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FURTHER TO GO: THE PERVASIVE USE OF UNDESIRABLE MODELS AND LANGUAGE IN RESEARCH ON NEURODIVERGENCE IN ACADEMIC LIBRARIES

Abstract

It has been suggested that LIS literature discussing neurodivergence uses undesirable models of disability and undesirable language despite growing advocacy for alternatives. We examine the models and language used in 46 works on neurodivergence and academic libraries and find that 91% of those works use undesirable language like patronising, person-first, and medicalised/deficit-focused language. The medical model is never explicitly used, but numerous works with no explicit model use medicalised/deficit-focused language. Although no works use explicitly ableist language, undesirable language is present even in works using the social model of disability. Recommendations for future research and practice are provided.

Introduction

Neurodiversity is an umbrella term that describes a diversity of people with differences in neurocognitive functions. Compared to neurotypical people whose neurocognitive functions fall into the societal standards of what is seen as *healthy* and *normal*, the neurocognitive functions of neurodivergent people differ from those standards (Clouder et al., 2020; Walker, 2014). However, what is *healthy* or *normal* – and what is not – is a culturally constructed evaluation or devaluation of otherness (Tumlin, 2009). These cultural values are embedded in the higher education environment and academic libraries, who are an extension of their parent institutions. Subsequently students and staff who do not fit into cultural norms, remain marginalised and disadvantaged (Brook et al., 2015; Hinson-Williams, 2024). Neurodivergent library users face additional barriers when interacting with library resources and services (Magnuson et al., 2024; Walton & McMullin, 2021), which makes them an important patron group to consider for the library practice and also library and information science (LIS) research. However, neurodivergent experiences, needs and opinions remain underrepresented research topics (Braumberger, 2021; Coghill, 2021). Additionally, existing LIS research has been criticised for reproducing ableism by using medicalised language that focuses heavily on deficits, which in turn reinforces systemic ableism and also leads to inaccurate descriptions of disability, which can affect research outputs (Gernsbacher, 2007; Hinson-Williams, 2024; Magnuson et al., 2024).

In this paper we aim to critically examine the language used in LIS literature about neurodivergence and academic libraries in the hope of encouraging more inclusive and respectful scientific discourse in the future. Specifically, we will explore the models of disability employed—whether the medical model, the social model, or the neurodiversity approach—and

analyse the terminology used, such as the prevalence of disability-first versus person-first language, as well as the presence of potentially patronising, medicalised, or deficit-based terms. We therefore pursue two research questions:

1. What models of disability are explicitly used in the literature on neurodivergence and academic libraries?
2. How pervasive is patronising, medicalised, deficit-based and person-first language in the literature on neurodivergence and academic libraries?

Context

Approaches and Models of Disability

Multiple models have been developed that conceptualise disability in different ways. Historically, the medical model of disability as well as medicalised and deficit-based language have been used to talk about disability in academic research but also in public discourses and everyday life (Bottema-Beutel et al., 2021; 2023; Dwyer, 2022; Hinson-Williams, 2024). The medical model mostly regards neurocognitive disabilities as medical *disorders* that limit an individual's functionality. Accordingly, the medical model strives to "fix" disabilities. However, this model has been criticised, since not everyone can or wants to be "fixed" in order to fit into the medical standards of health (Dwyer, 2022). Alternatively, the social model of disability is based on the assumption that disability only leads to physical inaccessibility and exclusion because of the social devaluation of disabled people, which creates barriers (Dwyer, 2022). Criticism has also been directed at the social model of disability that is said not to acknowledge that disabilities do come with differences and challenges (Hinson-Williams, 2024) and to imply that disabled people would, once social barriers are removed, not face barriers any more (Dwyer, 2022; Shakespeare & Watson, 2001). The neurodiversity approach is not a model but an approach to neurodiversity that views differences in neurocognitive functions to be a natural variety of biodiversity that is essential to achieve cultural diversity (Walker, 2014). There are some definitional approaches to this paradigm, that has also been called the neurodiversity paradigm or the neurodiversity framework. Here, physical and social barriers can be changed in order to foster a more inclusive environment, while neurodivergent people can also be taught strategies to adapt to unalterable environments (Dwyer, 2022).

Language

The term ableism describes the discrimination of disabled people and groups through perpetuating ideologies that devalue disabilities (Bogart & Dunn, 2019; Bottema-Beutel et al., 2021; Chellappa, 2023). These values are internalised and normalised in all areas of life, meaning they are systemic (Brown & Leigh, 2018; Hinson-Williams, 2024). Ableism can also intersect with and be aggravated by other oppressive ideologies such as sexism, homophobia, transphobia and racism (Bottema-Beutel et al., 2021). Furthermore, ableism is reflected through the use of language (Bottema-Beutel et al., 2021) that can be found in scholarly research (Chellappa, 2023). Medicalised and deficit-based language (e.g. terms such as "disorder", "special interests or needs", "high/low functioning", "symptoms" or "treatment") has been commonly used in scholarly research on neurodivergent people, which is in accordance with the medical model of disability and depicts disabled people as lesser than the healthy norm, since they are not living up to medical and social requirements, subsequently devaluing disability (Bottema-Beutel et al., 2021; Chellappa, 2023; Hinson-Williams, 2024). Many neurodivergent or

disabled people prefer to use “identity-first language” (Botha & Cage, 2022), since they view being neurodivergent as a central aspect of their identity that they can not be separated from. Using “person-first language” (e.g. *a person with autism*) has been criticised to describe disability as a part of a person that can be separated from their identity and is maybe even unimportant or negative (Sinclair, 2012; Tumlin, 2009). Although some neurodivergent people prefer people-first language, there is near consensus among scholars that the identity-first approach is preferable (Bottema-Beutel, 2021, Hinson-Williams, 2024; Sinclair, 2012). Even though some authors have criticised the use of language in the existing research on the topic (Hinson-Williams, 2024; Magnuson et al., 2024), no work has systematically researched the prevalence of harmful language in the scholarly literature on neurodivergence in academic libraries.

Method

Literature collection – To find relevant literature we searched LISA, Scopus, Google Scholar, and our Humboldt-University library catalogue across all years, using two-part queries that contained different variations of neurodivergent characteristics (Autism, ADD/ADHD, Dyslexia, Learning Disability, neurodivergence) in combination with keywords that describe academic libraries, for example: neurodiversity AND “academic libraries” OR “college libraries” OR “university libraries” ; or dyslexia AND academic librar* OR college librar* OR university librar*. Terms with common abbreviations were searched for in both their full and abbreviated forms (e.g. ADHD OR “attention deficit hyperactivity disorder” AND [...]). Although some terms were omitted from our search (e.g. outdated terms like Asperger's), the included terms represent a variety of common conditions, and variant queries with other conditions/terms — dyscalculia, dyspraxia, Tourette’s — returned no relevant results. Additionally, we followed citations backwards and forwards and checked publications lists of primary authors for further relevant work. Of the initially 91 retrieved items, 39 were upon closer inspection found to be not sufficiently relevant and 6 were inaccessible, resulting in 46 items: 36 journal articles, 2 conference proceedings, 2 book chapters, 2 theses, 2 newspaper columns, 1 report, and 1 training manual.

Data analysis – Each retrieved item was read in detail, their data was organised in a spreadsheet, and they were categorised according to (a) which models of disability they applied (i.e. medical, social, neurodiversity approach, or none) and (b) which categories of desirable and undesirable language they used. Categories of undesirable language as defined by Bottema-Beutel et al. (2021) were used, in particular the exact terms that comprise those categories (e.g. “problematic behavior” is patronising) were sought in the reviewed works. As patronising language was so frequent, we further distinguish person-first language (i.e. with its own category) from more general patronising language. Works that occasionally use identity-first language but otherwise rely on person-first language were categorised as using person-first language. Because ableist discourse as conceived by Bottema-Beutel et al. (2021) was operationalised as the example terms they provided (i.e. as language use), we refer to it as *ableist language*. As works can use multiple kinds of undesirable language, multiple categorisation was used (i.e. a work using two kinds of language will appear in both categories). Quotations and the mentioning of names (e.g. special needs offices) were not counted as uses of language.

Results

Table 1 shows the frequency of explicit use of approaches and models of disability in the literature on neurodivergence in academic libraries. Most works – 35 of the 46 (76.09%) – made no explicit use of a model of disability. Of those that did, all 11 (23.91%) stated use of the social model. One author used the neurodiversity approach *in addition to* the social model of disability; therefore, the works counted in Table 1 add up to 47 rather than 46. No works explicitly stated to use the medical model.

Table 1. Use of models and approaches.

Model (or lack thereof)	Literature
No explicit model (35)	Anderson, 2021; 2025; Anderson & Robinson, 2024; Belger, 2013; Black, 2004; Bliss, 1986; Bloss et al., 2021; Boyer & El-Chidiac, 2023; Carey, 2020; Cho, 2018; Chodock & Dolinger, 2009; Dow & Bushman, 2020; Dow et al., 2020; Everhart & Anderson, 2020; Everhart & Escobar, 2018; Giles-Smith & Popowich, 2020; Green, 2009; Gustavson & Langan, 1990; Hoover, 2013; Jones, 2019, 2021; Lamberts, 2022; Layden et al., 2021; Michael, 1988; Mulliken & Atkins, 2009; Nall, 2015; Napp & Obertacz, 2022; Onwubiko, 2022; Pionke, 2017; Pionke et al., 2019; Remy et al., 2014; Robinson & Anderson, 2022; Seelmeyer, 2024; Strub & Stewart, 2010; Walton & McMullin, 2021
Social (11)	Anderson, 2016, 2018; Braumberger, 2021; Everhart et al., 2016; Giles-Smith & Popowich, 2023; Hinson-Williams, 2024; Magnuson et al., 2024; Riant, 2022; Shea and Derry, 2019a, 2019b; Shea and Derry, 2022
Neurodiversity approach (1)	Hinson-Williams, 2024
Medical (0)	No explicit use of the medical model of disability.

Table 2 shows the use of desirable (identity-first) and undesirable language types used. We found person-first language used in 36 works (78.26%), patronising language in 22 (47.83%), and medical/deficit-based language in 22 (47.83%). Only ten (21.74%) works used the more desirable identity-first language, however six of those also used undesirable language (i.e. only two used exclusively identity-first language, presented in bold in Table 1). Notably, no works used the terms in the ableist language category. Nonetheless, 91.30% of the works examined used undesirable language in discussing neurodivergence in academic libraries.

Among the author names and dates in Table 2 one can observe that some author groups made a transition away from undesirable language; for example, some authors who used person-first language in their earlier works used identity-first language in newer works (Everhart and Anderson, 2018; 2020; 2024), and some authors who used medical/deficit-based language in

earlier papers (Anderson, 2016, 2018; Giles-Smith & Popowich, 2020) omitted such language in later papers (Anderson, 2021; 2024; Anderson & Robinson, 2024; Giles-Smith & Popowich, 2023). Exactly four works used identity-first language and no undesirable language, which are highlighted in the table below (Anderson, 2024; Bloss et al., 2021; Hinson-Williams, 2024; Walton & McMullin, 2021).

Table 2. Pervasiveness of desirable and undesirable language.

Type of desirable and undesirable language	Literature
Person-first language (36)	Anderson, 2016, 2018, 2021; Anderson & Robinson 2024; Belger, 2013; Black 2004; Boyer & El-Chidiac, 2023; Carey, 2020; Cho, 2018; Chodock & Dolinger, 2009; Dow & Bushman, 2020; Dow et al., 2020; Everhart et al., 2016; Everhart & Escobar, 2018; Giles-Smith & Popowich, 2020, 2023; Green, 2009; Hoover, 2013; Jones, 2019, 2021; Lamberts, 2022; Layden et al., 2021; Michael, 1988; Mulliken & Atkins, 2009; Nall, 2015; Napp & Obertacz, 2022; Onwubiko, 2022; Pionke, 2017; Pionke et al., 2019; Remy et al., 2014; Riant, 2022; Robinson & Anderson, 2022; Seelmeyer, 2024; Shea & Derry, 2019a, 2019b; Strub & Stewart, 2010
Patronising language (22)	Anderson, 2016, 2018, 2021; Black, 2004; Bliss, 1986; Braumberger 2021; Cho, 2018; Dow et al., 2020; Everhart & Escobar, 2018; Giles-Smith & Popowich, 2020; Green, 2009; Gustafson 1990; Hoover, 2013; Lamberts, 2022; Mulliken & Atkins, 2009; Napp & Obertacz 2022; Onwubiko, 2022; Pionke, 2017; Pionke et al., 2019; Remy et al., 2014; Robinson & Anderson, 2022; Shea & Derry, 2022
Medical/Deficit-based language (22)	Anderson, 2016, 2018; Belger, 2013; Bliss, 1986; Carey, 2020; Cho, 2018; Dow et al., 2020; Everhart et al., 2016; Everhart and Escobar, 2018; Everhart & Anderson, 2020; Giles-Smith & Popowich, 2020; Green, 2009; Jones, 2021; Magnuson et al., 2024; Onwubiko, 2022; Remy et al., 2014; Riant, 2022; Robinson & Anderson, 2022; Shea & Derry, 2019a, 2019b, 2022; Strub & Stewart, 2010
Identity-first language (10)	Anderson, 2025; Bliss, 1986; Black, 2004; Bloss et al., 2021; Braumberger, 2021; Everhart and Anderson, 2020; Gustavson & Langan, 1990; Hinson-Williams, 2024; Shea & Derry, 2022; Walton & McMullin, 2021

Discussion

Even though no author actively states that they used the medical model of disability, almost half of the works used medical/deficit-based language, and such use constitutes an implicit application of the medical model of disability, which, through its language, reinforces ableist stereotypes even when used unintentionally (Hinson-Williams, 2024). To further understand the pervasiveness of *implicit* use of models, especially since we did not systematically analyse for such use here, implicit model use should be the topic of future research on ableism in LIS research. Nonetheless, some explicit model use was identified. The social model of disability is explicitly used in 23.91% of the analysed works, with a notable trend toward its adoption in more recent works. Despite this positive trend, there is evidently still a need to further educate LIS scholars to correctly apply the social model and use language that is in accordance with the social model of disability. Notably, the neurodiversity approach – the preference of neurodivergent people – was used in only one work, which suggests that there is still a need for education about and further use of the neurodiversity approach. This enduring need for inclusion of neurodivergent stakeholders into LIS research and the development of academic library services echoes previous calls for such inclusion (Anderson, 2018; Hinson-Williams, 2024; Pionke, 2017; Pionke et al., 2019).

Undesirable language remains pervasive in the literature on neurodivergence and academic libraries: all works but four used some undesirable language, with person-first, patronising, and medical/deficit-focused language all being used pervasively. Furthermore, there are works where patronising language was used even though the social model of disability was applied (e.g., Braumberger, 2021; Giles-Smith & Popowich, 2023), which shows that even when authors attempt to use inclusive models they often (i.e. in 10 of 11 such cases) struggle to fully adopt them and their language. The simultaneous use of the social model with patronising language suggests that despite growing awareness of more inclusive language, and lack of explicitly ableist language, ableism nonetheless persists in the academic discourse. Evidently there remains a gap between the prescriptions for increased inclusivity and its practical implementation in academic writing. Accordingly, we can only recommend that LIS scholars double their efforts to fully apply the social model of disability or the neurodiversity approach, which entails using more respectful and inclusive language when discussing neurodivergence and neurodivergent patrons. LIS scholars could benefit from targeted training and workshops on inclusive language and disability frameworks, developed in collaboration with neurodivergent stakeholders. Learning materials could entail guidelines and documentation on applying the social model of disability and the neurodiversity approach. Furthermore, journal and peer review guidelines could be updated to include the use of the social model/neurodiversity approach and inclusive language.

Conclusion

LIS research has been criticised for using ableist language when discussing neurodivergence in academic libraries (Hinson-Williams, 2024; Magnuson et al., 2024). Indeed, this study found evidence of the pervasiveness of harmful language: 91.30% of the examined works used person-first, patronising, or medical/deficit language. Such language reflects and furthers ableist social

values and stereotypes (Botha, 2021; Hinson-Williams, 2024). The findings of the study also show a persistent gap between the stated use of the social model of disability and the continued reliance on medical/deficit-based language in the literature on neurodivergence and academic libraries. The pervasive use of hurtful language shows the need for improvement and more critical reflection on and intentional alignment with the preferences of neurodivergent stakeholders such as patrons and other researchers.

While our findings show the problematic use of the medical model and hurtful language in the specific topic on neurodivergence and academic libraries, they reflect more widespread problems as seen in other works on ableism in LIS research (Cowell, 2024) and ableism in academia and academic writing (Lindsay & Fuentes, 2022). The use of the medical model and hurtful language in LIS research creates the need to further address the topic of language in the existing research on neurodivergence in academic libraries in order to build an inclusive and accessible learning environment for all patrons. LIS scholars need to study both neurodivergent stakeholders but also the social context around them, and how systemic bias and social injustices are reflected and manifested within their research. This includes reflecting personal, institutional and social bias in order to challenge and change existing power structures, towards co-liberation away from oppressive systems that are harmful and limiting towards everyone (D'Ignazio & Klein, 2020; Gibson et al., 2021).

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