September 29, 2014

Toby Douglas, Director
California Department of Health Care Services
P.O. Box 997413, MS 0000
Sacramento, CA 95899-7413

Dear Mr. Douglas:

We, the undersigned organizations representing people with intellectual and developmental disabilities, their families, service-providers and researchers, write to provide input on the State of California's upcoming Medicaid State Plan Amendment (SPA) to provide coverage for autism services for individuals under age 21. As you develop the anticipated SPA, there are a number of critical priorities that we believe must be incorporated in order to ensure that the needs of autistic children and young adults are adequately addressed.

Ensure that the SPA covers a range of services.
While the State has already indicated that it intends to cover Applied Behavioral Analysis, we believe that it is essential that the SPA explicitly include coverage for other autism interventions and ensure that no single methodology is given a privileged position relative to others. As the Centers for Medicare and Medicaid Services recently noted in their July 7th, 2014 informational bulletin, "While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD."[1] A 2010 environmental scan on services for people on the autism spectrum provided by CMS supports this assertion, noting that the evidence supports numerous other autism interventions, including communication supports, peer training, joint-attention interaction, and supported employment for young adults.[2] Families should have the opportunity to select the methodology that works best for their children, just as young autistic adults under age 21 should have the opportunity to select the methodology that works best for them.

It is equally important that a variety of interventions be available at all levels of intensity. For individuals who need a high level of support, a plan that covers daily ABA sessions but only weekly sessions of other types of interventions would not offer a meaningful choice. Other methodologies, such as DIR/Floortime or SCERTS, and other related services professionals, such as Occupational Therapists or Speech Language Pathologists, should have parity in the number of hours available for reimbursement for their services as compared to those offered ABA and Board Certified Behavior Analysts.

[1] http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf
[2] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf.

Prohibit reimbursement to providers and methodologies utilizing aversive interventions.

The State of California should explicitly prohibit coverage interventions that are harmful to autistic children and young adults. In particular, the planned SPA should categorically prohibit reimbursement for any intervention or provider that utilizes aversive interventions. Aversives are defined as the use of pain or unpleasant stimuli as a means of modifying behavior, and may include contingent electric shock, ammonia spray, deprivation of food, seclusion, or mechanical restraints. These interventions pose a significant health risk to children and adults on the autism spectrum, are widely rejected by the professional and disability communities, and are never medically necessary. Incorporating this prohibition is particularly important given evidence indicating that ABA practitioners are more willing than other service-providers to utilize aversive interventions.[3]

Ensure compliance with the integration mandate in *Olmstead v. L.C.*

The SPA must ensure that autism interventions are provided in integrated settings such as the home, school, or other locations in the community. Providing services in these types of natural settings is not only considered best practice, but also required under the integration mandate of the Americans with Disabilities Act.

As the Supreme Court held in *Olmstead v. L.C.*,[4] the Americans with Disabilities Act (ADA) prohibits unnecessary segregation of individuals with disabilities in public services and programs. These public services include non-residential services funded through state Medicaid programs. When individuals with disabilities are required to spend a large number of hours per week in disability-specific, clinic-based settings in order to receive services that could instead be provided in the home, school, or community, their rights to integration into the community are compromised.[5]

We would welcome the opportunity to communicate with you further on this matter. Please don't hesitate to refer questions to Samantha Crane, Director of Public Policy for the Autistic Self Advocacy Network, at scrane@autisticadvocacy.org or via telephone at (202) 509-0135.

Sincerely,
The Autistic Self Advocacy Network
The Arc of California
Autism Society of Los Angeles

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[3] Brown, F., Michaels, C., Oliva, C. & Woolf, S. Personal Paradigm Shifts Among ABA and PBS Experts: Comparisons in Treatment Acceptability. Journal of Positive Behavior Interventions; Oct 2008; 10, 4. pgs 212-227.

[4] 527 U.S. 581 (1999).

[5] *Cf.* U.S. Department of Justice Letter of Findings regarding its Title II ADA Investigation of Employment, Vocational, and Day Services for Persons with Intellectual and Developmental Disabilities in Rhode Island (Jan. 6, 2014), available at http://www.ada.gov/olmstead/olmstead_cases_list2.htm.

California Academy of Family Physicians
California Foundation for Independent Living Centers
Disability Rights California
Disability Rights Education and Defense Fund
Interdisciplinary Council on Developmental and Learning Disorders, Inc.

Cc: Secretary Diana Dooley
Santi J. Rogers
Senator Darrell Steinberg