



Together we can end
**SYSTEMIC POLICY
DISCRIMINATION
AGAINST THOSE WITH
SEVERE AND
PROFOUND AUTISM**



What Is Severe / Profound Autism?

- **Autism Spectrum Disorder (ASD)** encompasses a broad array of social, communication and behavioral impairments, from mild to extremely severe. ASD is rooted in abnormal brain development and connectivity. About about 14% of cases are caused by known genetic defects; but in about 80% of cases causes are unknown.
- **Severe autism** denotes the subpopulation with significant social / communication impairment, intellectual disability (ID), and who are dependent on supports for most areas of daily living, including self-care, advocacy, and engaging in community life.
- Often, children and adults with **severe autism** exhibit **challenging behaviors** such as aggression, self-injury, property destruction, pica (ingesting inedible objects), disruptive vocalizing, and elopement. Seizure disorders, sleep disorders and medical problems such as GI distress are common, and debilitating.
- The similar but more restrictive term "**profound autism**" applies to older children and adults with minimal language, IQ < 50, and who cannot take care of daily needs. They require 24-hour access to an adult who can care for them.

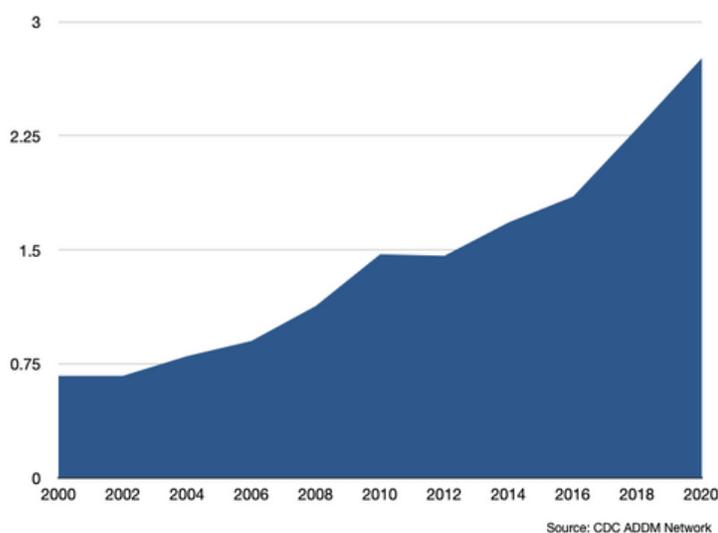
An acute crisis

Nationwide lack of:

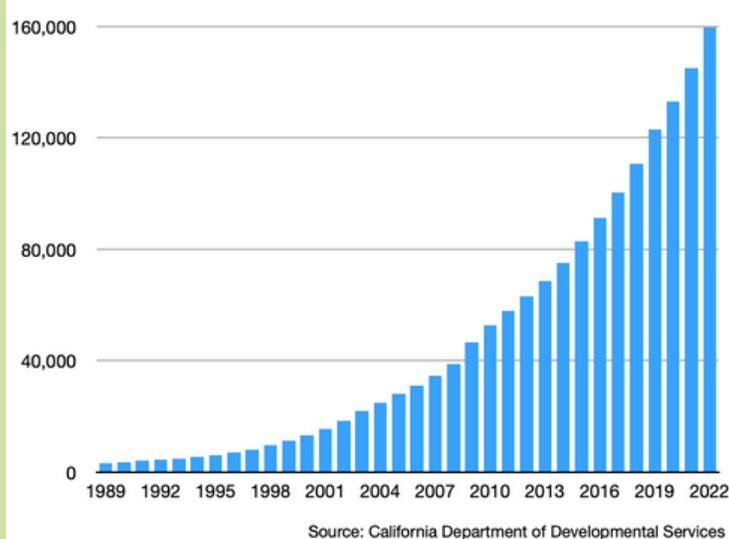
- (1) Inpatient and outpatient care
- (2) Housing options
- (3) Care workers, training, and case management
- (4) Day programs and community options
- (5) Research relevant to their needs

The Population Is Growing: Autism's Surge

Autism Prevalence, 8 Year-Old Children, CDC Surveillance Years 2000-2020



California DDS: Consumers with Autism, 1989-2022



According to a 2023 CDC report autism now impacts **2.76% of 8 year-old children**, including 4.3% of boys and 1.1% of girls. This is a 4-fold increase over just 2 decades. **61.4% of these cases suffer from ID or borderline ID.**

Severe cases increasing: California Department of Developmental Services autism cases (a high degree of mental/functional impairment) have skyrocketed, from about 3,800 in 1989 to **160,000 cases** in 2023.

Systemic Discrimination Against Severe Autism

In recent years, policy has taken a sharp turn away from the needs of children and adults disabled by severe forms of autism, and in favor of solutions appropriate for those with milder disabilities who can self-advocate or live independently. **This is imperiling the welfare and lives of our rapidly growing, vulnerable and voiceless population.**



COMMUNITY CARE

- **Medicaid waitlists** — Many families cannot access desperately needed waivers or care for even the most severely disabled people in our nation.
- **HCBS rejection** — Home and Community Based Services (HCBS) providers routinely reject clients who exhibit challenging behaviors.
- **Careworker crisis** — Direct Support Providers are scarce, a shortage particularly acute for the severe population which can entail difficult and dangerous work.
- **Parent penalty** — In some states, family members are not eligible to serve as HCBS providers even when there are no other options, and in the most extreme of cases.



HOUSING

- **Few rental subsidies** — Deinstitutionalization occurred without provision for adequate housing placements in communities. Except for the wealthy, without HUD or other vouchers this population has little access to community-based housing.
- **HCBS Settings Rule** — This regulation makes it more difficult to provide residential options for those with extreme support needs, while ignoring key quality metrics.
- **Site discrimination** — Some rules prohibit clustering of I/DD housing, a discriminatory practice that reduces needed options.
- **ICFs** — Licensed safety-net facilities, known as intermediate care facilities, meeting the needs of many severely challenged adults, are being shuttered.



EMPLOYMENT AND DAY PROGRAMS

- "**Competitive, integrated employment**" is unrealistic for this population yet non-competitive employment programs are being closed down.
- **Few day programs** accept adults with challenging behaviors. Adults with severe autism are often isolated at home with little access to the community.



TREATMENT ACCESS

- **Community medical care poorly equipped.** ERs are unequipped, we suffer a shortage of psychiatrists and trained medical professionals and crisis care.
- **Medical discrimination.** Many practitioners will not treat adults with severe autism.



GUARDIANSHIP

- **Guardianship/conservatorship is an essential legal protection** for adults disabled by severe autism who lack mental competence to manage their own affairs, yet this essential legal tool is under attack at the state and federal levels.



RESEARCH

- **Under-represented in research.** Research on treatment, causes, and prevention is desperately needed.
- The **CARES Act** has failed to move the needle; the **IACC** focuses on mild autism.

Equity for Severe Autism Means:

Medicaid HCBS rules that **fully embrace settings** with amenities needed by adults with severe autism.

An adequate safety net of Medicaid-funded **ICFs** for those who require a high level of care.

A federal rule ending the **HCBS Parent Penalty**.

Prioritizing **HUD housing vouchers and subsidies** for adults with severe autism where an "institutional level of care" is required.

Rules requiring provision of **HCBS services** for those with severe autism, not just those with milder developmental disabilities.

Fixing the **direct support provider** crisis through wage adjustments, training, and immigration reform.

Allowing for **non-competitive employment** options for those incapable of competitive employment.

A robust **guardianship** system that ensures adults disabled by severe autism have needed legal protections and to advance their welfare.

A **federal research program** calculated to advance treatments, improve quality of life, and identify autism risk factors.

"Those unable to speak for themselves have been overlooked and marginalized in policymaking. It's time to end systemic discrimination against severe autism."

—Jill Escher, President, NCSA

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