

OASIS · AT A GLANCE

The Functioning Labels Debate: Why It Matters for Your Family's Advocacy

This isn't an academic argument happening somewhere else. It shapes policy, drives funding decisions, and determines whether your adult child's needs are even visible to the systems meant to serve them.

BY JIM PALASTY · 10 MIN READ · A LANGUAGE DEBATE WITH REAL FUNDING CONSEQUENCES

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COMPETING PERSPECTIVES THIS DEBATE HOLDS IN TENSION

The autistic self-advocacy community's concern about labels erasing autonomy, and the high-support-needs caregiving community's concern about labels being erased entirely from policy visibility. Both are real.

How it works

THREE STEPS

STEP 1

The diagnostic language keeps shifting

Terms like high/low functioning have given way to support-needs language, support levels, and other evolving frameworks.



STEP 2

The autistic community raises real concerns

Functioning labels can erase individual variability, minimize real struggles in 'high-functioning' individuals, and inflate perceived capacity.



STEP 3

The high-support-needs caregiving community raises real concerns too

A shift away from functioning language can sometimes make Level 2/3 needs less visible in funding and policy conversations, not more.

Language that tends to work in advocacy settings

Instead of 'high-functioning'	Describe specific strengths and specific, real struggles
Instead of 'low-functioning'	Describe specific support needs and specific abilities
Instead of general severity labels	Cite documented, assessed support needs directly
In legislative testimony	Concrete impact and specific need beat broad labels
In CMH planning meetings	Documented, individualized need drives approval more than labels

THE TESTIMONY THAT DROPPED THE LABEL AND KEPT THE NEED

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Corinne had always described her son as 'severely affected' in CMH meetings, a phrase that felt accurate but somehow never seemed to move a stalled request forward. A disability rights attorney suggested she instead describe exactly what he needed and exactly what happened without it: specific hours, specific tasks, specific consequences of a gap. The next meeting, using that more concrete language instead of the label, approved a request that had been denied twice before.

DROPPING THE LABEL AND KEEPING THE SPECIFICS DID WHAT THE LABEL ALONE NEVER MANAGED TO DO.

What matters, at a glance

Where the terminology has moved

The DSM-5's severity levels, support-needs language, and identity-first versus person-first language all reflect an evolving, unsettled framework.

The autistic community's perspective

Many autistic self-advocates argue functioning labels erase real struggles in those labeled 'high-functioning' and real strengths in those labeled 'low-functioning.'

Visibility in policy is a genuine concern

Some caregivers of Level 2/3 adults worry that moving away from functioning language makes their family members' distinct, significant needs harder to see in funding debates.

Both concerns can be legitimate at once

This doesn't have to be a contest between communities. Both concerns point at real, documented problems worth taking seriously.

The practical advocacy impact is real

How you describe your family member's needs in a CMH meeting or legislative testimony directly affects whether services get approved.

Specific, concrete language works best

Describing actual, specific support needs, regardless of which broader terminology debate you favor, tends to be the most effective advocacy approach.

BRING THESE · CHECK AS YOU GO

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| ☐ A review of language currently used in your advocacy materials | ☐ Specific, concrete support needs written out, replacing general labels |
| ☐ Specific examples of impact without a needed service | ☐ Consistency across CMH meetings, testimony, and written appeals |
| ☐ Awareness of both community perspectives in this debate, without needing to fully resolve it | |

YOUR MOVE

When you're advocating and language becomes a factor, here is what to do

- 1 Notice which functioning labels you've been using out of habit.
- 2 Replace broad labels with specific, documented support needs.
- 3 Describe concrete impact: what happens without a specific service.
- 4 Use this specific language consistently across meetings and testimony.
- 5 Stay aware that this debate exists, without needing to resolve it personally.
- 6 Prioritize whatever language actually moves your specific advocacy forward.

This debate will keep evolving. Your advocacy doesn't have to wait for it to settle. Specific, documented need moves meetings regardless of which broader label debate you land on.

LANGUAGE AND ADVOCACY RESOURCES

The Autistic Self Advocacy Network (autisticadvocacy.org) publishes autistic-authored perspectives on functioning labels and identity-first language.

The National Council on Severe Autism (ncsautism.org) represents the caregiving perspective on ensuring Level 2/3 needs remain visible in policy and funding conversations.

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ABOUT THE AUTHOR

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