

OASIS · AT A GLANCE

Profound autism: one in four, and a different policy problem

The Lancet Commission drew a line: eight or older, needing 24-hour access to an adult caregiver, with an IQ under 50 or minimal spoken language. The CDC found 26.7% of autistic children on the far side of it.

PILLAR: WHY | COMPANION TO BLOG POST B159 | 2-PAGE BRIEF

26.7%

MEET THE DEFINITION

Of autistic children, across CDC data from 15 sites, 2000 to 2016.

How the term came to exist

DEFINE, COUNT, IGNORE

STAGE 1

A definition was proposed

The Lancet Commission on the future of care and clinical research in autism proposed the term profound autism in 2021, with three specific criteria.

STAGE 2

The CDC measured it

Applying the criteria to surveillance data from 15 sites across 2000 to 2016, 26.7% of autistic children met the definition.

STAGE 3

Policy did not follow

Adult service policy is still written around a population that can work, self-advocate, and direct their own supports. That does not describe this quarter.

The three criteria, and what policy assumes

LANCET COMMISSION, 2021

The definition against the policy frameworks

Employment First is built for people who can work. Self-advocacy for people who can self-advocate. Supported decision-making for people who can indicate a preference. All three are good policy. None describes this column.

ELEMENT	THE DEFINITION SAYS	POLICY ASSUMES
Age	At least 8 years old	Trajectory still open, wait and see
Supervision	24-hour access to an adult caregiver	Independent living with periodic support
Cognition	IQ below 50, or non-speaking or minimally verbal	Can weigh options and state a preference
Share affected	26.7% of autistic children	Framework built for the other three quarters
Adults counted	None nationally	That a population this size is visible
Data currency	Ends in 2016	That the number is being updated

50

The IQ threshold

Or non-speaking or minimally verbal. Either satisfies the third criterion, not both.

2016

Where the data stops

The most recent CDC prevalence report did not include updated profound autism figures.

2021

When the term was proposed

By the Lancet Commission on the future of care and clinical research in autism.

THE WORD THAT ENDED THE ARGUMENT

“
For eleven years Wendy described her daughter as high needs and watched the phrase land as an opinion. At a review she said instead that her daughter requires 24-hour access to an adult caregiver and is minimally verbal with a measured IQ below 50. The reviewer stopped writing and asked whether she had documentation.
”

SAY THE CRITERIA. NOT THE FEELING.

THE TAKEAWAY

There is no national count of adults with profound autism. A population that is not counted cannot appear in a budget projection or a performance measure. The counting problem is upstream of the policy failure.

TURN THE PAGE

Where the criteria language belongs in your paperwork, and what to ask for when you advocate.

Making the definition work in paperwork

CRITERIA, NOT ADJECTIVES

DOCUMENT

Get the criteria into the record

☐ Ask whether the clinical record uses these criteria

☐ Get the 24-hour supervision need stated explicitly

☐ Get the IQ or communication finding documented

☐ Ask the treating clinician to add it if missing

☐ Request two signed originals on letterhead

PLACE

Where the language belongs

☐ The physician functional limitations letter

☐ The Individual Plan of Service narrative

☐ The Medicaid work requirement exemption record

☐ Appeal filings and fair hearing testimony

☐ Hospital admission and emergency documents

PHRASE

Say it this way

☐ "Requires 24-hour access to an adult caregiver"

☐ "Non-speaking" or "minimally verbal", as applicable

☐ "Measured cognitive ability below an IQ of 50"

☐ Not "very high needs", which reads as an opinion

☐ Functional statements are what reviewers can act on

ASK

What to demand publicly

☐ That CDC resume collecting profound autism prevalence

☐ That your state say how many adults meet the criteria

☐ That NIH follow the FY 2026 congressional directive

☐ That research include the entire autism population

☐ Get the "we do not know" on the record

BRING ONE PAGE, NOT A BINDER

The criteria sheet

01

Age

Confirming the person is at least 8 years old.

02

Supervision

Requires 24-hour access to an adult caregiver.

03

Cognition

IQ below 50, or non-speaking or minimally verbal.

04

Evidence

Who assessed it, when, and where it is documented.

YOUR MOVE

When high needs is being read as an opinion

1

Learn the criteria

All three, in the published wording.

2

Get them documented

By the treating clinician, in writing.

3

Use them everywhere

Plan, letter, appeal, exemption file.

4

Drop the adjectives

Functional statements, not intensity words.

5

Demand the count

Ask CDC and your state for the number.

You are not relabeling your adult child. You are using words a clinician, a reviewer, and a federal agency have all already agreed mean something specific.

SOURCES

Hughes MM, Shaw KA, DiRienzo M, et al. The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016. *Public Health Reports*. 2023;138(6):971-980.

Lord C, et al. The Lancet Commission on the future of care and clinical research in autism. *The Lancet*. 2021. Profound autism criteria.

Autism Science Foundation. Profound Autism: definition and prevalence summary.

Profound Autism Alliance. Federal advocacy, including the FY 2026 congressional directive to NIH on including the entire autism population.

National Council on Severe Autism. Analysis of the profound autism designation and adult service needs.

ABOUT THE AUTHOR

JP

Jim Palasty

Jim Palasty is the founder of OASIS for Autism and a single father of an adult autistic daughter in Michigan.