

LANGUAGE GUIDE FOR NEURODIVERSITY-RESEARCH

Developed for R2D2-MH

Contributors:

Julie Segers, Leni Van Goidsenhoven, Jo Bervoets, Stéf Bonnot-Briey, Nand de Bont, Sofie de Klerk, Chantel Fouche, Anne Freulon, Vincent Grimaldi de Puget, Kristien Hens, Cecilia Ingard, Emily Mullock, Daniel Murray, Lydia Peets, Roderik Plas, Ana Sainz Yagüe, Joke Struyf, Gert-Jan Vanaken

This guide is a 'living document' that will be updated when needed.

Goal of this guide

When writing a scientific paper, words and terminology are tools we often take for granted. Many commonly used terms are considered “standard in the scientific field” and are used without giving them much thought. Many of these terms are assumed to be neutral. However, **language is never neutral**. Rather, language reflects your viewpoint and your way of thinking. **Many so-called “neutral” terms are viewed as offensive, harmful, and pathologizing¹ by neurodivergent people.**

We assume researchers who devote their careers to neurodiversity genuinely wish to help neurodivergent people. The wish to help neurodivergent people is incompatible with the use of pathologizing, deficit-based language. Yet, many researchers still cause harm by the (so-called neutral) language they use. We believe many researchers wish to use the appropriate terminology. Still, it can be challenging to know the preferred terminology as this often differs from terminology in textbooks and older research papers. Furthermore, terminology preferences frequently differ between countries and even between members of communities.

¹ What is pathologizing language?

Pathologizing language is based on deficit thinking. It presents e.g. autism and ADHD as disorders or diseases by default, and autism/ADHD characteristics as harmful or undesirable. It idealises ‘normalcy’ and suggests that e.g. autism and ADHD need to be treated, “cured” and/or prevented. Pathologizing language forms a barrier to cooperation between people with lived experience and researchers, and contributes to the stigmatization of neurodivergent people.

Sources
below

That’s why we designed this guide. **The intention of this guide is not to police your words or restrict your research. Neither is the goal to be more polite or to sugarcoat problems. The goal is to stimulate reflection on how to communicate (and think) about your work, to think about how you can communicate in a way that is both scientifically correct *and* ethically justifiable – without unintentionally causing harm.** We don’t aspire to offer “the” solution, as this does not exist: there is not one right way. We designed this guide to help you explore how your language can best reflect your intentions. We hope you will view this ongoing shift in language use not as a burden but as an opportunity to do better research and to help build a more inclusive world.

Basics of neurodiversity-affirming science

We firmly believe that good, helpful science can only be conducted when it starts from a neurodiversity-affirming viewpoint. So what does neurodiversity-affirming science look like?

In this section, we present some key aspects of neurodiversity-affirming practices. In this guide, we do not dive into the discussion of how neurodiversity can or should be defined. Rather, we zoom in on some important ideas and concepts that we believe researchers should take into account when they wish to conduct meaningful research that can have real-life impact in a positive way.

Different ≠ less

The concept of neurodiversity recognises the significant human diversity. It embraces the diversity regarding cognitive, sensorial, behavioural, emotional, and communicative ways of experiencing and engaging with the world, without stating that certain ways are superior to others. **A neurodiversity-affirming approach stresses the equal value of every human being.**

Writing tip

Neurodiversity or neurodivergence?

Neurodiversity refers to the broad diversity among all people. The whole human species is neurodiverse.

Neurodivergent people are people who diverge from the so-called norm, such as autistics and ADHD'ers.

Writing tip

Negative outcomes

The phrasing “positive / negative outcome” can never refer to the presence or absence of neurodivergence.

To indicate how many people in your sample were neurodivergent:

Do not write “x percent of participants had a negative outcome”

Do write “x percent of participants had autism/ADHD/was neurodivergent”

From this viewpoint, neurodivergence is not systematically seen as pathology or disease, and is therefore **not something to be “cured” or prevented.**

Writing tip

No need for cures

Avoid any language that suggests ADHD or autism should be prevented, “cured” or treated. Do not imply that neurotypical brains are superior or more desirable than neurodivergent ones, or vice versa.

Make lives better, not neurotypical

Some people think the neurodiversity paradigm is purely strengths-based and anti-therapy. This is a misunderstanding: **difficulties of neurodivergent people should not be ignored or minimized**. In line, support, interventions or therapy are not inherently bad. Neurodiversity-affirming support aims to minimize difficulties and increase quality of life. In the light of the neurodiversity-paradigm, the goal of therapy cannot be to prevent neurodiversity or to make neurodivergent people appear less neurodivergent.

Study design tip

Well-being, mental health and other personalized goals identified by neurodivergent people themselves should be the main focus of interventions and research. Therefore, a good study does not solely focus on the presence vs absence of neurodiversity (characteristics), but includes well-being, mental health and/or individualized priorities as outcome measures.

Examples:

- Investigate why a neurodivergent person develops depressive symptoms, rather than why a person develops neurodivergently.
- Investigate the impact of interventions on quality of life, rather than the impact on autism characteristics.

Difficulties ≠ individual problems

The concept of neurodiversity aligns with the social model of disability. **This means that experienced problems of neurodivergent people must be understood in relation to social contexts, which are often not ideally attuned to neurodivergent needs**. In other words, we cannot and should not point fingers towards a neurodivergent individual when difficulties arise. In line, therapy should not (solely) address the individual experiencing difficulties. Instead, we should maximize the fit between the neurodivergent individual and their environment.

Study design tip

Take environmental aspects into account when studying wellbeing and mental health in neurodivergence.

Also take into account that different people might need different environments to flourish.

Terminology for neurodiversity-affirming science

Starting on the next page, we present a glossary. This glossary is not exhaustive, nor “final” as debate is still ongoing (and will continue to evolve over time). We include some common examples of pathologizing language (in the left column) and propose alternatives (in the right column) which align more with neurodiversity-affirming practices. This glossary is based on the input of the CCG’s, the glossary of AIMS-2-TRIALS, terminology guides from international research journals, and research on community terminology preferences.

As mentioned above, there is no “one right way”, as there is rarely consensus across individuals. Therefore, we recommend to **always take into account the preferences of your participants** (if possible) and to **consult sources on language preferences regarding your target audience**. At the end of this document, we provide a reference list regarding language preferences in different contexts and countries, which could support you in justifying your choices on language.

Writing tip

When you step away from commonly used terminology, we advise you to add a statement to your text (e.g. in a footnote) wherein you explain that you consciously step away from the commonly used terms. This will ensure that

- there is no confusion on whether or not you refer to a previously described/studied concept.
- reviewers will not question if you are aware of “how it is usually done”.
- journals and editors are aware of your neurodiversity-affirming approach.

Furthermore, this explicit statement might encourage readers to join you in stepping away from pathologizing language.

GLOSSARY

Pathologizing language	Non-pathologizing alternatives
Autism spectrum <u>disorder</u> ¹	Autism ²
Normal people Healthy population Control group (Non-autistic people)	Allistic people People without [specify neurotype, e.g. autism, ADHD]
Disorder Syndrome Disease Handicap Retardation	Condition Disability <i>Note: also within a neurodiversity affirmative approach it is acceptable to speak of autism and ADHD as a disability. At the same time, there are members of the neurodivergent community who oppose the association with disability.</i>
Symptoms e.g. ADHD symptoms Tendencies e.g. autistic tendencies	Characteristics e.g. "ADHD/autism characteristics"
Comorbidities	Co-occurring conditions
<u>Risk</u> for neurodivergence	Increased/elevated likelihood for neurodivergence <i>Note: "risk" can only refer to negative, undesirable outcomes, e.g. anxiety or depression</i>
Being low/high functioning	Having higher/lower support needs Or be more specific e.g. with(out) co-occurring intellectual disability
Capacity	Capability

¹ It might be necessary to use the term ASD when referring to the diagnostic criteria/conceptualization of e.g. the DSM-5 and ICD11. A footnote or statement might be added to clarify the use of this pathologizing term.

² While the autism community favours the term 'autism' over autism spectrum *disorder* and fiercely advocated to get rid of the term 'disorder', the acronym ADHD functions in a different way. Of course, it still carries 'deficit' and 'disorder' in it, but the ADHD-community reclaimed the acronym and rarely uses the fully written out words. This means 'Disorder and deficit' is not uttered. Please refer to the acronym and do not use the full word that stresses *deficit* and *disorder*. The underlying conceptual shift (from pathologizing towards reclaiming, and inclusive language) is the same as with the autism community (and disability communities in general).

Special needs

Describe the specific support needs (*preferred option*)

Additional needs

Support needs

Additional support

Note: Call it needs when a person cannot function without, when it's a necessity. Call it support when someone can manage without, but it grants them upsides because they have a downside somewhere.

Intervention(s)

Support

(clinical) care

Disruptive behaviour

Problematic behaviour

Behavioural problems

Distress behaviours

Describe it as concrete as possible (*preferred option*), e.g.:

- Meltdown
(i.e. the community-preferred term used to describe behaviour that is uncontrollable and sometimes harmful to self and/or others as a result of sensory overload)
- Shutdown
(i.e. similar to meltdown, in that it occurs within a similar context such as painful sensory overload, but involves shutting off responses to the outside world to avoid further pain. This can be conceptualised as an internalised meltdown)
- Stimming/soothing
(i.e. repetitive behaviours used to relieve stress, decompress, or allow them to narrow their focus on specific activities)

Better vs worse

Deficit-led terminology or generalisations

(especially when discussing subjective issues)

Speak in terms of needs and differences without attributing value

Examples:



- needing support in ...
- not (yet) being able ...
- having difficulty with ...
- preference for parallel play (instead of "less sociable")
- preference for realistic play over fantasy play (instead of "lower level of play")

Note: keep strengths in mind as well! For example special/strong interests or hyperfocus

Resources

We provide you with some resources that can help you gain a deeper understanding and aid you on your journey to become a more ethically aware scientist.

Please note that this list is not exhaustive. We selected some of the most recent and useful resources with special attention for foregrounding neurodivergent researchers.



To facilitate navigating through this list, we sort resources based on content and specify which sources are autism-specific (indicated by ) or ADHD-specific (indicated by ) . When a resource is not marked as autism- or ADHD-specific, the resource discusses neurodiversity in general.

Contents



1. The neurodiversity paradigm.....	9
1.1 What is the neurodiversity paradigm?	9
1.2 On neurodiversity-affirmative interventions and support	9
1.3 On the importance of co-creation.....	10
2. Which words to use (when).....	11
2.1 Why words matter.....	11
2.2 Person-first vs identity-first language	11
In general:.....	11
Preferences per nationality	11
2.3 Journal guidelines	12
3. Sources on specific topics	13
3.1 Why it’s better to not categorise into so-called “high-functioning” and “low-functioning”	13
3.2 Strength-led approaches	13
3.3 Miscellaneous.....	13

1. The neurodiversity paradigm


1.1 What is the neurodiversity paradigm?

- **An accessible primer on the concept of neurodiversity:** see [this overview](#) by LEANS, a project from the University of Edinburgh.
- **Interview wherein Robert Chapman talks about the neurodiversity paradigm:** <https://www.psychiatrictimes.com/view/neurodiversity-paradigm-psychiatry>
- **Powerpoint presentation for researchers and practitioners:** [The Neurodiversity Paradigm: what is in it for researchers and practitioners?](#) By Gert-Jan Vanaken (2022)
-  Pellicano E, den Houting J. (2022). [Annual Research Review: Shifting from “normal science” to neurodiversity in autism science](#). *J Child Psychol Psychiatry*
- Bertilsdotter Rosqvist, H., Chown, N., & Stenning, A. (Eds.). (2020). [Neurodiversity studies: A new critical paradigm](#). Routledge.
-  [‘The Metanarrative of Autism’](#) by Sonya Freeman Loftis
- Dwyer, P (2022). [The Neurodiversity Approach\(es\): What Are They and What Do They Mean for Researchers?](#). Human Development

1.2 On neurodiversity-affirmative interventions and support



- **Common misconceptions** about the neurodiversity paradigm and its stance on interventions/support: [den Houting, J. \(2019\) Editorial: Neurodiversity: An insider perspective](#)
-  **Early autism care:**
 - [Early autism intervention and neurodiversity](#) by Sue Fletcher Watson (2021)
 - [Frontiers | Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice](#) by Leadbitter and colleagues (2021)
- **Support and accommodations in schools:**
 - **Paper** on [neurodiversity in the classroom](#)
 -  **Video** by Dr. Thomas Armstrong (2012): [Neurodiversity and ADD/ADHD: Strategies and Tools](#)
 - **Book** by Robert and Gary (2017): “Neurodiversity in the Classroom: A Strength-Based Approach to Help Students with Special Needs”

1.3 On the importance of co-creation

-  Why Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). [Whose expertise is it? Evidence for autistic adults as critical autism experts.](#) *Frontiers in Psychology*, 8, 438.

2. Which words to use (when)

2.1 Why words matter





-  Gert-Jan Vanaken (2022) [Inclusive Language Use in Autism Research: a Stepping Stone Towards better science?](#)
-  [“Avoiding Ableist Language: Suggestions for Autism Researchers”](#) by Kristen Bottema-Beutel, Steven K. Kapp, Jessica Nina Lester, Noah J. Sasson, and Brittany N. Hand

2.2 Person-first vs identity-first language


Person-first language is e.g. “person with autism” or “child with ADHD”.


Identity-first language is e.g. “autistic person” or “ADHD’er”

In general:


- [Blogpost on Identity first and disability](#) by Feder (2022)
- Gernsbacher, M.A. (2017), Editorial Perspective: [The use of person-first language in scholarly writing may accentuate stigma](#). *Journal of Child Psychology and Psychiatry*, 58, 859-861. doi: 10.1111/jcpp.12706
- In the disability communities (containing neurodiversity community and beyond) the phrase ‘disabled person’ is used the most ([Feder 2022](#); [Okundaye 2021](#))
-  From Autism Self-Advocacy Network (ASAN): [An article detailing the implications of person-first vs identity-first language](#)
-  Botha, M., Hanlon, J., & Williams, G. L. (2021). [Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti](#). *Journal of Autism and Developmental Disorders*, (2020).
-  [Blogpost on pros and Cons of person-/identity-first language](#) by Jevon Okundaye (2021)
-  Lei, J., Jones, L., & Brosnan, M. (2021). [Exploring an e-learning community’s response to the language and terminology use in autism from two massive open online courses on autism education and technology use](#). *Autism*, 1362361320987963.

Preferences per nationality


- **English (Western countries): identity first**
 -  Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2022). [Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation](#). *Autism Research*, 1–23.
 -  Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). [“It Defines Who I Am” or “It’s Something I Have”: What Language Do \[Autistic\] Australian Adults \[on the Autism Spectrum\] Prefer?](#) *Journal of Autism and Developmental Disorders*, 1–11.

 Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). [Which terms should be used to describe autism? Perspectives from the UK autism community](#). *Autism*, 20(4), 442–462.

- **Dutch: person-first**


 Buijsman, R., Begeer, S., & Scheeren, A. M. (2022). [‘Autistic person’ or ‘person with autism’? Person-first language preference in Dutch adults with autism and parents](#). *Autism*.

- **French: identity first**

 Geelhand, F., Papastamou, F., Belenger, M. (et al.) (2023) [Autism-Related Language Preferences of French-Speaking Autistic Adults: An Online Survey](#) in: *Autism in Adulthood*

2.3 Journal guidelines



Autism and JADD have formulated explicit guidelines for authors wishing to publish in their journals. Multiple other journals are following course, reflecting the ongoing nature of the current paradigm shift. When choosing a journal, please check their guidelines regularly, as their requirements might change.

 **Autism:**
<https://journals.sagepub.com/pb-assets/cmscontent/AUT/Autism-terminology-guidance-2021-1626860796.pdf>




 **JADD:** https://media.springer.com/full/springer-instructions-for-authors-assets/pdf/10803_JADD%20Inclusive%20Language%20Guide.pdf

3. Sources on specific topics




3.1 Why it's better to not categorise into so-called "high-functioning" and "low-functioning"

-  From Autism: [‘The misnomer of ‘high functioning autism’: Intelligence is an imprecise predictor of functional abilities at diagnosis’](#) - Alvares GA, Bebbington K, Cleary D, Evans K, Glasson EJ, Maybery MT, Pillar S, Uljarević M, Varcin K, Wray J, Whitehouse AJ (2020)
-  From the National Centre for Mental Health: [‘The Fallacy of Functioning Labels’](#) - blog post by advocate Kat Williams, an autistic parent of autistic children

3.2 Strength-led approaches

-  Kapp, S. et al. (2019) From Autism: [“‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming’ autism](#)
-  Pellicano E, (et al.) [‘A capabilities approach to understanding and supporting autistic adulthood’](#) (2022) *Nature Reviews of Psychology* 1, pages624–639.
-  Urbanowicz, A. (2019) [‘An Expert Discussion on Strengths-Based Approaches in Autism’](#) (2019) *Autism in Adulthood* doi: [10.1089/aut.2019.29002.aju](#)

3.3 Miscellaneous

- Hens & Van Goidsenhoven (2023) [Developmental Diversity: Putting the developmental back into research about developmental conditions.](#) *Frontiers in Psychiatry*
-  **Journal welcoming multi-disciplinary and critical approaches, founded by an autistic person:** [Autonomy, the Critical Journal of Interdisciplinary Autism Studies](#)
- M. Remi Yergeau (2017) [Authoring Autism](#), Duke University Press
-  Disability Studies focused view of the **cultural narratives** of autism: [Imagining Autism](#)
-  From Pediatrics: **‘Eugenics and the Origins of Autism’** - Jeffrey P. Baker (Professor of Pediatrics at Duke) & Birgit Lang (Professor of German at University of Melbourne, historian of gender, sexuality, and disability)
- Video in which representatives from various companies talk about the importance of employing neurodiverse individuals: ["Realising the Potential of Neurodiversity"](#)