A note on language and terminology used in ACoRNS projects and reports

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The language and terminology used in autism research and practice varies widely and often reflects long histories and knowledge bases related to different ways of understanding autism. These understandings vary according to geography, academic discipline, practice-context and individual experiences. Just as our understanding of autism has changed over time, so too has the language used to describe and discuss autism, and this will continue to evolve. It is an area of research and practice that is contended and gives rise to debate and discussion since there is no single way to talk about autism with which everyone will agree (Vivanti, 2020). Therefore, it is always important to make explicit the assumptions we make about this in our own work and to be transparent about our own decision-making and position. In short, the use of language and terminology is not neutral and should be justified.

In ACoRNS published research, on our website, and within project summaries and other dissemination, we use the terms 'on the autism spectrum' and 'autistic' to refer to people with an autism diagnosis unless quoting directly from other authors who use different terminology. We do not use language that directly or indirectly implies pathology or disadvantage, even though this is the formal term used for diagnostic purposes [Autism Spectrum Disorder (ASD)]. We do not use language which promotes or represents an 'ableist ideology' and therefore discriminates against disabled people, albeit unintentionally (Bottema-Beutel et al., 2020, p.1; see especially Table 1).

In taking this stance, we align with a preference for identity-first language ('autistic person') rather than person-first language ('person with autism') and do this for several reasons. First, this is a principled position that reflects and respects the views of many autistic self-advocates who have heavily critiqued person-first language, for example:

> 'Saying "person with autism" suggests that autism can be separated from the person…[and] is something bad – so bad that is isn't even consistent with being a person' (Sinclair, 2013, p. 1).

Second, this is also an evidence-based position: the terms 'autistic' and 'on the autism spectrum' were favoured by autistic people and their families in a large UK-based survey (Kenny et al., 2016). Additionally, an analysis of the use of language in published papers to describe adults and children (Gernsbacher, 2017, pp.860-1) found that person-first language was much more often used to describe disabled people rather than non-disabled people, concluding that:

> '…person-first language appears to stigmatize, rather than de-stigmatize, persons with disabilities, particularly children and particularly children with developmental disabilities.'

Nevertheless, we also acknowledge that 'autistic person' is not an identity that every person on the autism spectrum is comfortable or agrees with, as Adams (undated) argued:

> 'I am a young person with autism, my autism is a part of me, but it does not define me. I know what it is like to have labels put on me'

This, in part, underpins our use of the term 'on the autism spectrum' as well as 'autistic' to acknowledge and respect such differences. Furthermore, should any of our participants also express a strong preference for a specific term or to be referred to using specific terminology, we would also follow their lead within those pieces of work, and make this explicit in our writing.

Finally, we seek to promote a strengths-based approach to understanding and conceptualising autism based on the views of autistic children, young people and adults, their families and those who support and work with autistic people. This approach actively rejects a deficit-focused view of autism that prioritises difficulties and challenges over strengths, interests and capabilities. Instead, we aim for a more holistic understanding and representation of autism in our own work in a way that conceptualises autism as a cognitive difference in line with the neurodiversity movement (Kapp, 2013; 2019) rather than as a disorder or collection of deficits that require fixing. Thus, our approach is inclusive through seeking to prioritise the views and experiences of autistic children, young people and adults to inform practice, and placing the locus for change within attitudes, environment and awareness rather than within the autistic individual.

References

Adams, A. (n.d.). "My autism is part of me, but it does not define me". *Council for Disabled Children*. Retrieved July 8, 2020, from https://councilfordisabledchildren.org.uk/news-opinion/news/my-autism-part-me-it-does-not-define-me

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding ableist language: suggestions for autism researchers. *Autism in Adulthood*. https://www.liebertpub.com/doi/pdf/10.1089/aut.2020.0014

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*(7), 859-861. https://doi.org/10.1111/jcpp.12706

Kapp, S. K. (2013). Empathizing with sensory and movement differences: Moving toward sensitive understanding of autism. *Frontiers in Integrative Neuroscience*, 7(38), 1-6. https://doi.org/10.3389/fnint.2013.00038

Kapp, S. K. (2019). How social deficit models exacerbate the medical model: Autism as case in point, *Autism Policy & Practice*, 2(1), pp. 3-28. Retrieved May 2, 2020, from https://researchportal.port.ac.uk/portal/files/16090863/How_social_deficit_models.pdf

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. https://doi.org/10.1177/1362361315588200

Sinclair, J. (2013). Why I dislike "person first" language. *Autonomy, The Critical Journal of Interdisciplinary Autism Studies*, *1*(2). Retrieved August 29, 2020, from http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1/pdf

Vivanti, G. (2020). Ask the Editor: What is the Most Appropriate Way to Talk About Individuals with a Diagnosis of Autism?. *Journal of Autism and Developmental Disorders*, *50*(2), 691-693. https://doi.org/10.1007/s10803-019-04280-x