

Levels are for video games, not people:

The reimagining of functioning labels through the DSM-5's autism "levels"

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Note: Some of this toolkit reproduces material I have previously published in the book *An Introduction to Neurodiversity and Autistic Culture for (Music) Therapists*. I have made note of when this occurs, and indented these excerpts in an attempt to make it very clear when previously written content is used. To read an extended excerpt about functioning labels, see chapter 2 of this book.

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Support Levels in the DSM-5

In addition to the diagnostic criteria for an autism diagnosis, the DSM-5 includes the following “levels:”

- **Level 1. "REQUIRING SUPPORT"**

Individuals with this level of severity have difficulty initiating social interactions, may exhibit unusual or unsuccessful responses to social advances made by others, and may seem to have decreased interest in social interactions. Additionally, repetitive behaviors may interfere with daily functioning. These individuals may have some difficulty redirecting from their fixed interests.

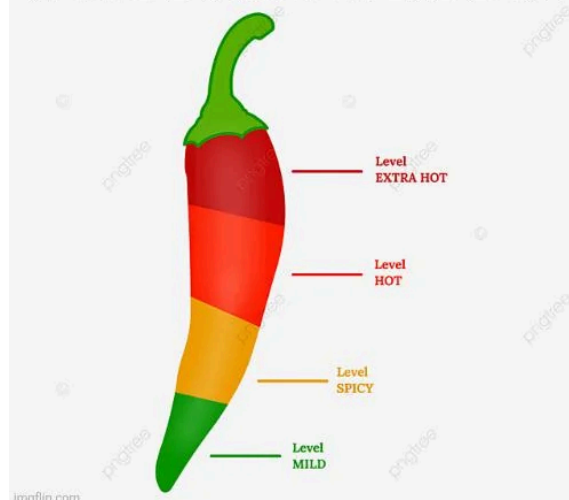
- **Level 2. "REQUIRING SUBSTANTIAL SUPPORT"**

Individuals with this level of severity exhibit marked delays in verbal and non-verbal communication. Individuals have limited interest or ability to initiate social interactions and have difficulty forming social relationships with others, even with support in place. These individuals' restricted interests and repetitive behaviors are obvious to the casual observer and can interfere with functioning in a variety of contexts. High levels of distress or frustration may occur when interests and/or behaviors are interrupted.

- **Level 3. "REQUIRING VERY SUBSTANTIAL SUPPORT"**

This level of severity causes individuals with ASD severe impairment in daily functioning. These individuals have very limited initiation of social interaction and minimal response to social overtures by others and may be extremely limited in verbal communication abilities. Preoccupations, fixed rituals, and/or repetitive behaviors significantly interfere with daily functioning, making it difficult to cope with change. It is very difficult to redirect this person from fixated interests.

How people think autism works



The autism diagnosis also has additional specifiers that include:

- With or without accompanying intellectual impairment
- Associated with a known medical or genetic condition or environmental factor

Catherine Lord, a distinguished professor of psychiatry and education at the University of California, Los Angeles and a member of the American Psychiatric Association's neurodevelopmental disorders committee that contributed to the DSM-5's changes for Autism Spectrum Disorder (ASD), straightforwardly acknowledges that ten years out from the release of the DSM-5, "nobody uses those, ...I mean, it's just not practical to have long phrases." She now considers the levels to be "almost tautological¹" and needs improvement to be considered evidence-based (Montanari, 2023).

Historical Background and Development of the Autism "Levels"

In previous conceptualizations of autism (e.g., DSM-IV-TR and prior), autism was divided into distinct "types," such as Asperger's syndrome, Rett syndrome, or pervasive developmental disorder not otherwise specified. This stratification contributed to a hierarchy of "high functioning" and "low functioning" autistic people.

People who were diagnosed with Autistic Disorder often had more apparent co-occurring disabilities, like apraxia of speech and intellectual disability, resulting in being labeled "low functioning." People diagnosed with Asperger syndrome, who did not have intellectual disability and who had the ability to use spoken language, were typically labeled "high functioning."

This created a range of problems. Writing in 2008, Witwer and Lecavalier found that when using the DSM-IV-TR's diagnostic criteria, the most salient group differences between autism and Asperger's amounted to performance on IQ assessments. Whether a person was diagnosed with autism or Asperger's syndrome was largely dependent on where a person went for their diagnosis, due to "the inconsistent application of diagnostic criteria and circularity in methods" (Witwer & Lecavalier, 2008, p. 1611). Choosing an autism spectrum diagnosis based on the presumed presence or absence of co-occurring intellectual disability is even more problematic when you realize that the standard IQ assessments like the WISC-IV often underestimate the cognitive potential of nonspeaking Autistic people (Nader et al., 2016).

Alvares et al. (2020, p. 221) describe how high-functioning autism, used to describe Autistic people without intellectual disability, particularly under the label of Asperger's syndrome, "[became] synonymous with expectations of greater functional skills and better long-term outcomes, despite contradictory clinical observations." Whether someone was labeled as intellectually disabled or not became a proxy for functional abilities. In practice, high functioning became a way to deny the needs and struggles faced by Autistic people who can speak and have typical intellectual development, while low functioning became a way to deny the strengths, skills, and potential of people with apraxia of speech and intellectual disability.

¹ A tautology is a statement that unintentionally repeats an identical idea using near-synonymous words or phrases. The repetition is not an intentional choice to emphasize a concept. An example from music is Van Halen's lyric "Only time will tell if we stand the test of time," from the song 'Why Can't This Be Love' or Blackalicious' lyrics "After we change the game it won't remain the same" from the song 'Blazing Arrow.' Other examples are phrases like "convicted felon" (you must be convicted in order to be a felon), or "illegal trafficking" (because all trafficking is illegal).

One group was told, “You should know better,” while the other was told, “You’ll never be able to do that.” In both instances, the end result was an act of segregating people who had much in common.



“[So-called] mild autism doesn’t mean one experiences autism mildly... It means you experience their autism mildly.”

While developing the DSM-5, the Neurodevelopmental Disorders Workgroup, responsible for revising the autism diagnosis, opposed the inclusion of a severity scale, even if it was one that attempted to revise focus to support levels, “because autistic people may function well *because* they have support” (Kapp, 2023, para. 14). However, the APA insisted that some form of severity scale must be included, and so the levels 1-3 were created in an attempt to resolve the demand while focusing on access needs.

Critical Analysis of DSM-5 Autism Level Labels

Notice that these levels exclusively examine social differences that are evaluated from the perspective of the neurotypical gaze, or an outside judgment coming from an allistic (non-autistic) perspective, as well as manifestations of a monotropic cognitive style (or a capacity for intense focus on preferred topics and activities, also called special interests). These leveling descriptions do not account for the double empathy problem, or the manner in which allistic people have impairments in their ability to socialize with or understand Autistic people. This lack of cross-neurotype competence is conceptualized as an autistic deficit because allistic, neurotypical parties have the position of power as the dominant social majority.

Vague, Subjective, & Ineffective

Autistic therapist Kaelynn Partlow (2024, p. 19) describes this system, writing that “the language describing the levels is vague and subjective.”

Writing in *The Transmitter*, Shaena Montanari elaborates on this, pointing out that the APA created this system without any “clear quantitative method to determine what the levels should be.” The Autistic Self Advocacy Network (ASAN) was clear in its position against the system, but the American Psychiatric Association (APA) insisted that some type of stratification or levelling system had to be included.

Recreation of Functioning Labels

While perhaps intended to avoid some of the well-documented pitfalls of functioning labels, in practice, they have merely expanded the high- and low-functioning binary to a mild-moderate-severe/profound linear hierarchy. Intellectual disability and the ability to use spoken language are now presented as low- or high-support needs.

In some ways, this may be an improvement because it somewhat shifts the focus to the needs of an individual Autistic person, but in practicality, it has still become a proxy for presumed Autistic capacity. Much of this can be seen in the argument in favor of introducing the label “profound autism.”



Profound Autism

Profound autism is a recent attempt to rebrand the idea of “low functioning” or “severe” autism, despite the long history of self-advocates with intellectual disability and AAC users speaking out against these constructs.

“Profound Autism” is a proposed term to describe autistic people who are:

- Presumed to have significant intellectual disability (e.g., IQ below 50)
- Requiring 24/7 supervision or care
- Nonspeaking and presumed to have limited access to language
- Presumed incapable of self-advocacy

Kapp (2023) notes that this definition is limited by the way it contradicts itself by describing co-occurring disabilities instead of autism itself, which may mislead professionals and family members into believing that these distinct, separately diagnosable conditions describe the nature of autism. At least half a dozen studies have shown that autistic traits are only modestly or insignificantly related to adaptive functioning (Franchini et al., 2018; Hill et al., 2015; Hodge et al., 2021; Pathak, Bennett, & Shui, 2019; Yang et al., 2016).

Just as the DSM's autism levels neglect all autistic traits outside of social differences and monotropic focus, the definition of "profound autism" neglects all Autistic traits and only includes the presence of specific co-occurring disabilities. This, despite the fact that a person with intellectual disability and speech impairments may not be significantly disabled by their Autistic traits, or they may have few Autistic traits. As a result, ASAN considers this to be a harmful oversimplification that neglects to acknowledge that there are both Autistic people who can speak and have an IQ above 50 while needing 24/7 services and nonspeaking people who use AAC while living independently.

Creating a segregated label for Autistic people presumed to have an intellectual disability gets even messier when you consider the findings of Constantino et al. (2020). The researchers reported in the journal *Pediatrics* that 1 out of 8 African American autistic children labeled with an intellectual disability was actually within normal ranges of nonverbal intelligence.

Critical Analysis of Autistic Typing in General

Many of the criticisms of the DSM levels also apply to related ways of dividing and categorizing Autistic people, such as the idea of low functioning vs high functioning, and mild vs severe/profound autism. Whether thinking in terms of step-like levels, mild to severe, or high and low, all of these ways of thinking flatten the heterogeneous, dynamic nature of Autistic lives into a static, neat, and orderly line. This may provide some people with a sense of mastery or competence over an inherently messy, complex subject, but it does not serve the best interests of Autistic people.

As I described in the book *An Introduction to Neurodiversity and Autistic Culture for (Music) Therapists*:

In the book *Sincerely, your autistic child*, Autistic author and activist Mel Baggs (2021, loc. 1562) asks allistic professionals not to compare autistic people to each other. Baggs acknowledges that autism is a heterogeneous condition while asserting that it is not a matter of autism or Asperger's or high- vs. low-functioning, but rather "differences that have no names."

Autism is Not Linear

Interestingly, the first autism theorists did not conceptualize intellectual disability as an expression of autism. Lorna Wing introduced the idea of autism as a spectrum, but never intended this to indicate a linear condition; instead, viewing it as a multidimensional difference.

Excerpt from *An Introduction to Neurodiversity and Autistic Culture for (Music) Therapists*, by Jessica Leza (2023, pp. 33-34):

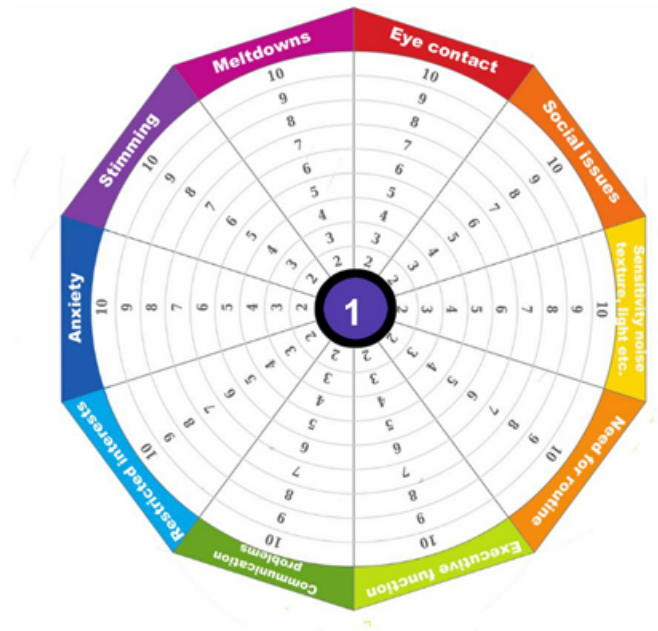
Fletcher-Watson & Happé (2019, p. 39) write in *Autism: A new introduction to psychological theory and current debate* that "when people write about some being at one end of the spectrum it seems to suggest that we might theoretically be able to line up all the autistic people in the world in order of how autistic they are! Rather, variability between autistic people is more like variability between feminine

people.” To cast people’s femininity linearly would be unhelpful at best, or even offensive. Nevertheless, it is still common to hear autistic people referred to in this manner.

.... The neurodiversity movement rejects flattened, linear, and simplistic conceptualizations of autism, instead proposing a flexible, multidimensional, and individualized constellation of characteristic traits and support needs (Silberman, 2012). Autistic advocates point out that linear perspectives of the autism spectrum fail to capture the spiky profile of disproportionate strengths and weaknesses (Lynch, 2019).

Rather than a unidirectional line with binary or ternary options, one could visualize the spectrum as a color wheel or pie chart spectrum, in which a circle is divided into slices corresponding to various autistic traits, providing individualized information in areas like sensory sensitivities, intense interests, or communication differences. Visualizing the ‘autism spectrum’ through models representing a diverse range of skills, areas of need, and personal traits or tendencies provides a more accurate representation of autistic reality.

For example, Claire Jack (2023) provides this example of a fillable pie chart spectrum:



Autistic Capacity for Change

Fletcher-Watson & Happé (2019, p. 40) wrote in *Autism: A new introduction to psychological theory and current debate* that “Asperger’s syndrome became problematic as a separate category as it was realized that often a ‘classically’ autistic child grows into an ‘Asperger-type’ adult.”

One of the problems with both the antiquated “functioning labels” and their modernized “levels” is how both neglect to integrate the fact that Autistic people have an enormous capacity for change – throughout the day, from week to week, and over a lifetime – in complex ways. People who have significant speech delays in childhood may be fluent speakers as adults. I myself had diagnosable speech impairments as a child, received speech therapy at school through an IEP, and am now a fluent oral speaker!

All living beings change. Why should Autistic people be any exception?!

This means that any attempt to describe someone's "level of support" or "functioning" would inherently require intensive and recurring monitoring and follow-up assessment. However, in practice, "clinicians and service providers often rely on the initial diagnostic assessment, treating the diagnosis as prescriptive when it is more accurate to think of it as descriptive" (Kapp, 2023, para. 16).

Finally, poor outcomes for Autistic people are often socially produced (Kapp, 2023). This is cemented by the manner in which the levels are open to subjective interpretation, and allistic interlocutors and evaluators who lack cross-neurotype competence, working in environments that cater exclusively to neurotypical needs, may, in fact, play a significant role in creating a support or functioning level. This issue is explored in depth in the book *Autistic intelligence: Interaction, individuality, and the challenge of diagnosis* by Douglas W. Maynard and Jason Turowetz.

References

- 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. doi: 10.1177/1362361319852831.
- Autistic Self Advocacy Network (ASAN). (2021, December 9). Functioning labels harm Autistic people. <https://autisticadvocacy.org/2021/12/functioning-labels-harm-autistic-people/>
- Baggs, M. (2021). 17 Ten things I wish my parents had known when I was growing up. In S. daVanport, M. G. Onaiwu, & E. P. Ballou (Eds.) *Sincerely, your Autistic child: What people on the autism spectrum wish their parents knew about growing up, acceptance, and identity* (loc. 1426-1568) [eBook]. Autism Women & Nonbinary Network.
- Constantino, J. N., Abbacchi, A. M., Saulnier, C., Klaiman, C., Mandell, D. S., Zhang, Y., Hawks, Z., Bates, J., Klin, A., Shattuck, P., Molholm, S., Fitzgerald, R., Roux, A., Lowe, J. K., & Geschwind, D. H. (2020). Timing of the diagnosis of autism in African American children. *Pediatrics*, 146(3). doi 10.1542/peds.2019 3629
- Fletcher-Watson, S., & Happé, F. (2019). *Autism: A new introduction to psychological theory and current "debate"*. Routledge.
- Franchini, M., Zöller, D., Gentaz, E., Glaser, B., Wood de Wilde, H., Kojovic, N., Eliez, S., & Schaer, M. (2018). Early adaptive functioning trajectories in preschoolers with autism spectrum disorders. *Journal of Pediatric Psychology*, 43(7), 800-813. <https://doi.org/10.1093/jpepsy/isy024>
- Hill, T. L., Gray, S. A. O., Kamps, J. L., & Varela, R. E. (2015). Age and adaptive functioning in children and adolescents with ASD: The effects of intellectual functioning and ASD symptom severity. *Journal of Autism and Developmental Disorders*, 45(12), 4074-4083. doi: 10.1007/s10803-015-2522-6

- Hodge, M. A., Boulton, K. A., Sutherland, R., Barnett, D., Bennett, B., Chan, E. Cramsie, J., Drevensek, S., Eapen, V., Ganesalingam, K., Masi, A., Ong, N., Williamsz, M., Guastella, A. J., Solive, N. (2021). Predictors of adaptive functioning in preschool aged children with autism spectrum disorder. *Autism Research*, 14(7), 1444-1455. doi: 10.1002/aur.2501
- Maynard, D. W., & Turowetz, J. (2022). *Autistic intelligence: Interaction, individuality, and the challenge of diagnosis*. The University of Chicago Press.
- Montanari, S. (2023). Debate remains over changes in DSM-5 a decade on: Changes to the DSM-5's diagnostic criteria for autism were meant to add clarity, but they also generated new questions. *The Transmitter*. doi: 10.53053/TNXZ2048.
<https://www.thetransmitter.org/spectrum/debate-remains-over-changes-in-dsm-5-a-decade-on/>
- Kapp, S. K. (2023). Profound concerns about “profound autism”: Dangers of severity scales and functioning labels for support needs. *Education Sciences*, 13(2), 106. <https://doi.org/10.3390/educsci13020106>
- Partlow, K. (2024). *Life on the bridge: Linking my world to yours as an Autistic therapist*.
- Jack, C. (2023). Here's a copy of the autism wheel! [image]. FaceBook.
<https://www.facebook.com/photo/?fbid=186639990838696&set=a.118579547644741>
- Leza, J. (2023). *An Introduction to Neurodiversity and Autistic Culture for (Music) Therapists*. La Migdalia Press.
- Lynch, C. L. (2019, May 4). 'Autism is a spectrum' doesn't mean what you think. Neuroclastic.
<https://neuroclastic.com/its-a-spectrum-doesnt-mean-what-you-think/>
- Nader, A. M., Courchesne, V., Dawson, M., & Soulières, I. (2016). Does WISC-IV underestimate the intelligence of Autistic children? *Journal of Autism and Developmental Disorders*, 46(5), 1582-1589. doi: 10.1007/s10803-014-2270-z. <https://pubmed.ncbi.nlm.nih.gov/25308198/>
- Pathak, M., Bennett, A., & Shui, A. M. (2019). Correlates of adaptive behavior profiles in a large cohort of children with autism: The Autism Speaks Autism Treatment Network registry data. *Autism*, 23(1), 87-89. doi: 10.1177/1362361317733113.
- Silberman, S. (2012). Autism awareness is not enough: Here's how to change the world. In J. Bascom (Eds.) *Loud hands: Autistic people, speaking* (pp. 358-390). Autistic Self Advocacy Network.
- Witwer, A. N., & Lecavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of Autism and Developmental Disorders*, 38(9), 1611-1624. doi: 10.1007/s10803-008-0541-2
- Yang, S., Paynter, J. M., Gilmore, L. (2016). Vineland Adaptive Behavior Scales: II profile of young children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(1), 64-73. doi: 10.1007/s10803-015-2543-1