

Autism Spectrum Disorder Advisory Council

Legislative Committee

MEETING MINUTES

Meeting Date	Meeting Time	Meeting Location
10/06/2025	2:00 pm – 3:00 pm	Zoom

Member Name and Attendance

ASD Advisory Body Members					
Jimnahs Miller, Chair	X	Meghan Gallagher, Member	R	Patrick Heick, Member	R
Yana Razumnaya, Chair	X	Carole Ryan-Hanlon, Member	R	Marcia Eckerd, Member	X
Melissa Hoon, Member	X	Sarah Schlegel, Member	R	Christine Faressa, Member	X
Kimberly Mearmen, Member	R	Julie Wolf, Member	X	Melissa Paul Perez, Member	X
Kari Sassu, Member	X	Lynne Altschuler, Member	R	Lois Rosenwald, Member	X
ASD Supporting Agencies & Other Participants					
Kathy Marchione, ADS BRS	X	Ann Gionet, DPH	X	Zani Imetovski, OPM	X
Bryan Klimkiewicz, CSDE	X	Tobey Partch-Davies, DRCT	R	Tara Viens, OPM	R
Dorothy Papa-Santini, CSDE	X	Christine Weston, DSS	X	Susan Stange, DSS	X
Stephanie Bozak, DCF	R	MaryBeth Miller, OEC	X	Jennifer Krom, Carelon	X
Krista Ostaszewski, DDS	X	Kolleen Kerski, OEC	X		
Jennifer Abbatemarco, DMHAS	X	Judy Dowd, OPM	X		
Attendance Key: R = attended remotely, I = attended in-person, X = absent					

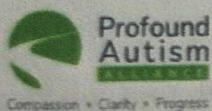
	Agenda	Responsible Person(s)
1.	Welcome & Introductions	Kimberly Mearmen, Chair
	Call to Order	
2.	Presentation on Legislative Priorities	Adrienne Benjamin & Rick Rothstein
	<p>Profound Autism Alliance The alliance worked with legislators to introduce HB 7108 with 2 goals, (1) to get data on number of people with ASD in DDS services, and (2) abuse and neglect reform.</p> <p>They are looking for independent investigators to be part of the abuse and neglect process, they meet once a month on Tuesday evenings at 7:30 pm.</p> <p>Additional information provided is attached below.</p>	
3.	Review & Approve Meeting Minutes	Kimberly Mearmen
	<p>August & September Motion by Patrick 2nd by Sarah</p>	
4.	New Business & Discussion	Kimberly Mearmen
	<p>No new policy proposals were submitted this month</p> <p>Priority 1: Insurance Mandate to Eliminate Age for ABA</p>	

	<p>A letter was sent to Human Service Committee Chairs and no word yet, the group would like to send the letter to the children's committee and all committee members.</p> <p>Priority 2: Autism Waiver Reform Waiver utilization is not only due to lack of staffing Some waiver participants are using minimum and don't feel they need additional services but do not want to "give up" access to the waiver Providers believe service utilization is related to a person's level of need so those who have a lower IQ and higher need are at the top of their budget and those with a higher IQ who are more self-sufficient are using the minimum Needs assessment will help identify what services are lacking and why there are unmet needs, it was brought up to consider exercise as part of life skills and DSS is looking at if this can be considered Additional conversation is needed with DSS</p>	
5.	Adjourn	Kim Mearmen
	Meeting ended at 3:05pm	

DEVELOPING GLOBAL CONSENSUS ON A RESEARCH DEFINITION FOR PROFOUND AUTISM

Utilizing the Delphi Method

- 01 Meets the diagnostic criteria for **Autism Spectrum Disorder**.
- 02 Is at least **8 years old**, acknowledging that some characteristics consistent with profound autism are evident earlier.
- 03 **Requires adult supervision, exceeding age-appropriate levels**, to ensure physical and mental health, safety, and well-being (due to risks such as elopement, injury, or lack of environmental awareness).
- 04 Demonstrates **adaptive functioning skills significantly below age level**, with an inability to independently perform most activities of daily living (e.g. bathing, food preparation, dressing)
- 05 **Severely impaired cognitive abilities**, reflected by IQ under 50 and/or does not verbally communicate other than single words or fixed phrases, and communicates predominantly only to have their basic needs met.
- 06 These characteristics are **neither intermittent nor transient** and persist across different environmental settings and situations



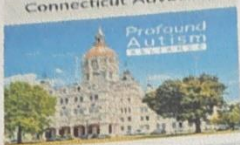
PANEL



203.001 - Developing a Consensus-Based Global Research Definition of Profound Autism

C. Lord¹, H. Tager-Flusberg², M. Siegel³, A. Halladay⁴, J. Ursitti⁵ and A. T. Singer⁴

(1)UCLA Semel Institute for Neuroscience and Human Behavior, Los Angeles, CA, (2)Psychological and Brain Sciences, Boston University, Boston, MA, (3)Boston Childrens Hospital, Boston, MA, (4)Autism Science Foundation, New York, NY, (5)Profound Autism Alliance, Boston, MA



email: ctprofoundautismalliance@gmail.com

Facts About Profound Autism

What is profound autism?

Simply stated, people with profound autism are those that require lifetime, 24/7 care.

According to a 2023 study by the Centers for Disease Control, children with profound autism were more likely to be:

- female;
- from racial and ethnic minority groups;
- of low socioeconomic status;
- born preterm or with low birth weight;
- have self-injurious behaviors;
- have seizure disorders;
- and have lower adaptive scores.

According to the CDC:

26%

The percentage of 8-year-old children with profound autism among those with autism is 26.7%.

6%

According to a 2019 study, only 6% of clinical research studies included people with profound autism as participants.

Their exclusion has become the norm.

Most home and community-based services exclude people with profound autism because of their intense support needs. Caregivers are left with nowhere to turn.

People with profound autism consistently experience unique, devastating, and often unseen challenges that require solutions, not only for them but for their caregivers.

Learn more at www.profoundautism.org/research/profound-autism-facts/

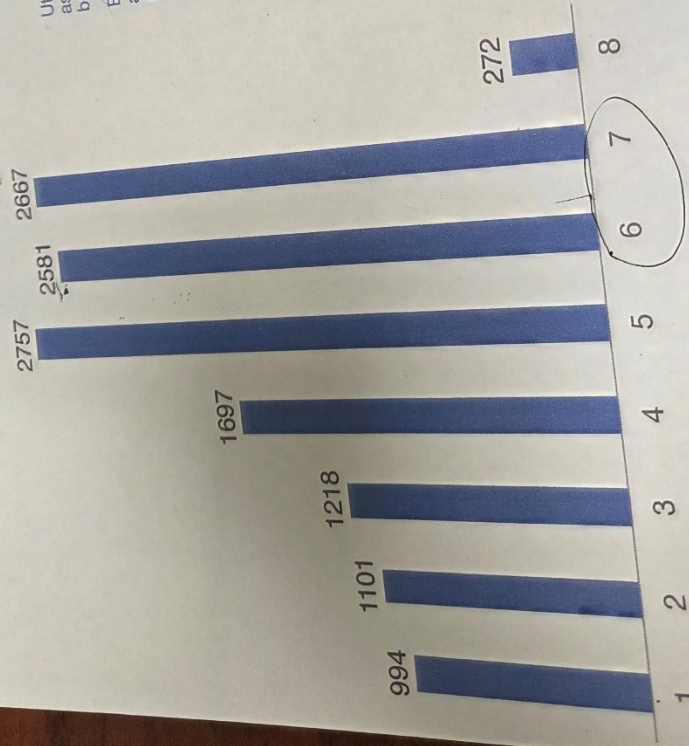
LON Data as of December 17th 2024

17th 2024

Utilizing a scoring algorithm, the individuals' completed LON assessment is then given an overall score ranging from 0 to 8 (8 being the highest level of need).

Both the LON score and the information collected in the assessment is used to develop a comprehensive Individual Plan (IP) that identifies areas of assistance to meet personal goals and address any potential health and safety risks. The IP determines what services and funding are needed.

- Per the June 2024 MIR, DDS supports 17481 people.
- A total of 13287 individuals have a recent LON.
- Commonly, DDS categorizes LON scores into Low, Medium, and High.
- A total of 3313 supported individuals fall between a score 1 to 3 (Low).
- Within the medium category, 7035 individuals have a score between 4 to 6.
- Additionally, 2939 individuals have a score between 7 and 8 (High).



LON Data



By His Excellency Ned Lamont, Governor: an

Official Statement

WHEREAS, the definition of autism has evolved over the years, creating an increasingly heterogeneous spectrum; and

WHEREAS, while the entire autism spectrum deserves recognition and support, the term "profound autism" is intended to clarify the needs of autistic individuals who require 24/7 care from an adult caregiver throughout their lives; and

WHEREAS, individuals with profound autism may also have a severe intellectual disability or possess minimal or no language, and are often excluded from research and support programs due to their unique needs; and

WHEREAS, the Centers for Disease Control and Prevention (CDC) released their first prevalence study on profound autism in April 2023, which revealed that 26.7% of 8-year-old children with autism in the United States have profound autism, meaning that 1 in 4 children with autism fall into this category; and

WHEREAS, compared to children with non-profound autism, children with profound autism are more likely to be female, from racial and ethnic minority groups, of low socioeconomic status, born preterm or with low birth weight, experience self-injurious behaviors, have seizure disorders, and have lower adaptive scores; and

WHEREAS, individuals with profound autism and those who care for them often live in isolation and require inclusion, recognition, and support within their communities; and

WHEREAS, it is crucial to give specific consideration to the unique challenges faced by individuals with profound autism and their caregivers to ensure they receive the care, attention, and inclusion they deserve; now

THEREFORE, I, Ned Lamont, Governor of the State of Connecticut, do hereby officially proclaim March 17, 2025 as

PROFOUND AUTISM DAY

in the State of Connecticut.



Ned Lamont

GOVERNOR