

The Impact of Nomenclature in Intervention on (Autistic) Persons (on the Spectrum)

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Disclosure

Financial:

- Katrina Quinones has no relationships to disclose.
- Karissa Marble-Flint completes research such as this study as part of her role at Wichita State University.
- Trisha Self completes research such as this study as part of her role at Wichita State University.
- Aaron Bowen completes research such as this study as part of his role at Wichita State University.

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- Katrina Quinones is a member of KSHA.
- Karissa Marble-Flint is a member of KSHA.
- Trisha Self is a member of KSHA.
- Aaron Bowen has no relationships to disclose.



Learner Objectives

1. Identify key models of disability and how autism nomenclature fits within those models.
2. Discuss findings from this systematic review detailing preferred terminology for (autistic) persons (on the spectrum) as well as rationale given for those preferences.
3. Identify potential effects terminology can have on stakeholders (i.e., autism community and professionals).



Models of Disability	Description
Medical Model of Disability	Views disability as an impairing health condition or process to the necessity of requiring medical care/intervention; focused on finding and providing a cure for the disability
Expert or Professional Model of Disability	Assigns an authoritarian/dominant role to the service provider and a passive/submissive role to the client
Social Model of Disability	Views disability as a sociological construct requiring social action to approach the problem
Identity Model of Disability	Views disability through the lens of “disability as a social construct”; claims disability as a positive identity, a component of the individual’s personality
International Classification of Functioning, Disability, and Health	Incorporates science and research with other disciplines as well as including culture and language to create a comprehensive and universal means to providing services



Bölte, S., et al., (2021).

Disabled World, (2010).



Terms

Neurodiversity- a term influenced by the social model of disability; recognizing strengths rather than pathologizing weaknesses. First coined by sociologist Judy Singer in 1998.

Ableism- discrimination or social prejudice in favor of those who are able-bodied; those who do not comply with the “expected norms” require fixing or a cure. Further stereotypes and misconceptions of persons outside the perceived norms.

Shah et al (2022).

Person-first language

Language that uses post-modifiers to describe [a person with a disability]. It is considered to be the standard language used by stakeholders within medical and professional settings.

Identity-first language

Language that uses pre-modifiers to describe [a disabled person]. It is typically the language utilized by stakeholders who attribute a disability to a component of their identity.

Research Question

What effect does person-first language vs. identity-first language have on the self-perception of autistic adults?

Method

<u>P</u>	<u>E</u>	<u>S</u>	<u>I</u>	<u>CO</u>
Autism Adulthood	Current Environments (Since 2017)	Direct, Secondary	IFL vs PFL	Impact on stakeholders/ Person

Databases:

1. PubMed (ProQuest)
2. CINAHL
3. PsychINFO
4. ERIC (EBSCO)

Table 1. Database search construction

Search	Search Term Construction	Articles Located
1 PubMed (Medline)	(autis* or ASD or "autism spectrum disorder*") AND (person-first OR identity-first) Filter: English, Adult 19-44 years, 2017-present	4
2. CINAHL	(autism or asd or autism spectrum disorder or autistic) AND (person-first OR identity-first) Filter: English, Peer-reviewed, 2017-present	16
3. PsychINFO	(autism or asd or autism spectrum disorder or autistic) AND (person-first OR identity-first) Filter: English, Adulthood (18 yrs & older), 2017-present	6
4. ERIC (EBSCO)	(autism or asd or autism spectrum disorder or autistic) AND (person-first OR identity-first)	2
	Filter: English, Peer-Reviewed, 2017-present	
TOTAL		28

Seven articles that were duplicates and/or not within the appropriate age demographic were excluded. This process left 21 articles total.

Results



<p>Arnhart, C., Neale, M., Collins, C., Chesher, T., Coffey, S., Rogers, T. C., Ottwell, R., & Hartwell, M. (2022).</p>	<p>Guage person-centered language (PCL) adherence in peer-reviewed research publications using a cross-sectional study.</p>	<p>Within research articles or scientific writings using IFL or non-PCL terminology, stigmatizing language is more often present than it would be found within writings utilizing PFL terminologies.</p>	<ul style="list-style-type: none"> Identifying language within medical research need to be intentional and used with care. Articles using PFL terminologies often demonstrate avoidance of stigmatizing language and mirror clinical and medical education and practices.
<p>Botha, M., Dibb, B. & Frost, D. (2020).</p>	<p>Investigate [autistic] persons' [on the spectrum] perceptions of the autism experience through use of critical grounded theory tools.</p>	<p>The interview-based qualitative study reported "identity" and "stigma" as the core categories in the overall findings.</p>	<ul style="list-style-type: none"> The neurodiversity (as opposed to a medical model of disability) falls more in line with the participants' views of autism.
<p>Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2023)</p>	<p>Investigate autism-related terminology preference/disinclination and possible reasons for/against particular terms in Australia.</p>	<p>{Quantitative}</p> <ul style="list-style-type: none"> Means of preference: autistic 4.56, person on the autism spectrum 4.47, autistic person 4.44, person with autism 3.64, person with ASD 3.37, person with ASC 3.36. Means of offensive: person with ASD 3.31, person with autism 3.11, person with ASC 3.03, autistic person 2.54, autistic 2.52, person on the autism spectrum 2.43. <p>{Qualitative}</p> <p>Six themes coded from free text responses:</p> <ul style="list-style-type: none"> Being autistic is my identity Having autism is a part of my identity Diversity within the spectrum I am different not disordered Language can stereotype and stigmatize Pragmatic 	<ul style="list-style-type: none"> Autism-related language (whether IFL or PFL) reflected participant perceptions of self-identity. autism-related terminology should be decided per individual case. The use of both IFL and PFL within academic literature may help to destigmatize terms that would otherwise be considered offensive.

Article	Study Aim/Research Question(s)	Findings	Conclusions
Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023).	Investigate autism-related terminology preferences and possible reasons for/against particular terms across 30 different countries.	<p>{Quantitative – Using ANOVAs for stats.}</p> <ul style="list-style-type: none"> Language preferences related to autism nomenclature: autism 92.8%, autism spectrum disorder 60.7%, autism spectrum condition 29.5%. Preferences relating to self/person: autistic person 79.5%, neurodivergent person 70.0%, autistic 67.4%, person on the spectrum 32.4%, person with autism/autism spectrum disorder/autism spectrum condition 23.9%. Preferences for referring to someone's autistic identity: is autistic 85.0%, is neurodivergent 68.8%, has autism/autism spectrum disorder/autism spectrum condition 37.9%. Language preferences relating to how autism is conceptualized more broadly: neurological/brain difference 79.8%, disability 62.4%, condition 46.3%, disorder 33.6%, disease 1.7%. Language preferences relating to how we talk about the difficulties of autistic people: differences 76.9%, challenges 76.3%, difficulties 75.1%, lower/higher performance 13.5%, deficits 11.8%, poorer/better performance 10.4%. Preferences of terms referring to non-autistic people: neurotypical people 75.4%, neurotypicals 73.2%, non-autistic people 65.1%, non-autistics 49.8%, allistic people 49.5%, allistics 44.3%, control participants 10.6%, typically developing people 9.9%, controls 9.5%, typical people 2.3%. <p>{Qualitative}</p> <p>Thematic analysis of participant responses yielded six core themes with varying numbers of subthemes under each theme. Core themes were labeled as the following:</p> <ul style="list-style-type: none"> Problems of differentiation We are different, not less Autism is me Claiming language and community Be concise, be accurate, be specific Respect and hear our voices 	<ul style="list-style-type: none"> Though there was a greater majority preference/endorsement for IFL (75.9%-88.1% across all countries studied) than for PFL (18.5-28.6% across all countries studied), these results were presented to participants as how they would refer to themselves rather than how should others refer to them. Due to the great variability of preferences for identifying language, it is imperative to defer to the community (of [autistic] people [on the spectrum]) and use their terminology.

Article	Study Aim/Research Question(s)	Findings	Conclusions
Donaldson, A., & Krejcha, K., & McMillin, A. (2017)	Introduce and discuss autism-related terminologies and topics.	Many disciplines utilize PFL as the standard; however, one should consider the stakeholder's preference when using autism-related terminologies.	<ul style="list-style-type: none"> • Professionals should exercise caution when using identifying language so as to not hinder the client-clinician relationship.
Lei, J., Jones, L., & Brosnan, M. (2021).	Develop the evidence-base of the Kenny et al. study (2016) that involved identifying language for [autistic] persons [on the spectrum].	<ul style="list-style-type: none"> • Self-advocates preferred autistic (20/37=54.1%), • Family and friends preferred autistic (87/250=34.8%) • Professionals indicated no preference (133/443=30.0%) or preferred "person with autism " (90/443=20.3%) or "on the autism spectrum" (91/443=20.5%). 	<ul style="list-style-type: none"> • Use of terminology (person-first or identity-first) has an impact on and can create conflict within primary stakeholders. • Though no definite term could be identified for all stakeholders, primary and secondary stakeholders all agreed that the [autistic] person's [on the spectrum] opinion carries the highest priority and should be respected.
Shakes, P., & Cashin, A. (2019).	Review empirical research and discussions relating to identifying language for [autistic] people [on the spectrum].	<ul style="list-style-type: none"> • The scoping review acknowledged that research relating to identifying language for [autistic] persons [on the spectrum] is scarce. • No identified research within this scoping review was found to address outcomes (positive or negative) associated with either identity-first language or person-first language becoming the dominant terminology used by primary or secondary stakeholders. 	<ul style="list-style-type: none"> • Further research is needed to investigate outcomes associated with identifying language. • As there is still a divide within the identifying language used for this population, professionals should address stakeholders as each individual prefers.

Article	Study Aim/Research Question(s)	Findings	Conclusions
<p>Taboas, A., Doepke, K., & Zimmerman, C. (2023).</p>	<p>Survey stakeholders (primary and secondary) to ascertain preferences for identifying language in the United States mirror results obtained in studies conducted in the United Kingdom (by Kenny et al., 2016) or in Australia (by Bury et al., 2020).</p>	<ul style="list-style-type: none"> • Primary stakeholders [autistic adults] rated IFL terms higher than PFL terms (M=3.21 SD=.73 vs M=2.48 SD=.85). • Parents of [autistic] children [on the spectrum] rated both IFL and PFL terminologies similarly (M=3.09 SD=.54 vs M=3.05 SD=.86, respectively). <p>Other groups preferred PFL</p> <ul style="list-style-type: none"> • family member/friend M=3.47 • professional M=3.44 • little to no experience M=3.42 <p>Rather than IFL</p> <ul style="list-style-type: none"> • family member/friend M=2.88 • professional M=2.79 • little to no experience M=2.89). 	<ul style="list-style-type: none"> • Though absolute global consensus regarding identifying language is not ascertained, [autistic] people [on the spectrum] are aligning autism terminology toward identity-affirmation and identity descriptors. • Research is needed to probe impact of IFL vs PFL terms.

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Systematic Review Articles

Arnhart, C., Neale, M., Collins, C., Chesher, T., Coffey, S., Rogers, T. C., Ottwell, R., & Hartwell, M. (2022). The Use of Person-Centered Language in Scientific Research Articles Focused on Autism. *Journal of developmental and behavioral pediatrics : JDBP*, 43(2), 63–70. <https://doi.org/10.1097/DBP.0000000000001038>

Botha, M., Dibb, B. & Frost, D. (2020). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*. 37(3). 427-453 <https://doi.org/10.1080/09687599.2020.1822782>

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2023). "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*, 53(2), 677–687. <https://doi.org/10.1007/s10803-020-04425-3>

Donaldson, A., & Krejcha, K., & McMillin, A. (2017). A strengths-based approach to autism: Neurodiversity and partnering with the autism community. *Perspectives of the ASHA Special Interest Groups*, 2(1). 56-68. <https://doi.org/10.1044/persp2.SIG1.56>



Systematic Review Articles

Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism research : official journal of the International Society for Autism Research*, 16(2), 406–428. <https://doi.org/10.1002/aur.2864>

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 : the international journal of research and practice*, 25(5), 1349–1367. <https://doi.org/10.1177/1362361320987963>

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