

*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.

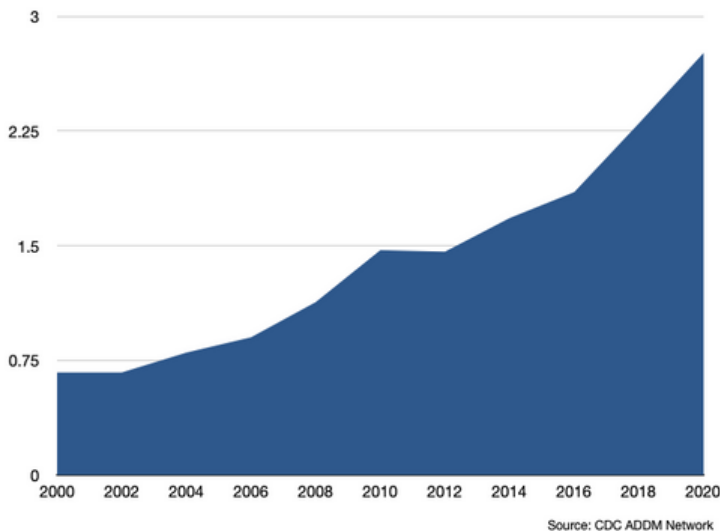
## An acute crisis

### Nationwide lack of:

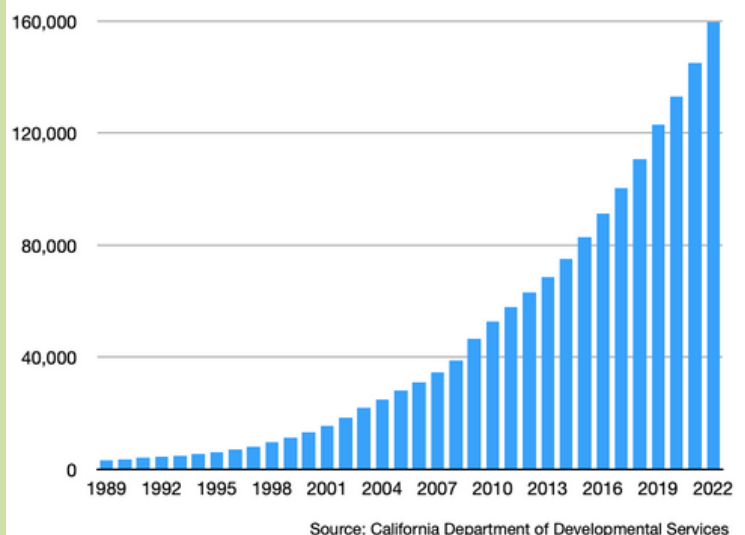
- (1) Inpatient and outpatient care
- (2) Housing options
- (3) Care workers, training, and case management
- (4) Day programs and community options
- (5) Research relevant to their needs

## 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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