental centers or ICFs/IID with the goal of competitive employment at or above minimum wage. The decision of any individual not to leave a segregated or facility-based placement must be informed and consistent with that person's needs. As a complement to supported employment, integrated day services shall be designed to allow individuals currently placed in developmental centers or ICFs/IID to participate in mainstream community-based recreational, social, educational, cultural, and athletic activities. These day services should be provided in the amount, duration, and intensity to allow individuals to engage in self-directed activities in the community at times, frequencies, and with persons of their choosing, during hours when they are not receiving residential or supported employment services.
8. Over the course of the next 10 years, facilitate and fund the provision of supported employment opportunities and integrated day services for individuals who currently are in ICFs/IID or developmental centers and sheltered workshops and/or facility-based day services.
9. Ensure that any expanded community-based residential, employment, and day services: (1) are integrated in, and support full access to, the greater community; (2) ensure individual rights of privacy, dignity, and respect, and freedom from coercion and restraint; (3) optimize autonomy and independence in making life choices; (4) facilitate choice regarding services and who provides them; and (5) facilitate opportunities for supported employment and community-based day services. The appropriate community-based residential, employment, and day placement for each individual shall be developed through person-centered assessments and planning to determine the most integrated, least restrictive setting appropriate to that person's unique needs.
10. Ensure the development of sufficient capacity, through qualified providers, to deliver supported employment and integrated day services, as well as training and technical assistance. The State should make any necessary adjustments to rate structures or state practices, policies, and procedures to ensure the development of this capacity. To ensure that consumers receive full integration, funding to providers shall be made contingent upon the attainment of specified numerical and qualitative targets along an implementation timeline. To ensure the quality of these integrated employment and day services, adopt policies and procedures for evidence-based vocational assessments based on person-centered criteria, career development plans, and situational assessments for supported employment and/or integrated day service assessments.
11. Develop a statewide core competency-based and value-based training program for all service provider and State agency staff to manage and facilitate the transition from a primarily institution-based system to one composed of quality community-based

residential and day supports. The training shall include person-centered practices, community integration, and self-determination awareness.

12. Develop an outreach, in-reach, and education program that explains the benefits of home and community-based residential services, supported employment, and community-based day services. The program must address family concerns and perceived obstacles to participating in integrated programs, and encourage individuals in developmental centers and ICFs/IID to seek integrated placements and services.

Toward these transformative goals, we request a meeting with the Governor's Office of Health Transformation, the Ohio Department of Developmental Disabilities, and the Ohio Department of Medicaid, with the hope that we can work collaboratively to resolve these matters without the need for formal legal action. If you are amenable to engaging in a collaborative process, we suggest that the parties enter into a negotiation process to ensure a timely and productive engagement.

We are available to meet with you in early or mid-August 2014 and would welcome the opportunity to discuss these issues and develop an agreed upon plan of action. We know that the State of Ohio shares our goal of improving the system so that people with disabilities can live full and productive lives, integrated in their home communities. We sincerely hope that we can reach a mutually satisfactory agreement without the need to involve the judicial system, and we ask that you respond to this letter by July 31, 2014.

Thank you for your consideration.

Respectfully,



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