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 though 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.

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