

Ohio, *Olmstead* and the Integration Mandate

People with I/DD
lives in their
communities



**Disability
Rights** OHIO

We have the
legal right of way.

Mission



The mission of Disability Rights Ohio is to advocate for the human, civil and legal rights of people with disabilities in Ohio.

Vision



- We envision a society in which people with disabilities
 - are full and equal members,
 - enjoy the rights of and opportunities available to all people,
 - are self-directed,
 - make decisions about where, how, and with whom they will live, learn, work, and play,
 - have access to needed services and supports, and
 - are free from abuse, neglect, exploitation, and discrimination.

Community



Where after all do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person: The neighborhood he lives in; the school or college he attends; the factory, farm or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere.

-- Eleanor Roosevelt, from remarks at the United Nations
March 27, 1958

DD Act



- DD Act, 42 USC 15001(a)(16)

the goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to—

 - (A) make informed choices and decisions about their lives;
 - (B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;
 - (C) pursue meaningful and productive lives;
 - (D) contribute to their families, communities, and States, and the Nation;
 - (E) have interdependent friendships and relationships with other persons;
 - (F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and
 - (G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual.

Title II ADA



- Title II, Americans with Disabilities Act
 - [N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. 42 U.S.C. § 12132
 - public entities must “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)

Title II ADA / 504



- Section 504 (29 U.S.C. § 794) provides a similar mandate for recipients of federal funds, including Medicaid
- 28 CFR 41.51(d) “Recipients shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons.”

Olmstead v. L.C.



- *Olmstead v L.C.*, 527 U.S. 581 (1999)
- A majority of the Court found
 - “Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life”
 - “Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” *Id.* at 600-01

Olmstead v. L.C.



- The majority held that Congress’s intent as stated at 42 U.S.C. § 12101(a)(2) was to end unjustified segregation of people with disabilities when it passed the ADA.
- “[H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”

Olmstead v. L.C.



- A plurality (4 votes) suggested that a state could avoid liability by
 - Having a “comprehensive, effective working plan” to place people in the community and
 - “a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.”

DOJ Regulations



- The “most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” 28 C.F.R. pt. 35 app. A (2010)

Segregated Employment



- *Lane v. Kitzhaber*, certified class action challenging state practices that promote segregated service system. Focus on structural issues, not individual
- DOJ motion to intervene: “[T]he State of Oregon unnecessarily segregates individuals with intellectual and developmental disabilities in sheltered workshops, where they have little to no interaction with the general population, by failing to provide or make available supported employment services that would allow for their integration into the community.”

Segregated Employment



- Changes in federal law (WIOA) require that individuals with I/DD be provided with an opportunity to transition to supported or competitive employment before being placed in workshop or 14c programs
- Ohio's Employment First initiative is moving forward

DRO Areas of Concern



- Braddock 2013 (2011 numbers)
 - HCBS waivers have grown to 29,227
 - 9626 live in significantly segregated placements:
 - 6,755 in ICFs or NFs of 16 or greater
 - 2,871 in ICFs of 7-15
 - **28% live in institutional settings**

DRO areas of concern



- **Findings**
 - Currently, there are approximately 6,000 individuals in Ohio who are institutionalized in private ICFs/IID and approximately an additional 1,000 in developmental centers.
 - Many feel they have no freedom, no opportunities to maintain relationships with people outside the facility and feel isolated and depressed.

DRO areas of concern



- **Their lives are regimented: residents eat and sleep according to the facility's schedule, and activities and outings to the community, when they do occur, are chosen by the facility's staff and occur only with other residents and staff.**
- **Some describe life in an institution as "prison" or "solitary confinement."**

DRO areas of concern



- As of fiscal year 2011, no other state has as many beds in large ICFs/IID (i.e. facilities with 16 or more beds) as Ohio
- The national trend reflects a 33% decrease in the number of people living in large ICFs/IID over the past ten years. But Ohio has experienced an *increase* of 6%, with a total of over 3,400 such beds

DRO areas of concern



- **Waivers**

- Recent expansion of HCBS in Ohio was the creation of the Self-Empowered Life Funding (SELF) waiver in December 2011
- Strict 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
- Same issue with \$5000 cap on Level 1

DRO areas of concern



- **Waivers**
 - I/O waiver has maintained and exceeded cost neutrality (e.g. projected \$69,683 waiver to \$142,761 ICF/IDD in yr. 5)
 - Is not being fully utilized as limited county funding goes to develop Level 1 and STEP waiver
 - Tensions around DDP and Prior Authorization; perception of conflict of interest for county as funder and employer of SSAs; counties sometimes use ICFs / DCs because match is state, not county
 - Lack of planning and commitment at state level to expand waivers (although still supporting 1500 *Nancy Martin* Waivers and approx. 200 DC transition waivers)

DRO areas of concern



Waivers

- **Lack of statewideness based on local funding model**
 - IO waiver High = Franklin – 2677, Low = Monroe – 1
 - Level 1 High = Cuyahoga –1546, Low = Ashtabula – 4 (OPRA 2012)
- **Transitions DD waiver closed, could support those with higher medical needs**
- **Access to waivers primarily in “emergency” situations**

DRO areas of concern



Waitlist

- **DD Council study states that over 40,000 are wait listed for HCBS waivers**
- **Median wait time for I/O waiver 9.3 years; in ICF over 13 years**
- **Currently, 8764 need a Level 1 waiver; 10,609 need an I/O**
- **Future need is 5367 Level 1; 27,632 I/O**
- **Study limitations: sample is small; few self-advocates; small number of people in ICFs**

DRO areas of concern



Employment and day services

- **93% of Ohio's employment services are in sheltered work or enclave settings paying subminimum wage under 14(c)**
- **nearly 17,000 people in Ohio receive services in sheltered workshops—more than in any other state**
- **Nearly all state (and county) funding for day habilitation in Ohio is for congregate facility-based services. DoDD records indicate that nearly all of the roughly 14,000 people receiving adult day support were in congregate, facility-based settings.**
- **These placements generally do not reflect the individualized planning process that is mandated by the ADA and DOJ guidelines and are not reflective of a person's skills, abilities, or interests and preferences.**

DRO areas of concern



Future Planning

- 6-8 bed ICFs are being developed in public private partnerships for people who leave state-operated Developmental Centers and other large ICFs, sometimes referred to as “reinstitutionalization.”
- These facilities, while smaller, lack the hallmarks of community as defined by DOJ and CMS, especially in the areas of personal choice and independence.

DRO areas of concern



Future Planning, cont.

- **There is no mandate to move people from private ICFs to HCBS settings**
- **DC reductions are incremental and would leave around 800 individuals in very expensive state run ICFs**
- **The DC Reductions waiver only addresses individuals in state-operated ICFs**

Ohio has had over 20 years to address these concerns and has made no systemic effort to do so.

CMS HCBS regulations and definition of Community



- After a thorough rulemaking process, in January CMS issued new regulations governing how states can use HCBS waivers.
- Waiver dollars can only be used in settings that are, in fact, community based
- States must engage in a planning process that requires waivers to meet the new requirements, and work with CMS to develop a plan to bring their program into compliance
- Emphasis on person centered planning and supporting the individual's choice in planning services

Definition of Community



The setting is integrated in and supports full access of individuals receiving Medicaid HCBS 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, to the same degree of access as individuals not receiving Medicaid HCBS**

Definition of Community



- Selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting.
- Options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board

Definition of Community



- Ensures the individual's rights of privacy, dignity and respect, and freedom from coercion and restraint
- Facilitates individual choice regarding services and supports, and who provides them

Definition of Community



- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact

What is NOT community



- Any setting that is located in a building that is also a publicly or privately operated facility providing inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution
- Any other setting that has the effect of isolating individuals from the broader community of individuals will be presumed to be a setting that has the qualities of an institution, unless CMS determines through heightened scrutiny, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings

What is NOT community



- a nursing facility;
- an institution for mental diseases;
- an intermediate care facility for individuals with intellectual disabilities;
- a hospital; or
- any other locations that have qualities of an institutional setting.

Transition Plan



- New waivers must meet the requirement of the rule
- State must submit transition plan to CMS for existing waivers
- Plan must include timeframes and benchmarks
- CMS will allow up to five years based on states individual circumstances

Concerns



- Changes in service and regulatory models mean that the system in Ohio has to change
- Ohio has not affirmatively or strategically addressed these issues for many years
- Ohio's waiver structure has not been reviewed or studied in over 15 years

Concerns



- The waiver reimbursement model is insufficient to meet new challenges
- Fiscal pressure on county governments is increasing as the state cuts taxes and support to local governments; increasing dependency on levy dollars

Concerns – day program



Q. Will I / my son or daughter lose sheltered workshop services?

- Nothing in current law requires the closure of sheltered workshops
- Client choice and person centered planning are major drivers in this area
- Stressed local finances and levy failures also lead to consolidation and closures

Concerns – day program



Q. Will I / my son or daughter have to be at home for more hours and will the waiver pay for that?

- **The CMS rule recognizes the linkage between vocational and day program**
- **Programs should be individualized and not used as an excuse to cut hours or increase reliance on “natural supports”**

Concerns - residential



Q. Will I / my son or daughter be forced to move from the current residence?

- Both *Olmstead* and the CMS rule recognize the right of the individual to choose where and how services are delivered
- The HCBS transition plan must address what the state and providers must do to bring their programs into compliance, not dictate where people live

Concerns - residential



Q. Will I / my son or daughter be forced to move from the current residence? (cont.)

- DRO's request is that individuals be given meaningful choice in where they receive services; the current system forces many individuals who desire HCBS services to ICFs and state developmental centers**
- Families in others states have indicated great satisfaction when their son or daughter was properly served in their own home**

Concerns - residential



Q. Will all the ICFs in the state close?

- ICFs are the most expensive service option in the I/DD system, even as many individuals in ICFs are waiting for a waiver. Others have not been assessed for or offered a choice of community based care**
- The issues in closing all ICFs would be daunting and complex, and would require years to be resolved even if the state was interested in doing so**

Concerns - residential



Q. Shouldn't I / my son or daughter be allowed to choose to live in a segregated community / enclave / "intentional community"?

- Cost concerns, not individual choices, are a major driver for providers in developing congregate living settings**
- Most people with I/DD, when given a real choice, select to live in home like settings in the community**
- Properly designed community based services address the safety and programming concerns that family members express in support of congregate settings**
- Programs should be designed for the people they serve; congregate settings contradict that principle**

Concerns - residential



Q. Don't I / my son or daughter need an ICF because my disability is more severe? Involves medical care?

- **It is a myth that people with severe disabilities or medical complexities need facility based care**
- **Many such individuals in Ohio currently live in their own home on HCBS waivers**
- **Limitations on services and payment in the current I/DD waivers prevent many such individuals from being served, and they are unnecessarily institutionalized even when they would prefer to stay at home**

Conclusion



- Thousands of Ohioans live, work, and play in segregated settings in violation of the Americans with Disabilities Act.
- The state must plan for and commit resources to a service system that allows individuals to be served in the most integrated setting appropriate to their needs

Conclusion



- Reimbursement rates must be revised so that qualified staff can be recruited, trained, and retained
- Service plans must be based on identified needs, not arbitrary standards (“natural supports”)
- The community system should ensure that the individual is not isolated, that there are routine interactions with others (not just staff), and that the person’s safety is ensured.

Conclusion



- This would not be a fundamental alteration of the existing system.
 - Ohio does not have a “comprehensive and effective plan to place people in the community”
 - Ohio does not move people off the wait list at a reasonable rate
 - Current waiver expenditures are far below the the “cost neutrality” principle required by CMS

Conclusion



“I do not pretend to understand the moral universe, the arc is a long one, my eye reaches but little ways.... But from what I see I am sure it bends toward justice.”

Theodore Parker, 1853