THE BEGINNING OF CHANGE: A LONG OVERDUE SHIFT IN POLICY FOR PROFOUND AUTISM

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INTRODUCTION

Since 2013, clinicians have diagnosed individuals across a wide range of abilities with the same condition: autism.[1] This broad label has been a point of contention within the autism community, and in turn, affects how services and research are allocated.[2]

Not that long ago, Charlie Lamb needed surgery to remove a screw from his colon.[3] Charlie is profoundly autistic and suffers from Pica, the urge to eat inedible items.[4] Charlie does not have the capacity to perceive danger, and his struggles are life-threatening.[5] Because Charlie requires around the clock care, his mom measures progress in milestones like his learning to brush his teeth and dress himself.[6] She applied for respite care nine years ago and is still waiting, because insufficient funding has left Charlie without the support he needs.[7] Families like Charlie's deserve better, and increased funding is crucial to provide the care and relief they need.

Doctors diagnosed Amy Gravino with autism at age eleven, and she struggled as other children bullied her because she was different.[8] Amy graduated from high school and college and became a certified autism consultant and business coach.[9] She continues to advocate for people with autism, emphasizing that autistic adults receive less attention than autistic children, even though autism is a lifelong condition.[10]

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[1] Francesca Happé, *Why Fold Asperger Syndrome Into Autism Spectrum Disorder in the DSM-5?,* THE TRANSMITTER (Mar. 29, 2011), https://www.thetransmitter.org/spectrum/why-fold-asperger-syndrome-into-autism-spectrum-disorder-in-the-dsm-5 [https://perma.cc/K8W6-AS9J]; AMERICAN PSYCHIATRIC ASS'N., DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS (5th ed. 2013).

[2] Simon Baron-Cohen, *The Concept of Neurodiversity Is Dividing the Autism Community*, SCIENTIFIC AMERICAN (Apr. 30, 2019), https://www.scientificamerican.com/blog/observations/the-concept-of-neurodiversity-is-dividing-the-autism-community [https://perma.cc/N8UB-CBCK].

[3] Eileen Lamb, *I'm a Mother of a Child with Profound Autism. I Want to Share Our Story*., AUTISM SPEAKS, https://www.autismspeaks.org/blog/im-mother-child-profound-autism-i-want-share-our-story#:~:text=I%20was%20born%20and%20raised,in%20many%20aspects%2C%20it%20was [https://perma.cc/2VFD-C2G3].

[4] *Id.*

[5] *Id.*

[6] *Id.*

[7] *Id.*; *Respite*, N.Y. STATE OFFICE FOR THE AGING, https://aging.ny.gov/respite [https://perma.cc/VUH3-R7SS].

[8] JOHN DONVAN & CAREN ZUCKER, IN A DIFFERENT KEY: THE STORY OF AUTISM (2016); Amy Gravino, *I Now Know What Caused My Autism, Which Changes Everything—and Nothing,* CNN, https://www.cnn.com/2021/04/21/opinions/my-autism-cause-changes-everything-and-nothing-gravino [https://perma.cc/LUA7-Y2QJ].

[9] Gravino, *supra* note 8.

[10] Gravino, *supra* note 8.

Autism diagnoses have significantly increased over the past thirty years.[11] A 2023 autism prevalence study in the *American Academy of Pediatrics* reported that clinicians diagnosed about eighteen out of every one thousand children with autism by the age eight in 2016, compared to about six per one thousand in 2000.[12] The Center for Disease Control and Prevention ("CDC") simiarly reported that, as of 2020, roughly twenty-seven per one thousand children are diagnosed with autism.[13] Much of this increase reflects improved awareness among practitioners and changes to diagnostic criteria.[14]

As the autism spectrum expands to encompass a larger and more inclusive population,[15] those on the spectrum who require the most intensive support are often left out of the conversation.[16] Among them are individuals with profound autism, also known as severe autism, who often require full-time care and live with co-morbid conditions.[17] The federal government must ensure that individuals with profound autism have equitable access to resources and services.[18]

For the past twenty years, the Autism Collaboration, Accountability, Research, Education and Support Act ("Autism CARES Act") has funded crucial autism research and programming.[19] On December 23, 2024, Congress reauthorized the Act and it was signed into law,[20] providing more

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[11] Josephine Shenouda et al., *Prevalence and Disparities in the Detection of Autism Without Intellectual Disability,* 151 PEDIATRICS 1 (2023).

[12] *Id.*; Aria Bendix*, Autism Rates Have Tripled. Is it Now More Common or Are We Just Better at Diagnosis?,* NBC NEWS (Jan. 26, 2023), https://www.nbcnews.com/health/health-news/autism-rates-rising-more-prevalent-versus-more-screening-rcna67408 [https://perma.cc/4QAT-GE5Q]; *Data and Statistics on Autism Spectrum Disorder,* CTR. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/autism/data-research/index.html [https://perma.cc/CQ9M-CNCE].

[13] *Data and Statistics on Autism Spectrum Disorder*, *supra* note 12.

[14] Shenouda et al., *supra* note 11.

[15] *Id.*; Bendix, *supra* note 12.

[16] Alison Singer, *Opinion: It's Time to Embrace "Profound Autism"*, AUTISM SPECTRUM NEWS (Nov. 29, 2022), https://autismspectrumnews.org/opinion-its-time-to-embrace-profound-autism/#:~:text=Addressing%20Mental%20Health%20Challenges%20for,tailored%20support%20and%20advocacy%20efforts [https://perma.cc/FRT5-YXMF].

[17] *Id.*; Un Sun Chung & Ji-Hoon Kim, *Common Comorbid Condition of Patients With Autism Spectrum Disorder and Pharmacotherapy for Patients With Autism Spectrum Disorder*, 35 J. KOREAN ACAD. CHILD ADOLESCENT PSYCHIATRY 39 (Jan. 2023).

[18] Lord et al., *The Lancet Commission on the Future of Care and Clinical Research in Autism*, 399 LANCET, 271 (Jan. 15, 2022).

[19] *Securing the Future: The Autism CARES Act of 2024 Passes in the U.S. House of Representatives,* AUTISM SPEAKS (Sep. 18, 2024), https://www.autismspeaks.org/advocacy-news/securing-future-autism-cares-act-2024-passes-us-house-representatives [https://perma.cc/C696-GTZJ].

[20] Autism Collaboration, Accountability, Research, Education, and Support Act of 2024, Pub. L. No. 118-180, § 2, 138 Stat. 2614, 2614 (2024).

than $1.95 billion in funding over the next five years.[21] Although the Autism CARES Act has been an impactful resource in funding autism research and programming, the language in the latest reauthorization falls short in clearly addressing the needs of individuals with profound autism.[22] The Act states that it "reflects the entire population of individuals with autism spectrum disorder, including those individuals with co-occurring conditions and the full range of needs for supports and services, including such supports and services to ensure the safety, and promote the well-being, of such individuals."[23] Yet it does not explicitly define and prioritize the needs of individuals with profound autism, leaving uncertainty about whether individuals with the most intensive support needs will be meaningfully centered in policy, funding, and programming concerning autistic individuals.[24]

This Note critiques the 2024 Autism CARES Act for failing to adequately address individuals with profound autism and explains why their explicit inclusion is critical. Part I traces the history of autism, defines profound autism and its functional impacts on individuals living with this condition, and summarizes the Autism CARES Act. Part II discusses how individuals with profound autism are often underrepresented in autism-related research, funding priorities, and legislation, framing the need for specificity in the Act's language. Part III proposes amendments to the Autism CARES Act to ensure meaningful inclusion of individuals with profound autism and suggests model wording should the Act be reauthorized in five years.

I. BACKGROUND

A. History of Autism

Despite the prevalence of autism throughout history,[25] it was not until 1943 when Leo Kanner, a child psychiatrist, first characterized autism as a distinct syndrome.[26] Before then, children with autism were misdiagnosed

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[21] Michael Finan, *A Christmas Miracle: Smith's $1.95 Billion Autism CARES Act Signed Into Law,* U.S. Congressman Chris Smith (Dec. 24, 2024), https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=413475#:~:text=A%20Christmas%20miracle [https://perma.cc/U9EY-LHRT].

[22] Rachel Zamzow, *In Updated U.S. Autism Bill, Congress Calls for Funding Boost, Expanded Scope*, THE TRANSMITTER (Sep. 5, 2024), https://www.thetransmitter.org/spectrum/in-updated-u-s-autism-bill-congress-calls-for-funding-boost-expanded-scope [https://perma.cc/RNJ2-6EY2].

[23] Autism Collaboration, Accountability, Research, Education, and Support Act of 2024, Pub L. No. 118-180 § 2, 138 Stat. 2614.

[24] Zamzow, *supra* note 22.

[25] DONVAN & ZUCKER, *supra* note 8, at 545.

[26] *Id.*

or depicted as "feeble-minded, retarded, moronic, idiotic, or schizoid."[27] In a letter to Mary Triplett, the mother of Donald Triplett—the first child Kanner diagnosed—Kanner described autism for the first time as its own condition, emphasizing "the inability of these children from earliest infancy to relate themselves to other people."[28] A year after this letter, Kanner went on to publish a paper titled, *Autistic Disturbances of Affective Contact*,[29] in which he termed "early infantile autism,"[30] based on his study of eleven children who shared similar characteristics.[31] Kanner described the children as largely indifferent to people and intensely drawn to repetition, routine, and sameness.[32] He also observed distinctive linguistic habits: some of the children were echolalic,[33] while others did not speak at all.[34] At the same time he noted their "excellent rote memory," documenting incredible memory of words, numbers, events, and patterns.[35] Kanner did not identify the cause of autism, and while we still do not know the exact cause, current research generally points to a combination of genetics and environmental factors.[36] Kanner's paper laid the foundation for the next eighty years of autism research.[37]

The history of autism also has a dark side: until the 1980s, many individuals with autism were routinely institutionalized, as doctors—working with limited research and resources—believed this was in their patients' best interest.[38] As a result, children as young as three were separated from their families;[39] for generations, people with autism were hidden from

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[27] Gerald D. Fischbach, *Leo Kanner's 1943 Paper on Autism*, THE TRANSMITTER (Dec. 7, 2007), https://www.thetransmitter.org/spectrum/leo-kanners-1943-paper-on-autism/#fn:1 [https://perma.cc/9MEB-LPBU].

[28] DONVAN & ZUCKER, *supra* note 8.

[29] Leo Kanner, *Autistic Disturbances of Affective Contact*, 2 NERVOUS CHILD, 217 (1943).

[30] Fischbach, *supra* note 27.

[31] *Id.*

[32] Kanner, *supra* note 29.

[33] "[T]he often pathological repetition of what is said by other people as if echoing them." *Echolalia*, MERRIAM-WEBSTER DICTIONARY, https://www.merriam-webster.com/dictionary/echolalia [https://perma.cc/6BFB-7TVZ].

[34] Kanner, *supra* note 29.

[35] *Id.*

[36] *Autism Spectrum Disorder: Symptoms & Causes*, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/autism-spectrum-disorder/symptoms-causes/syc-20352928 [https://perma.cc/ALZ6-LJ7L]; *Causes, Signs, and Symptoms*, AUTISM SCI. FOUND., https://autismsciencefoundation.org/causes-signs-and-symptoms [https://perma.cc/749J-CD4F]. In over 15 to 20% of people with autism, one can find specific genetic mutations that are later attributed to their autism.

[37] DONVAN & ZUCKER, *supra* note 8.

[38] Jessica Wright, *The Missing Generation*, THE TRANSMITTER (Dec. 9, 2015) https://www.thetransmitter.org/spectrum/the-missing-generation [https://perma.cc/9BA3-M2JA]; IN A DIFFERENT KEY (PBS 2022).

[39] IN A DIFFERENT KEY, *supra* note 38.

society.[40] Along with institutionalizing vast majorities of the autistic population, doctors forcibly sterilized autistic individuals.[41] In the early 1900s, the eugenics movement[42] paved the way for laws authorizing the state to forcibly sterilize certain individuals. The Supreme Court upheld a Virginia statue permitting the sterilization of individuals deemed "feeble-minded," "epileptic," or "unfit" for reproduction.[43] These laws led to the forcible sterilization of over 70,000 individuals, the majority of whom were disabled.[44]

In addition, in 1944, Hans Asperger, an Austrian pediatrician, published his post-graduate thesis on autistic psychopathy, work that would later contribute to the recognition of Asperger's syndrome.[45] However, in 2010, Austrian medical historian Herwig Czec exposed Asperger for signing off on sending multiple disabled children to be murdered at death camps during the Nazi regime.[46] Further, during the 1960s, theories popularized by Bruno Bettelheim—and generally accepted throughout society and by the medical community for decades—blamed mothers for their children's autism by accusing them of being too cold and emotionally distant.[47]

This history of harm toward autistic individuals and their families contributed to deep social stigma. Parents of autistic individuals began advocating for recognition and support for their children, and in 1965, they founded the National Society for Autistic Children to promote awareness and inclusion.[48] Further, during the 1980s, many larger institutions closed,[49] and Congress enacted landmark disability legislation, including Education for All Handicapped Children Act of 1975.[50] Advancements in understanding

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[40] Wright, *supra* note 38.

[41] IN A DIFFERENT KEY, *supra* note 38.

[42] NAT'L WOMEN'S LAW CTR., FORCED STERILIZATION OF DISABLED PEOPLE IN THE U.S (2021) ("The eugenics movement refers to the idea of improving the human race and preventing its degeneration through selective breeding and the elimination of undesirable traits.").

[43] Buck v. Bell, 274 U.S. 200 (1927).

[44] NAT'L WOMEN'S LAW CTR., FORCED STERILIZATION OF DISABLED PEOPLE IN THE U.S (2021).

[45] DONVAN & ZUCKER, *supra* note 8.

[46] Herwig Czech, *Hans Asperger, National Socialism, and "Race Hygiene" in Nazi-era Vienna*, 9 MOLECULAR AUTISM 29, 5 (2018).

[47] Mitizi M. Waltz, *Mothers and Autism: The Evolution of a Discourse of Blame*, 17 AMA J. ETHICS 353, 354 (2015). This has since been disproven, but the effects of Bettelheim's theories lingered for decades.

[48] *Historic Overview,* AUTISM SOC'Y, https://autismsociety.org/who-we-are [https://perma.cc/4ABC-HXRB].

[49] *Autism Through the Years: How Understanding Has Evolved Over Two Decades,* SW. AUTISM RSCH. & RES. CTR., https://autismcenter.org/autism-through-the-years [https://perma.cc/9V73-VQTR].

[50] Later renamed IDEA, the Education for All Handicapped Children Act required all public schools to provide a fair and appropriate education to children with disabilities. 20 U.S.C. § 1400 (1975).

autism led to the creation of more advocacy groups to raise awareness about autism.[51]

Today, much of the autism community focuses on acceptance and support.[52] Instead of aiming to hide their differences, many in the community want to create a world that is not only accepting of these differences but also supportive of their needs, enabling them to live more fulfilling lives.[53] Autistic self-advocates have been central to the neurodiversity movement, which seeks to instill pride in autism and demands that individuals with autism are included and empowered. In fact, many in the neurodiverse community do not view the differences caused by autism as deficits.[54] While there is still more work to be done in regard to broader acceptance of people with autism, society has nevertheless come a long way from the past.[55]

B. Autism Today

Autism Spectrum Disorder is a neurological and developmental disorder that impacts communication, behavior, and learning style.[56] Some of the most common symptoms of autism include difficulty with social communication, as well as repetitive behaviors and restricted interests.[57] Autism symptoms vary within individuals and how they experience them,[58] creating a spectrum disorder.[59] Prior to 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM) contained five distinct diagnoses for what later became known under the umbrella diagnosis, Autism Spectrum Disorder (ASD).[60] These diagnoses included: Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder Not Otherwise Specified

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[51] *The History of Autism and Institutionalization*, BLUEGEMS ABA, https://bluegemsaba.com/the-history-of-autism-and-institutionalization/#:~:text=As%20late%20as%20the%201960s,blamed%20for%20their%20child's%20condition [https://perma.cc/YS9E-M6JT].

[52] *Acceptance in Action: Honoring Autism Acceptance Month*, AUTISM SOC'Y, https://autismsociety.org/acceptance-in-action-honoring-autism-acceptance-month [https://perma.cc/8LHD-VPQ7].

[53] *Id.*

[54] Nicole Baumer & Julia Frueh, *What is Neurodiversity?*, HARV. HEALTH PUBL'G (Nov. 23, 2021), https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645 [https://perma.cc/M2C3-JG7T].

[55] *The History of Autism*, NAT'L AUTISTIC SOC'Y, https://www.autism.org.uk/advice-and-guidance/what-isautism/the-history-of-autism [https://perma.cc/JM8Q-8CSW].

[56] *Autism Spectrum Disorder*, NAT'L INST. MENTAL HEALTH (Dec. 2024) https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd [https://perma.cc/S38W-D4Y7].

[57] NAT'L INST. MENTAL HEALTH, *supra* note 56; *see also Autism Symptoms*, AUTISM SPEAKS, https://www.autismspeaks.org/autism-symptoms [https://perma.cc/9M6V-MKRQ].

[58] *Autism Symptoms, supra* note 57.

[59] NAT'L INST. MENTAL HEALTH, *supra* note 56; *Autism Symptoms, supra* note 57.

[60] *Asperger Syndrome*, AUTISM SPEAKS, https://www.autismspeaks.org/asperger-syndrome [https://perma.cc/K88K-PN6U].

(PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder.[61] Most notably, at this point in time, clinicians treated Asperger's syndrome as a separate diagnosis from autism.[62] Health-care providers considered Asperger's to be a milder form of autism.[63] In 2013, however, the DSM-5 consolidated these five separate disorders into a single diagnosis: Autism Spectrum Disorder (ASD).[64] The updated DSM-5 classifies ASD into three levels of severity.[65]

Individuals with Level 1 autism tend to struggle with initiating social interactions, which can impact their social life and overall well-being.[66] Many benefit from supports[67] such as behavior therapy, occupational therapy, speech therapy, and other interventions that build communication skills, social functioning, and behavioral regulation.[68] Although individuals with Level 1 autism can maintain typical cognitive and linguistic abilities,[69] they may still have trouble maintaining or initiating conversation.[70]

People with Level 2 autism require more social and life-skills support. [71] Many benefit from school-based accommodations and may be able to attent general-education settings with substantial supports, such as a 1:1 classroom aide.[72] Furthermore, individuals with Level 2 autism typically

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[61] *Id.* The DSM provides a unified language that allows mental health professionals to define and diagnose mental disorders, along with promoting consistency in research and treatment. *What is the DSM?*, AM. PSYCHIATRIC ASS'N, (Apr. 2025) https://www.psychiatry.org/patients-families/what-is-the-dsm [https://perma.cc/6TBS-G2EX].

[62] *Asperger Syndrome*, *supra* note 60. AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS 84 (4th ed., 1994). The DSM IV defines Asperger's syndrome as a "Qualitative impairment in social interaction," but "no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood." *Id.*

[63] *Asperger's vs. Autism: What's the Difference?*, CLEVELAND CLINIC (May 24, 2024), https://health.clevelandclinic.org/aspergers-vs-autism [https://perma.cc/UV4X-J6FB].

[64] *ASD Levels of Severity*, AUTISM SPEAKS, https://www.autismspeaks.org/levels-of-autism [https://perma.cc/5FMS-VAE7]. All five of these conditions shared similar symptoms, which often made it difficult for practitioners to decide on a diagnosis. This led to combining them into one spectrum disorder. *Asperger's vs. Autism: What's the Difference?*, *supra* note 63.

[65] *ASD Levels of Severity*, *supra* note 64.

[66] *Id.*; AMERICAN PSYCHIATRIC ASS'N., *supra* note 1.

[67] *ASD Levels of Severity*, *supra* note 64.

[68] *Support for Autism Spectrum Disorder in Children*, NYU LANGONE HEALTH, https://nyulangone.org/conditions/autism-spectrum-disorder-in-children/support [https://perma.cc/ZX2T-4H22].

[69] AMERICAN PSYCHIATRIC ASS'N., *supra* note 1.

[70] Lynn Kern Koegel, Zak Koplen, Brittany Koegel, & Robert L. Koegel, *Using a Question Bank Intervention to Improve Socially Initiated Questions in Adolescents and Adults With Autism*, 64 J. SPEECH, LANGUAGE, AND HEARING RSCH, 1331, 1331 (2021).

[71] *ASD Levels of Severity*, *supra* note 64; AMERICAN PSYCHIATRIC ASS'N., *supra* note 1.

[72] Katherine Martinelli, *Understanding the Levels of Autism*, CHILD MIND INST., https://childmind.org/article/understanding-the-levels-of-autism/#level-2-autism-requiring-substantial-support [https://perma.cc/ZE6X-VKNQ].

struggle with verbal and nonverbal communication skills.[73] This may include using fewer words, missing nonverbal communication cues, failing to respond or walking away during conversation, and difficulty maintaing eye contact.[74] Additionally, their autistic traits are more identifiable and noticeable, including hand flapping, rocking, and having a special interest.[75] Special interests are highly focused, intense fascinations with specific topics.[76] Because conversations and activities frequently revolve around autistic individuals' special interests, shifting focus or engaging with other topics can be difficult. Together, these communication barriers and support needs can make their ability to function independently more difficult.

Individuals with Level 3 autism typically require full-time care and support, whether from parents or a full-time caregiver.[77] They require around the clock support and are typically non-verbal or severely lacking in verbal communication skills.[78]

C. Profound Autism

Traditionally labeled severe autism, Level 3 autism resembles the commonly termed *profound autism*, which reflects the need for a clear separate category for those on the autism spectrum who require the most support.[79] Profoundly autistic individuals commonly experience co-morbid conditions in addition to their autism.[80] Some of these include seizures, self-injurious behavior, obsessive-compulsive disorder, gastrointestinal issues, and aggression.[81] Further, individuals with profound autism often require access to an adult who can assist and provide rudimentary needs such as food, shelter, and safety.[82] They cannot be left unsupervised and depend on others

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[73] *ASD Levels of Severity*, *supra* note 64; AMERICAN PSYCHIATRIC ASS'N., *supra* note 1.

[74] *What is Level 2 Autism?,* DRAKE INST. NEUROPHYSICAL MED., https://www.drakeinstitute.com/what-is-level-2-autism [https://perma.cc/RGX2-SNUP].

[75] AMERICAN PSYCHIATRIC ASS'N., *supra* note 1; Martinelli, *supra* note 72; Emily Singer, *Special Interests in Autism,* SIMONS POWERING AUTISM RSCH., https://sparkforautism.org/discover_article/special-interests-in-autism/ [https://perma.cc/S8UQ-2XBJ].

[76] Singer, *supra* note 75.

[77] *3 Levels of Autism: Differences & Similarities*, THE TREETOP: BLOG (July 17, 2024), https://www.thetreetop.com/aba-therapy/levels-of-autism [https://perma.cc/C3A4-8G6C].

[78] *ASD Levels of Severity*, *supra* note 64. Non-verbal individuals are unable to use spoken word or communicate with very few words. *'Nonverbal' Autism: What it Means*, NORTHWESTERN MED. (2023), https://www.nm.org/healthbeat/healthy-tips/nonverbal-autism-what-it-means [https://perma.cc/Z7YT-4U83].

[79] Azeen Ghorayshi, *Should the Autism Spectrum Be Split Apart?*, N.Y. TIMES (Oct. 1, 2025), https://www.nytimes.com/2025/10/01/health/autism-spectrum-neurodiversity-kennedy.html [https://perma.cc/3D23-U3NV].

[80] *Federal Advocacy for Profound Autism*, PROFOUND AUTISM ALLIANCE: ADVOC., https://www.profoundautism.org/advocacy/federal-advocacy [https://perma.cc/X3DD-R3U5].

[81] *Id.*

[82] Lord et al., *supra* note 18.

for very basic health and self-care needs.[83] As of 2023, 26.7% of people diagnosed with autism have profound autism.[84]

In 2021, the term "profound autism" was highlighted in a report published by *The Lancet*, discussing the future of autism research and care.[85] The report found that it is crucial to differentiate people with profound autism, who have higher needs, from the more "verbally and intellectually able" portion of the spectrum.[86] According to the report, adopting the label of "profound autism" would help individuals and their families access the appropriate support and resources needed during their lifetime.[87] Without a clear way to properly identify their child's disability, families may struggle to plan for schooling and residential needs and to locate care that most adequately can support them.[88] This is due in large part to how large the autism spectrum has become following changes to the DSM. Services created for people with Level 1 autism are significantly different than those with profound autism.

A 2025 survey conducted by the National Council on Severe Autism found that 80% of the 800 families surveyed were told that their child with profound autism was too disruptive for classrooms with services geared towards students with autism and other disabilities.[89] The founder of the National Council on Severe Autism, Jill Escher, states, "Autism has become so diluted, we can't really tell what we're talking about anymore."[90] The goal of the term, "profound autism" is to benefit the individual with autism, their families, health-care providers, and clinical providers, as well as researchers as a way of distinguishing this group within the broader autism spectrum for purposes of advocacy and support.

II. HISTORY OF THE AUTISM CARES ACT

A. Purpose and Origin

Improving the lives of autistic individuals requires research that identifies the support and services essential for their success. This research can only happen with adequate funding. The federal government has

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[83] *Id.*

[84] Michelle M. Hughes et al., *The Prevalence and Characteristics of Children with Profound Autism, 15 Sites, United States, 2000–2016*, 138 PUB. HEALTH REP. 971 (2023), https://pubmed.ncbi.nlm.nih.gov/37074176 [https://perma.cc/5GNE-H3AC].

[85] Singer, *supra* note 16; Lord et al., *supra* note 18.

[86] *Id.*

[87] *Id.*

[88] *Id.*

[89] Ghorayshi, *supra* note 79.

[90] *Id.*

contributed to financing autism research for over twenty years.[91] According to the latest *Autism Research Portfolio Analysis Report*, federal agencies funded about 80% of autism research, and private organizations funded approximately the other 20%.[92] The Autism CARES Act has improved the lives of individuals with disabilities by providing funding for research, education, and services.[93] The original enactment, known as the Combating Autism Act (CAA), amended the Public Health Service Act to update and expand provisions related to autism services.[94] It provided funding to the National Institute of Health ("NIH"), the Department of Health and Human Services ("HHS"), the CDC,[95] and the Health Resources and Services Administration ("HRSA").[96] The CAA also created the Interagency Autism Coordinating Committee ("IACC") to coordinate autism research efforts made within HHS.[97] Through this, IACC was responsible for developing reports on autism-related research.[98] The intended purposes of the CAA was to address research into the possible causes and treatments of autism, to increase awareness of autism, and to provide access to screening and early intervention services.[99]

B. Reauthorizations

Congress first reauthorization the Combating Autism Act in 2011 through the Combating Autism Reauthorization Act ("CARA").[100] In 2014, Congress reauthorized CARA, retitling it the Autism CARES Act,[101] and subsequently maintained that title in the 2019 and 2024 reauthorizations, preserving largely the same structure and broad definitions. Over time, these reauthorizations reflect Congress' evolving understanding of autism,

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[91] *Securing the Future: The Autism CARES Act of 2024 Passes in the U.S. House of Representatives*, *supra* note 19.

[92] *Release of the 2019-2020 IACC Autism Research Portfolio Analysis Report*, INTERAGENCY AUTISM COORDINATING COMM. (Mar. 7, 2024), https://iacc.hhs.gov/news/2024/portfolio-analysis-release.shtml [https://perma.cc/PJW7-HPZE].

[93] *The Autism CARES Act of 2024 Advances Through Congress with Enhancements Supported by Autism Speaks,* AUTISM SPEAKS (Aug. 5, 2024), https://www.autismspeaks.org/press-release/autism-cares-act-2024-advances-through-congress-enhancements-supported-autism-speaks [https://perma.cc/5NMV-QUAA].

[94] Combating Autism Act of 2006, Pub. L. No. 109-416, 120 Stat. 2821. Prior to this, funding provided by the government was included in the Children's Health Act, enacted in 2000. Children's Health Act of 2000, Pub. L. No. 106-310, 114 Stat. 1101.

[95] CONG. RSCH. SERV., R42369, THE COMBATING AUTISM ACT: OVERVIEW AND FUNDING (Dec. 27, 2012).

[96] *Id.*

[97] *Id.;* Combating Autism Act of 2006 §3.

[98] Combating Autism Act of 2006 §3.

[99] *Id.*; CONG. RSCH. SERV., *supra* note 95.

[100] CONG. RSCH. SERV., *supra* note 95.

[101] Autism CARES Act of 2014, Pub. L. No. 113-157, 128 Stat. 1831.

including who is encompassed within a formal diagnosis. The CAA, for example, expanded NIH research authority to address the entirety of the autism spectrum by amending the act to say, "autism spectrum disorder" instead of simply "autism,"[102] which had previously excluded many individuals on the spectrum—such as those with Asperger's. In principle, then, the Autism CARES Act is designed to include the entire spectrum. In practice, however, funding is not being proportionally allocated.

Further, across successive reauthorizations, autism advocates would raise their concerns about improvements that should be made to the Act.[103] Society's understanding of Autism has evolved over decades, and advocates have urged Congress to develop the Act in response to the ever-changing understanding of Autism.[104] For example, prior to reauthorizations, the Autism Society urged Congress to adapt improvements such as adding provisions that would provide respite support for caregivers and address premature mortality among Autistic individuals.[105] Other groups pushed to draw attention to understudied areas such as the lack of effective communication tools for non-verbal autistic individuals.[106] In the past, Congress has updated the Act to reflect changes in attitudes about autism, such as adapting the 2019 Autism CARES Act to expand the oversight of federal efforts to support people with autism across their lifespan, rather than focusing solely on childhood,[107] and required HHS to submit a report to Congress with recommendations on how to improve the health and well-being of those with autism.[108]

In the 2024 reauthorization, profound autism advocates urged Congress to include language that would explicitly include the term "profound autism."[109] As the Profound Autism Alliance explained, "We are not asking for special treatment. We simply ask to be treated equally to others included in research funded through Autism CARES."[110]

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[102] Combating Autism Act of 2006 §2(a).

[103] Christopher Banks, *Autism Society Applauds Passage of the Autism CARES Act of 2024 in the House of Representatives,* AUTISM SOC'Y, https://autismsociety.org/press-release-autism-society-applauds-house-hr7213/ [https://perma.cc/4ZTP-92DV].

[104] *Id.*

[105] Christopher Banks, *Why You Should Care About The Autism CARES Act*, AUTISM SOC'Y (Apr. 23, 2024), https://autismsociety.org/the-autism-collaboration-accountability-research-education-and-support-autism-cares-act-is-a-pivotal-law-for-individuals-with-autism-and-their-families-to-live-fully-as-discussions-around-this [https://perma.cc/N66V-TWDL].

[106] Zamzow, *supra* note 22.

[107] Autism CARES Act of 2019 § 2.

[108] *Id.* at § 3.

[109] Zamzow, *supra* note 22.

[110] *Include Profound Autism in the Autism CARES Act of 2024,* PROFOUND AUTISM ALLIANCE (July 2024), https://www.profoundautism.org/media/bb4oxuto/autism-cares-2024-one-pager-july-2024.pdf [https://perma.cc/6J5F-7QWL].

C. The Autism CARES Act of 2024 Language and Scope

The scope of the Autism CARES Act in terms of where federal agencies should direct their research is important, as it provides guidance on what will be funded for the next four years of its authorization period.[111] The language in the Autism CARES Act was negotiated and changed throughout the process of becoming law.[112] The original language that passed out of the House Energy and Commerce Committee directed federal agencies to support research that: "[r]eflects the entire population of individuals with autism spectrum disorder, *including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions* and needs for support and services, including care necessary for physical safety."[113] This version of the language includes the various aspects of autism that were ultimately excluded from the finalized Act.

The enacted statute narrows the directive. The official law requires that research "reflect the entire population of individuals with autism spectrum disorder, *including those individuals with co-occurring conditions* and the full range of needs for supports and services, including such supports and services to ensure the safety, and promote the well-being, of such individuals."[114] This ambiguity may exclude profoundly autistic individuals from research.

III. PROFOUND AUTISM IS LEFT BEHIND

A. Profound Autism's Lack of Funding

Profound autism is not funded or researched as much as the rest of the autism spectrum.[115] The lack of research is why it is vital for the Autism CARES Act to specify that funding should be equitably allocated for research, support, and services for profoundly autistic individuals. Federal autism research and services focus very little on individuals with profound autism, many of whom require around-the-clock, lifelong support and care.[116] The CDC estimates that approximately one in four people with autism have

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[111] *Securing the Future: The Autism CARES Act of 2024 Passes in the U.S. House of Representatives*, *supra* note 19.

[112] *Autism CARES Act of 2024*, INTERAGENCY AUTISM COORDINATING COMM., https://iacc.hhs.gov/about-iacc/legislation/autism/cares-act-2024 [https://perma.cc/XG5J-7QSX]

[113] H.R. REP. NO. 118-620, at 2 (2024) (emphasis added).

[114] Autism Collaboration, Accountability, Research, Education, and Support Act of 2024, Pub L. No. 118-180 § 2, 138 Stat. 2614 (emphasis added).

[115] Amy Stedman et al., *Are Children Severely Affected by Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature*, 49 J. AUTISM DEV. DISORDER 1378, 1378-90 (2018).

[116] *Federal Advocacy for Profound Autism*, *supra* note 80.

profound autism,[117] yet only about 6% of autism research includes this population.[118] A 2024 study further found that stigma and limited understanding of the autism spectrum have contributed to significant data gaps regarding the prevalence of profound autism and the lived experiences of those with profound autism and their families.[119]

Additionally, Dr. Matthew Siegel, a child psychiatrist at Boston Children's Hospital, conducted treatment studies of autistic individuals between 1991-2013 and found that studies including severely affected autistic participants decreased significantly year after year,[120] even as funding increased.[121] Dr. Siegel says that one of the reasons for this gap in research is due to convenience—"people with profound autism could not go online and fill out surveys for studies or tolerate sitting still for a brain scan inside a loudly humming machine."[122] Another explanation raised is that the neurodiversity movement has helped shift research priorities toward issues such as mental health and employment supports, rather than the urgent medical and safety questions many parents of profoundly autistic children face, such as, "why is my child having seizures?" and "why does my child bang their head against the floor?"[123]

B. The Split in the Spectrum

Individuals with profound autism should be treated equally to others on the autism spectrum, but achieving this initiative faces many challenges,[124] including from within the autism community itself.[125] There has been tension within the autism community ever since the DSM combined autism into a spectrum. Some autistic self-advocates find that dividing the spectrum will dismiss those on the spectrum who require less support.[126] Self-advocates have claimed that the term profound autism "provides no useful information

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[117] Elaine Clarke, James McCauley, Amy Lutz, Marina Gotelli, Stephen Sheinkopf & Catherine Lord, *Understanding Profound Autism: Implications for Stigma and Supports*, 15 FRONTIERS PSYCH 1, 3 (2024).

[118] *Newly Passed Autism CARES Act Recognizes Full Spectrum,* AUTISM SCI. FOUND. (2024) https://autismsciencefoundation.org/press_releases/autism-cares-act-recognizes-full-spectrum [https://perma.cc/47SL-6NLU].

[119] Clarke et al., *supra* note 117.

[120] Stedman et al., *supra* note 115.

[121] INTERAGENCY AUTISM COORDINATING COMMITTEE, 2019-2020 IACC AUTISM RESEARCH PORTFOLIO ANALYSIS REPORT 17 (2024), https://iacc.hhs.gov/publications/portfolio-analysis/2020/portfolio_analysis_2020.pdf?ver=5 [https://perma.cc/3R8S-GXHK].

[122] Ghorayshi, *supra* note 79.

[123] *Id.*

[124] Katherine Ellison, *A Rift Over 'Profound Autism Reveals a Community's Deeper Divide*, WASH. POST (Nov. 18, 2023), https://www.washingtonpost.com/health/2023/11/18/profound-autism-labels-neurodiversity/ [https://perma.cc/M6F8-NGLC].

[125] *Id.*

[126] Ghorayshi, *supra* note 79.

to others who may need to interact with the autistic person."[127] Some leaders of the Autistic Self Advocacy Network (ASAN), have expressed concern about the term profound autism, describing it as "misleading" and "dangerous."[128] ASAN identifies as a neurodiversity organization that celebrates their autistic identity.[129] ASAN's Executive Director has argued that allocating funds to profound autism could shift priorities toward attempts to cure autism, rather than improving services, and may ultimately result in more restrictive services for the entire spectrum.[130]

ASAN has expressed concern that genetic testing, for example, could be used to find cures for autism, which does not align with the values of their organization.[131] ASAN's director argues, "[t]hey deserve good lives with the right to make their own decisions, not yet another round of 'cures' that will not work."[132] ASAN has also advocated against placing people with autism in unnecessarily restrictive settings and has emphasized community-based, integrated living arrangements.[133] That orientation is reflected in federal disability policy initiatives, including the Medicaid Home and Community Based ("HCBS") Settings Rule.[134] While the rule was put into place with good intentions, [135] it has become a barrier in providing affordable housing and services to those on the spectrum with profound autism because it is not tailored to those with the most intensive support needs. Issued by the Centers for Medicare and Medicaid Services ("CMS"),[136] the rule requires that HCBS settings provide meaningful access to the benefits of community life.[137] This rule also states that individuals should be able to choose among residential and day-service options, including settings not exclusively designed for

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[127] Heta Pukki et al., *Autistic Perspectives on the Future of Clinical Autism Research*, 4 AUTISM ADULTHOOD 93, 95 (2022).

[128] Ellison, *supra* note 124.

[129] *Id.*

[130] *Id.*

[131] ASAN, *What We Believe*, AUTISTIC SELF ADVOC. NETWORK, https://autisticadvocacy.org/about-asan/what-we-believe [https://perma.cc/498E-SZJE]. Additionally, Profound autism advocates maintain that their efforts are not aimed at "curing" autism through genetic testing research. *Id.* The findings from genetic testing would be used for implementing therapies, such as early intervention to create better care and support for individuals with the highest needs. *Id.*

[132] *Id.*

[133] AUTISTIC SELF ADVOCACY NETWORK, *supra* note 131.

[134] *HCBS Settings Rule*, *Administration for Community Living,* https://acl.gov/programs/hcbs-settings-rule [https://perma.cc/DJD9-JBT5]

[135] Patrick Filbin, *The Unintended Consequences of CMS' Proposed HCBS Medicaid Rule*, HOME HEALTH CARE NEWS (May 11, 2023), https://homehealthcarenews.com/2023/05/the-unintended-consequences-of-cms-proposed-hcbs-medicaid-rule [https://perma.cc/JQR5-SS9C].

[136] *HCBS Settings Rule*, *supra* note 134.

[137] *What You Should Know*, HCBS ADVOC. COAL., https://hcbsadvocacy.org [https://perma.cc/EJK3-77AA].

people with disabilities.[138] Stating that housing must be chosen by the individual leaves out those on the spectrum who do not have the ability to do so.[139] In many cases, the guardians for those with autism end up making those decisions, and a rigid emphasis on individual choice can therefore exclude those who are unable to exercise it on their own.[140]

Furthermore, the HCBS Settings Rule seeks to pull their funding from residential programs that have institutional qualities.[141] Under the rule, a setting may be treated as institutional if it is isolated from the broader community.[142] There may, however, be many reasons why a residential program is isolated that have little to do with segregation and much to do with safety and clinical necessity.[143] Many parents of children with profound autism say there is a lack of specialized services such as long-term housing, and laws like the HCBS Setting Rule show how great the disconnect between the neurodiversity community and profound autism advocates can be. Even though it is unintentional, these kinds of regulations often neglect those with the most significant support needs.[144]

Autism can be a positive identity for some, but for others, it is a debilitating medical condition.[145] Many individuals with profound autism are non-verbal and may suffer from violent or self-injurious behavior;[146] this is not the same as self-advocates who can speak for themselves.[147] Parents of children with profound autism believe that their children's struggles have been overshadowed by higher-functioning members of the autistic community[148] and when these parents speak out, they are labeled as ableist. For example, Eileen Lamb, Charlie's mother, created a website, *The Autism Café*, where she writes about her life as a mother of a child with profound

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[138] *HCBS Settings Rule*, *supra* note 134.

[139] TOGETHER FOR CHOICE MEDIA, *My Life, My Choice - Ep.7: The Unintended Consequences of HCBS Settings Rule*, YOUTUBE (Sep. 29, 2020), https://www.youtube.com/watch?v=O4IegYjeyOs [https://perma.cc/CAB9-HLXV].

[140] *Id.*

[141] *HCBS Settings Rule*, *supra* note 134.

[142] *Id.*

[143] *What Is Residential Treatment and When Is It Necessary?*, LINDER CENTER OF HOPE (Aug. 18, 2025), https://lindnercenterofhope.org/blog/is-a-residential-treatment-center-the-right-choice/ [https://perma.cc/FVN2-WF92].

[144] Ellison, *supra* note 124.

[145] Singer, *supra* note 16.

[146] *Why the Term Profound Autism is Needed, Profound Autism Alliance,* https://www.profoundautism.org/research/profound-autism-facts [https://perma.cc/2SCL-KAJN].

[147] Pukki, *supra* note 127, at 93.

[148] Singer, *supra* note 16.

autism. [149] She is constantly criticized by people online claiming she is stigmatizing autism.[150]

C. The Consequences for Profoundly Autistic Individuals & Their Families

As a result of the gap in accurate data of profoundly autistic individuals, it becomes increasingly more difficult to evaluate what policies and funding are needed in order to support access to diagnoses and intervention services.[151] Since research is lacking on the stigma around profound autism,[152] studies on profoundly autistic individuals can increase awareness about the causes and traits of this disorder and potentially reduce stigma.[153] A clearer understanding of the prevalence of profound autism would help policymakers estimate how many autistic individuals will require lifelong, substantial support—information that is essential for preparing the public health system with services to adequately care for these individuals.[154] Additionally, there are comparatively few programs created for adults with profound autism, as programming is often geared towards adults with mild to moderate disabilities.[155]

Another consequence for the lack of distinction between profoundly autistic individuals and the rest of the spectrum is that studies yield unclear outcomes. Identifying which supports and services work for one person on the autism spectrum does not mean they necessarily fit the needs of the entire spectrum.[156] Past studies on adults with autism often have not reflected what "positive outcomes" look like for less cognitively able adults, or adults with profound autism.[157] When assessing the entire spectrum as one, there is little consensus on what a "good" outcome actually is.[158] Research on autistic adults often focus on factors such as independent living or paid employment; however, these are not usually the target goals for adults with profound autism.[159] For example, a study done on forty-four adults with profound autism found that at the age of twenty-five, 100% of them did not live

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[149] *See supra*, Introduction.

[150] Ghorayshi, *supra* note 79.

[151] Clarke et al., *supra* note 117, at 12.

[152] Lord et al., *supra* note 18, at 300.

[153] Clarke et al., *supra* note 117, at 12.

[154] *Id.*

[155] Ghorayshi, *supra* note 79.

[156] James McCauley, Andrew Pickles, Marisela Huerta & Catherine Lord, *Defining Positive Outcomes in More and Less Cognitively Able Autistic Adults*, 13 AUTISM RES. 1548, 1548 (Aug. 27, 2020).

[157] *Id.* at 1550.

[158] Julie Lounds Taylor, *When is a Good Outcome Actually Good?,* 21 AUTISM 918 (2017).

[159] McCauley, *supra* note 156 at 1549.

independently or have full-time paid employment.[160] This is a significantly different percentage than a study from 2017 on higher functioning adults with autism, finding that 61% of the 254 adults who participated in the study were employed.[161]

Additional research is needed to answer core questions about how to best support individuals with profound autism, such as: (1) whether community-based supports are appropriate for those with profound autism; (2) whether larger, more structured settings produce better quality-of-life outcomes; and (3) how to define and measure "better outcomes" for individuals who cannot always express their needs or preferences.[162]

Moreover, the *Lancet* report, which first defined "profound autism," suggested that caring for the autistic population needs to be personalized and that more research is warranted for individuals with profound autism.[163] They recommend conducting more research on the genetics, biomarkers, and medications for profoundly autistic individuals, as well as focusing on specified treatments and interventions.[164] The lead author of the report said that the term "profound autism" originated "from a concern that there are a lot of people who need help and are getting lost in the shuffle."[165] With a spectrum so large, saying someone has autism doesn't actually tell you anything specific about that person or what their struggles and needs are. The report also found that the term profound autism should only be applied when one reaches the age of eight or older, reasoning that language and cognitive ability continue to develop rapidly throughout early childhood.[166] Other studies, however, have found that these language and cognitive abilities become relatively stable around ages four and five.[167] This inconsistency suggests the need for further research not only on appropriate age criteria for diagnosing profound autism, but also on the condition itself.[168]

Allison Singer, president of the Autism Science Foundation, says that more research into genetic testing could aid in accessing early intervention programs sooner in life.[169] Further, the February 2024 Government

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[160] Lord et al., *supra* note 18; Clarke et al., *supra* note 117, at 279.

[161] Alisha Ohl et al., *Predictors of Employment Status Among Adults with Autism Spectrum Disorder,* 56 WORK: J. PREVENTION, ASSESSMENT & REHAB. 345, 350 (2017) ("To be included in this study, participants were required to . . . (b) have a previous diagnosis of Asperger's disorder.").

[162] Clarke et al., *supra* note 117, at 13.

[163] Singer, *supra* note 16.

[164] Lord et al., *supra* note 18.

[165] Ellison, *supra* note 124.

[166] Lord et al., *supra* note 18; Clarke et al., *supra* note 117.

[167] Clarke et al., *supra* note 117 at 12; Hughes et al., *supra* note 84.

[168] Lord et al., *supra* note 18; Clarke et al., *supra* note 117 at 13.

[169] Early intervention is a key factor in better outcomes for people with autism. Ellison, *supra* note 124.

Accountability Office (GAO) Report on Autism Research and Support Services found that the NIH could be doing more in tracking progress toward goals to "help agencies better allocate resources *where they are most needed.*".[170] Inadequate support comes from the lack of knowledge of what is necessary and supportive of the individual.[171] Without adequate research, there is less guidance, which leaves the profoundly autistic population behind.[172]

For these reasons, the 2024 Autism CARES Act should have been explicit in their language. It should not only identify those with profound autism but clearly identify and allocate funding for individuals with profound autism.

IV. REWRITING THE AUTISM CARES ACT

Everyone with autism has their own struggles and faces unique challenges, yet the Autism CARES Act is not formatted to properly meet these challenges. For many decades, autism has been stigmatized and those with the highest needs continue to feel the consequences of past stigma. This Note therefore proposes targeted amendments to the Autism CARES Act to ensure individuals with profound autism—and their families—are explicitly included in federal priorities for research, funding, and services. Everyone with autism deserves to be heard and understood. The language used in these bills have a big impact on how research funding is allocated.[173] Thomas Frazier, who serves on the IACC, states, "[w]hen we put language like this into the bill, we do see a shift in the funding agencies' foci."[174]

The current language of the 2024 Autism CARES Act includes: "the entire population of individuals with autism spectrum disorder, including those individuals with co-occurring conditions and the full range of needs for supports and services, including such supports and services to ensure the safety, and promote the well-being, of such individuals."[175] This language reflects meaningful progress for including and centering autism research around those with the highest support needs. The omission of explicit reference to individuals with profound autism and of specified funding allocations, however, undermines its ability to fully address their needs.[176]

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[170] U.S. GOV'T ACCOUNTABILITY OFF., GAO-24-106446, AUTISM RESEARCH AND SUPPORT SERVICES: FEDERAL INTERAGENCY COORDINATION AND MONITORING COULD BE FURTHER STRENGTHENED (Feb. 28, 2024) (emphasis added).

[171] Lord et al., *supra* note 18.

[172] Singer, *supra* note 16.

[173] Zamzow, *supra* note 22.

[174] *Id.*

[175] Autism Collaboration, Accountability, Research, Education, and Support Act of 2024 § 2.

[176] Zamzow, *supra* note 22.

Including the term profound autism in the Autism CARES Act would indicate to clinicians and researchers that individuals who are severely impacted by their autism present distinct challenges requiring their own studies and support.[177] Additionally, if individuals with profound autism represent roughly 25% of the spectrum,[178] then Congress should allocate, at least, 25% of funding to their research, support, and services through the Autism CARES Act. All other funding should remain in place for the rest of the entire spectrum as it is important that they receive proper support and services as well. By being more explicit, more resources will be allocated to those who cannot care for themselves.

Funding for research and services in medicine, treatment, and education is critical to the well-being of people with profound autism and their families. Families, caregivers, and these individuals deserve the same support as others on the spectrum. Because profound autism presents distinct and often intensive needs, those needs must be addressed explicitly to ensure this population is not left out of policy, programing, and funding priorities. The Autism Cares Act should reflect that, and currently it does not.

CONCLUSION

The Autism CARES Act has been a key tool in creating the best practices for individuals with autism and their families.[179] The funding has been a support to so many families, yet it should not stop us from asking for more. The Autism CARES Act should have a definitive order for an appropriate amount of funding to be directed to profound autism. The Autism CARES Act has been trending in the right direction throughout its legislative history, and because of that, this is an achievable goal. It is time to advocate for profoundly autistic individuals and allocate the appropriate amount of support and services that these individuals need and deserve.

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[177] Singer, *supra* note 16.

[178] Hughes et al., *supra* note 84.

[179] Kara Arundel, *Congress Extends Autism CARES Act for 5 More Years*, K-12 DIVE (Jan. 8, 2025), https://www.k12dive.com/news/congress-extends-autism-cares-act-special-education/736808/ [https://perma.cc/GLX4-LVZB].