



We pursue recognition, policy and solutions for the surging population of individuals, families and caregivers affected by severe forms of autism and related disorders.

- **Autism Spectrum Disorder** (ASD) encompasses a broad array of social, communication and behavioral impairments, from mild to extremely profound. ASD is rooted in abnormal brain development and connectivity. Rates have increased dramatically since the 1980s.
- **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.
- **In recent years, policy has detoured 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.**

It's time to end the *systemic discrimination against severe autism*. Needed reforms include:

- **End Medicaid's Severe Autism Penalty: Require HCBS services for those with severe autism**, not just those with milder disabilities who can access generic options. Enact Medicaid Home and Community Based Services (HCBS) Settings rules that **fully embrace settings** with amenities needed by adults with severe autism.
- Ensure an adequate safety net of Medicaid-funded **Intermediate Care Facilities** for those who require a high level of care.
- End the HCBS **Parent Penalty** and authorize family members to serve as HCBS providers.
- Prioritize **HUD vouchers** and subsidies for adults with severe autism where an "institutional level of care" is required.
- Fix the **direct support provider** crisis through wages, training, and immigration reform.
- Allow for **non-competitive employment** for those incapable of competitive employment.
- Ensure a **robust guardianship system** that provides adults disabled by severe autism, and who cannot manage their own affairs, with necessary legal protections.
- Enact a **federal research program** calculated to advance treatments, improve quality of life, and identify risk factors for severe and profound autism.