September 6, 2016

The Honorable Christopher Smith
2373 Rayburn House Office Building
United States House of Representatives
Washington, DC 20510

The Honorable Maxine Waters
2221 Rayburn House Office Building
United States House of Representatives
Washington, DC 20510

Re: Kevin and Avonte’s Law (H.R. 4919)

Dear Representatives Smith and Waters:

The undersigned members of the Consortium for Citizens with Disabilities (CCD) Task Force on Developmental Disabilities, Autism, and Family Support would like to express our support for Kevin and Avonte’s Law. We strongly support this bipartisan legislation that will help reduce the risk of injury and death to children with autism and other developmental disabilities.

CCD is a coalition of over 100 national disability organizations working together to advocate for public policy that ensures the education, self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society.

Children with developmental disabilities should have the appropriate tools and supports to be safe in their communities. We believe this legislation, developed with substantial input from disability stakeholder organizations, strikes a careful balance in helping to ensure personal safety and protecting individual rights.

The program created by Kevin and Avonte’s Law would build on the current Alzheimer’s program of the Department of Justice that awards competitive grants to organizations that assist in locating missing individuals. Grant funds would be used by state and local law enforcement agencies and nonprofit organizations for education, training, and technology to help prevent and reduce the harm from wandering.

There is great need for such a program. A study published earlier this year examined the prevalence and correlates of wandering (or “elopement”) in a nationally representative sample of U.S. children with developmental disabilities, including autism spectrum disorders, intellectual disability, and developmental delay. This cross sectional, nationally representative
survey of the parents and guardians of these children ages 6–17 found the overall rate of elopement within the previous 12 months was 26.7%.

We are very pleased that the legislation includes a process to develop standards and best practices for the use of tracking devices. These evolving technologies have great potential for saving lives also have the potential of being misused and violating individual privacy rights. In recognition of this, Kevin and Avonte’s Law would require the Attorney General, in consultation with leading research, advocacy, self-advocacy, and service organizations to establish standards and best practices relating to the use of tracking technology to monitor children with autism and other disabilities. These groups will work together to develop criteria to determine which individuals might benefit from tracking devices, whether use of the tracking device is the least restrictive alternative prior to issuance, who should have direct access to the tracking system, and procedures for safeguarding the privacy of the data.

Personal safety is an important element for integrated community living. We greatly appreciate your dedication to the personal safety of children with autism and other developmental disabilities.

Sincerely,

American Network of Community Options and Resources
Association of University Centers on Disabilities
Autism Society
Autism Speaks
Lutheran Services in America Disability Network
National Association of State Directors of Special Education
National Down Syndrome Society
The Arc