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Dear Senators Casey, Hassan, and Brown and Representative Dingell:

The Bazelon Center for Mental Health Law submits these comments on the HCBS Access Act discussion draft. Founded in 1972 as the Mental Health Law Project, the Bazelon Center is a national non-profit legal advocacy organization that advances the rights and dignity of individuals with mental disabilities and works to ensure access to the services they need for full participation in community life. Through litigation, public policy advocacy, education, and training, the Bazelon Center promotes equal opportunity for adults and children with mental disabilities in all aspects of life, including community living, health care, employment, education, housing, voting, parental and family rights, and other areas.

We thank you for the commitment to expanding and improving access to home and community-based services and we strongly support efforts to make these mandatory services under the Medicaid program. For far too long, dramatic gaps in Medicaid home and community-based services have existed. In addition to the limited availability of Medicaid HCBS waivers for people with intellectual and developmental disabilities and people who would otherwise be served in a nursing facility, there are severe shortages of community mental health services. Even though these services are typically provided through the Medicaid rehabilitative services option rather through capped waivers, state decisions concerning which rehabilitative services to cover, how much to cover, how the state plan benefit is defined, and the use of medical necessity and utilization management to ration the availability of services have resulted in severe shortages of these services.

As a result, large numbers of people with psychiatric disabilities experience repeated admissions to psychiatric hospitals, emergency rooms, and jails. Many are homeless due to lack of services. Creating a package of mandatory Medicaid HCBS that includes the core community-based mental health services would afford people with psychiatric disabilities the opportunity to live full lives in their own homes and communities. It would also enable significant cost savings by preventing needless hospital, emergency room, and jail stays, as well as physical health care costs associated with untreated



psychiatric disabilities; these cost savings would help offset the cost of expanded community-based services.

The Bazelon Center joined comments submitted by the Consortium for Citizens with Disabilities Long-Term Services and Supports Task Force. We offer these separate comments to highlight particular issues including ensuring that the needs of people with psychiatric disabilities are addressed.

1. Proposed changes to statutory language to ensure applicability to people with psychiatric disabilities

We recommend the following changes to ensure that the needs of people with psychiatric disabilities are addressed:

- a) Page 2: Purpose (2): "To eliminate shortages of and waiting lists for HCBS..."
 - **Explanation**: The shortages of community mental health services that exist are not reflected by waiting lists. Waiting lists exist for capped waiver services, but people with psychiatric disabilities are typically not placed on such waiting lists since these waivers primarily serve people with intellectual and developmental disabilities and people with physical disabilities.
- b) Pages 5-6: Description of personal assistance: "...professionals, home health aides, private duty nursing, homemakers and chore assistance, encouragement and cueing, and companionship services."
 - **Explanation**: Personal assistance for many individuals with psychiatric disabilities, along with many individuals with cognitive or intellectual disabilities, is most needed in the form of cueing and encouragement rather than hands-on assistance.
- c) Page 7: Peer support services: "Peer support services, including services provided by peer support specialists and peer recovery coaches, and including services in peer crisis respite centers."
 - **Explanation**: Peer support services are provided in many different contexts. This clarifying language would help ensure that the peer support benefit is not interpreted to exclude important services.
- d) **Page 8**: In the composition of the advisory panel, for (aa): "... including those with physical disabilities, behavioral health disabilities, and or intellectual or developmental disabilities, and including elderly individuals.



Explanation: Using "and" instead of "or" will ensure representation across different types of disabilities, which is important given the different services and different ways that Medicaid financing works for different disabilities.

e) Page 14: In paragraph (D) concerning standards for individualized assessments: "... in consultation with the Administration for Community Living and the Substance Abuse and Mental Health Services Administration..."

Explanation: It may be important for SAMHSA to be involved in the development of standards for individualized assessment of behavioral health needs since responsibility for mental health services policy falls largely within SAMHSA rather than ACL.

2. Clarification of role of advisory panel

To ensure clarity that the role of the advisory panel is to review services for addition or removal as "other services" in subparagraph xvi, we propose that in paragraph (B)(i) on Page 8, and also in paragraph (iii) "Duties" on pages 9-10, the text say "which shall be included as home and community-based services **under subparagraph (xvi)**" (instead of "under this paragraph."). Otherwise the language may be misconstrued to mean that the panel reviews all of the specified services. The intent is clearer in (iv) "Implementation of Specified Services" on Page 10, but to avoid misunderstanding, it should be clearer in the other paragraphs.

3. Ensuring an adequate scope of services

We strongly recommend adding a provision clarifying that Medicaid's "amount, duration and scope" requirement (requiring that each service be sufficient in amount, duration and scope to reasonably achieve its purpose) applies to the new HCBS services. Experience with Medicaid's rehabilitative services option has shown that state coverage of services rarely ensures that eligible beneficiaries receive needed services. The "amount, duration and scope" protection is important to ensure that these services are not so heavily rationed and/or narrowly construed that beneficiaries who need these services cannot receive them.

4. Ensuring adequate reimbursement rates

We recommend that the legislation include a requirement that HHS do regulations ensuring the sufficiency of reimbursement rates for the HCBS services, including rates for managed care entities, and that these rates translate into adequate wages for individual workers providing HCBS. CMS's process for approving reimbursement rates should ensure that states set rates in a manner in a manner that enables compliance with Medicaid's requirements that services be available statewide, that they be furnished with reasonable promptness, and that they be available in an amount, duration, and scope sufficient to reasonably achieve their purpose. Further, states should be required to specify how much of the reimbursement rates

1090 Vermont Ave NW Suite 220 Washington DC 20005 202 467 5730 www.bazelon.org @bazeloncenter



goes to workers directly providing each service (disaggregated by the type of worker, including peer support providers) and to demonstrate that rates are sufficient to ensure reasonable wages and benefits for direct service workers, taking into account the geographic area at issue. CMS should specifically review whether wages are set at a reasonable percentage of the rate.

5. Expanding the implementation plan equity requirements

We recommend expanding the provision requiring states to include in their implementation plans "Data and milestone requirements to ensure community integration, including such requirements with respect to utilization of such services by gender, race, ethnicity, geography, and other demographics." That provision should also include sexual orientation and gender identity, and type of disability. Implementation plans should also be required to include the actions that will be taken to address disparities in access to HCBS.

6. Improving Money Follows the Person to Ensure Coverage of People with Psychiatric Disabilities

We recommend that, as part of this bill or another HCBS bill, the Money Follows the Person program be modified so that it no longer effectively excludes most people with psychiatric disabilities. Such changes might include disregarding the Medicaid IMD exclusion for purposes of calculating cost neutrality of MFP services and allowing people with psychiatric disabilities to qualify if they are hospitalized one or more times over a two year period (or a similar measure that takes into account that avoidable institutionalization of people with psychiatric disabilities frequently takes the form of cycling in and out of psychiatric hospitals. We raise this issue now because, despite the fact that MFP has served a miniscule number of people with psychiatric disabilities due to its criteria, efforts to raise these issues at the time of MFP reauthorizations have gone unaddressed due to the need for simplicity in reauthorization discussions. This issue must be addressed for the program to be a meaningful avenue for people with psychiatric disabilities to access HCBS.

Thank you for the opportunity to submit comments.

Sincerely,

Jennifer Mathis

Director of Policy and Legal Advocacy

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