Disability Rights OHIO

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May 20, 2020

Seema Verma, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2418-P
B.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments on Proposed Rule Regarding Preadmission Screening and Resident Review (PASRR) CMS-2418-P

Administrator Verma:

Thank you for the opportunity to provide comments regarding proposed changes to federal regulations governing states' Preadmission Screening and Resident Review (PASRR) programs. Disability Rights Ohio ("DRO") is the state-designated and federally authorized protection and advocacy system for people with disabilities. Our mission is to advocate for the human, civil, and legal rights of people with disabilities in Ohio.

DRO's current priorities include addressing the widespread and pervasive segregation of thousands of people with mental illness, intellectual and developmental disabilities, and traumatic brain injuries in nursing facilities throughout Ohio.[1] People with disabilities have the right under the Americans with Disabilities Act (ADA) and the Supreme Court's *L.C. v. Olmstead* decision to receive services in the most integrated setting appropriate to their individual needs. In our experience, nursing facilities in Ohio are highly restrictive settings for the people who reside there. They have limited independence and autonomy, their lives are regimented and controlled, and there is little or no interaction with their communities. They do not have access to recovery-oriented services in nursing facilities, and therefore they languish, often for years or even decades.

PASRR in Ohio is largely ineffective in diverting or transitioning people from nursing facilities to home and community-based settings. DRO has been working with the Ohio Department of Mental Health and Addiction Services over the past few years on these issues to fix a system with inadequate community service capacity and that causes thousands of people with mental illness to be unwillingly trapped in nursing facilities. Our conversations with the state, and review of data and other records, confirm that its PASRR program is failing most of this population. In Ohio, the vast majority of people with mental illness are approved for admission or continued residence in nursing facilities, and few are connected with community services.

[1] DRO's FY 2020 priorities are available at https://www.disabilityrightsohio.org/priorities.

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Thousands of people with intellectual and developmental disabilities and those with traumatic brain injuries are also in nursing facilities and similarly suffer from the failures in Ohio's PASRR programs.

These enormous systemic problems in Ohio have been exacerbated by the global COVID-19 pandemic, as people in nursing facilities are infected and die at alarmingly disproportionate rates. Overall, about 60% of COVID-19 deaths in Ohio have occurred in long-term care facilities (1,031 deaths in these facilities, out of 1,720 deaths statewide, as of May 19, 2020), a figure that is likely higher.[2] Thus, the fundamental purpose of the PASRR program, and its implementing regulations– to prevent unnecessary admissions to nursing facilities and to ensure that those who are admitted receive appropriate services – is more urgent than ever.

DRO recognizes and supports one underlying goal of the proposed rules – to modernize PASRR regulations and to clarify the sequential PASRR process. We also recognize a second goal -- to better align the PASRR regulations with Congress' original purpose in enacting the PASRR program; with current legal and clinical standards, including the ADA, the *Olmstead* decision, and the many CMS Bulletins and Guidance documents that explain these requirements; with professional standards for people with mental illness and people with intellectual and developmental disabilities favoring community services; and with trends in virtually all states to reduce reliance on segregated settings. Regrettably, the proposed rules undermine and certainly are not consistent with the second goal, and will likely result in more people with mental illness or intellectual and developmental disabilities being admitted to nursing facilities, fewer people being transitioned to the community, and few specialized services being provided to those who remain in nursing facilities.

In this unique moment, when we have seen so clearly how nursing facility admissions often result in death, it is particularly inappropriate for CMS to adopt the proposed rules. Instead, CMS should reconsider and revise the proposed rules in light of the current pandemic, and then reissue them for public comment.

There are several glaring concerns with the proposed rules that undermine the congressional purpose of the PASRR program, that contravene the legal requirements of the ADA and *Olmstead*, and that are inconsistent with contemporary professional standards for people with mental illness or intellectual and developmental disabilities.

1. **The proposed rules substantially reduce the utility of PASRR preadmission screening (Level I) and evaluation (Level II) to prevent unnecessary admissions to nursing facilities.**

[2] *See* Columbus Dispatch May 19, 2020 article, "60% of Ohio Coronavirus Deaths Have Occurred in Long-Term Care Facilities," available at https://www.dispatch.com/news/20200519/60-of-ohio-coronavirus-deaths-have-occurred-in-long-term-care-facilities. *See also* Columbus Dispatch May 8, 2020 article "Coronavirus cases increase in Ohio's long-term care facilities, nearly 73% of week's cases," available at https://www.dispatch.com/news/20200508/coronavirus-cases-increase-in-ohiorsquos-long-term-care-facilities-nearly-73-of-weekrsquos-cases.

PASRR evaluations are supposed to determine if the person needs nursing facility level of services or could be better served in an alternative setting, like an integrated, home and community-based setting. But the proposed rules allow states to avoid all *preadmission* evaluations for individuals who are: (1) readmitted to a nursing facility (regardless of how long they have been out of that facility); (2) transferred from another nursing facility; (3) discharged from an acute hospital and presumably need only 30 days of care in the nursing facility (exempt admission), or (4) admitted for a short-term period (provisional admission). This last category is particularly troubling since it includes admissions for respite, crisis or protective services, and convalescent care.

Once a person is admitted, even if the PASRR evaluation is conducted weeks or months later, the opportunity for diversion is lost, the likelihood of a prompt return to the community is drastically reduced, and the probability of long-term institutionalization is significantly increased. While provisional admissions mirror and replace the concept of categorical admissions in the current regulations, they are mandatory, not optional (as in the current regulation), and entirely bypass the Level II process for determining appropriate placement until well after the admission. As a result, the proposed rules substantially undermine the diversion goals and elements of the PASRR program.

**2. <u>The proposed rules sharply limit the PASRR Level II evaluation with respect to diversion or transition to an alternative, home and community-based settings.</u>**

While the proposed rules add occasional references to "integrated settings," they authorize the admission of individuals who do not have a *currently available community option*, even if the person could be served in an integrated setting, or even if they could be better served in the community. Moreover, while the proposed rules require that states provide individuals or their guardians "information about community options," there is no requirement for informed choice, no specification of the type, amount, or frequency of such information. And contrary to *Olmstead*, there is an assumption that institutionalization is appropriate unless the person expresses a preference for community services, instead of an assumption that community services are appropriate unless the person opposes them.

**3. <u>The proposed rules significantly diminish the amount and scope of specialized services that must be provided to persons with mental illness or intellectual and developmental disabilities</u>.**

The proposed rules substantially restrict the assessments used for determining if specialized services are needed, focusing almost exclusively on activities of daily living (ADLs) and instrumental activities of daily living (IADLs) assessments instead of a broad range of social, vocational, educational, and communication areas, as in the current regulations. They allow states to drastically limit the type of specialized services that they will provide and eliminate any standard for determining what services should be provided. The proposed rules also afford states broad latitude to decide who conducts Level I identifications of mental illness or intellectual and developmental disability, who conducts Level II evaluations of needed services,

and what specialized services the state will provide, as well as the amount, duration, and scope of those services, without reference to any professional standard.

The proposed rules are particularly problematic for individuals with intellectual and developmental disabilities. The proposed rules significantly dilute the evaluation criteria for specialized services for this population and delete the active treatment standard for providing these services, allegedly to avoid an institutional standard of care, even though they only apply to an institutional setting – nursing facilities. The result of this proposed change will not be that fewer people are placed in nursing facilities, but rather, the people who are placed in nursing facilities will be there without services to address the needs of their disabilities. The proposed rule also eliminates the historical requirements that states must provide specialized services in the community to nursing facility residents (either long-term or short-term) who no longer need nursing facility services.

**4. <u>The decision to omit individuals with traumatic brain injuries (TBI) is inappropriate and illogical, particularly since a TBI that occurs before age 22 is a developmental disability or related condition.</u>**

The mere fortuity of when the TBI occurs determines whether the PASRR rules apply. Young persons may suffer a TBI just after their 22nd birthday and may be needlessly admitted to a nursing facility without the benefit and protections of PASRR.

The decision to exclude people with TBI from the PASRR process should be reconsidered. Nursing facilities house a large number of persons with TBI. The 2019 4$^{th}$ quarter MDS 3.0 Frequency Report indicates that 1,323 (1.93% of those with data) Ohio nursing facility residents had an active diagnosis of TBI during the previous seven days. Nationwide, this number was 20,260 (1.60% of those with data).

These residents face many of the same challenges to living in the community, and avoiding unwanted and unnecessary admission to nursing facilities, that persons with mental illness and developmental disabilities confront. In conjunction with the Ohio Brain Injury Program, Disability Rights Ohio conducted a qualitative investigation of 38 Ohio nursing facility residents with diagnoses of TBI who were living in a convenience sample of 16 facilities. One major finding of this investigation was the high frequency with which mental health and behavioral issues were given as the reason for nursing facility placement. Many people acquired a mental health diagnosis during prolonged institutionalization in a nursing facility, thus often evading PASRR requirements. These co-morbidities were the most common reason cited by caregivers as the barrier to community placement. Many residents had multiple psychiatric diagnoses that accrued over the years as they lived in nursing facilities and almost all were receiving psychoactive medications.

We also found that persons with TBI are not aware of programs designed to assist them to live in the community. With only a few exceptions, residents and family did not know about home and community-based services and reported that nursing facility staff had not discussed what supports might be available for them to live in the community. Many of the residents interviewed indicated a desire to return home to live with family or in other community settings. With only a few exceptions, residents with TBI did not have medical management requirements that would preclude living in the community.

To the extent that the above findings are reflective of the large number of nursing facility residents with active diagnoses of TBI, we believe that the inclusion of TBI in the PASRR program is consistent with the intent of the statute.

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For these reasons, and in light of what we now know even more clearly from the global COVID-19 pandemic about the consequences of residing in a nursing facility, we urge you to reconsider the proposed rules, substantially revise them to remove institutional bias, and revise them to align with prior CMS Guidance and directives from Congress and the Supreme Court. This simply is not the time to make it easier to admit, and harder to discharge, individuals with disabilities to nursing facilities.

We provide more detailed, section by section comments below.

**Part 483, Subpart B**

**§ 483.20(b)(2(ii):** This section defines "significant change in physical or mental condition," which in turn determines when a PASRR evaluation is required for a current resident of a nursing facility. The criteria for such review are vague and limited to a major decline or improvement that requires staff or clinical intervention *and* that justifies an interdisciplinary review or change in the person's care plan. This definition is likely to reinforce the present practice of rarely conducting a resident review for residents who have been in nursing facilities more than sixty days, and leaving the determination of whether the individual has experienced a change of condition that requires a PASRR evaluation entirely in the discretion of the nursing facility.

The definition fails to consider at all a change that: (1) indicates a need for specialized services; (2) reflects a change in preference for specialized services or transition; or (3) would make discharge or transition to the community appropriate. The definition should be expanded to include changes in the individual's ability to live in a home and community-based setting, interest in community transition, interest in specialized services, and a need for additional specialized services. This section should be revised to include these factors, or these factors should be included in the related § 483.114(a)(1).

**§ 483.20(e):** The commentary helpfully distinguishes the purpose, scope, and content of the MDS from the PASRR evaluation. But the proposed rule contains no such distinction. This subsection should be revised to explicitly state that the MDS does not satisfy the requirements of a PASRR evaluation and that the PASRR evaluation serves a different purpose, involves different assessments, and results in different types of recommendations.

**§ 483.20(k)(2)(i):** This section allows states to bypass the PASRR evaluation for all readmissions, regardless of how long the individual has been out of the nursing facility and the reasons why. For example, an individual who was admitted to a nursing facility from a home and community-based setting in January 2018, who received a PASRR evaluation in February 2018, who was discharged to a hospital in June 2019, and then was returned to the same nursing facility in September 2019 would not receive a new PASRR evaluation, unless the nursing facility determined that her condition had changed. This subsection should be deleted.

**§ 483.20(k)(2)(iii):** This section allows states to bypass the PASRR evaluation for the newly termed "provisional admissions: (formerly categorical admissions described in § 483.130(d)). For the reasons stated above, allowing states to admit people with mental illness or intellectual and developmental disabilities who are included in the five categories of provisional admissions results in large numbers of admissions avoiding all preadmission evaluation, thereby making it impossible to achieve the diversionary goals of PASRR. This subsection should be deleted.

**§ 483.21:** We support the clarifications included in this section, including the importance of using person-centered planning in all determinations of nursing, rehabilitative, and specialized services, and particularly the requirement of proposed § 483.21(b)(iii) requiring the nursing facility to implement PASRR evaluation recommendations for specialized services and incorporate them in the person-centered plan.

**Part 483, Subpart C**

**§ 483.102:** We support the new definitions of mental illness and intellectual and developmental disabilities.

**§ 483.106(a):** The description of the purpose of the PASRR program is vague and not in line with the legislative history, as expressed in House and Senate Reports that accompanied the enactment of the original legislation in 1987, as well as the requirements of federal law. The language should be revised to note that PASRR is intended to identify, screen, and evaluate people with mental illness or intellectual and developmental disabilities in order to determine if admission to a nursing facility is appropriate and the most integrated setting to meet the individual's needs, and if so, to ensure that the individual receives all needed specialized services to promote independence, to prevent deterioration, and to facilitate transition to the most integrated setting, if not opposed by the person.

**§ 483.106(b):** We generally support the clarification of this section and the description of each component of the PASRR program.

**§ 483.106(f):** We support the clarification requiring culturally-component communications.

**§ 483.112(b):** For the reasons set forth above and the specific comment to proposed § 483.20(k)(2), preadmission evaluation should be required for all readmissions, inter-facility transfers, and provisional admissions. Proposed §§ 483.112(b)(1), (3), (4), and (5) should be redrafted to require a preadmission evaluation for all admissions except exempt admissions, as provided by statute. Eliminating preadmission evaluations for all of the categories listed in proposed § 483.112(b)((3) effectively eliminates diversion opportunities for vast numbers of people.

**§ 483.114(a)(1):** As noted in our comment to proposed § 483.20(b)(2)(ii), a resident review should be required whenever there is a change in the individual's ability to live in a home and community-based program, interest in transition (like through MDS Section Q), interest in specialized services, or need for additional specialized services, regardless of whether there is a change in the individual's physical or mental condition.

**§ 483.120(a):** This section provides a new definition of specialized services, which allows states to determine what specialized services they will provide -- without any standard, guidance, or professional criteria. Thus, a state could decide to only offer one specialized service (i.e. transition planning), or even none, since there is no standard to measure the vague concept of "need" in § 483.120(a)(2). It deletes all references to active treatment or any professional standard of care, leaving states unfettered discretion to decide what specialized services it will offer, who will offer them, the method for providing them, and the frequency, intensity, and duration that the services will be provided.

The alleged rationale for ignoring the congressional mandate to provide active treatment and deleting all references in the regulations to this professional standard is to "avoid an institutional standard of care". But specialized services are services provided in nursing facilities and for residents of institutions – in this case, residents of nursing facilities. That is precisely why Congress adopted this term, why courts have relied upon this term, and why this term is uniquely appropriate in PASRR regulations. It is essential that this term be retained, in order to establish a clear professional standard to guide the State's determination of what specialized services it must provide, as well as the frequency, intensity and duration that specialized services are provided. In addition, the professional standard for assessing the adequacy of specialized services should include services necessary to effectively and timely transition individuals to the community.

The new definition of specialized services is deeply problematic. It allows the nursing facility treatment team to decide what services are appropriate to: (1) address the individual's needs; (2) to increase or delay loss of functional abilities; and (3) to promote transition to integrated, home and community-based settings. But assuming that the nursing facility care planning team is qualified and positioned to determine the habilitative needs of people with intellectual and developmental disabilities or the mental health treatment needs of persons with mental illness

is unrealistic. Similarly, expecting that this team will be an appropriately constituted interdisciplinary team that can develop treatment plans in a person-centered manner that promotes self-determination, is inconsistent with established practice in nursing facilities, and unsupported by many courts that have considered this issue.

The section should be deleted and rewritten to ensure that specialized services are those necessary to provide active treatment (as defined by §483.440(a)-(f) for person with intellectual and developmental disabilities) and to promote transition to the most integrated setting. CMS should encourage states to provide specialized services in the community, like integrated day services, and to have community case managers who participate in all nursing facility treatment planning and who monitor specialized services.

The focus of specialized services, as set forth in § 483.120(5), is limited to functional abilities, and ignores other core goals like maximizing independence, gaining a broad range of skills, promoting choice, and participating in community activities. The section should be deleted and rewritten to require states to: (1) provide all specialized services, in the amount, duration, and scope, necessary to constitute a program of active treatment, including both the standard and implementation process as defined by §483.440(a)-(f) for person with intellectual and developmental disabilities, and to promote transition to the most integrated setting; (2) provide all specialized services necessary to allow individuals with mental illness or intellectual and developmental disabilities to learn about, and engage in, community activities sufficient to make an informed choice about whether to remain in a nursing facility; and (3) include a case manager or service coordinator from the relevant component of the state's community service system on the interdisciplinary team.

**§ 483.120(b):** This section requires states to provide needed specialized services and allows the state to determine who can provide such services, including persons who are not professionals or specialists in the mental health and developmental disabilities fields, such as regular nursing staff if they are deemed "qualified personnel" by the state. This section should require that all specialized services are only provided by appropriately trained and qualified mental health and developmental disabilities personnel.

**§ 483.128(b):** This section allows the state to determine who will perform the Level II evaluation, subject to certain statutory restrictions. There is no requirement that evaluators be appropriately trained and qualified mental health and developmental disabilities professionals, even though they are required to assess the needs of people with mental illness and people with intellectual and developmental disabilities and recommend treatment or habilitative specialized services. Nor is there a requirement that they have any knowledge or experience in home and community-based programs, even though they are required to evaluate the need for and appropriateness of home and community-based alternatives to a nursing facility placement. This subsection should be modified to include these qualifications for all PASRR evaluators.

**§ 483.128(d)(2):** This section lists the data that must be reviewed to determine whether there has been a significant change in one's physical or mental condition. For the reasons set forth in the comment to §§ 483.20(b) and 483.114(b)(2), this data should include information concerning the individual's appropriateness and preferences for both specialized services and transition to an integrated, home and community-based setting.

**§ 483.128(e):** This section lists the data that must be collected and reviewed in order to determine the need for specialized services. It substantially reduces the types of assessments, areas of functioning, and appropriateness for placement in a nursing facility, currently described in § 483.128(f), that must be reviewed. It entirely ignores communication issues and assessments, as well as evaluations and preferences for home and community-based services. The current regulation requires that specialized service assessment must be based upon a list of assessments and data set forth in §§ 483.134(b) and 483.136(b). The proposed rule replaces these assessments with a new, abbreviated list of data to determine the need for nursing level of services and specialized services that mostly focuses on ADL and IADL issues and does not include information on appropriateness of alternative placement or informed choice. This subsection should be expanded to include all relevant assessments and data required by the current regulations, as well as information about community placement options and choices.

**§ 483.128(m)(3):** This section removes entirely the need to do a Level II evaluation of persons with severe physical illness (as required by § 483.130(f)) that precludes meaningful evaluation for nursing facility services and specialized services. This exception is likely to create a permanent bypass of the Level II process and the obligation to provide specialized services to individuals with severe physical illnesses. Moreover, the proposed rule is based upon a list of non-exclusive conditions that reflect the evaluator's judgment that the individual would not benefit from specialized services. This subsection should be eliminated.

**§ 483.130(b):** This section allows a state to decide who can make the determination of the need for admission to a nursing facility, and does not require any particular training, experience or qualifications, including any knowledge of home and community-based programs, even though a central aspect of the determination is whether the individual could be served in an integrated, home and community-based setting. The section should be modified to require knowledge and experience with the state's home and community-based programs.

**§ 483.130(c):** This section describes the criteria for determining whether an individual with mental illness or intellectual and developmental disabilities needs to be admitted to a nursing facility. It is unclear how this section relates to proposed § 483.130(c), which also describes the criteria for determining if an individual needs placement in a nursing facility. Nevertheless, this section would preclude admission if an individual's total needs can be met, with or without accommodations, by the state's home and community-based programs. Thus, if the state provides community programs that can appropriately address those needs, nursing facility admission should be denied. Notably, there is no requirement that such programs are immediately available. With this understanding, we support proposed § 483.130(c)(3)(i) as written.

The section subsection § 483.130(c)(3)(ii) would allow admission to a nursing facility if the individual "does not want community placement." There is no requirement that individuals are provided information about the community options, no obligation to offer opportunities to learn about or experience community options, or, most importantly, no requirement that the evaluator assess if individuals have made an informed choice about community placement.

Finally, this section uses two different terms, "home and community-based programs" and "community placement," suggesting that they have different meanings. Rather, a home and community-based program is a type of community placement. It is also unclear whether the term home and community-based program is limited to home and community-based waiver programs, pursuant to 42 U.S.C. §1396n. We assume they are not, but this should be clarified.

**§ 483.130(d):** This section describes the criteria for determining whether an individual with mental illness or intellectual and developmental disabilities needs specialized services. It is unclear how this section relates to §483.120(a), which also describes the criteria for determining if an individual needs specialized services. Nevertheless, because the two-part standard in this section (necessary to maintain the individual in or transition the individual to the most integrated setting possible, *and* the individual would benefit from such services) is conjunctive, it appears the neither prong is alone sufficient. It is confusing and unclear how the two prongs differ, and why "benefit" alone is not sufficient.

Moreover, the first prong is either impossibly vague or meaningless, since *no* specialized service are "necessary to maintain the individual in' a nursing facility." This is precisely what nursing facility services do – maintain people in nursing facilities. Nor are they "necessary to transition the individual" since that is what community services do. As written, a state could easily satisfy the first prong of this standard by providing no specialized services. This section should be modified by changing the "and" to "or" in the last line of this subsection.

**§ 483.132(a):** This section describes the method for evaluating whether admission to a nursing facility is appropriate. As noted in the comment to § 483.130(c)(i), there is confusion between the standard in that section and in this section for making the same determination. The proposed rule deletes all references to alternative placement options and, most importantly, whether the individual's "needs can be met in an appropriate community setting", as currently required by § 483.132(a). Instead, it allows institutional placement unless the individual has an (existing) "option of community placement," as opposed to whether the person would benefit from or could be served in integrated setting. In the absence of an *available placement option*, the evaluator must determine whether the individual's needs can only be met in an institutional setting, whether the nursing facility (with or without specialized services) is an appropriate setting, and if not, if another institutional setting is appropriate.

This section should be deleted or rewritten to conform to the revised standard in proposed § 483.130(c)(i) – admission is inappropriate if an individual's total needs can be met, with or without accommodations, by the state's home and community-based programs.

**§ 483.132(b):** This section requires an evaluation of the individual's preferences and requires information on community options. There is no specification of the type or scope of information, and no mention of informed choice. Most importantly, it contradicts the standard established by the Supreme Court in *Olmstead* and insists on an expressed preference for community placement, rather than opposition to such placement. This subsection should be rewritten to conform to federal law and require the evaluator to determine if the individual has made an informed choice to be placed in, or remain in, an institutional setting and in that specific nursing facility.

**§ 483.132(d):** This section allows an evaluator to determine if the nursing facility, as opposed to the state, should be providing any needed behavioral or rehabilitative services (presumably, physical therapy, occupational therapy, and speech and language therapy). This would allow states to impose on nursing facilities the obligation to provide these types of specialized services, contrary to the mandate in the current regulations that the State, not the nursing facility, is responsible for providing all needed specialized services. It also would expect nursing facilities, which normally do not employ professionals in the mental health and developmental disabilities fields, and which customarily restrict the amount, duration and scope of rehabilitative services, to provide specialized services. This section should be deleted.

**§ 483.134:** As noted in the comment to proposed § 483.120(a) (definition of specialized services), § 483.128(e) (data for determining specialized services), and § 483.130(d) (need for specialized services), the relationship between these subsections is confusing, and appear to set forth different standards for determining whether and what specialized services are needed. Most importantly, this subsection replaces the detailed list of assessments which are included in the current regulations, §§ 483.134(b) and 483.136(b), with assessments for the ability to perform ADLs and IADLs. This focus is inappropriate, unduly restrictive, omits key areas like communication and independent living needs, and completely ignores needs related to transitioning to, and living in, the community. This section should be substantially expanded to include all relevant assessments, as set forth in the current version of § 483.136(b), plus assessments of all relevant needs for a successful transition to an integrated setting.

Again, thank you for the opportunity to provide comments regarding proposed changes to federal PASRR requirements. If you have any questions or wish to discuss these issues further, please feel free to reach out to Lisa Wurm, Director of Policy at lwurm@disabilityrightsohio.org or 614-466-7264 ext. 102.

Respectfully,

Kerstin Sjoberg
Executive Director