



November 5, 2021

The Honorable Bill Cassidy, M.D.
United States Senate
Washington, DC 20515

The Honorable Chris Murphy
United States Senate
Washington, DC 20515

Dear Senator Cassidy and Senator Murphy,

Thank you for the opportunity to submit feedback as you develop new legislation to address mental health and substance use disorders in the United States. Our organizations – the [Association of Maternal & Child Health Programs](#) (AMCHP) and the [Association of University Centers on Disabilities](#) (AUCD) – write to provide input regarding how Congress can make significant progress in addressing the mental health needs of children and youth with developmental disabilities. This population faces unique barriers to mental and behavioral health care that deserve Congress' focused attention.

I. Background: Mental Health for Children and Youth with Developmental Disabilities

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas that begin during a child's early years and may impact day-to-day functioning. The Centers for Disease Control and Prevention (CDC) estimates that one in six American children ages 3 through 17 years old are diagnosed with one or more developmental disabilities.¹

The COVID-19 pandemic has laid bare the dire need for access to appropriate, high-quality mental health services for children and youth with developmental disabilities.² Data indicate that children and youth with developmental disabilities are 1.6 times more likely to be hospitalized for COVID-19 than their peers without developmental disabilities.³ While social distancing, virtual learning, and other mitigation measures remain necessary to protecting the health of children and youth with developmental disabilities, they have also resulted in increased loneliness, stress, and mental health challenges for many children and youth with developmental disabilities and their caregivers. It is imperative that mental and behavioral health services be made more widely available to this vulnerable population to both counteract the short-term effects of COVID-19 and to address long-term systemic barriers.

II. Legislative Recommendation: Authorize and expand the Learn the Signs. Act Early. program at CDC's National Center on Birth Defects and Developmental Disabilities' (NCBDDD) to build states' capacity to meet the mental health and developmental needs of children and youth with developmental disabilities.

¹ Centers for Disease Control and Prevention (2021, September 13). [CDC's Work on Developmental Disabilities](#) (retrieved on October 28, 2021).

² Patel, K. (2020). Mental health implication of COVID-19 on children with disabilities. *Asian Journal of Psychiatry* 54. <https://doi.org/10.1016/j.ajp.2020.102273>.

³ Tinker, C., Cogswell, M., Peacock, G., & Ryerson, A.B. (2021). Important considerations for COVID-19 Vaccination of Children with Developmental Disabilities. *Pediatrics* 148(4). <https://doi.org/10.1542/peds.2021-053190>.

The [Learn the Signs. Act Early. program](#) (LTSAE) improves early identification of developmental disabilities among children ages 0 through 5 years old by raising awareness of developmental milestones, encouraging early action on concerns, and promoting collaboration among state and territorial early childhood services through [Act Early Ambassadors](#).⁴ A formal authorization and expansion of this program will allow CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) to scale and implement effective activities to mitigate the impact of developmental disabilities and co-occurring mental health conditions on children and their families, especially those at highest risk of poor outcomes, such as children from racial-ethnic minority groups or low-resource families and communities.

Ensuring and expanding strategies to promote early identification of and services for developmental disabilities and co-occurring mental health conditions can improve the overall function and health of children and youth with developmental disabilities and reduce long-term costs to families and federal programs serving the developmental disabilities population. Increased, long-term investment in LTSAE is necessary to build the capacity of state and territory systems to adequately meet the mental health needs of children and youth with developmental disabilities.

Specifically, our organizations recommend that Congress authorize the Learn the Signs. Act Early. program at \$40 million per fiscal year to enable the program to carry out the following activities:

- 1. Expand and enhance the Act Early Ambassadors program to identify and serve children and youth with developmental disabilities and co-occurring mental health conditions ages 0 through 5 years old.**

This proposal would enable CDC to sustain and expand the Act Early Ambassadors program to **70 states, territories, large cities, and tribal communities**. It would enhance Act Early Ambassadors' ongoing efforts to integrate developmental monitoring, screening, referral, and linkage to intervention services into statewide child-serving programs, particularly programs serving children at-risk of developmental disabilities and delays due to systemic inequities driven by racism, ableism, and classism. This proposal would also expand the Act Early Ambassador-led efforts to create or strengthen an evidence-based single point of entry program for developmental monitoring, screening, referral, and linkage to intervention services from 30 states and territories to 56 states and territories.

- 2. Expand the Children's Mental Health Champions pilot program to identify and serve children and youth with developmental disabilities and co-occurring mental health conditions ages 6 through 18 years old.**

Launched in 2020, the Children's Mental Health Champions (CMHC) pilot program is an adaptation and extension of the LTSAE Ambassador program intended to build capacity and connect state mental health services for children and youth with developmental disabilities ages 6 through 18 years old. The 12 current Champions have supported children and youth with developmental disabilities with co-occurring

⁴ Centers for Disease Control and Prevention (2021, February 16). [Learn the Signs. Act Early.](#) (retrieved on October 28, 2021).



mental health conditions and their families in their respective states and territories throughout the COVID-19 pandemic.⁵

Expansion of the current CMHC pilot project to at least **50 states, territories, and tribal communities** will create a national community of practice similar to the LTSAE Ambassador program, through which best practices and effective strategies can be shared. These champions will improve monitoring, screening, referral, and intervention for developmental disabilities and mental health conditions that can appear in later childhood and adolescence (e.g., ADHD, depression) through training health care providers and educators, disseminating resources to families, and connecting the various systems serving children and youth with developmental disabilities.

3. Expand and enhance existing state-based surveillance systems to capture data on identification of and services for children and youth with developmental disabilities and co-occurring mental health conditions.

The collection of data is critical to informing and addressing inequities in early identification and timely receipt of services for children and youth with developmental disabilities and co-occurring mental health conditions. This proposal would both expand and enhance state-based surveillance programs, such as the [Autism and Developmental Disability Monitoring \(ADDM\) Network](#), to **25 states and territories** for the collection of information on early screening, referral, evaluation, diagnosis, and treatment of children and youth with developmental disabilities ages 0 through 5 years old.⁶ This proposal would also support the development of 10 pilot sites for the collection of information on early screening, referral, evaluation, diagnosis, and treatment of children and youth with developmental disabilities ages 6 through 18 years old.

Recommended legislative action:

Amend Title III of the Public Health Service Act ([42 U.S.C. 247b-4](#)) to include dedicated language authorizing \$40 million per fiscal year for the Learn the Signs. Act Early. program within the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Federal investment in mental and behavioral health programs for children and youth with developmental disabilities is a critical component to achieving health equity for these populations. We are grateful for the opportunity to make recommendations on this topic and stand ready to work with your offices to develop legislation that invests in the mental health of our nation's children and youth with developmental disabilities.

Sincerely,

Association of Maternal & Child Health Programs
Association of University Centers on Disabilities

⁵ Association of University Centers on Disabilities (2020, September 24). [AUCD Launches Children's Mental Health Champions](#) (retrieved on October 29, 2021).

⁶ Centers for Disease Control and Prevention (2020, March 6). [Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#) (retrieved on October 29, 2021).