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# Policy Backgrounder

**Autism is an urgent national crisis.  
We seek policy and practice based on reality,  
not fantasy.**

NCSA National Grassroots Network  
Revision: January 2023



# BACKGROUND

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## Severe and Profound Autism

National Council on Severe Autism (NCSA) advocates for the burgeoning population of Americans who are significantly disabled by Autism Spectrum Disorders (autism or ASD).

The NCSA recently created its National Grassroots Network (NGN) to promote its goal to further policies and practices that address real-life needs and challenges faced by individuals and families affected by more severe forms of autism, both at the federal level and in all 50 states.

We advocate for actions that are effective, efficient, and fair, and rooted in reality, not fantasy. Over the past decade we have witnessed the ascent of a feel-good narrative about autism — that autism is a “strength,” a mere “difference” or “neurodiversity.” But for the majority with ASD, the disorder is can be debilitating and even ruinous, as it can compromise higher-order cognitive processes, including language, social comprehension, abstract thought and learning. In addition to the impaired ability to engage in activities of daily living, many in this population have challenging behaviors, including aggression, self-injury, property destruction, and elopement, as well as medical conditions such as seizures. Due to pervasive functional limitations, these individuals are unable to live independently, and are incapable of earning a living. They typically require 24/7 support, for their lifetimes.

Recently an expert panel recommended the term “profound autism” to encompass those with ASD who require access to 24/7 care and supervision, and who have an inability to manage basic activities of daily living (Lord et al. Lancet Commission on the future of care and clinical research in autism, 2022). In this document we use the terms severe autism and profound autism interchangeably.

Our autism is not a benign “neurodivergence.” Extensive research underscores that autism is typically rooted in foundational abnormalities of very early brain development, resulting in impaired neuronal placement, structure, function, and connectivity. Though autism may be invisible from an external perspective, the disorder is rooted in very real dysregulation of essential neurodevelopmental processes very early in life, beginning in the womb.

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## Explosion in Cases

The U.S. population of children disabled by severe autism has increased dramatically over the past three decades. Data from several sources indicate that the U.S. autism population affected by forms of autism reaching the level of developmental disorder has ballooned more than 3,000% over the past 30 years. Despite much conjecture, there is no evidence that this explosion is attributable to “awareness” or “diagnostic shifts,” as is often suggested in the media. In one system based on objective and strict entry criteria, California's Department of Developmental Services, the autism caseload skyrocketed 50-fold over the past 35 years, from about 3,000 cases to about 158,000 today. The vast majority of this population is under age 30, with ever-larger cohorts aging into a stressed and overburdened adult care system each year. The CDC has found a rate of approximately 2.3% of U.S. 8 year-olds have autism. Studies from major metropolitan areas of New Jersey have seen upwards of 5% among 8 year-olds. Though once a rare disorder seldom seen in clinics or even in institutions, **autism now touches nearly every family in America today** — whether a son or daughter, a nephew or niece, grandchild or neighbor or friend.

Most recent autism data from the CDC, among 8-year-old children with ASD:

- 35.2% also had intellectual disability (IQ  $\leq$  70)
- 23.1% were classified in the borderline range (IQ = 71–85)
- 41.7% were classified in the average or higher range (IQ > 85)

*Therefore nearly 60% (58.3%) of U.S. children with autism have significant or borderline intellectual disability. (Maenner et al 2021)*

Despite substantial investments in research, the factors driving these dramatic increases remain largely unknown. Autism is strongly heritable, as judged by high recurrence among siblings. But genetic mutations in autism are generally *not* inherited from parents. Instead they are usually *de novo*, or DNA defects newly occurring in the affected child. Further, classic genetics can only explain about 10-20% of cases. Environmental factors such as preterm birth and maternal infection can influence risk, but again they cannot explain the dramatic surge in cases. Research is increasingly looking at factors that may be disrupting the way genes function, sometimes called epigenetics of transcriptional dysregulation. But generally speaking, autism largely remains as much a mystery today as 25 years ago, when research began in earnest in response to the unexplained uptick in cases perceived nationally.

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## Urgent Need for Realistic Policies to Meet the Needs — Today and Tomorrow

Given the ongoing increase in autism cases, particularly cases involving intellectual disability, it is urgent that policies, research and practice develop robust solutions for prevention, treatment and lifespan services. Most urgent is the need to create a roadmap — in all states — for the proper care and supervision of adults with profound autism after their parents lose capacity and pass away. However, this document sets forth priorities in multiple areas, based on input received from throughout a broad community of families, practitioners and experts.

This is not a strategic plan, but merely a collection of issues within the purview of NCSA’s endeavors.

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## WHAT IS THE NGN?

The NCSA National Grassroots Network, or NGN, is the “engine” behind our advocacy efforts. It is led by a Policy Committee of the NCSA board of directors, and the hundreds of network members are volunteers from across the country. A contractor assists the board with the coordination of the NGN.

We intend that the NGN will include members from all congressional districts to ensure the ability to connect with all federal elected officials, and over time the NGN will cultivate state leaders to coordinate state-based advocacy efforts.

The principles behind NGN efforts include but are not limited to:

- **Pragmatism:** Need for policies based on autism realities and common sense, and not fantasies
- **Equity:** Severe autism is an under-served community; we see a fundamental need to radically expand capacity to serve those with the greatest challenges
- **Efficiency:** Childhood and lifespan programs should feature highly efficient use of public funds
- **Person-centered:** Services must be driven by individual needs, not abstract ideology

The NGN will partner with other autism and disability advocacy groups to hone its policy activities and expand its reach.

# AREAS OF CONCERN FOR POLICY AND PRACTICE

For individuals and families affected by severe forms of autism, there are countless needs and priorities. Many of these are listed below, generally, without reference to particular bills that are pending or potential new efforts to develop legislation or policy. This is a broad reflection of important issues for our community, collected from board members, Policy Committee members, clinicians, researchers, parents, family members and people with autism, and it does not attempt to identify priorities for the NGN.

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## Federal Level

### **CENTERS FOR MEDICARE AND MEDICAID SERVICES (CMS)**

- Home and Community Based Services (HCBS) adequacy and availability
- HCBS - family caregiver eligibility — elimination of anti-family, anti-parent bias; more empowerment of parents and family members
- HCBS Settings Rule: ensuring true person-centered planning; reduce restrictive regulations
- Intermediate Care Facility (ICF) adequacy and availability
- Funding: Direct Support Professional (DSP) crisis
- Roadmap — in all states — for the proper care and supervision of adults with profound autism after their parents lose capacity and pass away

### **HOUSING AND URBAN DEVELOPMENT (HUD)**

- Expand access to HUD housing subsidies, eg, Section 8 portable vouchers
- Eliminate discriminatory limits on occupants with developmental disabilities

### **DEPARTMENT OF LABOR**

- Allow non-competitive employment for adults incapable of achieving competitive, integrated employment

### **IMMIGRATION**

- Enhance legal immigration of individuals who can serve in the DSP workforce

### **NATIONAL INSTITUTES OF HEALTH**

- Ensure that Autism CARES Act (Autism Collaboration, Accountability, Research, Education and Support Act), the primary source of federal funding for autism research, services, training, and monitoring addresses meaningful priorities calculated to improve lives, and decrease prevalence of autism
- Obtain full representation of individuals and families affected by severe autism in the IACC (Interagency Coordinating Committee)

- Ensure IACC Strategic Plan addresses our community's priorities

#### **DEPARTMENT OF EDUCATION**

- Implementation of IDEA - special education teacher crisis

#### **CENTERS FOR DISEASE CONTROL**

- Autism and Developmental Disabilities Monitoring Network: more fine-grained data on levels of functioning in individuals with autism; research on autism prevalence by birth year, including in adults
- Predictive modeling to inform policies for long-term care
- Research in humans that can help inform understanding of causation and prevention

#### **MILITARY**

- Improve Tricare access to services for military autism families
- Improve research on autism undertaken by the military

#### **SOCIAL SECURITY**

- SSI and SSDI increases to reflect actual costs of daily living expenses

#### **ADMINISTRATION ON COMMUNITY LIVING**

- Greater caregiver support
- Greater emphasis on the needs of those with severe impairment, not just the self advocates preferred by ACL

#### **ABLE ACT**

- Possible increases on limits of contributions and total amount

#### **FEDERALLY FUNDED DD ADVOCACY**

- Concerns that their work is often in opposition to the needs of those with severe autism, eg, State Councils on Developmental Disabilities

#### **FEDERAL ADVISORY COMMITTEES**

- Monitor committees such as President's Council on Persons with Intellectual Disability, National Council on Disability

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## **State and Local Level**

#### **PRIVATE INSURANCE COVERAGE AND PUBLIC INSURANCE (STATE MEDICAID PROGRAMS)**

- Medicaid state plans that provide a roadmap for long-term care of adults with profound autism after parents lose capacity and pass away
- Early intervention (ABA and related) and multidisciplinary approaches
- Behavioral interventions for children, teens and adults - Mental Health Parity
- Access to crisis care; step-down programs from ERs and acute care programs

- Access to inpatient programs for those with severe challenging behaviors, eg, aggression, self-injury, property destruction, elopement and pica

#### **WAITLIST CRISIS**

- Major issue: Reduce waitlists for waiver services funded by state Medicaid programs
- Major issue: direct support provider (DSP) crisis - rates, career path, burnout. Even when waivers are available, dearth of DSPs means individuals with severe autism often cannot find needed support

#### **HOUSING**

- Advocacy for state-and local-based DD housing projects and funding
- Retention of ICFs as part of the full continuum of care
- Maximize access to HCBS, with full continuum of care
- Fight discrimination against programs and families

#### **GUARDIANSHIP**

- Strengthen guardianship laws to ensure the highest degree of legal protections for adults disabled by autism or developmental disabilities and who lack cognitive capacity to make decisions about important matters.
- Monitor efforts regarding Supported Decisionmaking to ensure they do not undermine the needs of those who are incapable of managing their own affairs

#### **POLICE, SAFETY AND EMERGENCY PREPAREDNESS**

- Training for first responders
- Elopement and drowning prevention
- Prevention of neglect and abuse

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## Science, Research and Clinical Practice

#### **RESEARCH ON CAUSATION AND PREVENTION**

- Support research to identify risk factors for autism, particularly at the gene-environment interface
- Support research to reduce risks on a family and population level

#### **RESEARCH ON DIAGNOSTICS AND SUBTYPES**

- DSM-5 reform to create diagnostic categories that meaningfully reflect widely diverse clinical realities
- Improved assessments for children and adults with autism
- Improved access to genetic testing
- Biomarkers research to better inform diagnosis and treatment

#### **RESEARCH ON TREATMENT**

- Lack of generalizability of research that focuses on broad “ASD”; research must specifically identify the subpopulation under study rather than calling it “ASD”
- Exclusion of severe autism from clinical treatment
- More research on psychopharmacology and off-label medications
- Improved diagnosis of underlying medical problems
- For alternative treatments, we need a stronger evidence base, including cannabis
- Non-medical treatment, eg, behavioral and sensory, also requires a stronger base of evidence: who benefits, who doesn’t?

### **TREATMENT ACCESS**

- Expand access to telehealth evaluations, when appropriate
- Need for more meeting and networking of clinicians in this field
- Reduce disparities, ensure access to treatment for all, regardless of racial, ethnic or socio-economic background
- Recognition of comorbid mental health conditions, eg, not everything is due to “autism”
- Expand access to ECT for cases resistant to other interventions
- Adequate reimbursement rates - need for legislation similar to XSB 855 in California, which requires health plans to be trained on and use generally accepted standards of care specific to ASD developed by nonprofits in the field
- There are a small number of clinical programs with facilities and expertise necessary to serve the severe autism population; a specific designation for clinicians with expertise serving individuals with severe autism would help raise visibility

### **RESEARCH ON PREVALENCE AND PROJECTING FUTURE NEEDS**

- What is the true prevalence by birth year, in all states or at least a selection of states
- Need for more fine-grained qualitative data about levels of functioning and challenging behaviors
- Important to project future needs based on current birth-year prevalence

### **IMPROVEMENT IN CLINICAL CARE IN THE COMMUNITY**

- Development of standards of care for severe autism
- Need to expand number of psychiatric care providers
- Expand curricula aimed at training students about severe forms of autism
- Reduce fraudulent practices, eg, non-validated communication, non evidence-based treatments

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## Other

- **Autism Awareness Month:** Promote Authentic Autism Awareness during April
- **INSAR:** Promote visibility of severe/profound autism at the International Society for Autism Research
- **Language and representation:** Combat language policing and attacks on realistic portrayals of autism; support realistic portrayals of severe autism



- **September 26th Project:** Promote emergency preparedness for autism and special needs families
- **Tech:** Improve development of, and access to, new technologies that can help with recreation, anxiety, behaviors, self-care, safety, surveillance, etc.
- **Parent advocacy:** Promote legitimacy of advocacy for those who cannot speak for themselves

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## CLOSING WORDS

As the saying goes, we are facing a marathon and not a sprint. As the years pass the extreme nature and phenomenal extent of the nation's autism crisis will become increasingly evident. At present, our nation is somewhat cushioned against the crisis by the vast army of parent and family caregivers — a situation that offers a temporary band-aid on a mounting problem. While ambitious goals may be difficult to achieve in the long term, some policies may be more realistically achievable in coming years and decades. Honing in on the best goals to attack, year after year, will be a major aspect of the NGN's endeavors.

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