

The Neurodiversity Concept Was Developed Collectively: An Overdue Correction on the Origins of Neurodiversity Theory

Monique Botha^a

Robert Chapman^b

Morénike Giwa Onaiwu^c

Steven K. Kapp^d

Abs Stannard Ashley^e

Nick Walker^f

^a Division of Psychology, University of Stirling, FK9 4LA, United Kingdom; m.d.botha@stir.ac.uk

^b Institute for Medical Humanities, Durham University, Stockton Road, Durham, DH1 3LE, United Kingdom; rjpd12@durham.ac.uk

^c AJ Drexel Autism Institute, Drexel University, 3020 Market St #560, Philadelphia, PA 19104, United States of America; mgiwa.onaiwu@gmail.com

^d Department of Psychology, University of Portsmouth, King Henry I Street, Portsmouth, PO1 2UP, United Kingdom; steven.kapp@port.ac.uk

^e Department of English, University of Bristol, 3-5 Woodland Road, Bristol, BS8 1TB, United Kingdom; abs.ashley@bristol.ac.uk

^f California Institute of Integral Studies, United States of America; nwalker@ciis.edu

Abstract

We, an international group of autistic scholars of autism and neurodiversity, discuss recent findings on the origins of the concept and theorising of neurodiversity. For some time, the coinage and theorising of the concept of 'neurodiversity' has been attributed to Judy Singer. Singer wrote an Honours thesis on the subject in 1998, focused on autistic activists and allies in the autistic community email list Independent Living (InLv). This was revised into a briefer book chapter, published in 1999. Despite the widespread attribution to Singer, the terms 'neurological diversity' and 'neurodiversity' were first printed in 1997 and 1998 respectively in the work of the journalist Harvey Blume, who himself attributed them not to Singer but rather to the online community of autistic people, such as the 'Institute for the Study of the Neurologically Typical'. Recently Martijn Dekker reported a 1996 discussion in which one InLv poster, Tony Langdon, writes of the "neurological diversity of people. i.e., the atypical among a society provide the different perspectives needed to generate new ideas and advances, whether they be technological, cultural, artistic or otherwise." Going forward, we should recognise the multiple, collective origins of the neurodiversity concept rather than attributing it to any single author.

Lay Abstract:

This letter discusses the origins of the concept and theory of neurodiversity. It is important to correctly attribute concept and theories to the people who developed them. For some time, the concept of neurodiversity has primarily been attributed to one person, Judy Singer. We consider the available evidence and show that the concept and theory in fact has multiple origins. We draw particular attention to recent archival findings that show the concept of 'neurological diversity' was being used years earlier than previously thought. 'Neurodiversity' means the same thing as 'neurological diversity' and does not change the theory in any way. We conclude that both the concept of neurological diversity or neurodiversity, and the body of theory surrounding it, should be understood as having been collectively developed by neurodivergent people.

Title: The Neurodiversity Concept Was Developed Collectively: An Overdue Correction on the Origins of Neurodiversity Theory

To the editor,

We are writing, as an international group of autistic scholars of autism and neurodiversity, to correct an erroneous and harmful narrative regarding the origins of the concept and theorising of neurodiversity.

For some time, the coinage and theorising of the concept of 'neurodiversity' has been attributed to Judy Singer. While Singer published one early book chapter on the neurodiversity movement in 1999, she was only one of many working on theorising neurodiversity, and certainly not the first. In fact, as we detail below, the 'neurological diversity' or 'neurodiversity' concept – and body of theory surrounding it – was collectively theorised and developed by autistic activists, primarily in the autistic community email list Independent Living in the mid-1990s. While much of this earlier theorising, and that which followed, has been lost due to being on now defunct emails lists, forums, blogs, and so on, in our view it is important to clarify the multiple origins of the concept. This allows us to correctly show that neurodiversity theory arose and was developed *collectively* among autistic activist communities, rather than originating with any individual. We also want to caution against overly simple origin stories that can stifle our understanding of both past and the present. This is in line with the work of Patricia Hill Collins (Collins, 2017), who warns against how an overreliance on emphasis on coining can stifle our historical understandings. It also follows our concern that 'great man' (or woman) theories of history tend to erase complexity in favour of oversimplified, and ultimately inaccurate, misunderstandings.

To establish this, it will first help to go back over the texts that do survive from the 1990s to reconstruct how the currently dominant narrative regarding the history of neurodiversity theory arose. Singer is notable for having written an Honours thesis (roughly equivalent to a Masters) on the subject in 1998, focused on autistic activists and allies in the autistic community email list Independent Living. This was revised into a briefer book chapter, published the following year, forming the first sociological study of this movement (Singer, 1999). Interestingly, though, so far as we have been able to trace, at this time, Singer did not claim to have coined the term of neurodiversity herself and only used the term in passing. Indeed, in her original thesis (republished as a book in 2016), Singer cited earlier 1997 and 1998 articles by the journalist Harvey Blume (1997a, 1997b, 1998), who had written about "neurological pluralism" and "neurological diversity" in 1997 and about "neurodiversity" earlier in 1998. Notably too, Blume's own work had attributed these concepts not to Singer but rather to an earlier online community of autistic people in an email list called Independent Living (1997a) and to the 'Institute for the Study of the Neurologically Typical' or 'ISNT' (1998). This was a spoof of a medical institute that playfully reverses the medical gaze back onto neurotypicals, launched by autistic activist Laura Tisconcik (2020) in 1998.

It was largely after Steve Silberman published the best-selling 2015 book, *NeuroTribes*, that Singer began to be widely seen as the originator of the *concept* of neurodiversity. She and Blume had occasionally been credited with introducing the *term* previously, although without any consistency that we can detect in the writings

of the time. Silberman's account, apparently based on personal communication with Singer, positioned her as having coined the word. According to this view, it was Singer who "came up with the term neurodiversity" (Silberman 2015, p. 451) in phone conversations with Blume, but Blume who "was the first person to use the term in the press" (Silberman 2015, p. 452). This claim was never, to our knowledge, corroborated by Blume (who died last year) and none of his writings attributed the term, concepts, and ideas associated with neurodiversity to Singer in any way. On the contrary, as already noted, he explicitly credited such insights to multiple origins in online autistic communities, and wrote about neurological diversity prior to Singer's involvement. Yet in more recent years, Singer has increasingly claimed both coinage and development of the concept and theory, even being portrayed in *The Guardian* as "the mother of neurodiversity" due to an apparent leading role in the development of the concept (not just the term) (Singer 2020, 2021; Harris, 2023).

Against this backdrop, we wish to draw particular attention to a recent and important archival discovery from Martijn Dekker (2023). Dekker is the founder of Independent Living, the email list on which these ideas were developed (Chamak & Bonniau, 2013). Dekker has recently begun to carefully review his extensive archives from Independent Living, and has discovered clear evidence that the neurological diversity concept was fully formed in 1996, before either Singer or Blume were involved. (Dekker obtained permission from those involved in the discussion to be able to publish it.) In this 1996 discussion (Dekker, 2023), one poster, Tony Langdon, writes of the "neurological diversity of people. i.e., the atypical among a society provide the different perspectives needed to generate new ideas and advances, whether they be technological, cultural, artistic or otherwise." In response to a reply from another poster (longtime autistic advocate Phil Schwarz, who endorses the idea), Langdon adds that "a lot of this 'curing' needs to be applied to society at large" rather than to autistic individuals. Here we see a 1996 community discussion where the concept is already developed and being used.

As Dekker emphasises, what this shows is that the concept was developed collectively by autistic and "cousin" members of the autism rights/neurodiversity movement, certainly by 1996, and likely earlier. This has been further corroborated by other members of the community active during that period (Eidle, 2023). Indeed, prior to this, the 1992 founding of Autism Network International (ANI), may be a better place to locate the genesis of the movement. ANI members such as Jim Sinclair, queer intersex activist and author of the seminal 1993 piece 'Don't Mourn for Us', described by Sarah Pripas-Kapit (2020, p. 23) as a "touchstone for the neurodiversity movement"—and the cross-disability work of activists such as Ed Roberts and Judy Heumann as well as Anita Cameron (who is autistic) and others—laid much of the groundwork for the theory of neurodiversity to be developed.

Unless further archival evidence comes to light, it is possible we will never know who coined the term 'neurodiversity'. But in any case, the coining of this term did not add anything theoretically substantial to the already existing concept of neurological diversity, which as we have shown was already being used in 1996. Moreover, the body of theory that continued to grow through the 1990s and 2000s was also collectively developed in multiple places and dialogues rather than stemming from any single, coherent strand of literature. This includes Kassiane Asasumasu's coining of "neurodivergent" and "neurodivergence" as the opposite of neurotypical;

the application of neurodiversity frameworks far beyond the autistic population from the early 2000s (Antonetta 2007; Kirby, 2004: DANDA); and ultimately a lively and ongoing set of theories, debates, and research programmes relating to what is now termed the neurodiversity approaches or paradigm (Dwyer, 2022). All this and more has formed the basis for the now flourishing field of neurodiversity studies, which spans across the arts, humanities, and social sciences.

To be clear, Singer's work is certainly of scholarly interest as the first known sociological study of the neurodiversity movement. But from this point on we should attribute the coining and theorising of neurodiversity to the pioneering activists who collectively developed them in the autistic community alongside neurodivergent "cousins" (coined by Xenia Grant in the early 1990s: Baggs, n.d.; Sinclair, 2005). They have for too long been erased in favour of an alluringly simple yet ultimately inaccurate version of the history of the neurodiversity movement and its theory, which, in light of new evidence, and backed by our input here, is now clearer. To continue to attribute the coining and theorising of neurodiversity uncritically to any individual would from this point on be to knowingly and egregiously erase neurodivergent people from their own history.

Yours,

Monique Botha

Robert Chapman

Morénike Giwa Onaiwu

Steven K. Kapp

Abs Stannard Ashley

Nick Walker

(The authors wrote this letter collectively and are listed in alphabetical order.)

References

- Antonetta, S. (2007). *A Mind Apart: Travels in a Neurodiverse World*. Tarcherperigee.
- Baggs, n.d. Cousins, ACs, autistics and cousins, autistic cousins, etc. *as small as a world and as large as alone*. Retrieved from <https://withasmoothroundstone.tumblr.com/post/88305423555/cousins-acs-autistics-and-cousins-autistic>
- Blume, Harvey (1997a). "Autism & The Internet" or "It's The Wiring, Stupid". *Media in Transition*. July 1st 1997. http://web.mit.edu/m-i-t/articles/index_blume.html?fbclid=IwAR3vkHBJc8GiommvIZcGN2MPZMCZuV6XQuvGzMhq9LAq8CSzg4nod0GfAPU (accessed 5 September 2023)
- Blume, Harvey. (1997b). Autistics, freed from face-to-face encounters, are communicating in cyberspace. *New York Times*. June 30th 1997. <https://www.nytimes.com/1997/06/30/business/autistics-freed-from-face-to-face-encounters-are-communicating-in-cyberspace.html> (Accessed 1 September 2023)
- Blume, Harvey. (1998, September). 'Neurodiversity: On the Neurological Underpinnings of Geekdom'. *The Atlantic*. <https://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/305909/> (Accessed 1 September 2023)
- Chamak, B., & Bonniau, B. (2013). Autism and social movements in France: a comparative perspective. *Worlds of Autism*, 1, 239-57.
- Collins, Patricia Hill. (1991). *Black Feminist Thought : Knowledge, Consciousness, and the Politics of Empowerment*. Routledge.
- Collins, Patricia Hill. (2017). 'Intersectionality and Epistemic Injustice.' In: Kidd, Ian James; Medina, José; Pohlaus Jr, Gaile. (eds.) *The Routledge Handbook of Epistemic Injustice*. Routledge.
- Collins, Patricia Hill. (2019). *Intersectionality as Critical Social Theory*. Duke University Press. <https://www.jstor.org/stable/j.ctv11hpkdj>
- Dekker, Martijn. (2023). A correction on the origin of the term 'neurodiversity'. *independent living on the autistic spectrum: where those who are different find that they're not alone*. Martijn "McDutchie" Dekker. [blog.] <https://www.inlv.org/2023/07/13/neurodiversity-origin.html> (Accessed 1 September 2023)
- Dwyer P. (2022). The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers? *Human Development*, 66(2), 73–92. <https://doi.org/10.1159/000523723>
- Eidle, Ira, (2023). *Who Really Coined Neurodiversity? [video.]* https://www.youtube.com/watch?v=sNcFzIZCPNq&t=5639s&ab_channel=IraEidle (Accessed 1 September 2023)

Harris, John. (2023, July 5). The mother of neurodiversity: how Judy Singer changed the world. *Guardian*. <https://www.theguardian.com/world/2023/jul/05/the-mother-of-neurodiversity-how-judy-singer-changed-the-world> (Accessed 1 September 2023).

Kirby, A. (2004). *The Adolescent with Developmental Coordination Disorder (DCD)*. Jessica Kingsley Publishers.

Pripas-Kapit, Sarah. (2020). Historicizing Jim Sinclair's "Don't Mourn for Us": A Cultural and Intellectual History of Neurodiversity's First Manifesto. In: Kapp, S. K. (ed.) *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Palgrave Macmillan, Singapore. https://doi.org/10.1007/978-981-13-8437-0_2

Silberman, Steve (2015). *Neurotribes: The Legacy of Autism and How to Think Smarter About People who Think Differently*. Crows Nest Australia: Allen & Unwin. ISBN 978-1-76011-362-9.

Sinclair, J. (2005). Autism Network International: The development of a community and its culture. ANI. Retrieved from https://www.autreat.com/History_of_ANI.html

Sinclair, J. (1993). Don't mourn for us. *Our Voice*, 1(3). Retrieved from http://www.autreat.com/dont_mourn.html.

Singer, Judy. 'Why Can't You be Normal for Once in Your Life?: From a "Problem with No Name" to a New Category of Disability'. In *Disability Discourse*, edited by Mairian Corker and Sally French, 59–67. Buckingham: Open University Press, 1999.

Singer, Judy. *NeuroDiversity: The Birth of an Idea*, Self-published, Amazon, 2017.

Singer, Judy. (2020). *Taster: Explaining Neurodiversity*. Reflections on Neurodiversity. [blog] <https://neurodiversity2.blogspot.com/2020/08/neurodiversity-what-it-is-and-isnt.html> (Accessed 1 September 2023)

Singer, Judy. (2021). *Neurodiversity: It's politics, not science! ... or ...It's the name of a social justice movement, not a diagnosis*. Reflections on Neurodiversity. [blog] <https://neurodiversity2.blogspot.com/2021/02/neurodiversity-its-political-not.html> (Accessed 1 September 2023)

Singh, A.J. (2023). The Tweet That Rocked The Neurodiversity Boat: And the catalyst we didn't know we needed. *Mindbodies Decolonized*. [article] <https://ajs4dlq.substack.com/p/the-tweet-that-rocked-the-neurodiversity?sd=pf> (Assessed 1 September 2023)

Tisoncik, L.A. (2020). Autistics.Org and Finding Our Voices as an Activist Movement. In: Kapp, S. K. (ed.) *Autistic Community and the Neurodiversity Movement*. Palgrave Macmillan, Singapore. https://doi.org/10.1007/978-981-13-8437-0_5 (Accessed 1 September 2023)