Disability Rights Ohio’s Efforts to Change
the Developmental Disabilities System in Ohio

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~~ DRO’s response to the questions and concerns DRO has heard most often.

***What is the developmental disabilities system in Ohio?*** People with developmental disabilities in Ohio can choose to receive the services they need either in a facility or in a home and community-based setting if they are deemed eligible and can access funding for support. ~~Some~~ About 7% of people in Ohio’s developmental disability system ~~people~~ live in intermediate care facilities (ICFs). Many of these facilities are large and have 16 or more people who also live there. Several thousand people live with others, sharing services and supports, or ~~Others~~ live in their own homes in the community or with family and receive needed services through programs called Medicaid waivers. About 15% of people in Ohio’s developmental disability system ~~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 (at or above minimum wage). Finally, ~~many~~ about 15% of people in Ohio’s developmental disability system ~~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 or community based activities based on individual choice.

***What is meant by “community” and “home and community-based”?*** [It may be helpful to explain the meaning of home and community-based from a Medicaid perspective.] 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. [Many people without disabilities live “grouped together” and have full and included lives. Many people with disabilities live alone and have no interaction with people in their communities, leading isolated and segregated lives. The issue is segregation, not who your roommates/housemates are. This will apply to anyone with even one roommate with a disability in a waiver setting – was this your intention?]

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. [shouldn’t this include allowing people with disabilities to choose where and with whom they live?]

***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. [What is your source for this data, or is it a guess?] 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. [It is an inaccurate overgeneralization that the system assumes people should be in facilities. People are given the choice of ICF or waiver and it’s the lack of funding that creates the barrier. Also, it is about segregation and the person’s experience of life, not where they live or how their services and supports are paid for. This may be seen as insulting to parents whose children live in an ICF or waiver-funded group home. It may be seen as an empty promise – are you saying that everyone who wants to own their own home will be able to, or everyone who wants to live alone in their own apartment will as well? It is unrealistic and improper, to set unreasonable expectations of anyone. Many people cannot afford these options, in fact, a number of DSP’s now live with their parents because they can’t afford to live by themselves. Hopefully, the employment first and direct care workforce initiatives will help ameliorate these issues. Until then, we need to be honest with people and not set them up for failure.]

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~~ leading segregated lives. ~~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. [Not sure what question this answers?]

***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 and the amount of funding for each person. The availability of well-trained, well-paid direct care staff ~~providers~~ is another problem. Families may have challenges with finding the right provider for their loved one. Also, families have a critical role in supporting their loved ones, but no one’s family should ~~not~~ 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 this part of the system. Direct care staff turnover is at 47%, with the average direct care staff wage below poverty. To help reduce turnover and ensure a quality force, direct care staff need to be paid a decent wage.

***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. [Iowa has more people in ICF’s. And again, it’s about community integration and the experience of the individual – not the funding stream.]

***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 sheltered workshops or facilities. When this happens, demand for sheltered workshops or facilities 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. These new rules are very important for people who are already enrolled in waiver programs. DRO is focused on expanding access to these programs. Ohio has released its draft plan to come into compliance with the new CMS rule. DRO encourages families to comment on the state’s draft plan. For more information on the state’s draft plan and to see a copy of the draft plan, go to:

[Public notice](http://r20.rs6.net/tn.jsp?f=001ey0hArra2Mk0_P0N3na_fLzF8qZmhiipXetWN4x3iGZNX6E6o1jr9fc2X2wWhMTUmd35ApthNNY3unyH-9r4owjZL-0TK1G71-c5Db5xBx8TCmW9RpIrzGEc435OVIhCeb64M6TGeXEF49xyKqxivwNSFmiptYgFE0tBZibmcNvSX3Syf6pBDGGFCrg2_MAooLTklAItS5toZwO6hJIQa_ReKdniSQDjFyQJgaYFadwq1Ay1RT6sp5orGcyh7QXVhkFYNN5T7AuIn_tq5nemKQ==&c=ijcI6GBNf53ZSAV1AEFMa7Qq6rnS_QZZrTP4C51fjQnujiBnv_zOzQ==&ch=Hi8TcT5tpHS950tgy8LdnUJrsF-4yfCSxqHdzxdIysWmRVKRPsBdDg==)

[Summary](http://r20.rs6.net/tn.jsp?f=001ey0hArra2Mk0_P0N3na_fLzF8qZmhiipXetWN4x3iGZNX6E6o1jr9fc2X2wWhMTURBlImomMwEDjbTjv7OXfYfprBJCaoCedxy7NK-s4ZfixgC9piMMH3Q24xqmRZbXjITyk4bfNKyDgV3KzS99aWkg129lmUQFtaYDX7ksqB18HUmStLYfNS-sZ3ZJvAggF3IFZCfYQfCNaMYk6TSPTrnTGxpTgW-IiK41ZpNhfo48ZmAf4eyCdRnKEf2g9qyIIoJDZ2N0dnMjkf8YCRabq4g==&c=ijcI6GBNf53ZSAV1AEFMa7Qq6rnS_QZZrTP4C51fjQnujiBnv_zOzQ==&ch=Hi8TcT5tpHS950tgy8LdnUJrsF-4yfCSxqHdzxdIysWmRVKRPsBdDg==)

[Draft Transition Plan](http://r20.rs6.net/tn.jsp?f=001ey0hArra2Mk0_P0N3na_fLzF8qZmhiipXetWN4x3iGZNX6E6o1jr9fc2X2wWhMTUt2pv5BWSE5hZnpQs8P_b1hqADWtkZ-wr9F3yMMlLLnMcrFeS3SyjbrjYrbbXG62igczEmuf8FazH0DfvSb9-3gjAMu5k4DdeSkPfV6yZ3tQYVbO_C42COhGzZ1We0ChqWJu4Dv4ltHBoYr2MtEpaiJL1VOuJTktLQPT0GiUUli0cmWButJOibZ9cGn4P3oIQG9zXwugpIHxNI1eWRbq3eQ==&c=ijcI6GBNf53ZSAV1AEFMa7Qq6rnS_QZZrTP4C51fjQnujiBnv_zOzQ==&ch=Hi8TcT5tpHS950tgy8LdnUJrsF-4yfCSxqHdzxdIysWmRVKRPsBdDg==)

[Frequently asked questions](http://r20.rs6.net/tn.jsp?f=001ey0hArra2Mk0_P0N3na_fLzF8qZmhiipXetWN4x3iGZNX6E6o1jr9fc2X2wWhMTUM8ZEqt1KkxwjPi-anCFkcAwvJ7LibORuSo98sOqxeKefjmgB6mtMFU9Ds7MV4jm5cKQsfzDpBr6aRx8aTc3XFLO260xhLu_4vSMNJVAp35eluZEltkM2I_yt5engGlZRbD_vSz1vb8zOycSJxlz2mTib7920BsD8rDbbagH7sU33i8aoT0ez2QW2h1zhb6WHdj3jBHmiqdrOHKuszBgZ7g==&c=ijcI6GBNf53ZSAV1AEFMa7Qq6rnS_QZZrTP4C51fjQnujiBnv_zOzQ==&ch=Hi8TcT5tpHS950tgy8LdnUJrsF-4yfCSxqHdzxdIysWmRVKRPsBdDg==)

***What about the U.S. Department of Justice (DOJ)?*** The DOJ, another federal agency, has been very forceful lately in making sure states 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. Ohio is vulnerable because we do not have a plan to move people from sheltered employment and facility-based day services, nor do we have a plan to reduce Ohio’s 42,000-person waiting list.

***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 recognizes that without changes/additions to the waiver program, waivers are able to not provide the same level of care/services as ICF’s. For example, there is not accessible and affordable housing stock available that is safe for individuals with acute and complex needs, nor adequate ancillary services. DRO is advocating for more options to receive services in the community.