



December 20, 2018

The Honorable Lamar Alexander
Chairman
Health, Education, Labor & Pensions Committee
United States Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Health, Education, Labor & Pensions Committee
United States Senate
Washington, DC 20510

Dear Chairman Alexander and Ranking Member Murray,

We, the undersigned members of the Developmental Disabilities, Autism and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) are writing to share our priorities for supporting children with disabilities and their families, and parents with disabilities, in the reauthorization of the Child Abuse Prevention and Treatment Act (CAPTA). 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.

Research has confirmed that children with disabilities are nearly 4 times more likely than children without disabilities to be neglected or experience physical or emotional abuse, and more than 3 times more likely to be sexually abused. (Jones et al., 2012; Sullivan and Knutson, 2000; Smith and Harrell, 2013; UNICEF, 2013).¹ They are also more likely to be seriously injured or harmed by maltreatment (Sedlak et al., 2010).² Each year, the Children's Bureau collects and analyzes data through the National Child Abuse and Neglect Data System (NCANDS). In 2013, the last year in which the Children's Bureau reported on the number and percentage of children with disabilities who were victims of abuse or neglect, 12.6% of child victims were reported to have a disability (Child Maltreatment Report, 2013).³

¹ Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 380, 899–907. doi: 10.1016/S0140-6736(12)60692-8; Smith, N., and S. Harrell. 2013. *Sexual abuse of children with disabilities: A national snapshot*. <http://www.azcadv.org/azcadv2014wp/wp-content/uploads/2014/06/Sexual-Abuse-of-Childrenwith-Disabilities-A-National-Snapshot.pdf>; Sullivan, P. M., and J. F. Knutson. 2000. Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect* 24(10):1257–1273; and UNICEF (United Nations Children's Fund). 2013. *Children and young people with disabilities*. [https://www.unicef.org/pacificislands/UNI137485\(1\).pdf](https://www.unicef.org/pacificislands/UNI137485(1).pdf)

² Sedlak, A. J., Mettenburg, J., Basena, M., Petta, I., McPherson, K., Greene, A., & Li, S. (2010). Fourth National Incidence Study of Child Abuse and Neglect (NIS-4): Report to congress.

³ U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau. (2015). *Child maltreatment 2013*.

The National Council on Disability (NCD) estimates that approximately 4.1 million parents have at least one reported disability (National Council on Disability, 2012).⁴ This represents more than six percent of all American parents. Without adequate community supports, parents with disabilities may feel very isolated and under stress. Just because of their disability, they may be at higher risk for child welfare investigations of abuse or neglect or even child removal. Parents interviewed for the NCD report, said respite and peer parenting support groups would be helpful to enhance their social connections.

Current CAPTA law includes multiple provisions in both Title I, the Basic State Grant Program, and Title II, the Community-based Child Abuse Prevention Grants Program (CBCAP) that address the needs of children with disabilities and their families as well as parents with disabilities in the prevention and treatment of child abuse and neglect. The need to maintain the critical provisions outlined below are all the more pressing due to the opioid crisis and the increased risk of developmental disabilities for children who are prenatally exposed to this class of drugs. The need to refocus CAPTA on its original intent to prevent and treat child abuse and neglect should be a priority.

Title I. Basic State Grant Program

In Title I, we urge you to retain language that promotes linkages between child welfare, disability agencies, and Part C early intervention programs; encourages collaboration; and emphasizes cross-agency training opportunities to ensure appropriate interventions for children with disabilities in the child protective services systems. Specifically, we request the following sections be retained:

- Sec. 104(a) Research programs may focus on “(K) the impact of child abuse & neglect on the incidence and progression of disabilities”
- Sec. 105(a)(1) Secretary may award grants to public or private organizations
 - (E) “for the training of personnel in best practices to meet the unique needs of children with disabilities, including promoting agency collaboration”
 - (D) “for training to support the enhancement of linkages among CPS agencies and health care agencies, entities providing physical and mental health services, community resources, and DD agencies, to improve screening, forensic diagnosis, and health and developmental evaluations, and for partnerships”
- Sec. 108(d) Sense of Congress: The Secretary should encourage all states and public and private entities that receive assistance under this title to: “(2) ensure that individuals with disabilities who participate in programs under this title are provided with materials and services through such programs that are appropriate to their disabilities.”

Moreover, we request that states continue to be required to provide assurances that referrals of children under the age of 3 who are involved in a substantiated case of child abuse or neglect will be referred to early intervention services funded under part C of the Individuals with Disabilities Education Act [Sec. 106. (b)(2)(B)(xxi)]. We also strongly support Sec. 106(d) Annual State Data Report: report shall include “(16) the number of children determined to be eligible for referral, and

⁴ National Council on Disability (2012). *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*. Washington, DC: Author. <https://www.ncd.gov/publications/2012/Sep272012>

the number of children referred, under subsection (b)(2)(B)(xxi), to agencies providing early intervention services under Part C of the [IDEA].”

Finally, we continue to support the “Baby Doe” provisions in Sec. 106 Grants to States (b)(2)(C)(i-iii) that require a State Plan assurance that “the State has in place procedures for responding to the reporting of medical neglect (including instances of withholding of medically indicated treatment from infants with disabilities who have life-threatening conditions), procedures or programs, or both (within the State child protective services system).

Title II. Community-Based Child Abuse and Neglect Prevention Grants (CBCAP)

Title II contains provisions to ensure that children with disabilities and their families, and parents with disabilities, have access to and receive prevention information and services to support them. Title II language also specifies that families of children with disabilities and parents with disabilities are included in an advisory capacity in the planning and implementation of state and local activities to strengthen families and prevent child abuse and neglect. Given that children with disabilities are at high risk for abuse or neglect, and that parents with disabilities are in great need of information and support, such as respite, we feel strongly that this language remain in this title to ensure that these families have full access to community-based child abuse prevention activities, and that outreach is available to make sure that they are aware of the available services.

The CBCAP program has supported numerous interventions focused on families of children with disabilities, such as respite services in Alabama and parent education and support services in South Carolina, that have reported positive child and family outcomes (Alabama Lifespan Respite Network, 2018; Child Information Gateway, 2018).⁵ These and similar services across the country are helping to ensure that children with disabilities remain safe and healthy and with their families.

Finally, research has corroborated these findings and shown that respite and crisis care promote protective factors that can help prevent abuse and avoid out-of-home placements (ARCH Annotated Bibliography, 2018).⁶ As an evidence-informed service, we also know that the earlier respite is provided through prevention and family strengthening approaches, the more beneficial it will be over the long-term. Respite should remain as a *Core Service* in CBCAP Title II to encourage states and local entities to make such services available to all families as part of a comprehensive approach to prevention.

Thank you for your consideration of these issues. If you have any questions, please feel free to contact Annie Acosta with The Arc at acosta@thearc.org or Jill Kagan with the National Respite Coalition at jkagan@archrespite.org.

⁵ Child Welfare Information Gateway. (2018). *The risk and prevention of maltreatment of children with disabilities*. Washington, DC: U.S. Department of Health and Human Services, Children’s Bureau; and Alabama Lifespan Respite Network (2018). Personal Communication.

⁶ ARCH National Respite Network and Resource Center (2018). Annotated Bibliography of Respite and Crisis Care Studies. Chapel Hill, NC: Author. https://archrespite.org/images/docs/Bibliographies/Annotated-Bibliography_Web_2018.pdf

Sincerely,

Allies for Independence
American Psychological Association
American Therapeutic Recreation Association
The Arc of the United States
Autism Society of America
Autistic Women & Nonbinary Network
Family Voices
National Association of Councils on Developmental Disabilities
National Disability Rights Network
National Down Syndrome Congress
National Respite Coalition
School Social Work Association of America
Special Needs Alliance