

Review

# Profound Concerns about “Profound Autism”: Dangers of Severity Scales and Functioning Labels for Support Needs

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**Abstract:** Recently the *Lancet* published a Commission on the future of care and clinical research of autism, which included a side panel arguing for the adoption of “profound autism”, a term intended to describe autistic people who require constant supervision or care, thought to usually have significant intellectual disability, limited or no language, and an inability to advocate for themselves. This state-of-the-art review deconstructs problems with autism sublabels such as “profound autism” and low- and high-functioning labels. It then examines the communicative and cognitive capacities of minimally speaking autistic people, finding that such individuals can communicate (especially with responsive partners) and need nonverbal testing that allows them to demonstrate their potential strengths. It concludes with the ability of minimally speaking autistic people to self-advocate, and the influences of other people to both support and frustrate their communication.

**Keywords:** support needs; neurodiversity; profound autism; inclusion; education



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## 1. Introduction

Recently the *Lancet* published a Commission on the future of care and clinical research in autism, which included a side panel that proposed *profound autism* as an administrative term to describe autistic people likely to have high support needs [1]. The *Lancet* Commission lacks a clear definition or inclusion criteria for “profound autism” but operationalizes it through IQ at or below 50 (in the verbal *or* nonverbal domain, *or* overall) and *and/or* minimal or inconsistent use of phrase speech [1].

However, *because* autistic people have complex diversity in our manifestation of degrees and types of autistic traits and in our support needs, researchers have failed to clearly validate (e.g., independently replicate) subtypes of autism [2]. Even researchers who have championed the idea of multiple “autisms” [3] and described the need to “take autism apart” [4] have abandoned this fruitless quest to instead call for identifying features that are shared between multiple diagnostic categories, e.g., [5]. Indeed, transcending the neurodiversity of individuals, environmental influences such as acceptance versus victimization shape development [6,7]. For example, studies have found that peers are more likely reject autistic people with subtler or “milder” behavioral presentations of autism [8–14], such as the “active but odd” “social interaction style” proposed by Lorna Wing [9,10,15]. Autistic children with active initiation of prosocial approaches more often encounter rejection than autistic children with passive approaches [8–10]. This may explain why “social initiation and affiliation” shows only a weak relationship to other putative “subdomains” of autistic people’s social communication [16], as people who are able and motivated to actively initiate may feel less inclined to do so after rejection. Given the stressful nature of bullying that may target autistic people who appear “odd” rather than “disabled” [11–14,17–19], autistic adolescents’ tendencies to increase in social anxiety even while (a) their typically developing peers decline in it [20] and (b) their autistic traits tend to become less behaviorally pronounced [21], supports evidence that many peers put them into victimization spirals even as they try to “camouflage” or fit in [22,23].

Those who argue for reductionist labels often misapply if not misunderstand pioneers of autism research. While Lorna Wing introduced the notion of an autism “spectrum” [24], she did not intend this in a linear sense, but rather believed in autism’s multi-dimensionality [25,26]. Some have referred to autism with intellectual disability as “Kanner’s autism” or “classic autism”, but Leo Kanner in his first paper on autism described the “unquestionabl[e] . . . good *cognitive potentialities*” of all autistic children he assessed “Even though most of these children were at one time or another looked upon as fee-ble-minded” and railed against the ability of standardized IQ tests to measure the intelligence of autistic children [27] (p. 247). He decried the “dumped” institutionalization of an autistic girl dismissed as “feeble-minded” who he thus felt had an underestimated ability [27]. Concerns remain today that “profound autism” could be used to promote segregation, while lacking validity.

This evidence-based review argues against reductionist functioning terms and “profound autism” for reasons that overlap with the *Lancet* Commission’s repeated acknowledgements (e.g., of autistic people’s “heterogeneity” and “potential for change”) [1]. It questions “profound autism”’s limited scientific validity and feasibility in everyday practice. Next, it argues that the term describes autistics whose limited speech or verbal IQ has caused many to underestimate their communication and intelligence. The synthesis suggests instead evidence-based *personalized* provision for each individual’s profile of strengths and weaknesses, and unity around systemic issues for autistics with the highest support needs to live the lives they want.

## 2. Methodology

This article employs a state-of-the-art review in that it addresses the current matter of the novel “profound autism” category proposed by “The *Lancet* Commission on the future of care and clinical research in autism” [1]. As opposed to more traditional literature reviews, a state-of-the-art review offers a new critical perspective on current issues via a comprehensive review of the literature [28]. It conducts its analysis on the current state of knowledge using narrative synthesis and concludes with priorities for future research [28], focusing its critique on The *Lancet* Commission’s report and the historical context of failed attempts at functioning labels and subtypes for autism.

### 2.1. Research Questions

This state-of-the-art review aimed to address the following four research questions:

- (1) Are functioning labels for autism valid?
- (2) Is the intelligence of autistic people with lower verbal IQs, especially autistic people with intellectual disability according to tests with verbal components, often underestimated?
- (3) Similarly, on which IQ tests do such autistic people tend to fare best?
- (4) Overall, is the communication of autistic people with minimal speech underestimated?

### 2.2. Design

The review initially followed the following inclusion strategy [29,30]:

- (1) All papers published in the journals *American Journal of Intellectual and Developmental Disabilities*, *Autism*, *Autism Research*, *Intellectual and Developmental Disabilities*, *Journal of the American Association of Child and Adolescent Psychiatry*, *Journal of Autism and Developmental Disorders*, *Journal of Child Psychology and Psychiatry*, and *Research in Autism Spectrum Disorders* between 2005 and 2015.
  - a. Papers cited in relevant articles within these journals and time span.
  - b. Papers citing relevant articles within these journals and time span.
- (2) Searches for (a) “high-functioning” or “low-functioning” autism, (b) nonverbal IQ tests and IQ tests with verbal and nonverbal components to which the nonverbal IQ tests have been compared for autistic people (beginning with the “Raven’s” and “Leiter”),

and (c) “minimally verbal” in multiple databases (including Pubmed, PSYCHInfo, and Google Scholar).

Following publication of “The *Lancet* Commission on the future of care and clinical re-search in autism” [1], the inclusion criteria came to encompass:

- (3) The *Lancet* Commission and academic and community sources relevant to a critique of its:
  - a. scientific and social validity
  - b. feasibility
- (4) An updated search related to:
  - a. “minimally verbal” autism
  - b. any literature building from the previously identified sources.
- (5) A multi-database search of literature on autism and augmentative and alternative communication (AAC), in response to reviewer comments requesting content in this area.

### 2.3. Data Analysis

Any identified paper related to the research questions, or otherwise known to the author, was considered for fit, quality, and breadth [28,30,31]. No papers were excluded for contradicting other findings [29], but instead such results required critical analysis [28].

### 2.4. Research Type

This article is a state-of-the art review [28], adapted [31] from a critical narrative review [28,29]. It is adapted in that the original review (see (1) and (2) in the Design subsection for its inclusion criteria) was updated to critique the *Lancet* Commission’s report on the care and clinical research of autistic people [1], and the inclusion criteria grew to cover (3) to (5) as well. The author felt a state-of-the-art review was more appropriate as the scope of the various issues raised by the Commission’s report was too broad for a systematic review. It is critical because the original review, like the review explicated in this article, found that functioning labels for autism lack validity, IQ tests with verbal components may underestimate the intelligence of minimally speaking autistic people, and the communication of minimally speaking autistic people may be underestimated. Therefore, the author decided to critique the empirically unsupported or questionable claims of the *Lancet* Commission, throughout the article’s analysis of (1) functioning labels, (2) the “profound autism label”, (3) the communicative and cognitive capacities of minimally speaking autistic people, and (4) autistic people’s ability and need to self-advocate. My article extensively and flexibly researches and critically evaluates the literature through narrative synthesis [28].

## 3. Functioning Labels

### 3.1. Developmental Gains

Autism varies broadly in manifestations and autistic people have wide differences in support needs, although these have too much complexity to reduce to simple terms such as “profound autism” or “low-” or “high-functioning”. Autistic people tend to make gains over time, as acknowledged by the Commission’s repeated assertions of autistic people’s “potential for change”, that often occurs with age and intervention or environmental modifications [1]. This includes people the Commission retroactively labelled with profound autism, who “moved out” of the category through language and IQ improvements [1] (p. 279). It occurred to the point that the term showed poor stability (only 83%) according to the Commission’s own dataset, compared with autism as a whole (about 91%) [32]. This occurred for a cohort assessed at age 12 and reassessed at age 23 [1,33], yet the Commission claims “profound autism” works best for adolescents and adults [1]. Indeed, the Commission acknowledges that young autistic people with speech delays often improve dramatically [1], yet it says “profound autism” may be applied to “early school age” [1] (p. 278). Most autistics in early childhood with minimal speech may go on to have fluent

speech [34]. This dovetails with evidence that autistic people with speech onset delay tend to have strengths over autistic peers without a history of language delay that helps them to developmentally catch up [35].

### 3.2. Within-Person Variability

Autistic people experience so much within-person variability in their abilities and sensory processing that a participatory study recently identified these as core autistic traits [36]. Performance and functioning commonly change for the same tasks for the same autistic individuals even within the same day [37,38]. For example, sensory (e.g., visual, auditory, tactile) processing has shown atypical variability for autistic people [37]. Autistics have described how factors such as their mental state and the control they have over the environment affect how they perceive sensory stimuli [39]. Similarly, autistic people have shown more variability in their movement for the same tasks over time than people identified as hyperactive or with tics, i.e., people with ADHD and Tourette's [38].

### 3.3. Uneven Skills

Autistic people tend to have highly uneven skills [36,40], which invalidates the assignment to binary categories such as "high-" or "low-functioning". Autistic people often have large discrepancies between verbal and nonverbal IQ scores, with those who have more limited speech usually performing significantly better on nonverbal IQ tests [41]. IQ scores poorly predict academic achievement for autistic youth [42], who usually have verbal and mathematical strengths (e.g., hyperlexia) or weaknesses (e.g., dyslexia) significantly different from their overall IQ score [43]. Autistic people as a group tend to struggle in adaptive functioning, with a gap between (low) adaptive behavior and an IQ that rises with age and test scores. There is especially a mismatch between (low) adaptive behavior and IQ with higher age and test scores [44–52].

### 3.4. Social Context

As the Commission states, "a substantial proportion of the risk of poor outcomes is likely to be socially produced" (p. 277) and "the course of an autistic individual's development is determined by other factors as much as the condition itself" (p. 291), including the enrichment and modification of the social environment [1]. Social context also affects autistic people's functioning, such as the benefits from parental acceptance of autism [53–57] and inclusive educational settings [58–67]. Moreover, peer attitudes [11–13] and a services drop-off after high/secondary school [68–71] may disproportionately adversely affect the functioning of people with subtler autistic traits *without* intellectual disability. The rest of this review will explore how the "low-functioning" and "profound autism" labels may exclude opportunities for and underestimate autistic people. Relatedly, the Neurodevelopmental Disorders Workgroup that revised the autism diagnosis in the DSM-5 opposed a severity scale because autistic people may function well *because* they have support, sharing the concern raised by Ari Ne'eman and the Autistic Self Advocacy Network [72,73].

### 3.5. Need for Support

The DSM-5 Workgroup decided to consolidate all autism diagnoses into one and opposed a severity scale, not because autistic people all have similar needs, but because of the above nuances [40,72,73]. What diagnosis on the autism spectrum an individual received in the DSM-IV era had more to do with the site of assessment they went to than their individual characteristics [74]. Therefore, because the American Psychiatric Association (APA) imposed some form of severity scale, the classifier became reframed as being about "need for support" to try to focus on access needs even when individuals function well [40,73]. The Workgroup similarly also adopted ASAN's recommendation that the levels of need for support "should not be used for eligibility for and provision of services; these can only be developed at an individual level and through discussion of personal priorities and targets" [40] (p. 51, 72). Indeed, separate "severity levels" exist for

the domains of social communication and restrictive, repetitive behaviors [40], so service providers cannot reduce all autistic people to a single severity level.

How these levels get measured has huge implications if used for services, yet the DSM-5 does not offer specifics. As the Commission acknowledges, differences in the methods used to assess intellectual ability, language ability, and autistic traits make a big difference [1]. Against the DSM-5's advice, systems such as Australia's National Disability Insurance Scheme make decisions about eligibility for and the provision of services based on which "severity level" an autistic person supposedly has. It problematically prioritizes these severity levels above actual functional assessments [75]. As the Commission noted, autistic people's support needs have the potential to fluctuate, justifying monitoring and follow-up assessments [1]. However, clinicians and service providers often rely on the initial diagnostic assessment [1], treating the diagnosis as prescriptive when it is more accurate to think of it as descriptive. Despite recognizing such limitations of clinical practice, the Commission nevertheless introduces the term "profound autism" that presents further scientific and practical problems.

#### 4. "Profound Autism" Label

The "profound autism" term recommended by the *Lancet* Commission [1] comes with several self-contradictions that reflect its limitations. As the Global Autistic Task Force on Autism Research noted, the term implies that it describes profoundly autistic individuals [76]. Instead, it describes co-occurring intellectual disability or structural language impairment [1,76], or (implicitly) apraxia of speech (motor problems with speech production) [77,78]. Therefore, it may mislead practitioners and individuals or families to think of those separately diagnosable disabilities as core autistic traits [76]. Moreover, someone with intellectual disability or language impairment may not have "profound" autistic traits [76]. Indeed, autistic traits have only a modest, or even statistically insignificant, relationship to adaptive functioning [79–83]. Among minimally speaking autistic people, the number of words expressed do not clearly relate to autistic traits [41]. However, the Commission defines "profound autism" through cognitive and language skills, even as it admits that research has explained little about how these or co-occurring conditions "contribute to responses to different treatments" [1] (p. 291).

The Commission acknowledges that the DSM-5 [40] and ICD-11 [84] current classification systems encourage diagnosing co-occurring intellectual and language impairments in autistic people [1]. Nevertheless, the report notes that these "are not consistently used in practice or in research" (p. 278) in citing the need for a "profound autism" label [1]. This unofficial label would repeat the same DSM-IV problems of inconsistent research and the practical applications of autism. Indeed, the Commission acknowledges autism's "unreliable categorical subtypes" (p. 293), yet it proposes a new one [1].

##### 4.1. IQ below 50

One of the two main pathways to eligibility for "profound autism" is having an IQ below 50, which the Commission operationalized as being in either the verbal or nonverbal domain [1]. The discrepancy between these domains for such individuals favors nonverbal scores [41], such that someone may have a high nonverbal IQ alongside an extremely low (if testable) verbal IQ [85,86]. Some minimally speaking individuals with a high nonverbal IQ have a good understanding of language [87], and their support needs may look quite different from people who have profound intellectual disability (as the term "profound autism" may also imply).

Diagnosing "profound autism" in practice risks commonly diagnosing non-autistic people with severe to profound intellectual disability as autistic. The DSM-5 stipulates that the diagnosis of autism in the presence of intellectual disability should only occur when social communication traits exceed those expected for the (nonverbal) developmental level [19], which the Commission generally acknowledges [1]. However, among people with severe to profound intellectual disability, people with and without autism diagnoses



may share similar levels of social communication difficulties [88]. That data again comes from adolescents and adults [84], the Commission's recommended period for assigning "profound autism" [1]. It also comes from the first author of the *Lancet* Commission using the ADI-R [89] and ADOS-2 [90] tools the Commission recommended as being better at differentiating between autism and severe intellectual disability or developmental delay, whereas most other instruments perform worse [1].

Rather than express concern about the possibility of over-diagnosing non-autistic people with severe to profound ID as autistic, the Commission advocates for applying autism interventions to people who do not meet the criteria [1]. However, this conflicts with the Commission's repeated advocacy for personalized, evidence-based assessments and interventions that consider individuals' strengths and weaknesses [1], considering that autism-related weaknesses *and* strengths can inform treatment. Autistic people tend to have strengths in visual perception [91,92], which especially apply to autistic people with a history of speech onset delay and lower scores in verbal comprehension [93–98], including those who remain minimally speaking well into childhood [85]. These strengths related to greater core autistic traits [99–101], perhaps because autistic people can usually take in greater amounts of visual information [102,103], but this risks becoming overloading. Colored filters overlaid onto words enabled autistic children with and without intellectual disability to read faster than peers matched for receptive vocabulary, whereas peers had a marginal benefit [104]. Other studies reported similar patterns for colored overlays on photographs for reading facial expressions helping only autistic children [105,106].

#### 4.2. Minimal Speech

In addition to a (verbal or nonverbal) IQ below 50, the Commission describes allowing the eligibility for meeting "profound autism" through a lack of short phrases or sentences in speech [1]. However, autistic individuals may have expressive language or other communication without speech, especially if they have sensory-motor impairments such as apraxia of speech [77,78] and severe dyspraxia of movement [107–109]. These render some autistic individuals unable to produce their own speech without affecting an understanding of language [78], but through accessing a communication system they may express their ideas. While such individuals generally understand more language than they can convey, the *Lancet* Commission unfortunately does not necessarily advise assessing receptive language (only if "this is in question", p. 296), and never mentions apraxia of speech [1]. Individualized approaches to testing can help minimally speaking autistics demonstrate receptive language, which may require multiple types of assessments, such as eye-tracking and responses by touchscreen [86].

Assessment plays a gigantic role in understanding minimally speaking autistics. Studies vary widely in the measures and definitions they use [110]. Five commonly used instruments to measure "minimally verbal" autistics resulted in an overlap ranging wildly from 3 to 100% in a sample of 257 children [91]. However, the Commission did not offer specifics in its definition or how to implement it, and indeed applied different definitions and measurements that contributed to different results [1].

### 5. Establishing Communicative and Cognitive Competencies in Minimally Speaking Autistic People

Designation of "profound" or "low-functioning" autism risks creating the false impression that autistic people cannot communicate or advocate for themselves, an assertion that the *Lancet* Commission makes about most people they consider to meet criteria for "profound autism" [1] yet minimally speaking autistic children can agree or disagree, request, label, and respond [111]; make clear bids for attention [112,113]; and gesture [114]. Autistic children with minimal to no speech can generally learn from observation [115] and understand and engage with goals [116], the syntax of phrases [117]), and stories [118]. They demonstrate interest and affection (e.g., approach, active gaze, touch) and reciprocal imitation in response to others' interactive imitation of their behavior [112,119].

### 5.1. Responsive Communication from Social Partners

Labels such as “profound autism” may cause unintended underappreciation for the role of social partners in autistic people’s communication. It appears that minimally speaking autistic children often lack sufficient opportunity to engage, since others may act intrusively instead of following their lead and imitating their unusual behaviors to elicit their attention [120]. They often exhibit difficulties with disengaging their attention (or a sustained focus that resists distraction), turning their head, and executing intentional actions alongside possibly enhanced perception that may enable skill in peripheral vision. These features may give their bids for joint attention atypical and underrecognized manifestations [121]. Thus, especially perhaps because of these children’s difficulty with processing and producing quick and well-coordinated body language, slower facial expressions and other nonverbal cues from their communication partners help autistic children and adolescents with limited speech to imitate [122]. Similarly, parents’ observation of clinical sessions that model how to interact with their minimally speaking autistic child of elementary school age, and the first month of training on how to communicate with their child produced the greatest gains for parents’ implementation of an intervention for joint engagement with their child [123]. The parents’ fidelity drove the shared engagement [73] that helped the children produce language gains [124] through a greater initiation of interactions [125]. Parents’ use of strategies that synchronize their behavior in response to their child’s, such as matching their child’s pace, mainly account for the gains of this intervention across developmental levels [126].

### 5.2. Educational Inclusion

Such responsive rather than directive communication especially helps speech-delayed autistic people to build language and cognitive skills [127–130]. Responsive approaches require an understanding of the individual to follow their lead and focus of interest, yet autistic and non-autistic people often struggle to understand one another [131–133]. Early maternal understanding of and bond with their autistic child accounted for the child’s placement in an inclusive educational setting, beyond the effects of the child’s IQ or interpersonal competence [63]. Perhaps reflecting difficulties relating to their autistic children, parents have more often preferred inclusion for children with Down syndrome rather than autistic children [134]. Low IQ has also influenced placement decisions for autistic children [135,136]. Higher levels of education inclusion relate to the better functioning of autistic youth, including with intellectual disabilities, beyond the effects of demographic and individual characteristics [59]. The *Lancet* Commission likewise recognized and documented the evidence base of intellectual, educational, academic, and other improvements from educational inclusion for autistic children and adolescents of various abilities [1,114–117]. This evidence underlines the travesty that historically befell children with intellectual disabilities who were assigned diagnoses of *idiot*, *imbecile*, and *moron* and graded for their supposed educability [137,138].

### 5.3. Augmentative and Alternative Communication

Segregated settings for autistic children may cause them to suffer from the lack of typically developing peers as classmates as well as lower expectations and educational quality, such as less instruction and a focus on applied skill development [60–62,139,140]. In a classroom of minimally speaking autistic children, the classroom quality lacked an association with their IQ scores and the adults at school missed many of their frequent communication attempts, limiting them to little engagement mostly with aides [139]. Only one child in a study of 36 minimally speaking autistic students in segregated classrooms used an AAC device and he had among the greatest communication [139]. In the U.S., most special education teachers who supported students with complex disabilities using AAC identify challenges such as a lack of training and of comprehensive assessment, inadequate preparation time, and inconsistent implementation of AAC across staff [141]. Similarly, in Saudi Arabia, special education teachers recognized the school as the biggest barrier to

student access to AAC and professionals' need for training, but family members' support also played a role [142]. Indeed, the perceived value of both parents and professionals toward AAC affect whether and how it becomes used [143]. Unfortunately, many parents, teachers, clinicians, and other practitioners falsely believe AAC may interfere with their minimally speaking autistic child's language development [144].

Instead, AAC can be used to teach a variety of communicative functions, and all systematically reviewed studies showed improvements in communication skills, with the strongest effects for speech-generating devices (SGDs) and communication boards [145]; also see [146–148]. The study with the strongest quality of evidence [145] showed that an SGD-assisted tablets enabled more speech and communication for minimally speaking autistics [124], an effect maintained over time [149]. Individual preference also influences which AAC devices help students gain reliable access to communication [150].

Eye-tracking may help to design even better AAC systems for minimally speaking autistic children [151], given their reduced demands [152]. For example, studies from autistic children suggest that using less realistic and less socially complex images and showing the displays for long enough for them to interpret may help [151]. Minimally speaking autistic children have had less success with eye-tracking trials (60%: [82]) than the rates of the above 80% for non-autistic children with intellectual disability and 90% for autistic children without intellectual disability [152]. Perhaps significant eye-movement problems complicate eye-tracking use; poor oculomotor control relates to lower IQs for both autistic and non-autistic children [153].

#### 5.4. Nonverbal IQ Testing

Searching for strengths, especially among those with less language, may help them to communicate and demonstrate their intelligence. The following section will argue that, among IQ tests, minimally speaking autistic people tend to perform best on the Raven's (Colored) Progressive Matrices, followed, respectively, by the Leiter, Stanford–Binet, and Wechsler. A study recruited 30 autistic children ages six to 12 with minimal or no spoken language attending schools for profoundly impaired autistic children, who could not complete a standard IQ test with a verbal component (the Wechsler). Almost all could complete a nonverbal IQ test that taps into many autistic people's visual–spatial skills (the Raven's Colored Progressive Matrices), and related visual–spatial tasks (a visual search task, and the Children's Embedded Figures Test). Raven's scores varied extremely but the children scored an average IQ of 83, well outside of intellectual disability and nearly within a standard deviation of typical. The autistic children performed faster than Raven's-matched typically developing children, with positive relationships among their performance on the tests. These results indicate that many children potentially considered "low-functioning" or "untestable" show autism-typical perceptual strengths; recognizing them may help tap into their abilities or potential [85]. Indeed, tasks and interventions that use adaptations such as visual supports help to unveil stronger understanding than the expression of language among many minimally verbal autistic children [117,118].

Another study likewise found that autistic children who could not complete tests with verbal IQ scores such as the Wechsler had a mean at the boundary of the normal range of intellectual performance on both the original and revised nonverbal Leiter IQ test, with strengths in visual processing [154]. Their findings parallel the mean IQ at the border of the average range for autistic children on the Leiter at a time (1985) when autism had much more restricted criteria, which surpassed that of the Wechsler [155]. Similar to Courchesne and colleagues' results through the Raven's test [85], Krueger [139] found an extreme range of scores on the Leiter test among the 28 able to complete it in a sample of 36 minimally speaking autistic children, with a child in both samples at the 90th percentile (equivalent of IQ of 120). Studies using the Leiter with autistic children classified as intellectually disabled, "minimally verbal", or untestable on IQ tests with verbal components have consistently reported a mean score at least near the threshold of the average range of intellectual ability: 65 to 72 [124,154–156]. Another study finding a



mean in the intellectual disability range (66.5) on the classic Stanford–Binet Intelligence Scales for autistic children reported a score fully within the average range (88) on the Leiter [157]. Courchesne et al. [85] argue the superiority of the Raven’s over the Leiter for most autistic people, with the mean they reported comparable to the much more verbal children in Grondhuis and Mulick’s [157] sample.

Ravens’ greater appropriateness over even the Leiter, especially for autistic children with the lowest language [85], may support the notion that most minimally speaking autistic people qualify as “high-functioning” if defined by an IQ above 70. The Leiter has resulted in higher scores for most autistic people over not only the Wechsler and Stanford–Binet tests but also the Kaufmann (KBIT-2) scale, even when compared with peers with language impairments [158]. The Leiter and nonverbal IQ of the KBIT-2 almost exactly matched means for autistic children (above 86), while the average verbal IQ on the KBIT-2 again scored in the intellectual disability range (below 67: [158]). In turn, the nonverbal IQ of the Kaufmann test resulted in higher scores for autistic children than the Wechsler. Three quarters classified within the mild intellectual disability or below average ranges on the Weschler compared with the same proportion scoring in the average or above average ranges on the Kaufmann, with none in that highest range on the Weschler [159]. Timing constraints of the Weschler apparently contributed to the discrepancy in this study, as autistic children in this study performed slowly on subtests other than Block Design [159]. That task taps into visuospatial abilities, which several studies have replicated as an area of strength, particularly for autistic people with lower verbal IQ scores [160]. Carothers and Taylor [161] analyzed additional problems of how the challenges of autism and the design of the Wechsler may deflate IQ scores.

This analysis of IQ tests and their applications has shown that the IQ of autistic people with language impairments is often underestimated. The publication date of the studies using the Leiter nonverbal test covered above ranged from 1985 to 2022 [124,139,154–156]. In 1987, prevailing views in the autism field included that three quarters of autistic children possessed intellectual disability and that intelligence tests did not underestimate autistic children’s intelligence [162]. Teachers and especially parents often resisted [163], and by the mid-2010s scientific research overturned [164,165] these beliefs as misconceptions. This brought research full circle to the original accounts of autism, which declared the cognitive potential of all autistic people and, at times, the inadequacy of standard measures of intelligence or otherwise to assess their abilities [27,166,167]. Furthermore, the analysis of claims that most autistic people have intellectual disability suffer from serious empirical problems, such as the fact that most studies repeating this long-standing claim measured development or adaptive behavior rather than intelligence [168,169].

Critics might point out that, in some minimally speaking people, measured expressive [78] and even receptive language [78,170] does not relate to a nonverbal IQ yet this means that an autistic person may have little language but a high IQ; families, schools, and clinicians are likely underestimate their intelligence. Critics might also point out that some minimally speaking autistic people test on the floor even on the Ravens [86]. However, tests may generally underestimate autistic people, who may choose to engage little in them [86,171]. Adaptations such as for visual support [118], timing [117], and attention [172] may help to produce higher scores. Autistic people generally do not perform on command for audiences, which has accounted for why some have scored low on tasks measuring supposed core deficits, such as in ‘theory of mind’ [173].

## 6. Recognizing the Self-Advocacy of Autistic People

As the *Lancet* Commission says, meeting autistic people’s needs requires our inclusion and participation, and must consider our preferences [1]. However, the *Lancet* Commission has little focus on self-advocacy, and few autistic people contributed to it [74]. Indeed, autistic advocates and autistic researchers have lined up against “profound autism”, just as we did against functioning labels [74,174,175].

### 6.1. A Call for Calm

While the Commission reports that “profound autism” concept often means minimal ability to self-advocate, this appears to discount the communication and self-advocacy of autistic people limited by language. As the late nonspeaking autistic advocate Mel Baggs said, “When people generally said to be incapable of communication find ways of making clear what they do and don’t want through means other than words, this is self-advocacy” (p. 223). Baggs clarified that self-advocacy includes what some refer to as behavioral problems in response to abuse or violence against them [176]. For example, bidirectional effects exist between autistic people’s externalizing behaviors and parental distress or criticism, but they appear more driven by parents’ impacts on their children [177,178]. People may tend to underestimate a trend for self-other emotional blurring in autistic people associated with affective sharing in a variety of contexts that may lead to dysregulation from overarousal. For example, autistic people experience heightened distress in response to parents’ distress [178–180], or embarrassment [181] and anger [182] in reaction to other’s such emotions outside the family. Emotional dysregulation may constitute a core feature of autism [183], and anxiety overlaps with core traits in various domains [184]. Anxiety often manifests atypically in autistic people, such as the possibly automatic “flight” or “freeze” responses of shutdowns, avoidance, or withdrawal [185,186] and the “fight” responses of meltdowns (externalizing frustration as aggression or irritability [187,188]). Non-autistic people often misunderstand autistic people’s facial expressions [189,190], further complicating an understanding of the emotions of a minimally verbal autistic person. Autistic people’s relationships with teachers often fares better than with parents [191,192] (although both may function well [193]), which may help to explain why autistics may demonstrate more externalizing behavior around their parents than teachers [194–196]. Certainly, a positive teacher-student relationship promotes academic engagement [197].

### 6.2. Relevance of Neurodiversity

Moreover, the claim of a limited ability to self-advocate for individuals labelled with “profound autism” [1] might have unintended consequences for discrediting the relevance of any advocacy autistic people make on their behalf. Autistic activists’ attempts to speak on behalf of fellow autistics often encounter resistance. These include designations as either “too autistic” to have insight or “not really autistic” and thus not representative because of their articulate capacities. Similarly, critics have defined “functioning” in terms of an ability to effectively communicate and autism advocacy as focused on “low-functioning” individuals [198–201].

Likewise, many classify the neurodiversity movement as only inclusive of or relevant for “high-functioning” people, or—as the *Lancet* Commission hinted—as against all treatment or mitigation of autistic people’s core struggles [1], despite evidence to the contrary [202,203]. In 1992, autistic rehabilitation counselor Jim Sinclair co-founded the neurodiversity movement that originated with autism, and galvanized autistic culture and community through coordinating the first autistic-run autism organization: Autism Network International (ANI; [204,205]). The founders all had speech delays as children, such as Sinclair’s which was onset at age 12 [204], who noted “we had all fit descriptions of ‘low functioning’ autistic people when we were younger” [205] (p. 22). Sinclair [206] emphasizes developmental principles such as the importance that parents learn to speak their child’s language for the growth and well-being of the family. This need finds widespread agreement among self-identified autistic people and non-autistic people regardless of neurodiversity views [202].

Perhaps some confusion about neurodiversity stems from the views of the main coiner of the term *neurodiversity*, Judy Singer. As she stated regarding her thesis, the first time *neurodiversity* appeared in print within the autistic community, “My thesis made clear from the start that I was only advocating for people with high-functioning autism, (or the Syndrome-formerly-known-as-Asperger) when I argued that Aspies should view ourselves as a neurological minority, and that our focus should be on minority rights, not

medicalization" [207] (p. 15). However, autistics active in the neurodiversity movement have denounced "aspie supremacy" [208,209], acknowledge *both* difference *and* disability [210,211], and advocate for supports that ameliorate aspects of autism that threaten quality of life [202]. For example, the movement has prioritized AAC and meaningful communication for all autistic people [212]. Organizations such as the Autistic Self Advocacy Network promote services that particularly benefit people with the highest support needs, such as home- and community-based services for people to live in their own home with the support they need [213].

The tendency for greater support for the neurodiversity movement or opposition to autism's medical model among autistic people includes autistic people who are close to other autistic people with intellectual disability or non-speaking autistic people [214]. Furthermore, both autistic and non-autistic people who are close to non-speaking autistic people tend to have enhanced support for the notion that "Autistic people who can communicate their needs should play a leading role in the development of intervention goals" [214]. Similarly, parents' acceptance of their child's autism [53–55,215] and positive emotions toward their autistic child [216] do not relate to their autistic child's core traits or support needs, or, if anything, acceptance grows as their child's autism becomes more apparent [217]. These studies suggest the potential for consensus in helping autistic people to express their needs and listening to them when they do.

### 6.3. A Call for Unity

A unified autism diagnosis can allow practitioners to provide support at a personalized level with the recognition of individual strengths and needs; developmental, psychiatric, and medical co-occurring conditions; and demographic and social factors. Advocates have more strength in numbers to find a common cause with people with other disabilities for cross-disability systems change, so more people can live happy, safe, self-determined lives in the community. As the Lancet Commission acknowledges, around the world autistic adults often lack access to services, and biomarkers have not usefully helped autistic people [1]. Instead, governments and research organizations can fund more applied services research (including for adults), which may benefit many non-autistic disabled people as well. Research has identified interventions to increase self-determination in high school for students with intellectual disabilities [218,219], which can be adapted as needed for autistic people with intellectual disabilities. Interviews can creatively include minimally speaking autistic youth where possible to discuss what they would like in their future, such as one with an IQ of 33 [220]. With the right support (perhaps consultation with organizations such as ASAN), many parents may elect for supported decision-making rather than guardianship, to help autistic people with the highest support needs make choices about their lives. Indeed, the Commission advocates for "shared decision-making that takes into account patient and family preferences and resources" (p. 283) [1], yet its rhetoric about "profound autism" might inadvertently encourage parents to conserve their children.

With systems change more people can live like Joaquin, a minimally speaking autistic man regarded as having significant intellectual disability, with a history of aggression, self-injury, and seizures. He lives in his own house in the community with around-the-clock paid support staff, friendly neighbors who accept him, and chores and walks in the community he enjoys. His nearby sister, Diana Pastora Carson, understands his limited speech that may seem meaningless to a stranger, and together they advocated to get him out of an institution [221].

## 7. Conclusions

Let us always consider the transactional dynamics of communication and have humility when we do not understand others' communicative acts. We also need to have humility about the vague terms that define "profound autism" and our ability to measure capacities and needs, remembering that the choice of assessment (such as an inappropriate IQ test

with verbal components) may have serious consequences for the individual. Indeed, the implementation of “profound autism” could backfire into service providers only offering services to autistic people who meet that designation, applied conservatively (restrictively) in definition and measurement (e.g., IQ below 50 on the Raven’s). Overall, we must strive for inclusion in society and not use terms to promote segregation.

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