



Via email (Statementsfortherecord@finance.senate.gov)

June 5, 2024

Chairman Ron Wyden
Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-219
Dirksen Senate Office Bldg.
Washington DC 20510

Ranking Member Mike Crapo
Senate Committee on Finance
Attn. Editorial and Document Section
Rm. SD-219
Dirksen Senate Office Bldg.
Washington DC 20510

RE: The Family First Prevention Services Act: Successes, Roadblocks, and Opportunities for Improvement

Dear Chairman Wyden and Ranking Member Crapo:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) Long Term Services and Supports (LTSS) Task Force appreciate the opportunity to submit a statement for the record for the hearing, *The Family First Prevention Services Act: Successes, Roadblocks, and Opportunities for Improvement*, held on May 22, 2024. We thank the Committee for holding a hearing focused on better supporting youth in foster care, including youth in foster care with disabilities that may be placed in congregate settings.

The Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

The CCD LTSS Task Force advocates for the services and supports that enable individuals with disabilities of all ages to live in their own homes and communities. Medicaid is a primary payer of mental health services, and Medicaid-funded community-based mental health services and supports are necessary to ensure that youth and families can stay together and experience community integration, full participation, and inclusion in all aspects of society. One of the Task Forces' priorities is to reduce the use of long-term institutional care for children with disabilities, and to advocate for robust implementation of children's right to community-based mental health services pursuant to the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) mandate, the Americans with Disabilities Act, and Family First Prevention Services Act.

We thank the Committee for its ongoing support of and commitment to ensuring that parents and families can access the services and supports they need prior to entering foster care, and without subjecting youth to unnecessary trauma. We agree that children and adolescents—including youth with disabilities—belong with families. When children cannot be with their family of origin, they should be in family-like settings.¹ As the U.S. Department of Health and Human Services' (HHS) regulation implementing Section 504 of the Rehabilitation Act states, “[C]ongregate care is virtually never the most appropriate long-term placement for children.”²

We oppose the Ensuring Medicaid Continuity for Children in Foster Care Act (S. 3196) because we believe it would create new financial incentives to expand institutional care, and undermine efforts to keep youth with families. The LTSS Task Force has

¹ American Academy of Pediatrics, Children's Defense Fund, Foster Club, Think of Us, and Youth Law Center (Jan. 2022), *The Path to Well-being for Children and Youth in Foster Care Relies on Quality Family-Based Care*, <https://familyfirstact.org/resources/path-well-being-children-and-youth-foster-care-relies-quality-family-based-care-what%E2%80%99s>.

² U.S. Dep't of Health & Human Servs., *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*, 89 Fed. Reg. 40106 (May 9, 2024), <https://www.federalregister.gov/documents/2024/05/09/2024-09237/nondiscrimination-on-the-basis-of-disability-in-programs-or-activities-receiving-federal-financial>.

consistently opposed legislation that would exempt states from having to comply with the “institutions for mental diseases” (IMD) exclusion for children in foster care.³ Changes to the IMD exclusion will not solve the very real inadequate access to high quality mental health services for children and youth. Instead, we urge you to continue to invest in community-based trauma-informed mental health services to ensure young people receive the care they need in the least restrictive environment.

Thank you for your attention to these important issues. The Task Force looks forward to continued partnership as the committee works to move forward legislation that would support people with disabilities and improve access for Medicaid services. Please feel free to contact Jennifer Lav at lav@healthlaw.org with any questions or comments.

Sincerely,

Access Ready Inc.

American Academy of Pediatrics

American Association of People with Disabilities

Autistic Self Advocacy Network

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Caring Across Generations

Center for Public Representation

Disability Rights Education and Defense Fund (DREDF)

Family Voices

National Association of State Directors of Developmental Disabilities Services

National Association of Councils on Developmental Disabilities

National Disability Rights Network (NDRN)

³ See, e.g. Letter from CCD LTSS Task Force Co-Chairs to the Honorable Ron Wyden, et al (May 9, 2022) <https://c-c-d.org/fichiers/CCD-QRTP-letter.pdf>.

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