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# Preferences for Person-First Language and Identity-First Language in Autistic Communities

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## Article Information

**Article editor:** Jonathan Henner  
**Article type:** Research article  
**Review type:** Double anonymized  
**Submitted:** 2 August 2022  
**Revised:** 30 January 2023  
**Accepted:** 10 April 2023  
**Published:** 20 December 2023

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**DOI:**

[https://doi.org/10.48516/jcscd\\_2023vol1iss2.13](https://doi.org/10.48516/jcscd_2023vol1iss2.13)

**Published by:**

Adelphi University Libraries

(<https://www.adelphi.edu/libraries/open-access/digital-publishing/>)



**Citation:** Smith, M., Horton, R., & Fitzgibbons, M. S. (2023). Preferences for person-first language and identity-first language in autistic communities. *Journal of Critical Study of Communication and Disability*, 1(2), 106-140. [https://doi.org/10.48516/jcscd\\_2023vol1iss2.13](https://doi.org/10.48516/jcscd_2023vol1iss2.13)

## Abstract

The purpose of this study was to investigate and describe the preferences for identity-first language (IFL) and person-first language (PFL) in autistic individuals and their parents or caregivers. A 25-question online survey was distributed via REDCap to identify preferences for these terms and further understand the characteristics of respondents and their perspectives regarding these two terms. The 53 respondents who participated in the survey represented a range of ages from 16 to 58. Findings indicated that most autistic individuals and their parents preferred IFL over PFL. However, the responses from the parent group were more heterogeneous, with greater acceptance of PFL. Additionally, many autistic individuals stated that they had no desire to reduce, alleviate, or cure their symptoms associated with autism. In contrast, most of the parent group expressed the opposite view. Thematic analysis was used to analyze and discuss other traits and factors that were identified as possible influences on terminology preference. Autistic individuals and parents of autistic children prefer identity first language. These preferences can be influenced by age of diagnosis, gender, and perspectives on autism.

## Keywords

Disability; identity first language; person first language; autism; culture

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## Positionality Statements

Positionality Statements can be found at the end of the article.



It is vital for education and healthcare professionals to understand how to provide culturally competent services to individuals within *disability culture*. According to data from the 2021 American Community Survey, approximately 42.6 million people, or 13.7% of U.S. citizens, have a long-lasting health condition or disability (Erickson et al., 2023). Disability is considered socially constructed and encompasses chronic impairments that affect daily routines and functioning (World Health Organization, 2013).

*Disability culture* is an overarching term that identifies a diverse group of people made up of subgroups of specific disability types, such as Deaf culture (Leigh et al., 2020; Padden et al., 2009). Self-advocates within disability culture often celebrate their differences from the mainstream population, advocating for accessibility and promoting understanding within the non-disabled community (Ferguson & Nusbaum, 2012; Goodley et al., 2019). The conceptualization of disability as an identity can directly affect specific aspects of one's behaviors, beliefs, and attitudes (Riddell & Watson, 2014). Understanding more about the types of frameworks, approaches, concepts, and language used to examine and discuss disability will prove to be helpful in guiding professional practice and providing treatment that respects autonomy and recognizes the individuality and self-agency of those with disabilities (Smart, 2003).

## Disability Framework

It is vitally important that health care professionals understand the underlying assumptions of historical and current disability frameworks. Such knowledge can guide clinical practice when considering patient preferences and environmental factors that affect services (Smart, 2003).

Historically, the medical model was used to guide a great deal of research, policy, and practice concerned with services and resources for individuals with a disability. The medical model of disability, also sometimes understood as the "personal tragedy model" (Thomas & Woods, 2003), came to prominence in the 19<sup>th</sup> century (Dunn & Andrews, 2015; Retief & Letšosa, 2018). Proponents of this model viewed disability as a primarily physical (as opposed to mental) condition. They may also have pathologized and objectified disabled individuals (Smart & Smart, 2006). During this period, when disabled individuals were sent to live in institutions, they often experienced abuse, were isolated from their families, and were called "mentally retarded," "crippled," or "feeble-minded" by professionals (Dunn & Andrews, 2015). In the context of the medical model, professionals viewed disabled individuals as outsiders and focused their interventions on managing symptoms rather than treating the person as a whole, addressing activities of daily living (Retief & Letšosa, 2018), or modifying the individual's environment (Kasser & Lytle, 2013; Smart & Smart, 2006).

However, the social and identity models which view disability as a social construct are currently used to help guide our understanding

of disability across multiple disciplines (Wasserman & Aas, 2022). For the purposes of the current study, orientations rooted in the social and identity model of disability were used to guide its design and the interpretation of its findings.

## **Social Model**

Inspired by the lack of empathy, limitations, and discrimination presented in the medical model, the social model, otherwise known as the minority model, began gaining momentum in the late 19<sup>th</sup> century and throughout the 20<sup>th</sup> century (D'Alessio, 2011). The social model proposes that individuals are not burdened or disabled because of their medical condition, but rather their difficulty stems from societal views of disability and lack of accessibility (Smart & Smart, 2006). The social model places responsibility for limiting individuals with disabilities on the values of society itself. It postulates that it is society that must change to inspire acceptance of individuals with disabilities (Barnes, Mercer & Shakespeare, 2010). The Union of the Physically Impaired Against Segregation (UPIAS) defined disability as a restriction in activity due to social constructs implemented by people who do not consider the needs of individuals with physical or cognitive impairments, and therefore excludes them from participation in social activities (UPIAS, 1976). This ideology that disability is the result of lack of accessibility provides a framework for patient care that addresses the environment in which services are received, rather than the impairments of the individual. It also recognizes that the environment extends beyond physical barriers and can include social, structural, and psychological factors.

In 1990, the Americans with Disabilities Act (ADA) was signed into law, prohibiting discrimination based on disability and requiring equal opportunities for employment,

accessibility, and participation in daily life (United States Department of Justice, 2008). As a result of ADA, public environments were retrofitted to increase accessibility in recognition that consideration of the environment can help to improve the participation of individuals with varying abilities. Rose and Meyer (2002) extended this principle of environmental concerns to learning, encouraging educators and professionals to shift their teaching strategies to make learning more accessible for everyone, regardless of ability level.

In 1991, social psychologist Beatrice A. Wright utilized the social model to create a new standard of language for psychologists and medical professionals: Person-First Language (PFL). Wright argued that by placing the person before the disability, emphasis is placed on the individual rather than the impairment, allowing them to be acknowledged apart from their medical condition (Dunn & Andrews, 2015).

## **Identity Model**

The identity model has gained popularity throughout the 21<sup>st</sup> century. Like the social model, the identify model recognizes that disability is a social construct shaped by the environment and current policies. However, the identity model differs as it also asserts that disability should be celebrated as a unique attribute of individuality (Retief & Letšosa, 2018). The identity model establishes a conceptual framework for terminology related to disability by eliminating the assumption that disabilities are solely diseases to be cured, with an emphasis on language that acknowledges disability as an important dimension of one's identity. This model encourages recognition of the cultural aspects of disability as well, postulating that there are benefits to identifying as a member of a specific disability subculture. Like race, disability is marked as a marginalized identity in the recognition that there are certain

limitations placed on disabled individuals by the majority abled population. The underlying assumptions for this model center “disability” and view it as a positive characteristic of one’s identity as opposed to a burden to the individual and their family. As the identity model values the positive aspects of a person’s disability, the use of identity-first language (IFL) is encouraged within this framework. Identity-first language is a concept that recognizes one’s disability as a core facet of one’s personal identity. And this is an important shift in the perceptions of disability affecting preferences for terminology.

The view of disability as a culture also encourages and promotes self-advocacy to address barriers, accessibility, and ableism. Advocacy is another important aspect of disability culture and often stems from a desire to work towards the elimination of ableism or the othering, discrimination, and inaccessibility that these individuals face daily (Brown & Ramlackhan, 2020; Khasnabis et al., 2010). Affinity group membership based upon disability status has inspired many individuals to fight for change in policy to improve accessibility and acceptance within the non-disabled community.

## Literature Review

Identity-first terminology places the identifying language on the disability, which is presented as a singular identifying noun, such as “Deaf,” rather than a “person who is deaf.” Advocates within the community have established the use of the uppercase “D” in “Deaf” to distinguish individuals who identify as a member of Deaf culture from those who identify as only having the audiological status of being deaf (National Association of the Deaf, 2023). Deaf culture is a prime example of disability as a culture and is reflective of the importance of incorporating aspects of disability

identity when providing services. Under this model, focus for treatment incorporates familial, personal, and environmental contexts that affect the functioning of the individual, including preferences for communication such as the use of American Sign Language (ASL).

PFL is a specified syntactical form where a noun such as person, individual, child, or adult, precedes the disability being described (e.g., “person with autism”) (Gernsbacher, 2017). Since 2010, the American Psychological Association (APA) has suggested that healthcare professionals utilize PFL when referring to individuals with disabilities, noting that this standard of language use reduces biases in research writing, clinical practice, and educational settings (Dunn & Andrews, 2015). Despite the widespread use of this language concept within multiple disciplines of the medical community, many neurodiverse individuals have advocated for the use of IFL and have challenged professionals exclusively using PFL in clinical and medical practice (Dunn & Andrews, 2015).

Many self-advocates within various disability groups view disability as a core aspect of one’s identity and so they have encouraged the use of IFL rather than PFL (Sinclair, 2013). Identity language recognizes an individual’s disability as part of who they are by referring to the disability before the noun (e.g., “the autistic person,” or just “autistic”.) The APA has recently acknowledged the importance of disability identity and endorses the interchangeable use of IFL and PFL until a clear distinction of preference has been made (APA, 2019). Members of disability culture often suggest that PFL may further stigmatize the disability rather than prioritize the pride and sense of community often seen in disability culture (St. Louis, 1999). Therefore, the purpose of this study was to investigate and describe the preferences for IFL and PFL within

the autistic<sup>1</sup> community. In the proceeding sections, the authors discuss the role of the neurodiversity movement in advocating for identity first language and summarize findings from similar studies examining language preferences. Qualitative methodology using thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2018) is used to describe important information from a survey instrument used to examine preferences and perspectives on autism.

## **Identity, the Neurodiversity Movement, and Autism**

Given concerns expressed by disability rights advocates, there also has been a push for the use of identity language associated with autism in the neurodiversity movement. According to Jaarsma and Welin (2012), the “neurodiversity claim” consists of two parts. The first idea stipulates that the vast spectrum of neurological conditions are simply variations of the human brain. These variations present typical, yet different ways of processing information, communicating, and existing. The second aspect of this claim advocates for change in policy to reduce discrimination and inaccessibility for these diverse individuals. This neurodiversity perspective is shared by some autistic advocates, communities, and groups, such as the Autistic Self Advocacy Network, and has received a great deal of support within disability studies and among disabled scholars (Savarese & Savarese, 2010; Sinclair, 2013).

## **IFL vs PFL and Autism**

The neurodiversity movement is particularly popular within the autism community because a group of online autistics

founded it in the 1990s (Ortega, 2009). According to Ortega (2009), self-advocates within this movement view differences as inseparable aspects of one’s identity that should be celebrated and respected, rather than cured. Many advocates who align with the neurodiversity movement have expressed concerns with the use of PFL when referring to individuals with autism, stipulating that by saying “person with autism,” it is implied that the person is trapped by their diagnosis (Jaarsma & Welin, 2012). Furthermore, autistic individuals and researchers now recognize that there is a “culture” of autism (Grandin & Panek, 2013; Mesibov & Shea, 2010; Sinclair, 2010). Autism presents with a range of complex differences affecting socialization, adaptive skills, and behavior that impact each individual and family differently. This diversity in how autism impacts families may result in differences between preferences for identifying language.

Within the last decade, several studies have examined perceptions of disability and identity within the autism community. For example, Kapp et al. (2013), Kenny et al. (2016), and Cooper et al. (2017) have provided helpful, foundational insights into the preferences of these individuals. In the study conducted by Kapp et al. (2013), the authors sought to understand the perceptions of disability within the autism community and to correlate beliefs with either the neurodiversity movement or the medical model of disability. The survey was distributed to autistic individuals as well as parents, siblings, and friends. The authors of the study found that individuals with autism and friends of individuals with autism were more likely to be aware of the neurodiversity

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<sup>1</sup> The authors are choosing to use identity-first language, in contrast to APA style conventions for person-first language, based on the results of the study.

movement than parents of an autistic person. Awareness of neurodiversity and self-identification as autistic was positively correlated with an increased likelihood of preferring IFL. However, parents of autistic people and friends or acquaintances of autistic people who were not exposed to the neurodiversity movement did not show a preference for either term. Regarding emotions toward autism, the researchers found that people who were aware of the neurodiversity movement had more positive emotions about autism than those who were not aware of the movement. It was also determined that being the parent of an autistic person was not correlated to positive or negative emotions about autism. This study shows the diverse nature of preferences for disability language within this population and presents a preliminary investigation of the factors that influence the development of preferences for identity language. Other studies indicate that the more time that caregivers, family, and friends spent with autistic individuals, the more likely they were to endorse use of IFL (Kenny et al., 2016).

Through an online survey, Cooper et al. (2017) sought to understand the relationships between identifying with autism as part of social identity, self-confidence, and psychological well-being. The study included responses from 272 participants with autism and 267 typically developing individuals. The participants in the study were over the age of 16. They self-identified as having a diagnosis of an Autism Spectrum Condition (ASC) such as Asperger's syndrome, high or low functioning autism, or pervasive developmental disorder (PDD). Data indicated that identifying as autistic was positively correlated with high personal self-esteem due to the group or collective self-esteem seen within the autism community (Cooper et al., 2017). Findings from this study suggest that adoption of a positive autistic

identity can improve self-esteem and therefore general well-being.

A recent study by Bury et al. (2020) explored preferences for identifying terminology in 198 autistic adults. This study utilized an online survey that included dual-format questions which allowed participants to identify and explain which terms they preferred and which they found offensive. Results showed that participants rated the terms 'autistic,' 'person on the autism spectrum' (highest preferred), and 'autistic person' as the least offensive and most preferred terms of the given choices (Bury et al., 2020). An analysis of short responses identified six themes present in the data: (a) autism as core to identity, (b) autism as part of identity, (c) the 'spectrum' reflecting diversity, (d) the rejection of stigmatizing, (e) medicalized language, and (f) pragmatics. Bury et al. (2020) discussed limitations of the study that were similarly reported in other online survey research (Cooper et al., 2017; Kapp et al., 2013; Kenny et al., 2016), such as being unable to confirm diagnosis, online format, and the self-selection method of recruitment. Such findings indicate that it is important to be sensitive to, and respectful of, each person's unique preferences for terminology.

The previous literature described in this study offers valuable, foundational insights into trends of preferences for IFL and PFL within the autistic community. These studies included autistic participants, those that identified as extended and immediate family members, and other related individuals and service providers who work closely with the autistic community. Only a few studies have included adolescent participants in work examining language preferences. Kapp et al. (2013) included participants ages 16 and older. Cooper et al. (2017), Bury et al. (2020), and Kenny (2016) included participants ages 18 and older. By understanding preferences for IFL and PFL across the lifespan, therapists,

teachers, and paraprofessionals can use such knowledge to provide culturally responsive services that better align with the autistic person's values and beliefs.

Previous studies indicate that while there is variability in the terminology preferences of autistic individuals and their families, many individuals, particularly those who are active in social and self-advocate groups, prefer IFL compared to PFL (Kapp et al., 2013). However, previous research has not conclusively identified the factors that affect each person's preference, such as the severity of autism, age of the autism identification, participation in various treatment approaches, year in school, and level of education (Bury et al., 2020; Cooper et al., 2017; Kapp et al., 2013; Kenny et al., 2016). By incorporating aspects of the individual's personal identity, environmental influences, and ability to participate in activities, educational and healthcare professionals will be able to prioritize treatment to fit the needs of the person, thereby improving outcomes and the quality of outcomes for the autistic community (WHO, 2013). To better understand language preferences for IFL and PFL, and to address the limitations of previous studies regarding perspectives guiding those preferences, we asked the following research questions:

- 1) Do autistic individuals and their caregivers prefer IFL or PFL?
- 2) Are there any demographic and background factors, beliefs, attitudes, or practices that influence the development of IFL or PFL preferences?

Information from the present study can help identify key areas of focus for awareness, training, and policy initiatives aimed at eliminating structural barriers by improving the knowledge base of educators, community

service providers, legislators, and broader society.

## Method

### Participants

The study was approved by the institutional review board (IRB) of the Midwestern University. Participants targeted for inclusion in the study were autistic individuals, ages 14 and older, and parents/caregivers of autistic children. Inclusion criteria included a medical or educational diagnosis of autism, being a primary caregiver of an individual diagnosed with autism and being at least 14 years of age. Exclusion criteria included a self-diagnosis of autism and those with limited English proficiency. Participants were asked to complete an online survey questionnaire. Parents were allowed to assist their child in filling out the survey and were encouraged to ensure that the question responses were individual to the child. There was no financial compensation for participation. In the 10-week time span that the survey was available, 41 autistic teenagers and adults and 26 parents/caregivers initiated the survey. However, only 32 autistic individuals and 23 parents submitted partial or complete responses to all questions in the survey.

### Recruitment

Online advertisements and direct e-mail were used to recruit participants for the study. Online advertisements were posted to autism-related websites, forums, and social networking platforms (e.g., Facebook). The snowball sampling method was utilized in which recipients of the survey were encouraged to forward the survey to potential participants or colleagues (Naderifar et al., 2017). E-mail advertisements were sent to SLPs and other

allied healthcare professionals who were current members of the National Student Speech Language Hearing Association (NSSLHA) and the American Speech-Language-Hearing Association (ASHA) Special Interest Groups 1, 12, and 14. This approach to recruitment encouraged each professional to send the survey information to their clients or others who could participate.

## Procedures

The online survey was distributed using a web-based platform called REDCap (Research Electronic Data Capture; Harris et al., 2009). The REDCap survey software allowed participants with limited reading capabilities to utilize text-to-speech software while completing the survey. The survey contained a variety of questions that targeted information regarding demographics, level of autism severity (APA, 2012), preferences for identifying language, attitudes about autism, and other factors that may affect these preferences and attitudes. The survey included both multiple choice and open-ended questions that allowed the participants to elaborate on their answers (see Appendices A and B). Participants were not required to answer all questions, but for a participant's survey responses to be included in the sample they did need to officially "submit" the survey in RedCap.

## Pilot Survey

A preliminary version of the survey was piloted with two autistic youths and their parent. These participants were asked to complete the survey and provide additional information regarding estimated time to complete, ease of navigating the survey, wording of the questions, order of the questions, and overall content of the survey. All three participants were able to complete the survey in 15-20 minutes and found that it was easy to navigate. The parent

who completed the survey commented that she needed additional clarification on how to complete the survey since she had more than one child with autism. This was judged to be an especially relevant comment given the evidence that autism has a genetic component. This feedback was incorporated within the revised version of the survey and a more specific question regarding the number of children with autism was added to the survey. In addition, a specific REDCap string was created so that if the participant indicated that they have more than one child diagnosed with autism, they were presented with the ability to provide requested information for each child on a question-by-question basis without having to complete multiple surveys.

## Data Analysis

### Quantitative

Descriptive statistics were used to analyze responses to demographic questions including age, gender, race, and level of education. Data regarding preferences for IFL or PFL were also calculated via frequency. A Chi-square test of homogeneity was used to answer research question one, by determining whether the distribution of responses for questions 11, 15, 16 (individual survey) and questions 13, 20, 21 (parent survey) differed across the two groups. There were three questions asked in surveys for both groups, but phrased differently and included: Do you prefer the term "person with autism" or "autistic"? Do you believe that there is a need to reduce or alleviate your (child's) symptoms associated with autism? If a cure was available, would you want it for yourself (your child/children)?

### Qualitative

Thematic analysis (Braun & Clark, 2006) was used to examine all free response questions and answer research question two



regarding patterns of perceptions and experiences shared between and within participant groups. Overarching themes between responses were identified and categorized into coded groups to recognize patterns in the data based on the six-phase model created by Braun and Clark (2006). An inductive coding approach to thematic analysis was taken, allowing for detailed synthesis and analysis of data which were coded into categories in response to the research questions (Braun & Clark, 2006). Reflexivity, constant comparison, and discussion among the first two authors were used throughout the coding process and to reach agreement on themes and subthemes (see Appendix C).

### **Reflexivity**

Reflexivity has been described as a dynamic, ongoing, and collaborative evaluation of the researchers' orientation and subjectivity in the process and context of constructing knowledge about phenomena under investigation (Holmes, 2020). Throughout the current investigation the authors engaged in reflexivity during all phases of the research process. The positionality statements at the end of this article provide an overview of our own subjectivity regarding disability and our outsider status (not being autistic). We were consistently reflecting on our own orientations and the feedback that we received from our pilot participants, those who reached out to indicate their interest in participating in the study, and the existing literature base. During the coding of the data, the interpretation of the data, and the writing up the findings, we were always discussing and integrating feedback, frequently seeking to understand and describe the autistic groups data and how to prioritize their perspectives. As outlined in the conclusion, we were very mindful of making sure that even in writing up our findings, that there was ongoing reflection and inclusion from

the autistic community working through language choices given the topic of the paper and the limitations of our own outsider status.

### **Coding**

In phase one, we focused on familiarizing ourselves with the data to identify patterns throughout the participants' responses. Phase two incorporated the creation and mapping of preliminary codes by assigning a label to concepts, preferences, or experiences that were frequently expressed by participants. In phase three, these codes were clearly defined and analyzed to determine overarching patterns of ideas within the data sets to organize them into themes (i.e., overarching patterns) and subthemes (i.e., distinctions within identified themes). During phase four, the identified subthemes and themes were reviewed and modified to determine whether they could be broken down further to better organize the codes. In phases five and six, these themes and subthemes were named (Braun & Clark, 2006).

## **Results**

### **Participant Characteristics**

Participants in the individual group ranged in age from 16-56 years old ( $M = 32.06$ ,  $SD = 12.3$ ). Respondents reported that they were diagnosed with autism at a wide range of ages (3-43), with an average age of diagnosis at 28 years of age (median = 27, mode = 29). Participants were either diagnosed by a primary care physician/pediatrician (9.4%), psychologist/psychiatrist (87.5%), or by an IEP team (3.1%). Five participants, or 16.1% of the sample, reported that they were still in high school. Approximately 68% of respondents reported that they also had a mental or physical disability in addition to autism. Additional

participant demographics are reported in table one.

For the parent/caregiver group, ages ranged from 24-57 years old ( $M = 38.83$ ,  $SD = 8.15$ ). Parents reported having a range of one to four children, with an average of two children per household. Children of parents were either diagnosed by a primary care physician (39.3%), psychologist/psychiatrist (42.9%), or by an IEP team (17.8%) at 3 years old on average. The current age of the participants' children was an average of 9 years old. Additional demographic information for parent participants is reported in Table 1.

### **Research Question One: Frequency Data Forced Choice Responses**

Table 2 provides an overview of participants' responses to questions 11, 15, 16 (individual survey) and questions 13, 20, 21 (parent survey). Of the total 54 participants who completed the survey, 18 parents (78% of sample) and 31 individuals (97% of sample) responded to questions 11 and 13 regarding preferences for IFL and PFL. Many of the autistic individuals preferred IFL, while there was greater diversity of preferences among the caregiver/parent group (See Table 2). The chi-square test of homogeneity indicated that the distribution of responses was not comparable,  $\chi^2(2, N = 49) = 6.404$ ,  $p = .041$ .

Participants in both groups were asked to identify whether it was important to them to be identified with their preferred term by service providers and professionals. Forty-four percent of the parents answered yes to the question, and 45.16% of autistic individuals responded similarly. When asked whether the participant thought they faced more challenges in their daily life due to their autism, 84.6% of autistic individuals responded "yes."

**Table 1***Participant Gender, Race/Ethnicity, and Level of Education.*

	<b>Percentage of Autistic Individuals</b>	<b>Percentage of Parent/Caregivers</b>
<b>Gender</b>	n = 32	n = 23
Male	53.1	13
Female	31.3	82.6
Non-binary	15.6	4.3
<b>Race/Ethnicity</b>		
	n = 32	n = 23
Multi-racial	3.1	0
Asian	3.1	0
Black or African American	3.1	8.7
White	84.4	65.2
Hispanic/Latino	6.3	26.1
<b>Level of Education</b>		
	n = 31	n = 23
Middle school	6.3	0
High school	21.9	4.3
Technical school	9.4	4.3
Community college	9.4	30.4
4-year college	31.3	43.5
Graduate/professional school	18.8	17.4

*Note:* The reported numbers (n) reflect how many participants responded to each given question.

**Table 2***Frequency of Participant Responses to Multiple Choice Questions*

	<b>Percentage of Autistic Individuals</b>	<b>Percentage of Parent/Caregivers</b>
<b>Preferred Terminology</b>		
"Person with Autism"	6.5	33.3
"Autistic"	64.5	38.9
No preference	29.0	27.8
<b>Reduce/Alleviate Symptoms</b>		
Yes	33.3	75
No	66.7	25
<b>Hypothetical Cure for Autism</b>		
Yes	16.7	73.3
No	83.3	26.7

Participants were also asked a forced-choice question regarding whether they had a desire to reduce or alleviate their own or their child's symptoms associated with autism. Sixteen parent/caregiver participants (70% of sample) and 30 autistic individual participants (94% of sample) responded to this question. The chi-square test of homogeneity indicated that the distribution of responses was not comparable,  $\chi^2(1, N = 46) = 7.260, p = .007$  (see Table 2). For the third forced-choice question, participants were asked whether they would want a cure for autism. Of the parent group, 15 participants responded to this question (65% of sample), while 30 autistic individuals (94% of sample) responded to this question. The chi-square test of homogeneity indicated that the distributions were not comparable,  $\chi^2(1, N = 45) = 14.014, p < .001$  (see Table 2).

## Research Question Two: Thematic Analysis of Survey Data

Qualitative data were coded and analyzed utilizing thematic analysis (Braun & Clark, 2006). Short response questions were transcribed, coded, and organized into themes for autistic individuals and for parents of autistic individuals. We captured seven broad themes in the responses from autistic individuals and parents of autistic children. Five out of the seven themes shared by both groups included: identity, perceptions, supports, barriers, and socio-emotional well-being. The two unique themes for the autistic group were non-monolithic, adult aspirations/responsibilities. The two unique themes for the parent group were 'desired traits' and 'parenting challenges'.

### **Autistic Individuals: Survey Themes** **Autistic Communities are not**

**Monolithic.** This theme captures the idea that there are various perspectives, attitudes, and preferences of individuals with autism/autistic individuals. For example, one participant stated, "Because you've met one person with autism only means you've met one person with autism. We are each very unique and individual cases and can experience autism all very differently than one another." Given the vast array of differences within these communities, many participants commented on this idea of the variability of perspectives.

**Identity and Autism.** The idea that the autistic community has varying views regarding the importance of their autism in their lives was highlighted within this theme. This theme encompassed subthemes in accordance with the ideas seen in the sample: "autistic identity" and "autism as a trait." The subtheme of "autistic identity" describes the cultural view of autism that recognizes an individual's differences as central to his/her identity, perceived as a valuable aspect of a person's life. For example, one participant shared their reasoning for preferring IFL by stating, "It is not something that I am afflicted with, it is part of who I am. It is not something to cure but to understand, and work with." Many individuals explicitly expressed the importance of autism in their lives. For example, one participant stated, "Autism is an inherent part of my being. It influences everything about me from my likes to my dislikes. Without autism I would not be the same. So yes, autistic is an important term because it identifies my neurology."

The second subtheme of "autism as a trait" conveys the belief that autism is a singular aspect or trait, whether it be perceived as positive or negative, that does not define a person. The respondents who described their autism as separate from their identity also

expressed a preference for PFL. For example, one individual stated, “I like how it's person first language, that way my disability doesn't define who I am” and “I am a human being, not a diagnosis.” Some participants perceived their autism as a secondary characteristic rather than their identity. The interaction between identity and autism was a theme that appeared frequently in the data.

### **Self-Perceptions of Their Own**

**Autism.** This theme discusses how autistic individuals perceive themselves and their diagnosis. Subthemes further break down this concept into “positive outlook,” in which the individual perceives their own autism as a positive and beneficial aspect of life that he/she would prefer to not live without. An example of a participant response that fits under this subtheme includes:

I say autism is a gift honestly, it makes me see things in such a unique way. It helps me to understand other people with autism too way better than others can and helps me to educate the world on something that is truly beautiful if we allow ourselves to see it that way.

However, other respondents discussed some “challenging” aspects of living with autism in our society, where their diagnosis was discussed as being difficult and burdensome. Given the variability of symptoms presented in autistic individuals, the reported self-perceptions of participants were complex. For example, the most frequent codes utilized in the data under this thematic framework included indifference regarding term preferences, gifted, and social challenges.

**Supports.** This theme is defined as a discussion of the various services, supports, and personal strategies that the autistic participants from the sample have used. Some respondents chose to discuss the personal supports and strategies that they use to navigate their daily life. For example, one

participant shared helpful supports and personal strategies such as, “AAC apps on my mobile devices, supportive spaces run by autistic people and AAC users online and in person, [and] trauma-informed counselling with a counsellor that uses an anti-oppressive approach.” Many other individuals shared sensory-regulation strategies, such as “ear plugs,” “soft blankets,” or “a quiet home” and time management strategies, such as “calendar notifications with reminders” and “to-do lists.”

Others discussed having received many different domains of services including, but not limited to, ABA therapy, speech-language therapy, social work services, and counselling. The most frequently occurring codes included, sensory needs, feeling supported, and psychological services or counselling.

**Barriers.** This theme portrays the idea that autistic individuals and communities face many external barriers to accessibility and participation in their daily routine. The first subtheme acknowledges the environmental barriers that autistic people/individuals with autism face. Most respondents who discussed ideas under this subtheme described ‘society’ as a major barrier to accessibility. For example, one respondent stated that, “our disability isn't a result of being autistic, but rather a result of how society treats us.” Another participant discussed the challenges of “interpreting and navigating through a neurotypically dominated world.”

Other respondents discussed the attitudes and perceptions of others that act as barriers to them. For example, one individual identified the following barriers: “Ignorance, discrimination, dehumanization, infantilization, erasure, and silencing from people who see us as a burden on society even when we contribute more than our allistic counterparts.” In response to the question of a cure, one

participant acknowledged the perceptions of others and reflected on how it impacts him in the following quote:

I am painfully, painfully aware that most other people think it's bad, that I am widely seen as less valuable or not acceptable as a person because of it and I have moments of despair when I wish I was not autistic just so life would be easier and I would fit better/be accepted into a world where I really don't fit very well and am often not accepted... but to me, other people being [judgmental] and closed-minded about who I am is not a good enough reason to permanently fundamentally alter my brain.

Some of the most-frequently mentioned barriers identified during the analysis of short responses included societal burdens, neurotypical impositions, and lack of support.

#### **Adult Aspirations & Responsibilities.**

The “adult aspirations and responsibilities” theme contains participants’ thoughts regarding their current responsibilities and future. As many participants were identified to be employed, middle-aged individuals, many respondents described their current occupations, experiences in higher education, and families. Some younger participants described their experiences in college. Others explained their desires to become employed, go back to college, or explore romantic relationships in the future. For example, participant responses included statements such as “I am married and hope to have kids one day” and “[I plan to] continue to work full time until retirement”. Responses aligned with this theme frequently discussed employment, higher education, and ‘adulthood.’

**Socioemotional Well-Being.** The last theme for the autistic participants describes the feelings and emotions experienced by individuals with autism/autistic people. The

respondents discussed both the positive and negative emotions experienced due to various factors. One individual discussed the emotional impacts of bullying, sharing that “workplace bullying is my largest hurdle; this has been a great source of anxiety and depression.” Experiencing feelings of anxiety and depression was a common feeling discussed by participants in this study, particularly anxiety around social interactions. Some participants described the positive emotions they experience, for example, one participant stated that “I am happy with my life; I may not get along with the friends I have now or my husband who is also Autistic.”

While some respondents discussed these positive emotions, most participant responses primarily focused on the negative emotions they felt due to external and personal barriers. The most prevalent descriptions discussed anxiety, emotional burdens, and trauma.

### **Parent/Caregiver Survey Themes**

**Identity and Autism.** This theme represents the values and ideals of parents and individuals regarding the importance and role of their autism in their lives. This overarching theme was broken down into three subthemes: autistic identity, unimportant, and autism as a trait. The first subtheme defines the cultural view of autism that enables parents and caregivers to perceive their child’s differences as central to his/her identity, which is a valuable aspect of a person’s life. One parent participant stated that, “[autism] is not something that can be changed or cured, you are not a person with an illness you are an autistic person.” Like the autistic group of participants, some parents discussed their preference for language that is disability centered by stating that PFL is not used to describe other personal attributes of their child.

For example, this quote describes one parent's thought:

I prefer this term because it best describes who [my son] is. It's straight forward and to the point. People don't say '[Name] is a person with enthusiasm'. They say, '[Name] is enthusiastic'.... So why would they say '[Name] is a person with Autism', instead of '[Name] is Autistic'.

The second subtheme purports that distinguishing between having an autistic identity or not is irrelevant. Some participants stated their belief that these distinctions are unimportant, for instance, one caregiver stated, "I don't believe a term defines a person. Whether you refer to him as someone with autism or someone who is autistic, it does not change who my son is." Some parents and caregivers shared that they had never thought about or considered which term they preferred more. Others questioned the importance of distinguishing between PFL and IFL. As stated by one parent, "the terms used are totally irrelevant and another example of people focusing on unimportant issues instead of important issues."

The last subtheme under this theme encompasses the belief that autism is a singular aspect or trait that does not define a person. Parent participants discussed this idea of "autism as a trait" in both a positive and negative light. Many participants described their child as "more important than autism," highlighting the individuality of their child and separating the person from their disability. One caregiver shared her preference for PFL as it "[makes] them more than what their disability is. They are their own person with a uniqueness quality." Many parents expressed no desire to change their child, described their child as more than autism, and/or shared that the autistic term was simpler and more direct.

**Perceptions of Child's Autism.** This theme discusses how the parents who completed our survey perceive their child's gifts, differences, and challenges. The two subthemes that were identified are positive outlook and challenging. The first subtheme discusses the positive perceptions of a child's autism, which is ultimately seen as a beneficial aspect of their life. One parent discussed how "being a parent of an autistic kid is not all bad. He is an amazing person who everyone loves the second they meet him." Many parents who discussed their positive perceptions of their child's autism discussed having no desire to change their child. For example, one parent stated, "we love our son exactly the way he is. We don't want to change or cure him. We only use therapies to better understand him and give him the skills he needs to thrive."

This second theme also discusses the difficulties the child faces or describes autism as challenging and/or burdensome. Many parents discussed their child's and family's challenges with behavior, communicating basic wants and needs, sleeping, eating, and performing other activities of daily living. Some described autism as "a serious disability, [which] prevents my children from becoming independent." Another participant stated, "my son's autistic brain makes life very challenging for himself as well as the rest of our family."

Most responses aligned with this theme describe the challenging aspects of autism as perceived by parents. This included difficulty communicating, child social challenges, sensory needs, and maintaining positive perception of child's capabilities.

**Supports.** This theme is defined as a discussion of the various services, supports, and personal strategies that have been utilized. Parent participants discussed having received many services including, but not limited to, ABA therapy, speech-language therapy, social work services, and counseling.

Others chose to discuss their own personal supports and strategies used to navigate their daily life. For instance, one parent shared that “it takes a lot of patience, no sleep on some nights, a very strict routine, being absent for family social gatherings, tons of therapies and doctor's appointments - planners become your best friend.” The most common services reportedly received by parents for their child included ABA therapy, speech-language therapy, and general support from peers, family, or professionals.

**Barriers.** This theme portrays the idea that individuals within the autism/autistic communities face various external barriers to accessibility and participation in daily life. The first subtheme acknowledges the environmental barriers that individuals in the autism/autistic communities face. The primary environmental barrier that was discussed by parent participants was a lack of accessibility to services due to financial or insurance challenges. For example, participants wrote statements such as “everything is full, has long waiting list, or insurance is a problem” and “my child needs behavioral therapy but right now it's not an option due to insurance coverage.” These barriers were often described as being a large contributor to the stress of parent participants.

The second subtheme discusses the attitudes of others and how they impact themselves as parents, as well as their families. For example, one caregiver shared that, “people are rude and judge both him for his behaviors and me for being a bad parent”. These attitudes were often attributed to other children's and adults' lack of knowledge or understanding about autism. One parent described the “staring from uneducated people. And [from] children who are not educated being hateful and disrespectful.” The external attitudinal and environmental barriers that were identified by caregivers included

lacking support from peers, family, and professionals, others lack understanding or knowledge about autism, receiving judgement from others, and financial challenges.

**Desired Traits of Professionals, Peers, and Community Members.** Under this theme, parents discussed their own desires that would improve their child's, and their own, lives. Parents discussed their own thoughts regarding desired traits of service providers, peers, and community members with whom they work. Parents offered many traits of service providers that they found to be important, such as “compassionate, educated, [and] do[esn't] look at autism as only negative characteristics.” One parent stated that they desire working with professionals and peers who have a “personal connection to autism, people who see my son's full potential, people who don't get frustrated and give up, people who still help us during those messy, emotional, overwhelming times. Not fair-weather ‘friends.’” Parents used many different words to describe the desired traits of the individuals with whom they interact, including caring, patient, and understanding.

**Parenting Challenges.** Participants were asked to identify and explain the challenges that they and their children face regularly. When asked this question, many parents identified not being able to understand or communicate with their child as a primary challenge. Other parents compared their own experiences to other parents of children without autism. For example, one respondent wanted to note that “[autism] is isolating at times because simple things for other people can be very complicated for parents of children with autism.” Other parents acknowledged that all parenting is challenging, stating that “raising kids in general is tough enough. You throw the uncertainty of autism into the equation; it only becomes tougher.”



Other challenges identified by parents of children with autism included parent social challenges, lack of personal time, and describing their life as complicated.

**Socioemotional Well-being.** The final parental theme identified from the participant responses describes the positive and negative emotions experienced by parents. One respondent discussed the emotional challenges they face, such as “sleep, energy, difficulty focusing on anything without worrying about how he is. I feel guilty, am I doing things right.” Some parents discussed the socioemotional well-being of their children, with many parents describing their child as “frustrated” due to difficulties with communication.

In addition to describing their own socio-emotional well-being, some parents discussed the feelings their child experiences as well. Parents reported that they and their child experience emotions such as anxiety, emotional burdens, emotional responses to seeing their child in distress, and exhaustion.

## Discussion

In this study, we sought to describe and understand the nuanced preferences and perceptions of caregivers and individuals within the autism/autistic communities. This study builds upon previous research that discusses language preference and its importance. The findings of the current study indicated that a higher percentage of autistic individuals expressed a preference for IFL than the caregiver group. While most of the caregiver respondents preferred IFL, the distribution of terminology preferences was much more variable than autistic individuals. The following section discusses how these preferences may be influenced by personal factors related to age, gender, participation in social or self-advocate groups, conceptions of autism, the severity of autism, and level of education.

### Research Question One

In response to the first research question, the results of this study found that the group of autistic respondents and the parent group preferred the term autistic over person with autism. However, there was greater variability within the parent group. Several parents discussed their lack of preference for either term, or their strong preference for PFL. This within-group variability is consistent with previous research that discussed the complexity of preferences between parents, siblings, peers, and individuals within the autistic communities (Bury et al., 2020; Kenny et al., 2016).

Demographic data collected from these groups provided insight into the characteristics and backgrounds of participants that may influence preferences for PFL or IFL. Data indicated that the autistic participants were diagnosed at an average age of 28, which is a

much later age of diagnosis comparatively to the reported ages of children of the parent group ( $M = 8$  years old). Diagnosis of autism after childhood and adolescence may be a factor that influences preferences for PFL or IFL; however, there is no current research regarding this topic. The majority of the participants' children were reported to require moderate to maximal support, with most parents spending 15+ hours per day with their child or children. Kenny et al. (2016) suggested that relative time spent with an autistic person may influence the development of preferences for IFL or PFL. They hypothesized that those who spend more time in a day with an autistic person develop a preference for disability-centered identity-first language. The results of this study reinforce this idea, as most of the parent participant sample reportedly spent 15+ hours with their autistic children and preferred IFL more on average.

Previous research has primarily explored the language preferences of autistic adults. In comparison, this study sought to describe further and understand the preferences of autistic students in high school as this information could prove helpful during the planning and implementation of transition services. After administration, only 9.7% of the sample included survey responses from individuals ages 14 to 18. Given the small percentage of high school students who completed this survey, the results cannot be generalized to the greater community of students with autism. Future research would benefit from the inclusion of a large sample size of autistic students.

A final interesting trend identified in the quantitative data indicated that most autistic individuals had no desire to alleviate symptoms or take a hypothetical cure, while the opposite was apparent for the parent group. Research shows that many individuals

who identify as autistic also perceive autism as a positive or neutral trait and align with ideals of the neurodiversity movement (Gillespie-Lynch et al., 2012; Kapp et al., 2013). Evidence from Gillespie-Lynch et al. (2012) echoes the findings of this study, in that more autistic individuals reported that finding a cure was unimportant compared to non-autistic participants. This suggests that those who perceive autism as a positive trait rather than a disease to be cured may be more likely to prefer language that is disability centered.

## Research Question Two

The participants in this study offered valuable insight on the perception and importance of autism in their lives. While most of the autistic participants perceived their diagnosis as central to their identity, some individuals perceived it as a trait or as simply one aspect of themselves. Those who perceived autism as a core aspect of themselves often discussed the positive aspects of being autistic, many of whom explained the benefits of belonging to a gifted and neurodiverse community. This finding echoes the results of Kapp et al. (2013), who determined that positive perceptions of autism and awareness of the neurodiversity movement were correlated to preferences for IFL. Autistic individuals and parents who preferred PFL shared their desire to be seen as a "human" separate from their diagnosis, while others emphasized the challenges of living with autism. These qualitative observations are supported by research conducted by Bury et al. (2020), who indicated that individuals who prefer PFL often expressed a desire for common humanity and acknowledgement of individual uniqueness within autism.

Given the vast spectrum of differences and symptoms presented in autistic individuals, it is not surprising that study

respondents reported various experiences, perceptions, and beliefs about autism. Kenny et al. (2016) emphasized this phenomenon, as their large-scale study on language preference also discussed the variability of perceptions and preferences within these communities.

The topic of societal norms as a barrier to participation and accessibility was frequently discussed in the qualitative data by the autistic participants. This idea of societal barriers is often discussed in disability literature in association with the social model of disability. As Smart and Smart (2006) stated, individuals who align with this view perceive the challenges they face because of lack of accessibility due to societal attitudes and perceptions of autism. Under this ideology, it is society that must change to meet the needs of, and fully include, neurodiverse individuals (Barnes et al., 2010). Disability studies scholars and advocates have also highlighted the social political reality of disability and importance of language and terminology in changing attitudes rooted in fear of disability and about the helping professions' need to fix the person (Goodley et al., 2019; Ferguson & Nusbaum, 2012). Goering (2015) notes that, "if we live long enough, we will all, eventually, be impaired in one way or another if we are not already. Learning to accept this fact will not only perhaps help to eliminate the us/them divide that continues to segregate many people with disabilities in social life but could be used to diminish the desperation with which many people seek the elusive state of perfect health." (p.137). Promoting the use of identity first language then becomes a strategy for individual and broader community reflection and action that disrupts ableist practices which view disability as a deficit and aberration to that which is desired, ableness.

Other identified barriers to accessibility reported by autistic individuals and parents included financial and insurance challenges;

attitudinal barriers, such as judgment and bullying; and environmental barriers. It is important to acknowledge these external barriers to participation and accessibility, as research shows that many autistic individuals and their families struggle to access the services that they need (Taylor & Marrable, 2011). While some participants in the present study reported feeling supported with adequate and appropriate services, others discussed having received little or no support. Access to supports and services may be a factor that influences preferences for IFL and PFL; however, further research must be conducted to substantiate this claim. As Hodgetts et al. (2015) stated, it is vital that researchers continue to learn about the services that best fit the needs of students and families within the autistic community by learning *from* them.

Another valuable contribution this research provides is a list of common desired traits of service providers offered by parents and caregivers. Participants emphasized the importance of open communication, empathy, and respect when working with service providers and their child. Future research would benefit from delving further into the traits of service providers that best meet the needs of their clients.

Despite research indicating that autistic individuals have a difficult time obtaining and maintaining a job (Chen et al., 2015), a large percentage of the autistic participants in the study were older in age and reported being employed, receiving higher education, and living independently. Given these characteristics of many of the participants, the reported preferences for IFL or PFL may have been influenced by the age and abilities of this sample. According to Blustein (2008), employment is an important aspect of adult life that not only contributes to financial independence, but also improves overall mental health and self-esteem.

Mental health and socio-emotional well-being in individuals with autism continues to be an important topic, as individuals with autism are four times more likely to experience depression in their lifetime (Hudson et al., 2018). Negative emotions experienced by our participants with autism were discussed in short responses, many of whom described their symptoms of anxiety, depression, and PTSD. Previous research has indicated that anxiety and depression may be indirectly correlated to identifying as a *person with autism*, due to poor personal and community self-esteem (Cooper et al., 2017). This may have been a factor that influenced some of our individual participants' preferences for PFL.

As many caregivers discussed in the short response data, raising a child, with or without autism, is a challenge. However, research indicates that parents, particularly mothers, of children with autism are likely to experience significant challenges that influence their own mental and physical well-being as compared to parents of non-autistic children (Giallo et al., 2011). The parent respondents in the present study reinforced this finding, describing specific personal challenges due to prioritizing the care of their child such as lack of socialization, sleep, and personal time. Feelings of anxiety and depression were also discussed in addition to their own or their child's feelings of isolation, frustration, and exhaustion. Research has identified that parents of children with autism are shown to experience more negative emotions that are correlated with increased maladaptive child behavior (Rezendez & Scarpa, 2011). As many of the caregiver participants qualitatively shared their concerns for their child's safety, behavior, and ability to complete activities of daily living, this may have influenced some of our parents' preferences for PFL.

## Reflections on Themes from Three Autistic Individuals and their Parent

The results of this study were discussed with three autistic individuals and one mother of autistic children to share this information with people who are impacted by it. Themes and subthemes identified in the data and preferences for IFL and PFL within both groups were relayed to these individuals and they were asked to provide their reflections on these findings.

The three autistic individuals with whom these results were shared were asked various questions regarding their perceptions of the collected and interpreted data. All three individuals expressed their strong belief that autism is a spectrum, describing the various abilities, conceptions, and preferences among themselves, their siblings, and friends on the spectrum. Two of the individuals expressed having no preference for IFL or PFL, while the third preferred IFL. When asked about the theme regarding perceptions of autism, the group was in agreement, stating that there "are both pros and cons to being autistic." In response to the explanation of the "adult aspirations and responsibilities" theme, one individual described the uncertainty he feels about the future but expressed his desire to find a job and go back to community college. This individual also stated that he was surprised and motivated to learn that so many of our participants had received higher education and were employed. These reflections reinforce and align with some of the themes identified in this study, while continuing to display the nature of differences in preference and perspective within the autism/autistic communities.

The parent who was consulted shared that she was unsurprised at the variability of parent preferences for PFL and IFL. She

reported that she has no strong preference for PFL or IFL, but she typically uses *autistic* due to the term being shorter. When asked whether she believed that her preferences aligned with her children's, she stated that their entire family uses both terms interchangeably. This mother related her experiences to the "parenting challenges" theme, discussing the emotional and physical demands of caring for multiple autistic children. Conversely, when discussing the "barriers" theme, she shared her unfamiliarity with the idea of "societal burdens," stating that her family's barriers primarily included challenges obtaining services and insurance.

## Limitations and Suggestions for Future Research

Although this research study offered interesting information regarding the characteristics, preferences, and experiences of individuals in the autistic/autism community, it is essential to discuss the limitations that may have influenced the study. The relatively small sample size is a limitation of this study, particularly given that the parent participant group was significantly smaller than the autistic group. In addition, the dual format of multiple-choice and short responses questions may have impacted the overall results of the survey. While short response questions were used to allow participants to share details regarding their preferences and experiences, these open-ended questions did increase participant demand and may have resulted in fewer responses from both groups. Additionally, the online data was collected during the COVID-19 pandemic, which may have impacted participant willingness to complete the survey, how participants responded to the questions or interpreted their experiences related to environmental barriers and supports.

The participant sample was homogenous in that the majority of participants were Caucasian females with higher-than-average educational levels. The experiences and perspectives of disability and autism are likely to be impacted by sociocultural factors such as race, gender, and level of education and intersectionality (Annamma, et al., 2013a; Annamma et al., 2013b; Morgan & Stahmer, 2021). To improve the generalizability of results, it would be beneficial to have data from a more extensive and diverse representation of autistic individuals (Cascio et al., 2021). To gain further insight it is vitally important that research incorporates a more diverse representation of participants from different racial/ethnic backgrounds. More complex analyses would capture the unique experiences of disabled people of color.

Finally, disability studies emphasize the importance of including autistic voices when conducting research with this population (Ferguson & Nusbaum, 2012). Goodley et al. (2019) warns against the danger of situating disabled people as objects of inquiry rather than co-constructors of knowledge. For example, Gernsbacher et al. (2006) notes that some autism researchers have often explained neutral or positive attributes of autistic participants as deficits. A "participatory approach" to autism research is encouraged, where autistic individuals engage with and provide input on research methods and design. Unfortunately, recent literature exploring the use of the participatory approach concluded that very few autism studies incorporated autistic feedback (Wright et al., 2014). While this study gathered feedback from autistic students and the parents of those children from piloting stage to the write up of the findings, it is important to acknowledge that this study was conducted and written up by individuals who are not autistic. We also acknowledge that without the inclusion of

autistic researchers on this project, this project and its findings may still not be as revealing as they could be or go far enough in revealing why IFL and PFL matter when thinking about ableism (Nuwer, 2020).

As outsiders it becomes important for us acknowledge this limitation and explicitly respond to Goodley et al.'s (2019) question posed to non-disabled individuals engaged in disability work and research, "Why are you here?" In other words, why are we doing this work? As noted in the positionality statements, all three authors have family members with disabilities, and therefore this work was motivated through our own desires to raise awareness about the importance of the perspectives and lived experiences of autistic individuals in guiding the professional practices of those who are supposed to be a source of support for disabled communities. We work in a discipline that continues to grapple with orientations to disability that are not informed by pathologization and the medical model of disability (Ferguson, 2012). The perspectives of the participants in the current study indicate that addressing the discourse of disability will be vitally important for non-ableist professional policy and practices.

## Conclusion

Disability centered IFL was the preferred language terminology in both groups of participants for the current study. This finding reinforces previous research that reflects the importance of incorporating IFL into clinical practice and research writing. There are likely many more personal and external factors outside of the ones discussed in this paper that influence preferences for terminology, and future research would benefit from exploring these nuances further with the input of autistic individuals. Because some terms may be perceived as offensive to some

people, it is of the utmost importance to ensure sensitivity when identifying a persons' preferred term (Bury et al., 2020). For researchers who are still grappling with institution and policy preferences for PFL, the incorporation of critical frameworks and participatory action and inclusive design principles to guide research efforts may help contextualize the importance and relevance of IFL for prioritizing, honoring, and respecting the needs, preferences, and differences of those who have been marginalized.

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## Positionality Statements

### **Mackenzie Smith**

I am a white, cisgender female who had the opportunity to work with many students and adults within the autism/autistic communities. I worked with autistic individuals in multiple settings including a therapeutic day school, private practice, and public elementary school with students ranging in age from 2 to 30 years old. In addition to my clinical experience with individuals on the spectrum, I have a personal connection to autism, as I have several autistic relatives. Growing up with my family members on the spectrum, I developed a passion for working with and advocating for this population. That being said, my ideals align with the identity model of disability, perceiving autism as a unique aspect of a person that should be celebrated. While I am a neurotypical individual and cannot demonstrate a preference for PFL or IFL, for the purposes of this paper, I utilized both PFL and IFL to accommodate both language forms. The interpretation of the results of this paper may have been influenced by my life experiences working with this population and personal ideals.

### **RaMonda Horton**

I am a Black woman who grew up in a poor/working class family in the southern United States with an aunt with Cerebral Palsy and two cousins with autism. My own perspectives and orientation of disability has been informed by my observations of the detrimental impact of ableism, racism, and classism on the lives of disabled people and communities of color. I have benefitted from non-disabled power and privilege. I also recognize that my training in the speech, language, and hearing sciences has been mired in ideologies and practices that are in need of transformation. As an ally, I continue to work towards engaging in more critical analysis, reflection, and actions that can help create a profession and society that are anti-ableist.

### **Meredith Saletta Fitzgibbons**

I identify as a white, cisgender female, who is a member of the LGBTQIA+ community and an early-career scholar in the Chicago area in the midwestern United States. My undergraduate, Masters level, and doctoral level education has prepared me to work as a speech-language pathologist, teacher at the undergraduate and graduate levels, researcher in the field of communication sciences and disorders, and author of a graduate-level textbook on language and literacy. My world view is shaped by my formative experiences and current relationships, including being the sister and co-guardian of a young man with Down syndrome. My brother has encouraged me to ask questions pertaining to the lives of adults with intellectual and/or developmental disabilities. Our relationship makes me in one sense an “insider” – an inhabitant of the very world I am investigating – and an “outsider” – one who understands these issues through interacting with my brother and his friends rather than actually living their experiences. A quote that continues to shape my teaching and scholarship is that of Howard Zelaznik and Lisa Goffman: “Language production, whether spoken, signed, or written, is a motor activity” (2010, p. 393). This quote speaks to the interconnectedness of the systems that underly human communication, to which I would add the powers of creativity, courage, integrity, patience, and flexibility in expression and understanding.

## Appendix A

### Autistic Individual/Individual with Autism Survey

1. Who did you receive your diagnosis of Autism from?
  - a. Pediatrician/Primary Care Physician
  - b. Psychiatrist/Psychologist
  - c. IEP team
2. How old were you when you received a diagnosis of autism (or ASD)?
  - a. Free response
3. What is your gender?
  - a. Male
  - b. Female
  - c. Nonbinary
4. What is your race/ethnicity? (Select all that apply)
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or Other Pacific Islander
  - e. White (not of Hispanic origin)
  - f. Hispanic or Latino
  - g. Other
5. How old are you?
  - a. Free Response
6. What is the highest level of education you have completed?
  - a. middle school
  - b. high school
  - c. technical school
  - d. community college
  - e. 4-year college
  - f. Graduate or professional school (including masters, doctorate, medical/law degree)
7. Are you currently in school?
  - a. Yes
  - b. No
8. If yes, currently what year in school are you?
  - a. Freshman – 9<sup>th</sup>
  - b. Sophomore – 10<sup>th</sup>
  - c. Junior – 11<sup>th</sup>
  - d. Senior – 12<sup>th</sup>
  - e. College

- f. Graduate or Professional school (including masters, doctorate, medical/law school)
8. Do you currently work? If so, please describe your job. If not, please put N/A in the box.
    - a. Free response
  9. Do you have any other physical or mental conditions?
    - a. Yes
    - b. No
  10. If you answered yes to the above question, please list the conditions.
    - a. Free response
  11. Do you prefer the term “person with autism” or “autistic”?
    - a. Person with autism
    - b. Autistic
    - c. No preference
  12. Why do you prefer this term?
    - a. Free response
  13. Is it important to you that people such as doctors, teachers, and therapists use this preferred term when you see them? Why or why not?
    - a. Free response
  14. What are words that you would use to describe autism?
    - a. Free response
  15. Do you believe that there is a need to reduce or alleviate your symptoms associated with autism?
    - a. Yes
    - b. No
  16. If a cure was available, would you want it for yourself?
    - a. Yes
    - b. No
  17. Why or why not?
    - a. Free response
  18. What challenges do you face every day?
    - a. Free response
  19. Compared to others without ASD, do you think you face more challenges in your daily life?
    - a. Yes
    - b. No
  20. What treatments and services have you received in the past related to your autism (e.g. occupational therapy, speech therapy, etc.)?
    - a. Free response

21. In what ways were those treatments helpful or not helpful?
  - a. Free response
  
22. What do you wish most people knew about what it is like to have autism/be autistic?
  - a. Free response
  
23. What are your plans for the future? (i.e. finish high school, get a job, go to college, spend time with family, unsure of future plans, etc.)
  - a. Free response
  
24. What types of supports or resources have been useful in helping you on a day-to-day basis?
  - a. Free response
  
25. Someone else helped me complete this survey.
  - a. Yes
  - b. No

## Appendix B

### Parent/Caregiver Survey

1. Are you the primary caregiver for an individual with autism?
  - a. Yes
  - b. No
  
2. What is your gender?
  - a. Male
  - b. Female
  - c. Nonbinary
  
3. What is your race/ethnicity? (Select all that apply)
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or Other Pacific Islander
  - e. White (not of Hispanic origin)
  - f. Hispanic or Latino
  - g. Other
  
4. How old are you?
  - a. Free Response
  
5. What is your highest level of education?
  - a. Less than high school
  - b. high school
  - c. technical school
  - d. community college
  - e. 4-year degree
  - f. graduate or professional school (including masters, doctorate, medical/law degree)
  
6. Have you ever been diagnosed with any type of disability? If so, what?
  - a. Free Response
  
7. How many children do you have?
  - a. Free Response
  
8. From whom or how did your child/children receive their diagnosis of Autism?
  - a. Pediatrician/Primary Care Physician
  - b. Psychiatrist
  - c. IEP team
  
9. How old was your child when he/she/they received an autism diagnosis?
  - a. Free response

10. How old is your child with autism?
  - a. Free Response
11. What is the severity of your child's autism?
  - a. Mild – requires some support, may have difficulty with social situations and planning that can affect independence
  - b. Moderate – requires substantial support, limited or specialized interests that impact interactions, may have repetitive behaviors
  - c. Severe – requires maximal support, severe difficulties with verbal and nonverbal communication skills
12. Approximately how many hours per day do you spend with your child who has autism?
  - a. 1-5
  - b. 5-10
  - c. 10-15
  - d. 15 +
13. Do you prefer the term “person with autism” or “autistic” in reference to your child/children?
  - a. Person with autism
  - b. Autistic
  - c. No preference
14. Why do you prefer this term?
  - a. Free response
15. Is it important to you that your child is identified by your preferred terminology when working with healthcare and educational professionals?
  - a. Yes
  - b. No
16. What types of challenges do you face in your day-to-day living?
  - a. Free response
17. From your perspective, or observations, what challenges do your child/children experienced during their day-to-day life?
  - a. Free response
18. What types of services or treatments has your child/children received in the past for issues related to their autism diagnosis?
  - a. Free response
19. In what ways were these treatments helpful or not helpful?
  - a. Free response
20. Do you believe that there is a need to alleviate symptoms associated with your child/children's autism?
  - a. Yes
  - b. No



21. If there was a cure for autism, would you want it for your child/children?
  - a. Yes
  - b. No
  
22. Please explain why you selected the response yes or no.
  - a. Free response
  
23. What do you wish most people knew about what it is like to care for and parent someone with autism?
  - a. Free response
  
24. What types of supports and resources have been useful in helping you in your daily living?
  - a. Free response
  
25. Please list some personal traits and characteristics that you value in service providers and team members working with you and your family as you navigate life with autism.
  - a. Free response

## Appendix C

### Themes and Subtheme Matrix

Theme	Definition
<b>Autism/Autistic Communities are not Monolithic</b>	View that there are a wide variety of perspectives, attitudes, and preferences of individuals with autism/autistic individuals given a vast spectrum of differences within the community.
<b>Interaction of Identity and Autism</b>	Idea that individuals within the autism/autistic community have varying views regarding the importance of their autism in their lives.
<b><i>Sub: Autistic Identity</i></b>	Cultural view of autism that perceives differences as central to a person's identity that is a valuable aspect of a person's life.
<b><i>Sub: Autism as a Trait</i></b>	Belief that autism is a singular aspect or trait of a person that does not define them as a whole.
<b>Self-Perceptions of Their Own Autism</b>	Discussion of how individuals with autism/autistic individuals perceive themselves and their autism.
<b><i>Sub: Positive Outlook</i></b>	Perceiving autism as a positive and beneficial aspect of life that a person would prefer to not live without.
<b><i>Sub: Challenges</i></b>	Perceiving autism as challenging and burdensome and discussing these challenges.
<b>Supports</b>	Discussion of the various services and personal strategies that individuals with autism/autistic people have used.

<b>Barriers</b>	Individuals within the autism/autistic communities face various barriers to accessibility and participation in daily life.
<b><i>Sub: Environmental</i></b>	Acknowledging the environmental barriers that autistic people/individuals with autism face.
<b><i>Sub: Attitudinal</i></b>	Discussing the attitudes of others and how they impact autistic people/people with autism.
<b>Adult Aspirations &amp; Responsibilities</b>	Discussion of the current responsibilities and future plans of people in the autism/autistic communities.
<b>Socioemotional Well-Being</b>	Describing the feelings and emotions experienced by individuals with autism/autistic people.