



April 1, 2022

Thank you for the opportunity to submit written comments in advance of the IACC's public meeting on April 13-14th, 2022. In prior comments to the IACC, the Autistic Self Advocacy Network¹ has continually emphasized the need for research concerning high quality, individualized services and supports for autistic children and adults. Specifically, we have encouraged the IACC to determine which services and supports are effective, evidence-based tools for supporting the daily living, health, communication, and community integration related needs of autistic people across the lifespan, including autistic people with the most significant support needs. However, ASAN has continually opposed attempts to split autism into multiple diagnoses. These attempts will not improve services for autistic people, and are largely based on the desire to segregate autistic people with the most significant cognitive disabilities and support needs.

We submit this comment in response to the growing desire of some stakeholders in the autism community to adopt a new diagnostic label of "profound autism." ASAN opposes this attempt to reclassify some autistic people because of its high potential to further segregate autistic people from our communities. The term, rather than expanding the knowledge base on autism or accurately categorizing autistic people, would merely retread old ground by bringing back old conceptions of functioning labels with a new name. We call upon the IACC to reject these attempts and to focus its attention on providing recommendations and support for high-quality autism research.

The Background Behind "Profound Autism"

On December 6, 2021, the Lancet Commission, a group of 32 autism researchers, clinicians, and advocates, released a report that laid out their vision for the future of autism services and research over the next five years (Lord et. al, 2021). The vast majority of the report addressed important topics such as the need for individualized services, as well as research that prioritizes the quality of life for autistic people (e.g., Lord et. al., 2021). Unfortunately, the report also included a recommendation for a new "administrative term" called "profound autism" (Lord et al., 2021, p. 278).

Lord et. al. (2021) stated that this new term would be applied to autistic people who require 24-hour support, are not able to be left alone, and are not able to take care of basic

¹ For more information on ASAN, please visit <https://autisticadvocacy.org/>.

adaptive needs (p. 278). The authors (Lord et. al., 2021) opined that these specific support needs are primarily associated with autistic people with intellectual disabilities and/or limited spoken language ability (p. 278). This proposal is a recast of past attempts to divide autistic people into “low-functioning” and “high-functioning” groups. These attempts are based on the mistaken belief that autistic individuals have impairments and support needs which are fixed and uniform across multiple dimensions, including IQ, speech, language, daily living skills, social communication, executive functioning, emotional regulation, and sensory processing (e.g., Gardiner, 2018; Zeliadt and Spectrum, 2016).

Media coverage of the report zeroed in on the term “profound autism,” which quickly overshadowed the rest of the commission’s work. Some proponents promoted the new term extensively as a means of segregating a subset of autistic people into a “severe autism” category mandating separate and highly restrictive services (Lutz, 2021; Singer, 2021a, December; Singer, 2021b, January). There have been calls by these individuals to include the term “profound autism” as a separate sub-category in the DSM-V (Bernhard, 2021). This is the case even though the Lancet report explicitly stated that they did not intend to introduce a new diagnostic term (Lord et. al., 2021, p. 278).

Functioning Labels Like “Profound Autism” Are Not Helpful to Autistic People

Autistic self-advocates and people with intellectual disabilities have spoken out for years about the harm caused by functioning labels like “severe autism” or “low-functioning.” Parents of autistic people with complex needs, additionally, have stated that functioning labels fail to help their children access supports and services (Shannon Des Roches Rosa, 2021). For example, the “profound autism” term conflates needing 24/7 support, “being unable to be left alone in a residence,” and “not being able to take care of basic daily adaptive needs” --and conflates all of these things with speech ability and IQ (Lord et. al., 2021, pg. 278). But the reality is much more complex. Someone may not be able to take care of their basic daily adaptive needs, but be able to be left alone. Someone may not be able to be left alone, but may not require 24/7 support. Someone may be able to take care of their basic adaptive daily needs, but require 24/7 support for other reasons. These differences matter. Furthermore, someone can be autistic and have an intellectual or speech disability *without* requiring the level of support with daily living described by this term--and there exist autistic people with high IQs and fluent oral speech who nonetheless require this level of support. These individuals are not exceptions to the rule, but common expressions of autism's famously "spiky" profile.

The Lancet report (Lord et. al., 2021) itself acknowledges that someone can have these needs without having correspondingly "severe" autistic traits--but it fails to recognize that people fitting any of the above descriptions can *and do* have any IQ and any communication

profile. Substantial research shows, for example, that cognitive and adaptive functioning can be quite different within the same autistic person, regardless of intellectual disability. Bottema-Beutel et. al. (2021), for example, summarized research showing that autistic people tend to have “spiky” cognitive profiles, wherein their “intellectual and adaptive functioning can vary significantly across domains” (pg. 24). Researchers in 2019 found that, for individuals labeled as “high functioning” based solely on their IQ, that this was not an accurate predictor of their adaptive functioning skills (Alvares et. al., 2019). In other words: individuals who supposedly do *not* have “profound autism,” according to proponents, may require the same level of services described by the Lancet Commission nonetheless.

Rather than trying once again to divide up the autism spectrum with old, flawed assumptions, we should focus on ensuring that every autistic person has access to an individualized, person-centered service plan that identifies our specific needs and connects us to appropriate, personalized supports.

Intellectual Disabilities and Being Nonspeaking Are Not Predictive Labels

The push to create a new “profound autism” designation also rests on flawed assumptions about intellectual disability. These definitions explicitly conflate intellectual disability with specific support needs for daily living and a lack of speech. However, this does not actually reflect what the evidence says about people with intellectual disabilities or nonspeaking autistic people.

Nonspeaking autistic people are impossible to place in a narrow box. In fact, there is “no single set of defining characteristics or patterns of skills or deficits...” (Tager-Flusberg and Kasari, 2013, pg. 468). Nonspeaking autistic people have diverse disabilities and communication profiles, including but not limited to: the extent to which they can speak any words and what kind of speech they can produce in what context, their overall verbal and nonverbal IQ scores (ranging from very low to very high, although IQ tests lack validity for nonspeakers), their overall motor abilities (which greatly impacts the reliability of any assessment), their overall communicative abilities outside of speech (ranging from limited ability to robust use of Augmentative and Alternative Communication (AAC)), their social cognition, and their underlying language processing (Tager-Flusberg and Kasari, 2013, pgs. 468-470). Most importantly, there is a tremendous amount of variation in whether or not nonspeaking autistic people have been given access to best practices and evidence-based supports, including inclusive education and robust, language-based AAC. This lack of consistent access to high-quality support calls into question any attempt to globally summarize the abilities of nonspeakers, or predict their future abilities and outcomes. (Tager-Flusberg and Kasari, 2013; see also TIES Center, 2022). Nonspeaking autistic people would be greatly harmed by the creation of a “profound autism” designation.

Autistic people with intellectual disabilities have historically been referred to as “low-functioning.” The idea behind this type of functioning label, similarly to the current argument over “profound autism,” is that a person’s IQ is predictive of their ability to perform activities of daily living. Nonetheless, as noted earlier, research on this issue has shown that “intelligence estimates are an imprecise proxy for functional ability in ASD” and that similar executive functioning difficulties exist in autistic people with and without ID (Alvares et. al., 2020, pg. 227; Panerai et. al, 2013). Credible resources on intellectual disability, such as the American Psychiatric Association and American Association on Intellectual and Developmental Disabilities, as well as many studies, indicate that a wide variety of inclusive supports may be required by people with intellectual disabilities and that support needs are individualized (American Psychiatric Association, 2021; American Association on Intellectual and Developmental Disabilities, n.d.; Thompson et. al., 2009; Dew, Collings, Savage, Gentle and Dowse 2018). Indeed, most people with intellectual disabilities do not require the level of support described by the Lancet Commission (American Association on Intellectual and Developmental Disabilities and Association of University Centers on Disability, 2016). It therefore is profoundly un-useful and inaccurate to categorize autistic people with intellectual disabilities as a single sub-population that by default requires specific types of supports, such as 24/7 care.

Although research does exist which indicates that autistic people with intellectual disability may as a whole have worse outcomes than autistic people without intellectual disability, this research has not been performed in a vacuum. For example, although some research shows that autistic people with higher Verbal IQs specifically tend to achieve more positive outcomes, such as competitive integrated employment or friendships (McCauley, Pickles, Huerta & Lord 2020; *see also* Anderson, Liang & Lord 2014), all studies on the subject have been performed among a group of people who vary significantly in the extent to which they have received high-quality, inclusive support. It is entirely possible - indeed, likely - that providing consistent access to supports that reflect best practices throughout life would alter outcomes for autistic people with ID. It is therefore premature to state that the presence of an intellectual disability in and of itself is fully predictive of outcomes for autistic people. Over the past 50 years, we have seen expectations about other developmental disabilities such as Down Syndrome radically change as the people with those disabilities were provided with improved supports. There is no reason to think that the autistic community is any different.

Finally, the conceptualization of “profound autism” also rests on the assumption that having an intellectual disability and being nonspeaking are two conditions which invariably occur together. This assumption is not supported by evidence. Autistic people with intellectual disabilities have a wide range of communication profiles, and include many

individuals with fluent verbal speech. As described above, nonspeaking autistic people have a range of assessed verbal and nonverbal IQs, and IQ tests lack validity for nonspeakers. Both populations do share one key aspect—they have a wide range of support needs that can only be truly ascertained by knowing the specific individuals. The variance of supports used by both people with intellectual disabilities and nonspeaking people show that these labels do not singularly illuminate the support needs of any one person. And considering the lack of predictive power of these traits, it begs the question of what utility there is in placing these traits into an even broader and less defined category such as “profound autism.”

We are not arguing that autistic people with high support needs do not need and deserve access to better services than they currently receive. However, the way to improve services is not to create a label that does not provide any actionable information about why a person needs support or what support they need, while encouraging low expectations and restrictive services.

This is not simply a disagreement about what language to use. Functioning labels often dictate whether an autistic person will be given the support and encouragement to live a life of their own choosing. Labeling a young person as “profoundly autistic” could be the difference between them getting to be a full member of their community or ending up in an institution.

We Should Promote Community Inclusion for All Autistic People

As we have established, the label of “profound autism” does not accurately describe a particular group of autistic people with particular support needs. We are also disturbed by arguments from some proponents (and others who have made similar arguments) that people with this label require not merely *more* services, but fundamentally more *restrictive* services than people with other developmental disabilities (Together for Choice, n.d.; Escher, 2021a, August; Escher, 2021b, December; Lutz, 2015; Lutz, 2017; Singer, 2021b, December). Indeed, proponents have been explicit that their underlying motivation for supporting the “profound autism” designation is to justify funneling certain autistic people into these services (Lutz, 2021).

Research overwhelmingly supports one central idea: that people with developmental disabilities - including those with the highest support needs - can not only live in the greater community of people without disabilities, but *do better* in the greater community (American Association on Intellectual and Developmental Disabilities and Association of University Centers on Disability, 2015; Esteban, Navas, Verdugo, and Arias 2021; National Council on Disability, 2015). Research has shown that community living improves factors

as seemingly unrelated as social skills, number of friends, language/communication, overall well-being and employment (Lakin, Larson and Kim, 2011; National Council on Disability, 2015). Furthermore, the benefits are not only limited to people without ID or people with lower support needs. In fact, people transferring from institutions into the community - people who by definition require a high level of support due to service eligibility requirements - show very high gains in all of the above areas (Lakin, Larson, and Kim, 2011). People with intellectual disabilities tended to have a higher self-reported quality of life in community-based settings, greater control over their lives, and higher-quality and larger numbers of friendships and social connections (Kozma, Mansell and Beadle-Brown, 2009; Noonan Walsh et. al. 2010).

The overwhelming majority of evidence over a period of decades shows that community living and inclusive services are a *necessity* for a high quality of life for people with developmental disabilities, including autistic people with high support needs. We urge the IACC to follow the evidence and recognize autistic people as one diverse population of people with IDD who need a range of individualized supports to live in the community. The IACC should reject any arguments that a separate group of people with “profound autism” require institutionalization or similarly restrictive services. Instead, we encourage the IACC to lead the call for substantive and non-duplicative research which builds on the existing evidence base with regards to people with developmental disabilities broadly, and looks further into which specific inclusive services and supports will best help autistic people with complex support needs of many types thrive in the community.

We Should Focus on Improving the Services Available to All Autistic People

Lost in the discussion of “profound autism” was the fact that the Lancet report was written to help illustrate how services for autistic people could be improved. There are too many autistic people who do not have access to the supports necessary to live full, self-determined lives. Research needs to focus on matching services with individual needs, and not segmenting autistic people into groups based on unfounded assumptions. Therefore, instead of drawing arbitrary lines between people with developmental disabilities to segregate services that are not evidence-based, the IACC should instead continue to focus on which services and supports are effective for *all* autistic people and others with IDD across the lifespan.

ASAN will continue to advocate for research and services that meet the needs and promote the dignity of all autistic people. For more information on our positions on this topic, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.

Works Cited

1. Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević, M., Varcin, K., Wray, J., & Whitehouse, A. J. (2020). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*, 24(1), 221–232.
2. American Association on Intellectual & Developmental Disabilities. (n.d.). *FAQs On Intellectual Disability*. Retrieved March 30, 2022, from <https://www.aaid.org/intellectual-disability/faqs-on-intellectual-disability>.
3. American Association on Intellectual and Developmental Disabilities & Association of University Centers on Disability (2015). *Community living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us* [white paper]. TASH. <https://tash.org/wp-content/uploads/2015/08/CommunityLivingPaper-Final-1.pdf>.
4. American Association on Intellectual and Developmental Disabilities & Association of University Centers on Disability (2016, June). *Community Living and Participation for People with Intellectual and Developmental Disabilities*. American Association on Intellectual and Developmental Disabilities. <https://www.aaid.org/news-policy/policy/position-statements/community-living-and-participation>.
5. American Psychiatric Association (2021, August). *What is Intellectual Disability?* American Psychiatric Association. <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>.
6. Anderson, D., Liang, J. & Lord, C. (2014). Predicting Young Adult Outcome among More and Less Cognitively Able Individuals with Autism Spectrum Disorders. *The Journal of Child Psychology and Psychiatry*, 55(5), 485-494. doi: 10.1111/jcpp.12178.
7. Bernhard, Blythe. (2021, December 17th). *Push To Add 'Profound Autism' Label Gains Steam*. Disability Scoop. <https://www.disabilityscoop.com/2021/12/17/push-add-profound-autism-label-gains-steam/29638/>.
8. Bottema-Beutel, K., Kapp, S., Nina Lester, J., Sasson, N. & Hand, B. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, 3(1), 18-29. <https://doi.org/10.1089/aut.2020.0014>.
9. Des Roches Rosa, S. (2021, December 8). *Creating a "Profound Autism" Category Is Segregation, Not Progress*. Thinking Person's Guide To Autism. <https://thinkingautismguide.com/2021/12/creating-profound-autism-category-is.html>.
10. Dew, A., Collings, S., Dillon Savage, I., Gentle, E. & Dowse, L. (2019). "Living the life I want": A framework for planning engagement with people with intellectual disability and complex support needs. *Journal of Applied Research in Intellectual Disabilities*, 32, 401-412. doi: 10.1111/jar.12538.
11. Escher, J. (2021, August 31). *I visited a 21-unit disability housing complex and it was nothing remotely like an "institution."* National Council on Severe Autism. <https://www.ncsautism.org/blog/i-visited-a-21-unit-disability-housing>.

12. Escher, J. (2022, February 9th). *1,000 Shades of Profound Autism*. National Council on Severe Autism. <https://www.ncsautism.org/blog//1000-shades-of-profound-autism>.
13. Esteban, L., Navas, P., Angel Verdugo, M. & Arias, V. (2021). Community Living, Intellectual Disability and Extensive Support Needs: A Rights-Based Approach to Assessment and Intervention. *International Journal of Environmental Research and Public Health*. doi: [10.3390/ijerph18063175](https://doi.org/10.3390/ijerph18063175).
14. Gardiner, Finn. (2018, March 23). *The Problems With Functioning Labels*. Thinking Person's Guide to Autism. <https://thinkingautismguide.com/2018/03/the-problems-with-functioning-labels.html>.
15. Kosma, A., Mansell, J. & Beadle-Brown J. (2009). Outcomes in Different Residential Settings for People With Intellectual Disability: A Systematic Review. *American Journal on Intellectual and Developmental Disabilities*, 114(3), 193-222. doi: <https://doi.org/10.1352/1944-7558-114.3.193>.
16. Lakin, C., Larson, S. & Kim, S. (2011). *The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities?* [policy brief]. National Association of State Directors of Developmental Disabilities Services and Association of University Centers on Disability. http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf.
17. Lord, C., Charman, T., Havdahl, A., Carbone, P., Anagnostou, E., Boyd, B., Carr, T., de Vries, P., Dissanayake, C., Divan, G., Freitag, C., Gotelli, M., Kasari, C., Knapp, M., Mundy, P., Plank, A. Scahill, L., Servili, C., Shattuck, P. ... McCauley, J. (2021). The Lancet Commission on the future of care and clinical research in autism. *The Lancet Commissions*, 399, 271-334. doi: [https://doi.org/10.1016/S0140-6736\(21\)01541-5](https://doi.org/10.1016/S0140-6736(21)01541-5).
18. Lutz, A. (2015, May 26). *Who Decides Where Autistic Adults Live?* The Atlantic. <https://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>.
19. Lutz, A. (2017, May 2). *Adults with disabilities deserve right to choose where to live*. Spectrum. <https://www.spectrumnews.org/opinion/viewpoint/adults-disabilities-deserve-right-choose-live/>.
20. Lutz, A. (2021, December 7). *Lancet Commission Calls for New Category: "Profound Autism."* Psychology Today, <https://www.psychologytoday.com/us/blog/inspectrum/202112/lancet-commission-calls-new-category-profound-autism>.
21. McCauley, J., Pickles, A., Huerta, M. & Lord, C. (2020). Defining Positive Outcomes in More and Less Cognitively Able Autistic Adults. *Autism Research*, 13(9), 1548-1560.
22. National Core Indicators. (2016). *Working in the Community: The Status and Outcomes of People with Intellectual and Developmental Disabilities in Integrated Employment –Update 2* [policy brief]. Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services. http://www.nationalcoreindicators.org/upload/core-indicators/NCI_DataBrief_Employment_Update_2014_2015edit_6_28_2016.pdf.
23. National Council on Disability. (2015). *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community* [white paper]. National Council on Disability. <https://ncd.gov/publications/2015/02242015>.
24. Noonan Walsh, P., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R. & Moseley C. (2010). Supported Accommodation for People With Intellectual Disabilities and Quality of Life: An Overview. *Journal of Policy and Practice in Intellectual Disabilities*, 7(2), 137-142. doi: <https://doi.org/10.1111/j.1741-1130.2010.00256.x>.

25. Panerai, S., Tasca, D., Ferri, R., Genitori D'Arrigo, V. & Elia, Maurizio. (2014). Executive Functions and Adaptive Behavior in Autism. *Hindawi Psychiatry Journal*, Article 941809. <https://www.hindawi.com/journals/psychiatry/2014/941809/>.
26. Singer, A. (2021, January 6). "Profound autism" is the term we need to provide critical specificity to a broad spectrum. Autism Science Foundation. <https://autismspectrumnews.org/profound-autism-is-the-term-we-need-to-provide-critical-specificity-to-a-broad-spectrum/>.
27. Singer, A. (2021, December 7). *Labels can harm, but they also can help: See 'profound autism'*. Stat News. <https://www.statnews.com/2021/12/07/labels-can-harm-but-they-also-can-help-see-profound-autism/>.
28. Tager-Flusberg H, Kasari C. (2013). Minimally verbal school-aged children with autism spectrum disorder: the neglected end of the spectrum. *Autism Research*, 6(6), 468-78. doi: 10.1002/aur.1329.
29. TIES Center (2021, April). *What is Communicative Competence for and with Augmentative and Alternative Communication (AAC) Users?* U.S. Department of Education, Office of Special Education Programs. <https://publications.ici.umn.edu/ties/communicative-competence-tips/what-is-communicative-competence-for-and-with-aac-users>.
30. Thompson J., Bradley, V., Buntinx W., Schalock, R., Shogren, K., Snell, M., Wehmeyer M., Borthwick-Duffy, S., Coulter, D., Craig, E., Gomez, S., Lachapelle, Y., Luckasson, R., Reeve, A., Spreat, S., Tassé M., Verdugo, M. & Yeager, M. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities*, 47(2), 135-46, doi: 10.1352/1934-9556-47.2.135. PMID: 19368481.
31. Together for Choice. (n.d). *Enhancing the Lives of All Individuals with Disabilities*. Retrieved March 30, 2022, from https://www.togetherforchoice.org/files/ugd/91b55f_564f35feb28441029778f049809020ae.pdf?index=true.
32. Zeliadt, Nicolette & Spectrum. (2016, April 1st). *Where the Vocabulary of Autism is Failing*. The Atlantic. <https://www.theatlantic.com/health/archive/2016/04/the-language-of-autism/476223/>.