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Differentiation of autistic adults' perceptions of research by gender: a mixed methods exploration

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Abstract

Introduction: The funding breakdown of autism research diverges with the research priorities of the autism community and stakeholders (Putnam et al., 2023), prompting concern about the disconnect between researchers and the autism community (Keating, 2021).

Objective: The current study addresses this gap in the literature through an exploration of autistic adults' opinions of the current research landscape and what autism research should address through a survey disseminated to the autistic community.

Methods: Eighty-nine autistic adults completed the survey. Participants rated their agreement to statements with a 5-point Likert Scale, ranging from "Strongly Disagree" to "Strongly Agree." Participants were asked "What should autism research be focused on?" and answered via long answer text.

Quantitative Results: A numerical difference was found in participants' ratings of autism research as more harmful than helpful. Participants who identified as nonbinary felt the research community was significantly less helpful and more harmful to the autistic community than those who identified as male ($p < .01$). Nonbinary participants expressed that community involvement in autism research is lower than those who identified as males or females ($p < .01$).

Qualitative Results: Six main themes were identified: "Representation of Diversity in Gender and Ethnicity", "Improving Quality of Life", "A Strength-Based Approach", "Autistic Subjective Experiences", "Comorbid Mental and Physical Health Disorders", and "Autistic People Involved in Research".

Discussion: This research identified intersectional relationships between identity and feelings about autism research, and explored recommendations from the autistic community on autism research that serves the best interests and desires of the community.

Keywords: Autism, Adulthood, Neurodiversity, Mixed Methods, Survey, Research Perceptions

Conflict of interest statement

We have no conflict of interest to state.

Differentiation of Autistic Adults' Perceptions of Research by Gender: A Mixed Methods Exploration

The prevalence of autism diagnoses has increased substantially in the last decade with a prevalence rate of 1 in 36~~44~~ children, leading to the increased funding of research focusing on understanding autism through genetic research and evidence-based interventions for children (~~Matson & Kozlowski, 2011~~Maenner et al., 2023; Pellicano et al., 2014). With this came the rising popularity of disability awareness campaigns, vouching for disability researchers to acknowledge the various needs of the disabled community. Despite efforts on behalf of the autistic community, minimal research employs the use of community stakeholders to inform research (Frazier et al., 2018), leading to research topics and thus their funding to skew towards a distribution that may not reflect the priorities of the autistic community.

Most frequently funded autism research tends to prioritize biological research and studies examining risk factors of autism (56%) over research on evidence-based treatments and interventions (16%) and autism beyond childhood (2%) (Cervantes et al., 2020). This funding breakdown of autism research in diverges with the research priorities of the autism community and stakeholders (Singh et al., 2009; Putnam et al., 2023). As such, there has been increasing concern about the disconnect between researchers and the autism community (Woods and Waltz, 2019; Keating, 2021).

The heavy emphasis on genetics research has been criticized by the Neurodiversity Movement, or the movement behind the idea that diversity in neurotype is as natural as any other human variation that is not pathologized, and individuals who are neurodiverse deserve support to develop their strengths. The Neurodiversity movement is strongly rooted in the social model of disability, or the idea that being disabled is caused not by impairments within the individual, but rather the barriers faced in society both by lack of accommodations and by prejudice (Oliver, 2013). A society in accordance with the social model of disability would therefore prioritize accommodations and acceptance. The Neurodiversity Movement has been vocally opposed in recent years to research that seeks to ‘cure’ autism or reduce autistic behaviors (Dwyer, 2022; Hoekstra et al., 2018). Instead, the Neurodiversity movement favors research that focuses on autistic strengths, creating accommodations and changes in society to support autistic wellbeing, and calls for the involvement of ~~neurodiverse~~ neurodivergent people in research and information seeking that involves and affects their own communities. Following these principles, members of the autistic community have increasingly called for research focusing on areas of high need for autistic individuals such as supports, applied science, and mental healthcare (Pellicano et al., 2014).

The disparity between the allocation of research funds and priorities of the autism community has been thought mainly to be a result of characteristics of autism research. There has been historical underrepresentation in relation to sex and gender as a result of a “male bias” in autism research, as the vast majority of autism research historically was conducted exclusively with white males (Pellicano et al., 2014; Putnam et al., 2023). W~~While w~~omen conversely have been vastly underdiagnosed due to disparities in the male and female autism phenotypes as well as clinician biases and public perception of autism as an exclusively male phenomenon (Howe et al., 2014; Lai et al., 2017). Transgender and gender diverse individuals are even further underrepresented in research, with a lack of focus in exploring the interaction between gender identity and autism (Putnam et al., 2023). This lack of representation is particularly egregious given the increased rates of transgender and gender diverse individuals in the autistic community relative to the ~~neurotypical~~allistic community (Strang et al., 2021). The unique lived experiences of women and transgender and gender diverse individuals may result in a unique set of research priorities, the breadth and complexity of which has yet to be fully explored in academic circles. Furthermore, the majority of stakeholder-engaged research involves parents of autistic individuals rather than autistic individuals themselves, who may have different perspectives on research priorities (Pellicano et al., 2014). As a result, autistic individuals' perspectives are often ignored by the research community.

While the overarching goal of autism research is to improve the lives of autistic individuals, it has inadvertently caused harm and sustained ongoing stigma by failing to actively involve and include autistic voices. Whether conscious or unconscious, this stigma continues to influence subsequent research by shaping the methodology, frameworks, outcomes, and overall conclusions of future studies (Kaplan-Kahn & Caplan, 2023). The prevalence of autism-related stigma significantly impacts the approaches taken by researchers, potentially compromising the validity of their findings and detrimentally impacting the well-being of the autistic community. By marginalizing the autistic community, the significance of their experiences and insights are drastically diminished. ~~Neurotypical~~Allistic researchers may devalue the lived experiences of autistic individuals through reinforcement of their own knowledge and perspectives which may be biased through lack of lived experience (McVey et al., 2023). This dearth of representation in autism research is a critical problem in autism research, as autistic individuals spend most of their life as adults lacking adequate resources that may help them navigate poor outcomes in employment, independent living, and friendship quality and quantity (Henninger & Taylor, 2013). As autistic individuals are the only ones with the lived experience to clarify the priorities of their own communities, a community-partnered approach to autism research is necessary to remedy these disparities (Putnam et al., 2023). Furthermore, it is critical that autistic collaboration in research projects concerning their best interests be present throughout the study, from inception to publication, rather than allowing the research project to proceed without autistic input until the end of the study. This engagement is important to ensure that the research is designed in an accessible and relevant way to the community it hopes to serve.

In recent years, the research community has increasingly recognized the importance of research-community partnerships. This type of research is defined as the incorporation of meaningful input from autistic people in the allocation, design, and implementation of research and resources (Fletcher-Watson et al., 2018). With the inclusion of autistic people in research, common misperceptions about autistic priorities and experiences can be avoided, and emerging ideas within the field can be discussed through a direct source with first-hand lived experiences (Pukki et al., 2022). Research that allows for participant input and feedback since the data that is collected comes directly from demographics such as the autism community, parents, service providers, and other directly involved stakeholders should be prioritized to remedy this lack of representation. Centering stakeholders' lived experiences is integral for creating research outcomes directed towards those areas where it is most needed and impactful by the autism community, which is not something that can be accomplished solely by intervention or genetics research, especially since these domains of inquiry often exclude autistic adults (Lloyd and White, 2011). As autism diagnoses and prevalence rates increase, more community-partnered mixed methods or qualitative research studies are called to ensure that the field is prioritizing and maximizing the research benefits of the autism community (Bölte, 2014; Putnam et al., 2023).

In recent years, there have been several studies that examined stakeholders' opinions about the focus of autism research. In a 2014 study by Pellicano and colleagues, the priorities of stakeholders in autism research in the UK was investigated. Through focus groups and online surveys, Pellicano and colleagues found that many autistic individuals in particular expressed disappointment with the emphasis on biomedical research in autism, preferring research that improves quality of life for autistic individuals and other issues of more immediate concern. Lifespan issues were the most common priority for research identified by autistic adults, while family members, practitioners, and researchers listed interventions for autistic children as a top priority. Despite the positive step forward in representing autistic interests this study represents, only 8% of their sample was comprised of autistic individuals, with the remaining stakeholders being ~~neurotypical~~allistic family members, practitioners, and researchers. Additionally, this study did not examine the breakdown of gender identity among their autistic participants and how this may have influenced their opinions.

Putnam and colleagues (2023) examined priorities for autistic adults in autism research and the role of gender identity in their attitudes towards funding priorities for autism research. These findings suggested that the current funding structure is misaligned with the needs of autistic community. Despite this finding, little research exists to suggest how connected the autistic community feels to the development and impact of autism research and the autism research community as a whole.

The Current Study

The current study addresses this gap in the literature through an exploration of autistic adults' perceptions of the current research landscape as well as their opinions of what autism research should address through a survey disseminated to the autistic community. Instead of addressing the community of stakeholders at large, this study examines the priorities of autistic individuals, allowing their opinions and priorities to be center stage. This narrower focus allows research priorities to be studied in relationship to the demographic information of the participants, as opposed to sorting their opinions on the larger scale of autistic compared with ~~neurotypical~~allistic priorities for autism research. This study delves into responses from participants of their priorities and recommendations for the research community. The goal of this research is to employ community participatory methods to involve the autistic community in shaping future research and to provide a platform within the literature to allow autistic adults to express their thoughts, opinions, and desires for the research community.

Therefore, this study was designed to answer the following research questions:

1. Does the autistic community believe the autism research community and subsequent research focuses are helpful or harmful?
2. How does this differ for individuals who with different diagnostic statuses, ages of diagnoses, or gender identities?
3. What are the goals the autistic community has for the research community?

Language Statement

The language used in this paper is modeled to reflect the language used in the autistic community. Autistic, rather than the person-first language of ‘person with autism’, will be used in deference to the stated preferences of the autistic community. Furthermore, the term ‘allistic’ will be used to refer to individuals who are not autistic as well as the term ‘~~neurotypical~~allistic’, as many participants used this language in their responses to the survey.

Author Positionality Statement

~~The study team is comprised of neurotypical and neurodivergent researchers~~This research is co-produced by both a non-autistic (primary) and autistic (secondary) researcher, and was derived from lived experiences as both hold stakeholder identities. The two primary authors ~~s~~ have spent many years working with and within the autistic community and speaking with stakeholders. Both primary authors participated in creating the content, collecting data, interpreting the results, and writing the manuscript.

Methods

Participants

Participants were recruited via social media, through an account that solely advertised research in autism. Individuals were eligible to participate if they identified as autistic (either through diagnosis or self-identification) and were over the age of 18. Participants were recommended to reach out to researchers if there were accommodations that were needed to complete the survey.

Eighty-nine autistic adults completed the survey. A power analysis was conducted with a power of .8, Cohen's *f* of .4, and an $\alpha > .05$, which indicated a sample of at least 66 participants with three quasi-categories. As such, we instituted a rule of collecting the data until the end of the academic term. Participants self-reported their gender using fill in the blank, which was sectioned into the categories present in **Table I**. 36.4% of the sample identified as ~~non-binary~~nonbinary, genderqueer, or agender. 34.1% of the sample identified as female and 22.7% of the sample identified as male. Participants similarly self-reported their autistic identity, with 56.8% of the sample reporting having a formal diagnosis. The age of diagnosis ranged from 2-68

(*M* = 28.11, *SD* = 14.61). Fifteen people reported participating in autism research prior to this survey, either as a participant or researcher. Seventy-three reported never having participated in autism research prior to this survey. Two participants were excluded from the survey due to not identifying as autistic and reporting themselves below the age limit threshold required for the study. For more demographic information, please refer to **Table I**. For survey content, please refer to **Table II.**

Materials

Google survey was utilized for data collection and demographic information. Instagram was used for recruitment.

Procedure

Upon clicking on the survey link through social media posts, participants were briefed on their participation and consented using a survey form. Participants then were directed to answering demographic questions, reported in **Table I**, and were given the option to skip as many questions as they chose. They were then directed to a question asking whether they had participated in an autism research study as a participant. If they answered yes, they answered 12 questions about their participation (refer to **Table II**), before proceeding to the rest of the questions about their attitudes towards the research community. Participants who had not participated were immediately jumped to this section of questions. Questions were presented as a statement and participants were instructed to rate their agreement with the statement of a 5-point Likert Scale, ranging from “Strongly Disagree” to “Strongly Agree.” Participants then answered as many of the 17 questions presented about autism research as they chose to, with the option to skip any. Lastly, participants were asked “What should autism research be focused on?” and answered via long answer text form. This study was approved by the University of California, Los Angeles North Campus General Institutional Review Board.

Results

Quantitative Data Analysis

Survey questions captured five main categories of attitudes towards research: the helpfulness of autism research and researchers, the harms posed by this research, community involvement, minimally verbal and nonverbal representation, and its representation (see **Table II**). When running reliability analyses, these categories varied in their results. The grouping for attitudes towards participation and whether the research community was helping yielded high levels of reliability ($\alpha > .8$). Attitudes towards whether the research community was hurting the autistic community yielded acceptable reliability ($\alpha > .6$). However, the involvement, minimally-verbal, and representation groupings all yielded below acceptable reliability and thus were excluded from analyses ($\alpha < .6$).

On average, participants rated the helpfulness of the research community as 2.69 (out of 5) and the harmfulness of the research community as a 3.20 (out of 5), indicating that autistic individuals found the research community to be more harmful than helpful with a large numerical difference. Similarly, they rated a 2.97 for how representative the research community is of minimally verbal and non-verbal individuals, and a 3.68 for how involved the autistic community is in developing further findings in research. For those who participated in research, they rated their experience as a 3.98 (out of 5). Specifically, these participants rated most highly that "I was treated with respect throughout the study," "I felt I could quite the study at any time," and "I was clear on my compensation (whether or not I would be paid for my time)". In contrast, participants rated most poorly "Recruitment materials were easy to understand" and "My participation in the study benefitted me."

To examine differences in the sample, the group was split using the demographics in several ways. The first examined whether the individuals who were officially diagnosed differed in the attitudes in comparison to those who are self-diagnosed. No significant differences were found between these two groups ($p > .1$). The next examined whether those who had participated in research had a more positive attitude about research than those who had not, of which there were also no significant differences ($p > .1$).

Additionally, the question of whether those with different gender identity responded differently to the survey were analyzed. Using an One-Way ANOVA, significant differences between different gender identities were found in attitudes about the helpfulness of the research community, $F(83) = 9.30$, $p < .001$; the harmfulness of the research community, $F(83) = 5.70$, p = .001; and the representation of the autistic community in autism research, $F(83) = 4.78$, p = .004. Analyses utilizing Tukey's HSD and Bonferonni post-hoc tests found that those who identified as ~~non-binary~~nonbinary ($M = 2.20$, $SD = .75$) felt the research community was significantly less helpful to the autistic community than those who identified as male ($M = 3.16$, $SD = .76$) and females ($M = 2.90$, $SD = .65$), $p < .001$. Similarly, those who identified as ~~non-binary~~nonbinary ($M = 3.65$, $SD = 0.83$) expressed that the research community is harmful to the autistic community, significantly more than those who identified as male ($M = 2.87$, $SD = 0.79$), *p* = .006 and female (*M* = 2.92, *SD* = 0.81), *p* = .004. Lastly, those who identified as ~~non-binary~~nonbinary (*M* = 2.00, *SD* = 0.55) rated the community involvement in autism research as lower than those who identified as females (*M* = 2.43, *SD* = 0.57), *p* = .018, and those who identified as males (*M* = 2.53, *SD* = 0.62), *p* = .008. No other significant differences of attitudes by gender identity were found.

The research team next examined whether the age of diagnosis or identification as autistic would correlate with attitudes about the research community. A series of Pearson's *R* Correlations found that there was no significant relationship between these two variables.

Qualitative Analysis

Seventy-nine participants responded to the qualitative research question, "What should autism research be focused on?" Responses of research topics and questions fit into six main themes: "Representation of Diversity in Gender and Ethnicity", "Improving Quality of Life", "A Strength-Based Approach", "Autistic Subjective Experiences", "Comorbid Mental and Physical Health Disorders", and "Autistic People Involved in Research".

Representation of Diversity in Gender and Ethnicity

The most frequently arising theme (*N* = 19) in response to the inquiry of what participants wished autism research to focus on was increased representation in the areas of gender and ethnicity. Several participants cited the lack of diversity in multiple fields of identity, such as one participant who advocated for research exploring "how to support quality of life in transgender and nonbinary autistic individuals…how the intersection of race and autism affects autistic people of color and how to better support people of color." Several comments focused on the importance of researching the intersectionality of identity, explaining that “most research we have now is focused on white males and has made it difficult for highly masking women of color to be diagnosed, causing significant life impairments.” This theme intersects with the second most popular theme, improving quality of life, which was seen as impossible without increased representation of diverse communities in autism research.

Improving Quality of Life

The theme of improving Quality of Life (*N* = 13) was frequently mentioned among responding participants, and is interwoven with the other five themes, as each of these areas of research was believed to be important as a result of their potential to improve autistic individuals’ quality of life. For instance, one participant encouraged researchers to focus on “how to best identify and support autistic individuals of all ages, races, sexes, genders, ability levels, modes of communication, and educational levels to have the best quality of life.” Another participant gave more specific examples of how researchers might measure quality of life, suggesting that this construct may be measured on “axes including social connection and well-being, desired levels of independence, ability to communicate effectively (where interventions are measured relative to baseline), and where applicable, academic and professional outcomes.” Several participants (*N* = 8) specifically requested research to focus on interventions to promote improved quality of life in this population, as well as more accessible and timely diagnoses for the same purpose (*N* = 9).

A Strength-Based Approach

Participants emphasized the importance of a strength-based approach in research, as well as the need to shift away from a deficit-oriented approach (*N* = 11). As one participant points out, “There are differences between us and allistics (not to mention that every human is unique in their struggles and strengths), but too often (almost always, frankly) our differences are painted as deficit in the bias comparison to the traits of allistics.” Along these lines, participants emphasized the importance of the allistic community as well as the research community to focus on understanding instead of attempting to cure autism (*N* = 7), with the aim of reducing discrimination against the autistic community from allistic individuals (*N* = 8). Poignantly, one participant stated that “if you want to do unbiased and accurate autism research, you need to let go of the idea that Allism is “normal” or default. I’d like to see some research comparing Allistic and Autistic aptitudes… for the purpose of showcasing… that it isn’t better or worse to be Autistic or Allistic, because each condition comes with their own struggles and strengths.” Participants reported wishing that research would stop focusing on their perceived deficits in comparison to a ‘default’ community, but rather, examine them as individuals with strengths and weaknesses, as well as talents to offer. One participant summarized the collective sentiment by saying, “We don’t want research for a cure, we want more support and understanding.”

Autistic Subjective Experiences

Subjective experiences frequently arose in responses as a desired focus of autism research. One participant wrote, “Autism research should be focused on understanding people’s inner experiences of autism rather than how it manifests outwardly… so that more patterns can be discovered and a clearer picture of autism can be created.” Another similar response noted that autism should be understood based on “how it feels to be autistic, not what allistics have decided based on their observations." Many participants reported feeling as though their internal experiences were not represented in research (*N* = 10), and that research instead focused more on external 'symptoms' observed by ~~neurotypical~~allistic family members or researchers. Several participants requested research focusing on the autistic subjective experience of masking, or suppressing autistic characteristics in a public setting or social situations to conform to socially acceptable behavior (*N* = 8), sharing such experiences as "the emotional toll and journey of learning how to unmask and return to a more authentic self" and requesting "more support options for high-masking autistic adults". One participant connected the topic of masking to the lack of diversity in autism research, stating that "most research we have now is focused on white males and has made it difficult for high-masking women of color to be diagnosed, causing significant life impairments."

Comorbid Physical and Mental Health Disorders

Participants spoke at length about the importance of researching comorbid physical and mental health disorders (*N* = 10). As autistic individuals are more likely than ~~neurotypical~~allistic individuals to have comorbid physical and mental health disorders, as well as a lower likelihood of receiving appropriate medical treatment (Adams & Young, 2021), their concern about comorbidities is warranted. Many participants reported concern about the intersectionality of autism and other mental and physical ~~disorders~~conditions, as well as the potential consequences of failing to detect such comorbidities: "Autism research should be focusing on understanding the physical health co-morbidities that are so rampant in the community; one of the most devastating things I see in my line of work is Autistic youth (especially non-verbal folks) being essentially punished for behaviors that were later found or suspected to be caused by physical health issues. So many of us have chronic pain, GI issues, seizure histories, hyper mobility, migraines, etc. yet this is chronically under diagnosed and overlooked, and there is no clear understanding on why these issues are so prevalent in our community." Another participant suggested researching more practical solutions: "More cutting-edge interventions and more support groups for those that have dual diagnosis of mental health issues".

Autistic People Involved In Research

Several participants (*N* = 10) believed that any research conducted by an Allistic person could not get at the heart of the autistic experience, with one respondent commenting, "Allistics are incapable of being experts in autism, on account of [them] lacking an Autistic nervous system, and subsequently the lived experiences of an autistic person." Another participant emphasized the importance of "including actually Autistic folks in every stage of research". One participant, who is the autism research field themselves, noted that part of the reason that autism researchers should be involved behind the scenes has to do with the little regard or respect they have experienced at the hands of others in their profession: "I've had colleagues in my field say incredibly dehumanizing things about autistic people. It's clear many researchers don't see autistic people as valuable, or worthy of being listened to." Participants generally reported frustration with being written out of the research narrative and wished that research would be more inclusive of their desires, viewpoints, and recognize their humanity. Many felt this would be accomplished by including people from their community in the research, behind the scenes, to prevent the research from being ableist, exclusionary, and infantilizing.

Discussion

This study sought greater understanding of how the autistic community feels about the research community and whether those with intersectional identities or later diagnoses would feel differently. Furthermore, this study investigated the goals of the autistic community for autism research moving forward. This study was designed to promote further understanding and participatory action research with the autistic community and increasing autistic representation in research priorities and interests, in addition to taking the temperature of contemporary perceptions of current autism research from the community it aims to serve.

In general, the attitudes reported on the survey indicate that the autistic community views the research community as being more harmful than helpful. This finding is in stark contrast to how those who had participated in research felt about autism research, as this subcategory of participants rated their experience with research fairly highly. This finding is particularly notable considering that these questions probed into whether they would recommend participating to another autistic individual and whether they had an overall positive experience. This disparity indicates that even if autistic individuals feel positively about their individual experiences as a research participant, this may not carry over to their overall feelings about the types and content of research that is being ~~produced, or~~produced or lead to an endorsement of autism research more generally. It is therefore unsurprising that many of the qualitative responses echoed this wariness towards autism research, with many participants outright decrying any autism research conducted without autistic researchers behind the scenes involved in research design, and others simply reporting that autism research failed to address the issues that mattered most to them. Additionally, it was surprising to find no significant relationships between attitudes towards the research community and diagnostic status, age of diagnosis, and age in general. Despite a wide variation in the needs of those who identify as autistic, there appeared to be some uniformity in the poor opinion of autism research held by the autistic respondents.

The finding of nonbinary autistic individual's poorer perceptions of research compared to cisgender men and women is particularly striking, as gender diversity is notably minimal in much autism research. It is perhaps unsurprising, therefore, that nonbinary individuals do not feel represented in autism research, find it less helpful than their cisgender counterparts, and feel that autism research that does not represent them is more harmful on average than those who are more frequently represented in this work. Future research may consider incorporating more gender diversity into both participant sampling and study design, prioritizing incorporating researchers who are nonbinary and gender nonconforming and consulting members of this community when designing research questions to promote more accurate representation, and to improve the accessibility and applicability of the research.

In addition to the insight into gendered perceptions of autism research, the qualitative responses allowed for a greater understanding of the areas of need and interest for the autistic community themselves. The high priority on representation of diversity, strength-based experiences, autistic subjective experiences, and autistic involvement in research design indicate that autistic people wish more generally to be included in the research process and for the outcomes of research to be more focused on their internal experiences and lived realities. The themes of quality of life and comorbid health conditions indicate the importance of focusing research in adulthood and in examining not only autism-specific traits, but rather the aspects of an autistic person's life that may be causing them suffering, such as poor healthcare, ailing health, or discrimination from a ~~neurotypical~~allistic world.

While this study aimed to represent as many people in the autism community as possible, the format and questions asked pose significant limitations. Due to the nature of an online survey, only English-speaking individuals with internet access were able to participate. Additionally, only those who were literate and had the intellectual means to comprehend the language used in the survey were able to respond. As a result, the full spectrum of language and intellectual ability of those in the autism community likely was not captured. Future research should pursue avenues of inquiry to allow those with less language ability, poorer executive functioning skills, and less of an online presence to contribute their opinions. Furthermore, many questions were multiple-choice, leaving much of each individual's sentiment to be expressed in solely one qualitative response question. Future studies may consider an interview or focus group format to capture more of the nuanced opinions of the community in a less structured and restricted setting.

A large proportion of our sample size self-identified as autistic rather than receiving a diagnosis of autism. We did not differentiate between these two categories of autistic identity in our analyses; however, it would be interesting in future research to investigate differences of opinions between these two groups on the subject of autistic representation in research. Lastly, although the research team strove to represent the opinions and reactions of the autistic community, the majority of the research team is not neurodivergent. It is the eventual goal of studies such as this to have more autistic researchers and participants be fully involved in the creation, participation, and dissemination of research in which they have a significant stake. To create this reality, studies must actively prioritize involving autistic researchers and collaborators from the inception of the project. Future research may also consider providing compensation, both for collaborators (e.g. advisory board members) and for participants who are giving their valuable time and expertise in their life experience to this research. There should be an active effort to recruit participants through a variety of avenues to ensure a diverse representation of people from the autistic community, as well as additional accommodations to allow people to participate in different modalities to ensure accessibility. Furthermore, institutions and funding agencies should shift their priorities towards research improving quality of life and projects involving community partnership, rather than allocating the majority of their funding towards genetics and intervention research (Howlin & Magiati, 2017). These suggestions are merely a starting point in moving autism research towards a place where the autistic community can feel represented, understood, and supported by the research community.

Despite ~~these limitations~~the limitations of this study, the results ~~, this study~~ mark~~s~~ a step forward in representing autistic interests in the research community, as autistic voices are rarely heard in academic spaces. Interventions that affect their lives are frequently created and disseminated without any involvement from the people who will be the subjects of said interventions. It is critical that the research community takes account of the lived experiences and opinions of autistic individuals and shapes research to serve them and their best interests, desires, and goals for their lives in order to promote a more inclusive future.

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