

May 18, 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: Preadmission Screening and Resident Review

CMS-2418-P

Dear Administrator Verma,

Thank you for the opportunity to submit comments on behalf of the Center for Public Representation (CPR). CPR is a national legal advocacy organization that promotes the full inclusion of people with disabilities in all aspects of life. We have a unique perspective on the Preadmission and Resident Review (PASRR) rules, since we have been engaged in enforcing these rules in several states on behalf of both people with intellectual and developmental disabilities (IDD) and persons with mental illness (MI) who are referred to, admitted to, or remain in Medicaid-certified nursing facilities. Recently, we have become actively engaged in protecting these individuals from infection and death due to the rapid spread of COVID-19 in nursing facilities. In our state alone, as in many other states, approximately half of all COVID-19 related deaths involve persons in nursing facilities. Thus, the fundamental purpose of the PASRR program, and its implementing regulations – to prevent unnecessary admission of persons with MI or IDD to nursing facilities and to ensure that those who are admitted receive appropriate services – could never be more urgent.

We recognize, and support, 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 Americans with Disabilities Act, the Supreme Court's decision in *Olmstead v. L.C*, and the many CMS Bulletins and Guidance documents that explain these requirements; with professional mental health and IDD standards favoring community services; and with the trend in virtually all states to reduce reliance on segregated settings for persons with IDD and MI.

The historical foundation of the statute is an important guide for evaluating the appropriateness of the proposed rules in meeting the purpose and goals of the PASRR program. In the 1980s, in order to avoid the burden and costs of complying with ICF/DD requirements and particularly its active treatment mandate, States began to transfer large numbers of persons with IDD from their ICF/DD institutions to Medicaid-funded nursing facilities. Many nursing facilities, ill-equipped to offer appropriate habilitation or treatment for these conditions, soon became warehouses for persons with IDD. Because active treatment was not then required in nursing facilities, the conditions of individuals with IDD placed in those facilities deteriorated. As a consequence, Congress found itself subsidizing the nursing facility care of individuals with IDD that did not meet professional standards—precisely the situation it sought to rectify when it made compliance with active treatment standards a condition for receipt of federal funding for the care of persons with IDD in ICF/DDs.

In 1985, the Senate convened hearings to investigate the effects of improper institutionalization of individuals with IDD, including the inappropriate transfer of these individuals from state-operated institutions to nursing facilities. The Senate heard testimony about the warehousing of individuals with IDD in nursing facilities and the failure to provide proper care in those settings. The widespread practice of dumping individuals with IDD into nursing facilities was also documented by the General Accounting Office in a 1987 report. *See Medicaid: Addressing the Needs of Mentally Retarded Nursing Home Residents*, GAO/HRD-87-77 (1987). A full two-thirds of the residents evaluated by GAO were determined to require active treatment. *Id.* at 23. However, not a *single one* of these residents was receiving this necessary treatment. *Id.*

Congress responded with the Omnibus Budget Reconciliation Act of 1987 ("OBRA '87"), Pub. L. No. 100-203, § 4211(c), 101 Stat. 1330-198 (1987), that included a dramatic reform of nursing facility care for persons with IDD. OBRA '87 incorporates the NHRA, 42 U.S.C. § 1396r, which is designed to prevent and remedy the pervasive warehousing and neglect of people with disabilities in nursing facilities. Congress intended the NHRA to end the inappropriate placement of mentally ill or developmentally disabled individuals in nursing facilities. H.R. Rep. 100-391(I) at 459, *reprinted in* 1987 U.S.C.C.A.N. 2313-1, 2313-279 (1987).

Given this history and Congress's purpose in enacting the statute, we believe the proposed rules undermine and certainly are not consistent with the second goal, and will likely result in more people with IDD and MI being admitted to nursing facilities, less people being discharged, and few specialized services being provided to these 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.

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¹ Care of Institutionalized Mentally Disabled Persons: Joint Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources and the Subcomm. on Labor, Health and Human Services, Educ., and Related Agencies of the Senate Comm. on Appropriations, 99th Cong., S. Hr'g. 99-50 (1985) at 352.

² Available online at http://www.eric.ed.gov/PDFS/ED288331.pdf.

Instead, we urge CMS to reconsider and revise the proposed rules in light of the current pandemic, and then reissue them for public comment pursuant to a new NPRM.

There are three 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 IDD and MI:

First, the proposed rule substantially reduces the utility of PASRR preadmission screening (Level I) and evaluation (Level II) to prevent unnecessary admissions to nursing facilities. PASRR evaluations are supposed to determine if the person needs nursing facility level of services and/or could be better served in an alternative setting, like an integrated setting in the community. The proposed rule allows 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 needing only 30 days of care in the nursing facility (called exempt admission), or (4) admitted for a short term (called provisional admission). This last category is particularly troubling since it includes admissions for respite, crisis or protective services, and convalescent care. In Texas, which has adopted all of these categorical admission options, the State's own data indicates that 97% of all admissions of individuals with IDD were not subject to preadmission evaluation, either because they were categorical admissions (90%) or exempt admissions (7%). Data from other States, like Illinois, is almost as dramatic. 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 drastically reduced, and the probability of long-term institutionalization 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.

Second, the proposed rule sharply limits the PASRR Level II evaluation with respect to placement in an alternative, community setting. 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 who could be better served in the community. Moreover, while the proposed rules require that states provide individuals (or 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*, an assumption that institutionalization is appropriate unless the person expresses a preference for community placement, instead of an assumption that community placement is appropriate unless the person opposes such placement.

Third, the proposed rule significantly diminishes the amount, duration, and scope of specialized services that must be provided to persons with IDD or MI. It substantially restricts the assessments used for determining if specialized services are needed, focusing almost exclusively on ADL and IADL assessments instead of a broad range of social, vocational, educational, and communication areas, as in the current regulations. It allows States to

drastically limit the type of specialized services that they will provide, and eliminates any standard for determining what services should be provided. It affords states broad latitude to decide who conducts Level I identifications of MI and IDD, 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 rule is particularly problematic for individuals with IDD, by significantly diluting the evaluation criteria for specialized services, and deleting 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 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.

Finally, 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 disabilities or related condition. Thus, the mere fortuity of when the TBI occurs determines whether the PASRR rules apply. We know many young persons who suffered TBIs just after their twenty-second birthday who were needlessly admitted to a nursing facility without the benefit and protections of PASRR. One individual, in particular, who was paralyzed during a drive-by shooting at his twenty-second birthday party while attempting to protect his girlfriend, languished in a nursing facility for years since no one evaluated him prior to or after his admission for a possible community transition.

For these reasons, and in light of what we now know even more clearly from the pandemic about the consequences of nursing facility admission, we urge you to reconsider the proposed rule, substantially revise it to remove its decided institutional bias, and revise it to align with prior CMS Guidance and directives from Congress and the Supreme Court. The revised rule should be reissued for public comment pursuant to a new NPRM. 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 on a current resident of nursing facility. The criteria for such review are vague and limited to: (1) a major decline or improvement; (2) that requires staff or clinical intervention; *and* (3) that justifies an interdisciplinary review or change in 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 [Sec. Q]; or (3) would make discharge/transition appropriate. The definition should be expanded to include changes in the individual's ability to live in a home and community based program, interest in transition, interest in specialized services, and need for additional specialized services. This

section should be revised to include these factors, and 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 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 for what reasons. Thus, an individual who was admitted to a nursing facility from a home and community based program in January 2018, who received a PASRR evaluation in February of 2018, who was discharged to a hospital in June of 2019, and then was returned to the same nursing facility in September of 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 MI or IDD who are included in the five categories of provisional admissions results in the vast majority 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 PCP.

Part 483, Subpart C

- § 483.102: We support the new definitions of MI and IDD.
- § 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 MI and IDD 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. As evidenced by data from Texas and other states, eliminating preadmission evaluations for all of the categories listed in proposed § 483.112(b)((3) effectively eliminates all diversion opportunities for approximately 90% of all admissions of people with IDD.

§ 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 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. 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. The best way to address any institutional focus is to ensure that active treatment equally emphasizes services necessary to promote community integration. 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. Thus, 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 settings. By assuming that the nursing facility care planning team is qualified and positioned to determine the habilitative needs of persons with IDD or the mental health treatment needs of persons with MI is unrealistic. Similarly, expecting that this team will be an appropriately constituted interdisciplinary team that can develop treatment plans in a personcentered 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 IDD) 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.

- § 483.120(b): This section requires the State to provide needed specialized services and allows the State to determine who can provide such services, including persons who are not MI or IDD professionals or specialists 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 MI or IDD personnel. States should be encouraged to include community-based case managers/service coordinators, through targeted case management, as a type of specialized service.
- § 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 MI or IDD professionals, even though they are required to assess mental health or IDD needs, 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 of physical or mental condition. For the reasons set forth in the comment to §§ 483.20(b) and 114(b(2), this data should include information concerning the individual's appropriateness and preferences for both specialized services and transition to an integrated community 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 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 community placement evaluations and preferences. The current regulation requires that specialized service assessment must be based upon a list of assessments and data set forth in §§ 483.134(b) [MI] and 136(b) [IDD]. 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 medical. 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 the 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 if whether the individual could be served in such a program. 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 MI or IDD needs to be admitted to a nursing facility. It is unclear how this section relates to proposed § 483.132(a), which also describes the criteria for determining if an individual needs placement in a nursing facility. Nevertheless, this section would appear to *preclude* a determination of a need for nursing facility services, and thus admission to a nursing facility, 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, § 483.132(c)(3(i) does not require that such programs are immediately available. Thus, a PASRR evaluator should deny admission to an individual whose needs can be met through placement in a home and community based program, with or without a reasonable accommodation. This reading of the section is consistent with *Olmstead* but may not be consistent with other provisions of the proposed rule, including § 483.132(a).

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. This section should be rewritten to only allow admission if the individual has made an informed choice to be admitted to a nursing facility.

Finally, this section uses two different terms, "home and community based programs" and "community placement", suggesting that they means something different. 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 MI or IDD 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 sufficient standing

alone. It is confusing and unclear how the two prongs differ, and why "benefit", alone, is not sufficient. 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 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 confirm 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 <u>individual</u>'s preferences and requires information on community options. There is no specification of the type or scope of information, or mention of informed choice. Most importantly, it contradicts the standard established by the Supreme Court in *Olmstead*, and incorporated in the Department of Justice's *Olmstead* Guidance, by insisting on an expressed preference for community placement, rather than opposition to such placement. This subsection should be rewritten to conform to federal law, as well as the DOJ Guidance, 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 MI or IDD professionals, and which customarily restrict the amount, duration and scope of rehabilitative services, to provide specialized services which requires MI or IDD professionals, and which are not subject to such restrictions. This section should be deleted.

§ 483.134: As noted in the comment to proposed § 483.120(a) (definition of specialized services), § 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) (MI) and 136(b) (IDD), with assessments for the ability to

perform ADL and IADL. 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.

Thank you for your attention.

Sincerely,

Steven Schwartz Legal Director