



May 9, 2022

The Honorable Ron Wyden
Chair
Finance Committee
U.S. Senate

The Honorable Mike Crapo
Ranking Member
Finance Committee
U.S. Senate

The Honorable Patty Murray
Chair
Health, Education, Labor & Pensions
Committee
U.S. Senate

The Honorable Richard Burr
Ranking Member
Health, Education, Labor and Pensions
Committee
U.S. Senate

The Honorable Frank Pallone
Chair
Committee on Energy & Commerce
U.S. House of Representatives

The Honorable Cathy McMorris Rodgers
Ranking Member
Committee on Energy & Commerce
U.S. House of Representatives

The Honorable Richard Neal
Chair
Ways and Means Committee
U.S. House of Representatives

The Honorable Kevin Brady
Ranking Member
Ways and Means Committee
U.S. House of Representatives

Dear Senators Wyden, Crapo, Murray, and Burr, and Representatives Pallone, McMorris Rodgers, Neal, and Brady:

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 undersigned co-chairs of CCD's Long Term Services and Supports Task appreciate the recent bipartisan efforts to address serious gaps in the youth behavioral health system, and are extremely supportive of many of the efforts that both the House and Senate are considering. However, we have been extremely concerned about recent discussions to carve youth in foster care out of the Institution for Mental Diseases (IMD) exclusion in Medicaid. Children—including children with disabilities—belong with families. When they cannot be with their family of origin, they should be in family-like settings. To the extent that group homes are used, small (less than 17 beds) is better.¹

Changes to the IMD exclusion will not solve the very real problems that exist regarding access to high quality mental health services for children and youth. To the extent that inpatient services are deemed necessary for youth in Medicaid, Medicaid already covers such facilities via the “psych 21” benefit.² Under Medicaid, children under 21 can obtain long term inpatient service in psychiatric residential facilities, as long as those facilities meet very specific conditions of participation intended to protect youth who are admitted. Thus, the changes to the IMD exclusion being discussed regarding youth in foster care will not remove any “barrier” to treatment, as pathways to coverage of such services already exist. However, by taking psychiatric inpatient services out of the context of the psych-21 benefit, it will create “short cuts” for states to get funding for congregate facilities for children, thereby undermining hard-won civil rights for people with disabilities and decades of federal policy initiatives stressing the importance of increasing community integration.⁷

Attempts to repeal or modify the IMD exclusion for youth in foster care are contrary to the basic tenets of the disability rights movement, and current efforts to reform child welfare to encourage more use of family-based care. Long-standing litigation has established children's right to community-based services pursuant to both the EPSDT mandate and the Americans with Disabilities Act, and in 2018, landmark

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 42 U.S.C. 1396d(a)(16); 42 U.S.C. 1396d(h)(1).

legislation—the Family First Prevention Services Act—was enacted to help make this a reality.³ Now is not the time to undermine this progress and make it easier for states to obtain federal funding for foster children in institutions.

We appreciate your commitment to improving services to support children with mental health disabilities, and we urge you to continue to pursuing solutions that will strengthen the system of care. Please feel free to reach out to Jennifer Lav at lav@healthlaw.org with any questions or concerns.

Sincerely,

Julia Bascom
Autistic Self Advocacy Network

Dan Berland
National Association of State Directors of Developmental Disabilities Services

Nicole Jorwic
Caring Across Generations

Jennifer Lav
National Health Law Program

Gelila Selassie
Justice in Aging

³ See *Rosie D. v. Romney*, 410 F. Supp. 2d 18 (D. Mass. 2006); *Katie A. ex rel. Ludin v. Los Angeles County*, 481 F.3d 1150, 1158 (9th Cir. 2007); Settlement Agreement, *T.R. v. Dreyfus*, C09-1677-TSZ (W.D. Wash. Dec. 19, 2013), https://www.disabilityrightswa.org/wp-content/uploads/2017/12/Settlement-Agreement-and-Ordersigned-8.30.2013_0.pdf; Dep't of Justice, Findings Letter, Investigation of West Virginia Children's Dep't of Justice, Findings Letter, Investigation of West Virginia Children's Mental Health System Pursuant to the Americans with Disabilities Act 22 (June 1, 2015), https://www.ada.gov/olmstead/documents/west_va_findings_ltr.pdf.