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Sent by email to becky.phillips@dodd.ohio.gov

Ms. Phillips:

Disability Rights Ohio is the protection and advocacy system in Ohio. Our mission is to advocate for the human, civil and legal rights of people with disabilities throughout the state. We appreciate the opportunity to provide our perspective on Ohio Administrative Code ("OAC") 5123-9-04, a proposed rule of the Ohio Department of Developmental Disabilities ("Department"). The proposed rule governs waiting lists for the Department's home and community-based waiver programs. This has been a very important concern to our clients and their families for years.

The Department's proposed rule must be analyzed with broader principles in mind. Under the Americans with Disabilities Act and the Supreme Court's decision in *L.C. v. Olmstead*, people with disabilities have the right to live, work, and spend their time integrated in our communities. The Department's overarching goal should be to ensure there is sufficient waiver capacity in the system to serve people with intellectual and developmental disabilities who need and choose community-based services. To date, it has not done so. This has resulted in waiting lists for these essential services. The Department anticipates the proposed rule will reduce these numbers, as only those with "current needs" unmet by "community-based alternatives services" will remain on waiting lists. The proposal will not, however, change the lack of long-term planning to address the critical service needs of people with intellectual and developmental disabilities and their families.

Without increasing waiver capacity and correcting other well-known systemic issues (like the lack of a robust pool of well-paid, adequately trained community-based providers), the same problems in the system will persist. A substantial number of people will remain waiting for the services they need. Without a plan to expand services to meet the growing need statewide (not dependent on county funds), many will continue to be needlessly institutionalized or at risk of institutionalization. Families will be overburdened. In this wider context, flaws in the proposed rule become apparent.

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- 1. People with an “immediate need” under the proposed rule will often be denied meaningful choice and may be forced into institutional care. People with a “current need” will remain at risk of institutionalization.**

Under the proposed rule, a person with an “immediate need” receives highest priority for enrollment in a locally-funded waiver program, but there is no assurance in the rule that the individual will have immediate access to necessary home and community-based waiver services. While paragraph (D)(3)(b) obligates the county board to “take action necessary to ensure the immediate need is met,” there is no process or obligation to offer home and community-based services until after the individual has first been offered and has declined institutional care in an intermediate care facility (“ICF”).

This provision encourages a bias toward institutional care in violation of both federal Medicaid law and Title II of the Americans with Disabilities Act and should be removed. Also, it disregards the reality many people are experiencing if they have an “immediate need.” These situations are by definition emergencies. It takes time (often months or longer) to coordinate community-based waiver services for a person, locate housing, and identify and choose providers. The Department should ensure people have the supports they need before they are in these urgent situations in the first place. But under the proposed rule, even people with unmet current needs are placed on waiting lists. Many therefore will have no meaningful choice except admission to an ICF to meet their immediate needs.

This proposed rule governs waiting lists for waiver services. The recent inclusion of language regarding ICFs should be removed, and access to necessary home and community based services should be ensured.

- 2. Without sufficient waiver capacity, the proposed rule abandons thousands of people with intellectual and developmental disabilities in ICFs and NFs.**

The Department has removed language from a previous version of the proposed rule, which said that a person has a “current need” if he or she is living in an ICF or nursing facility and has a viable discharge plan. Under the latest version of the proposed rule, a person in an ICF likely cannot meet the criteria for “current need,” based on the way the Department has historically interpreted the current waiting list rule. And a person would only have an “immediate need” if he or she has received a notice of termination from the ICF provider. This proposed rule ignores the needs of thousands of individuals in ICFs who, without an appropriate process for identifying and meeting their needs through sufficient waiver capacity, will remain institutionalized indefinitely.

Similarly, under this proposed rule, people with intellectual and developmental disabilities in nursing facilities only meet the criteria for “immediate need” if they

have received a thirty-day notice of discharge or an adverse PASRR determination. As of January 2015, there were over 2,000 people with intellectual and developmental disabilities in nursing facilities throughout Ohio.¹ These people are effectively trapped in these isolated settings without access to community-based waiver services.

The proposed rule should provide priority enrollment to people currently institutionalized in ICFs or nursing facilities.

3. Excluding those who live with family limits their options to lead fully independent lives and places enormous burdens on aging family members who function as “natural supports.”

Under the proposed regulatory scheme, many adults with intellectual and developmental disabilities who live with their parents will not have necessary supports and community engagement. Their needs are currently being met (albeit often with heroic efforts by families), but the Department’s proposed system will not support these families in providing supports and care available through a waiver. Parents often forgo employment, financial, educational, social, and cultural opportunities to support their loved ones but are then penalized for these sacrifices. The narrowly-defined “current need” under the proposed rule perpetuates this, requiring the primary caregiver to have a “declining or chronic physical or psychiatric condition that significantly limits his or her ability to care for the individual.” The proposed rule should expand the definition of “current needs” to include situations where the person, in the absence of natural support, would need services. And the Department should ensure people and their families receive the support they need.

4. The proposed rule obligates the Department to maintain the original date of request only for those who are determined to have a current need upon their first assessment, creating arbitrary and unfair orders of enrollment.

The proposed rule maintains the original date of request for waiver services (which could be years or even decades ago) for some people but not for others. Once a county board administers the assessment to someone who is on the current waiting list (which will become the “transitional list”) and makes a determination, it must then notify the Department. The Department must then remove the individuals’

¹ http://www.jmoc.state.oh.us/assets/meetings/Dev_Disabilities_Sys_Bkgd_Member_Brief.pdf.

“According to the Braddock report, there are about 2,000 individuals with DD who are in a nursing home, and this number has been stable for more than a decade. The County Boards of DD perform preadmission screenings and resident reviews for these individuals to ensure appropriate placement. Just as with behavioral health consumers, limited system capacity can lead to inappropriate placements or to longer than necessary placements while seeking a home and community based option. Nursing home care is paid from the ODM Medicaid budget.”

name from the transitional list. For those assessed to have a “current need,” the Department must record and maintain his or her original date of request in its new web-based waiting list management system. For all others, the Department does not maintain this information.

But under paragraph (E)(1)(b)-(d), one element in determining the order of enrollment in locally-funded waiver programs for people with “current needs” is the original date of request. But people’s needs fluctuate, as paragraph (D)(6) explicitly recognizes. Take one example, which illustrates the Department’s faulty approach. An adult has been on a waiting list for a waiver since 2008. The county board accurately assesses her to have neither an immediate need nor a current need, but months later her primary caretaker can no longer effectively care for her. She requests a second assessment, which determines she has a “current need,” but the Department did not maintain her original date of request. Therefore, this person loses the benefit of having been on the waiting list for ten years, simply because her “current need” manifested a few months later, and as a result, is placed in a lower priority for enrollment. With insufficient waiver capacity, she waits for a waiver for a prolonged period of time and is at serious risk of institutionalization.

Similarly, the proposed rule obligates the Department to remove a person’s name from the transitional list when he or she fails to respond to efforts by the county board or Department to establish contact. But there could be countless reasons why these efforts fail (including the circumstances that cause someone to meet the criteria for “immediate need”). While people can subsequently request an assessment, the Department does not maintain their original date of request once they are removed from the transitional list. This adversely affects their order of enrollment and could be the difference between community-based services and institutional care in an ICF.

The Department should commit to maintaining the original dates of request for all people currently on waiting lists.

5. The proposed rule constitutes a drastic change in the state’s waiting list system, requiring effective due process rights and clear, consistent communication.

Legally, the Department must provide written notice and an opportunity for a state hearing to every person who is denied placement on the new waiting list, who is removed from the transitional list (or current waiting lists), and who disagrees with the outcome of an assessment. The current practice, however, for similar denials of services is that many people receive a verbal decision with which they disagree but are never properly provided written notice of their due process rights. In rolling out this proposed rule, the Department must ensure that due process rights are consistently provided, including unequivocal written notice for every decision that changes the status of a person to his or her detriment, along with hearing rights.

Furthermore, since the proposed rule enacts major changes to the state's waiting list system, the Department must ensure clear, consistent communication with people who have intellectual and developmental disabilities and their families. Clarity and consistency is especially important in communications about the outcomes and consequences of an assessment completed under the proposed rule and about how to challenge a decision with which people disagree. Individuals and families should be provided with information about their options in a meaningful, non-technical manner that accommodates communication needs.

6. The Department should be flexible with the strict timelines in the proposed rule.

The proposed rule obligates the Department to maintain the transitional list only until December 31, 2020, at which time county boards must have completed all assessments for those currently on waiting lists in Ohio. This number is approaching 50,000. This deadline is almost certainly impossible to meet, and could lead to perverse incentives to short-cut the assessment process. Timelines should not get in the way of ensuring that the needs of all individuals with developmental disabilities are accurately assessed and met.

Conclusion

This proposed rule misses the mark. The focus should not be on managing those on the waiting list, but instead on fixing the system. Better pay, training and certification of direct service providers; expanding capacity of state funding for waivers, or at least a focus on equalization of opportunities for those in poorer counties; and ensuring that the long-term services and supports system offers real choice to people with intellectual and developmental disabilities with higher needs and their families all would eliminate the need to "fix the list."

Thank you for this opportunity to comment on the proposed rule.

Respectfully,



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