
COMMUNITY INTEGRATION:

Changing Ohio's Developmental Disabilities System

For years, Disability Rights Ohio (DRO) has heard from many people with developmental disabilities and their families that Ohio's system does not give them opportunities to live, work, and spend time in their communities. With its partners, DRO investigated the system more closely and found this to be true. This violates federal law, so DRO sent a letter to state officials on July 1, 2014, and said that the system must change. DRO is now talking with the state to fix the problems in the system.

Through phone calls, letters, and emails DRO has received since then, and through seven family forums it recently held across the state with the Arc of Ohio, families have shared their questions and concerns about the system and DRO's work to change the system. Below is information on the questions and concerns DRO has heard most often.

What is the developmental disabilities system in Ohio?

People with developmental disabilities in Ohio can receive the services they need either in a facility or in a home and community-based setting. Some people live in intermediate care facilities (ICFs). Many of these facilities are large and have 16 or more people who also live there. Others live in their own homes in the community or with family and receive needed services through programs called Medicaid waivers. A person may work (often for less than minimum wage) in a facility called a sheltered workshop with others who also have developmental disabilities. Others work in jobs in the community and receive services to help them maintain their employment. Finally, many people with developmental disabilities spend part of their time in facilities (called day programs) where they do group activities, like playing games or arts and crafts.

What is meant by "community" and "home and community-based"?

People with developmental disabilities should be able to be our neighbors and co-workers. Our lives and communities are enriched when people with disabilities are all around us and we can all interact. People with disabilities should not be grouped together and separated from everyone else just because they have similar needs. This prevents many people from living the lives they would choose to live.

All people, with and without disabilities, have different interests. Some people like nature and animals, some enjoy sports. Some people like to read books, others like to watch movies or make art or hang out with friends. Some people like to make their own meals, others like to go to their favorite restaurants. Some people are good at building things with their hands, others are good at being creative with their minds. The system should treat each person with a developmental disability as a unique individual and empower and support people as they try to reach the chosen goals in their lives.

Why does the system need to be changed?

Thousands of people across Ohio live and work and spend their days in facilities but do not have the opportunity to choose home and community-based services. For example, there are people living in facilities who want to live in their own homes in the community. But long waiting lists for waiver programs mean that most people have to wait over 13 years for the services they would need in the community. The system should not assume that people with developmental disabilities should be in facilities.

The law also requires these changes. The Americans with Disabilities Act (ADA) became law in 1990, and the Supreme Court made its decision in *L.C. v. Olmstead* in 1999. In this decision, the Court said that, under the ADA, a state must provide services to people with disabilities in the most integrated, least restrictive setting in the community appropriate to their individual needs. Over the years, Ohio has not changed its service model to comply with the law, leaving thousands of people in facilities when they would like to live and work in the community.

Shouldn't people be able to choose where they live and work and spend their days?

Yes. People with developmental disabilities should be able to make their own decisions about their lives (with support from their families, if needed). The system should not choose for them. But without real options to live and work in the community, this is exactly what happens. No decision should be forced on anyone, but people must have all of the information they need to make the best decision.

Aren't some people unable to live and work in the community?

Many people with complex medical or behavioral needs already live or work in the community or would be able to do so safely with the right support. Ohio's system should support any person who wants to live or work or spend their days in the community, regardless of the person's needs. Studies have shown that people with disabilities have a higher quality of life and better outcomes living and working in the community.

Will there be high-quality services in the community to support people?

Right now, there are a lot of limits on the types of services covered (nursing services, for example) under waiver programs and the amount of funding for each person. The availability of well-trained, well-paid direct care staff is another problem. The average wages for direct care staff who support people with developmental disabilities in the community are below poverty levels, and there is far too much worker turnover (47%). Also, families have a critical role in supporting their loved ones, but no one's family should be expected to provide support or care if they are unable to do so (for example, a parent who works full-time). DRO is trying to fix these parts of the system.

How fast will changes to the system happen?

Any change should be made carefully. This may require many years to do. The state should not act too quickly and put people at risk. Services must be available in the community first. The changes to the system may seem drastic to some, but this is because Ohio has lagged behind many other states for a long time. Even the state acknowledges that it has more people in large facilities and in sheltered workshops than any other state.

Will all residential facilities and workshops close?

DRO is not asking the state to close facilities or workshops. But programs may need to change based on the choices made by the people they serve. When more options become available to live or work in the community, people may choose these instead of facilities or workshops. When this happens, demand for facilities or workshops may fall and some could close.

How are new rules from the Centers for Medicare and Medicaid Services (CMS) affecting Ohio's system?

A lot of different things are causing the system to change, apart from the work DRO is doing. CMS is a federal agency that makes rules for each state's Medicaid program, and it has made new rules for home and community-based waiver programs. These rules for the first time define "home and community-based settings." Many people go to workshops or attend day programs through their waivers, so these facilities must be "home and community-based settings" to receive waiver funding.

Each state must have a transition plan for how it will follow these new rules, and the public has a right to provide input on the state's plan. Ohio has released its plan, and DRO encourages people to provide their opinions to the state. More information on this process is available on DRO's website, disabilityrightsohio.org.

DRO's current work is focused on expanding access to these programs. But many people enrolled in waiver programs are still isolated from their communities, so these new CMS rules are very important.

What about the U.S. Department of Justice (DOJ)?

The DOJ, a federal agency, has recently taken aggressive action against states to make sure they follow the ADA and *Olmstead*. Ohio is vulnerable to a formal investigation by the DOJ because of the high number of people living and working in facilities who do not have options in the community.

Will services be cut or eliminated?

DRO is not advocating that any service be cut or eliminated. People should receive all of the services and support they need to live the lives they want to live and, at the same time, remain healthy and safe. DRO is advocating for more options to receive services in the community.