May 10, 2022

By electronic mail

The Honorable Frank Pallone, Jr.
Chairman
House Committee on Energy & Commerce
2107 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Committee on Energy & Commerce
1035 Longworth House Office Building
Washington, DC 20515

Re: Statement for the Record for May 11, 2022 Hearing on H.R. 7666, the "Restoring Hope for Mental Health and Well-Being Act of 2022"

Dear Representatives Pallone and McMorris Rodgers:

We write on behalf of the Bazelon Center for Mental Health Law, the Autistic Self Advocacy Network, the Center for Public Representation, and the National Disability Rights Network, in conjunction with the Committee's April 5, 2022 hearing entitled "Communities in Need: Legislation to Support Mental Health and Well-Being."

Our organizations advocate for the rights of adults and children with disabilities to live in their own homes and communities whenever possible, consistent with the community Integration mandate in the Americans with Disabilities Act (ADA), as interpreted by the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999). We appreciate the Committee's attention to the mental health challenges faced by people with disabilities and their communities, which predate but have been exacerbated by the COVID-19 pandemic. A number of the many bills that the Committee is considering would support measures that have been shown to help meet the needs of people with the most significant mental health issues.

Medicaid is by far the largest payer for behavioral health services in our country, and is a key tool for states supporting people with mental health disabilities. We appreciate the House's passage last year of the Build Back Better Act, which would provide $150 billion in federal Medicaid funding for home- and community-based services, including those services shown to be effective in helping people with mental health disabilities, including those with co-occurring substance use disorders (SUDs), succeed in the community. These include Assertive Community Treatment (ACT), intensive care management, housing services, supported employment, and crisis response services. In addition, people with lived experience working as peer specialists to help provide these services have been shown to provide additional benefits to individuals with behavioral health issues.

We have serious concerns, however, about certain proposals that would weaken the Social Security Act's exclusion from Medicaid reimbursement for services provided in "institutions for mental disease" (IMDs). An IMD is a hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including both mental health disabilities and SUDs. Since 1965, Medicaid has not authorized federal reimbursement for services provided to individuals between the ages of 21 and 64 in IMDs, consistent with the states' historic responsibility for providing inpatient psychiatric services.

Since the Centers for Medicare & Medicaid Services (CMS) issued guidance in 2018 allowing states to seek Medicaid reimbursement for short-term psychiatric services providing in IMD settings, a number of states have applied for this funding. We are concerned that Congressional support for measures that would weaken or end the IMD exclusion will incentivize overreliance on institutionalizing people with behavioral health disabilities, instead of ensuring that they have access to the full continuum of community-based services they need. This is inconsistent with the *Olmstead* decision's prohibition of unnecessary institutionalization of people with disabilities, and the ADA's requirement that states offer individuals with disabilities the opportunity to be served in the most integrated setting appropriate. It is also inconsistent with what we have long known: many individuals served in IMDs receive better care and achieve recovery in home and community-based settings.

Discussion about Congressional support for reimbursement for services provided in IMDs ignores the root of the problem: a lack of sufficient community-based services in too many communities. The need for acute hospital behavioral health services is directly related to how available and easily accessible outpatient services in the community are, both before and after hospitalization. Increasing access to outpatient community-based services decreases the crises that lead to hospitalization and reduces inpatient admissions as well as allowing hospitals to discharge individuals more quickly to the aftercare services they need.

The implementation this year of the 988 system for responding to behavioral health service calls should not lead to an increased need for inpatient services in IMDs. Congressional support for 988 should provide communities resources to develop capacity for a robust behavioral health response to these calls. Within the behavioral health system, there should be a unit that functions much like 911, receiving and responding to calls directly received, calls redirected from 911, and calls from the police. Many calls can be resolved by providing advice, making referrals, or providing transportation. Others will require dispatching a mobile response team, a team of mental health professionals, including at least one person with lived experience working as a peer specialist and one clinician, trained to de-escalate individuals in behavioral health crisis.

Mobile teams should resolve most calls to which they are dispatched in the community. For individuals already receiving services, the team may include the person's Assertive Community Treatment or other multi-disciplinary team, which should function as that person's first responder. In addition, there should be an array of facilities available for crisis care, including respite apartments; apartments for short-term stays staffed by behavioral health personnel including peers; walk-in or drop-off crisis centers also staffed by peers, including those following a "living room" model; and short-term detox centers. Communities with a robust array of community-based alternatives for crisis observation and stabilization see a significant reduction in utilization of hospital emergency rooms for stabilization—as well as jails and detention centers—and subsequent inpatient admissions.

Some argue that providing additional federal support for services in IMD settings will indirectly "free up" dollars that can then be redirected to community-based mental health and SUD services. But proposals we have seen for such funding do not contain a mandate or guarantee that any money saved will be spent on community-based behavioral health services. If Congress would like to increase access to community behavioral health services, Congress should—as it did in the Build Back Better Act—direct federal dollars to those services, instead of weakening or ending the IMD exclusion. Creating more inpatient beds at the expense of the community-based services that prevent inpatient admissions will only generate additional pressure on inpatient capacity.

Further, in our experience individuals with mental health disabilities experience better treatment and better outcomes in community-based settings than they do in IMD settings. From 2012-2015, the federally mandated Medicaid Emergency Psychiatric Demonstration (MEPD) reimbursed eleven states and the District of Columbia for inpatient treatment in private IMDs. The program's final evaluation found no decrease in emergency department admissions or lengths of stay, no decrease in general hospital admissions or lengths of stay, no significant

improvement in access to inpatient care, and no improvement in follow-up care.[1] A later report to Congress regarding the MEPD noted that utilization rates for IMDs in the eleven states were, at an average of 93%, "very high" and "substantially above the national average of 66% across all hospital types."[2] The report states that "utilization rates above 85 percent are associated with deterioration in care quality. . . . [and] imply an increased likelihood that patients will be unable to access needed care, particularly at smaller facilities."[3]

We are engaged in legal advocacy in one of the MEPD states, Illinois. Following the conclusion of the demonstration, the Court Monitor for the federal "*Olmstead*" litigation *Williams v. Pritzker* conducted data reviews and onsite visits for the IMD nursing homes that are the subject of the litigation. The Monitor found "no evidence of active treatment" during her visits to the facilities.[4] Further, during the site visits

> the Court Monitor observed that most Williams facilities residents were either in their beds (even though visits occurred during the day) and not engaged in any individual or group activity or treatment (e.g. occupational therapy, individual counseling, case management, groups for skill-building, anger management, substance use recovery, illness self-management, etc.) or smoking tobacco in designated smoking areas. . . . The Court Monitor fears that residence in these facilities may hinder recovery and cause some Class Members to lose concrete living skills and confidence as opposed to gain living skills and confidence, in preparation to transition back into the community.[5]

In a later report, the Monitor sounded a "cause for alarm": critical incidents including sexual assaults, abuse, neglect, deaths, assaults, missing persons, and criminal conduct were much more prevalent among residents of the Illinois IMDs than among persons who had been transitioned to the community from the IMDs.[6] Affirmative responses to quality-of-life survey questions were more prevalent for those in the community than for persons in the IMDs.[7]

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[1] Crystal Blyler et al., *Medicaid Emergency Psychiatric Services Demonstration Evaluation: Final Report*, Mathematica Pol'y Rsch. 27, 54-55, 74 (Aug. 18, 2016).
[2] U.S. Dep't of Health & Human Servs., *Medicaid Emergency Psychiatric Demonstration: Response to 21st Century Cures Act Requirements Report to Congress* 12-13 & Table II.4 (Sep. 30, 2019).
[3] *Id.*
[4] Court Monitor FY2018 Compliance Assessment Annual Report to the Court 52, *Williams v. Rauner*, Case No. 05-C-4673 (N.D. Ill. Nov. 5, 2018).
[5] *Id.*
[6] Court Monitor FY2021 Compliance Assessment Annual Report to the Court 53-54, *Williams v. Pritzker*, Case No. 05-C4673 (N.D. Ill. Jan. 18, 2022).
[7] *Id.*

Finally, we are extremely concerned about how Congress would pay for any change to the IMD exclusion. The Congressional Budget Office has scored repeal of the IMD exclusion at $40 billion to $60 billion.[8] We would strenuously object to any cuts to Medicaid to pay for increased federal funding for services provided in IMDs. We would also note that Medicaid already covers inpatient behavioral health care in general hospitals, which are much better suited than IMDs serving only people with behavioral health issues to treat the "whole person" including medical complications from psychiatric medications and co-occurring medical problems, which IMD settings are often ill-equipped to diagnose and treat.[9]

We appreciate the Committee's focus on mental health, and are grateful for this opportunity to contribute to the Committee's consideration of solutions for the challenges we face. The past 50 years has seen a clear and deliberate public policy shift away from the historic overreliance on psychiatric institutions and toward increased investment in the cost-effective community behavioral health services that reduce the need for hospitalization. The Medicaid IMD exclusion rule has been an important driver of this positive shift. Additional federal funding for services provided in IMD settings would undermine this historic trend and would be inconsistent with Congress's intent in enacting the ADA. The National Council on Disability has recommended that waivers from the IMD exclusion end, and we agree.[10]

[8] Congressional Budget Office, *Direct spending effects of title V of H.R. 2646, the Helping Families in Mental Health Crisis Act of 2015* (Nov. 3, 2015), at https://www.cbo.gov/sites/default/files/114th-congress-2015-2016/costestimate/hr2646directspendingeffectsoftitlev.pdf.

[9] For example, see Syracuse.com, *NY faults Hutchings Psychiatric for misdiagnosis, neglect in death of girl*, 14 (Apr. 11, 2018), at http://www.syracuse.com/health/index.ssf/2018/04/post_58.html.

[10] National Council on Disability, Health Equity Framework for People with Disabilities (Feb. 2022), at file:///C:/Users/Guest1/Downloads/NCD_Health_Equity_Framework%20-%20highlights%20(1).pdf.

Thank you for your leadership on these important issues. Should you have any questions about this letter, please feel free to contact Lewis Bossing, Senior Staff Attorney, Bazelon Center for Mental Health Law, at lewisb@bazelon.org or (202) 467-5730 x1307 (office).

Sincerely,

/s/

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