

Autistic Adults as Educators:**Exploring Parent Perceptions of Autistic Presenters**Josephine Blagrove¹, Aaron Koch², and Amanda Widgay³^{1, 2, 3} California State University, Chico**Abstract**

In the field of disability studies, Autistic voices have been historically excluded from the autistic narrative, and it is time for Autistic voices to be heard. The purpose of this qualitative study was to consider how autistic adults are viewed by parents of autistic children and how these parents make use of the information provided by autistic adults. Results of this study indicate that parents of autistic children hold a positive view towards autistic adults and value information shared by autistic adult presenters. The research showed that mothers of Autistic children have more hope for the potential of their Autistic children if there are other Autistic role models in their children's lives. The research study focused on the importance of mothers in the lives of Autistic children as mothers often play the most important role in raising children. In cases of children with disabilities, the mother will try to seek out every avenue to provide the most supports to their child, often feeling they must be the biggest advocate for their disabled child.

Keywords: autism, autistic adults, lived experience, parent education, autistic child, family

Autistic adults as educators—exploring parent perceptions of autistic presenters

As we move towards a more connected society, information has become easier to access, digest, and disseminate. Through this process of increased connectivity, minority voices have gained access to spaces that were previously unavailable (Ashing et al., 2017). Understanding the ‘lived experience’ of minority groups has provided insight to broader stakeholder groups and helped improve services and outcomes (Bernard & Harris, 2019; Corby, Taggart, & Cousins, 2018; McAuliffe, Upshur, Sellen, & Di Ruggiero, 2019; Mouchet, Morgan, & Thomas, 2019; van Zelst, 2020). Autistic voices, often conspicuously absent from the narrative of their experiences, have been amplified by both autistic and non-autistic populations. For example, the past five years have seen a call to increased autistic inclusion in research (Nicolaidis et al., 2019), a rise in media representation (Wolff, 2018), and an increased presence in social media (Beykikhoshk, Arandjelović, Phung, Venkatesh, & Caelli, 2015).

Through this increased exposure, there has been a heightened increase of autistic culture and autistic identity that mirrors the understanding and embracing of deaf culture (Beykikhoshk et al., 2015). Language use and identity first identification of those who are autistic (Kenny et al., 2016) have shifted the narrative from “cure” to “acceptance,” with a growing number of adolescent autistic individuals embracing their autistic identity (Cage, Bird, & Pellicano, 2016). As parents seek to understand and support their autistic child(ren), many have turned to social media platforms and parent support groups to gain insight into their child’s behaviors and needs in an effort to provide better accommodations and supports both at home and school (Shepherd, Goedeke, Landon, & Meads, 2020). This shift has led to greater understanding by parents of autistic children and has increased the prevalence of a

strengths-based approach to autism (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016) and consideration for all stakeholders of the autistic community (Gibson & Hanson-Baldauf, 2019).

Research has included parents, professionals and autistic adults in exploration of the meaning and process of an autism diagnosis (Crane et al., 2018) and has shown that autistic individuals are the experts in their lived experience (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017). While there has been an upsurge in the acceptance, celebration and experience of the autistic voice, no study to date has explored how parents with autistic children view autistic adults who are presenting information in a formalized setting, nor the implementation of that information by parents. To that aim, the purpose of this qualitative study was to explore how autistic adult presenters are perceived by parents who have autistic children and how parents of autistic children utilize the information provided by autistic adults.

Methods

All research activities were approved by the California State University, Chico Institutional Review Board. Participants for this study were purposively recruited through an attendee pool from the 3rd annual Northern California Autism Symposium via opening remarks for the program, and material in the program booklet to identify participant needs. Interested participants responded to the researchers by email or phone, and a follow-up phone call was held to discuss the general overview of the study, answer any potential questions, and schedule a day, time, and location for the interview. Inclusion criteria for this study were to self-identify as a) a parent of an autistic child and b) to attend an autistic adult's

presentation. Table 1 shows participant demographics.

Table 1

Participant Demographics

Participant	Age of Autistic Child	Age Diagnosed	Number of People in Household
Rebecca	26	14	2
Tracy	5	3	5
Jasmine	10	3	4
Shelly	5	3.5	4
Karen	5	3.5	3
Kylee	50+	5	1
Grace	6	2.5	3

Parents in the study had children ranging from 5 to 50+ years old. Though not a criterion for this study, only mothers were represented in this sample. Most children in the study were diagnosed under the age of 5 with a diagnosis for at least 1.5 years. Household size varied between families ranging from 1 to 5 members, and there was only one autistic child in each family units.

Interviews

Semi-structured interviews were conducted with each participant and lasted approximately 30 minutes. Interview questions followed the same order for each participant, with follow-up prompts as needed. Interview questions are shown in Table 2.

Table 2

Interview Schedule

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- Have you heard autistic adults speak about their experiences in the past?
 - If yes, please explain that setting/feelings it gave you, etc.
 - What autistic adults did you hear speak?
 - Before hearing autistic adults speak, what were your perceptions of what that would be like?
 - What were your perceptions about your child with Autism Spectrum Disorder (ASD)'s future before hearing the speakers? Did your perceptions change in any way (positive or negative) after hearing this?
 - Was there a big "take away" message you heard from the autistic presenters? If so, can you please share and describe why that resonated with you?
 - Do you think hearing autistic adults share their experiences are important (why or why not?)
 - Who are your child's role models? (If respondent did not identify anyone on the spectrum: is it important for your son or daughter to have role models who are on the spectrum? Why? Why not?)
 - Was there anything that was discussed by the autistic adults that was unexpected or eye-opening? If yes, what and why?
 - Was there anything that was not discussed by the presenters that you wish would have been?
 - Do you use identity first (autistics) or person first (individual with ASD)? Can you explain why that is the language preference for your family?
 - Is there anything else you would like to share, either positive or negative about the experience of autistic adult speakers?
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Interviews were audio-taped and transcribed verbatim for analysis. Data were hand-coded by all three authors using a first-cycle coding method, looking for exploratory categories as described by Miles, Huberman, and Saldana (2014). Thematic analysis was used in a linear method using the following steps outlined by Braun & Clarke (2006): 1) familiarization with the data; 2) coding; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) the writing up. All authors independently identified

categories and themes and then reviewed each other's for similarities and differences. Any differences in interpretation were discussed and resolved through that discussion process.

Results

Through analysis, three themes emerged from the experience of those with autistic children of hearing autistic adults speak: (1) "always trying to see around the corner": gaining insight from autistic adults; (2) "guilty of misconceptions": ideas about autistics from non-autistic parents; and (3) "it's important to show them what's out there": the importance of diversity and role models.

"Always trying to see around the corner": gaining insight from autistic adults

This theme was defined as any time a parent discussed obtaining insight autistic adult presenters or the wish to gain more insight about the autistic experience. Parents in this study shared that they were always on the lookout, anticipating what is next for their child, trying to see how they can support their child, and getting information from as many sources as possible. For these parents, autistic adults provided meaningful insights in multiple ways as to how they could better support their child. For Jasmine, how she interacted with her child in public shifted dramatically once she heard autistic adults share their experiences:

It makes me think of the things as a parent that I would do wrong. It has taught me to—hearing adult speakers and their experiences teaches you as a parent, "Oh I need to do more of this or less of this. When I am in public, I don't jump to tell he has autism to make a 'problem' ok or not even a 'problem' or make a situation ok."

This shift happened for all of the parents in the study. Presenters changed how parents

advocated for their children in school and in extracurricular activities, what services they sought out or rejected for their child, and what sensory supports they put in place in their child's daily life. Parents were constantly worried about their child's future and wanted as much information as possible on what autistic adults thought they should be doing as parents. These parents really wanted to get it right and felt that hearing autistic adults' perspectives was important. For example, Tracy shared that hearing from an autistic adult who had considered ending her own life because she didn't feel accepted or understood really made Tracy think about how to support her own child and how she felt about parenting:

“I feel like I am always questioning, like am I doing all the things I can or making all the wrong choices, which I think we all do no matter what our kids are or what is going on, but they [autistic adults] have a unique perspective.”

For all the parents in the study, it was important for them to hear from autistic adults so that they could learn as much as they could about neurodiversity as well. It was one thing, parents shared, to learn from professionals, but quite another to hear from those with the lived experience. Rebecca offered, “I find it's not just a preference, it's a need to listen to people who are neurodivergent speak about neurodiversity. I can't say it enough.”

***“Guilty of misconceptions”*: ideas about autistics from non-autistic parents of autistics**

This theme was defined as any time a parent discussed misconceptions they had before they heard autistic adults speak. More than half of the parents in the study initially shared a general idea that an autism diagnosis was a barrier to their child having a successful or fulfilling life, and that they expected the autistic adult presenters to be socially isolated. Jasmine found comfort in learning that the autistic adult presenters “do have friends, and

they're not by themselves, and they're not on the street." This sentiment was echoed by Karen: "This will happen. It'll just take time, and it will happen on [my son's] own terms."

Parents also shared that they were nervous for the presenters at first and felt protective of them, like they would for their own children. Shelly reported her expectation that:

It might be hard for [the autistic adults] with so many people in the room. I was not quite expecting so much humor, which was really refreshing for me...My son is very rigid, so I expected it to be that way...I always worried about him being teased, and hearing Alex talk about how he was teased but then found his place made me hopeful that my son's going to find his place and 'his people' so to speak.

Grace shared a similar view: "It was inspirational to see that we can carve out spaces for our kids to exist in the culture and it doesn't have to be this [segregated] society that we perceive it to be." Her original perception of autism was that it was "scary" because the representation of autistic people has been limited to the dichotomy of savants and autistic people identified as developmentally disabled, but the autistic adult "speakers have shown us what they really can be like. Even with the successful examples, it's still real."

Another shared belief was that autism was a negative identity. This perception was also swayed by hearing from the autistic adults. Grace shared her understanding that autism is "not the death sentence that some of us are really made to feel... This doesn't feel bad. It's just different, it's not bad." Shelly gave a similar response, considering the possibility of autism as a positive trait: "It's a positive thing. It doesn't mean you're less at something, it just means you do things in a different way... [it's] okay to be who you are. It's not like a lot of these behaviors are negative. There's a lot of positive attributes to it."

This shift from "scary" to "this is my child; they are their own person" was something

that caused a shift in thinking that was translated and promoted to extended family members, friends and professionals who interacted with their children. For some parents, it helped to shift their tone in parent support groups and to challenge negative stereotypes when encountered in the community.

***“It’s important to show them what’s out there”*: the importance of diversity and role models**

This theme was defined as any time a parent discussed the importance of diversity and role models for their autistic child. Parents were asked if they used identity-first or person-first language and to explain why their family chose the language they did. Many of the parents shared that they had initially used person-first language because that is what they had heard from professionals and other parents. However, after hearing autistic adults speak, all but one family chose to use identity-first language and to promote that type of language use in the autism community in which they participated. This change would not have occurred or may have come more slowly had they not been exposed to autistic speakers who explained why they thought identity first language was important. Grace shared, “I probably didn’t pay as much attention to language until it was brought forward by autistic adults. I do it [use identity first language] forcefully now because I’ve heard from autistic adults it’s important to them.”

All participants in this study attended multiple presentations led by autistic adults. Many parents spoke about how that range of autistic experience was important and that hearing those with varying experiences was important in helping them understand how to best support their child. Additionally, parents wanted even more breadth of experience, with parents asking for more female representation and to hear from autistic adults who use augmented communication. Tracy summed up parental feelings about autistic speakers best:

If parents are really willing to listen to [autistic adults] and accept what their experiences are, I think it helps us make better decisions for our children while they can't communicate. I think it's really important to listen to autistic adults of how they felt about things that were done to them or the therapies they had to go through and really respect what they have to say.

All parents shared that although their autistic kid(s) did not currently have autistic people that they looked up to as role models, they felt like it was very important for that to be a possibility for their child. Grace added how "important [it is] to have autistic role models. I think that it's an opportunity to make it better for our kids. Maybe he would connect more and have human role models if he felt he could see himself in them."

Discussion

This study is the first to explore how parents of autistic children perceive information from autistic adult presenters. Each of the seven participants reported a positive experience attending the presentations of autistic adults and wished to hear more information as a result. Additionally, parents attributed changes in their parenting behaviors and attitudes to insight gained from these experiences. For example, many parents began using and promoting identity-first language, implementing various sensory tools, and taking a step back to understand some of their child's behaviors as communication of anxiety or a need.

By improving understanding between stakeholders in the autistic community, parents may gain insight from autistic adults who have the expertise of their lived experiences. For the parents in this study, a majority of their children did not have expressive verbal language skills, which left many parents unsure of what needs were being met, or not met, what experiences may be too overstimulating, or what therapies were more harmful than helpful to

their child. While professionals in the autistic community are a valuable resource, unless they themselves are autistic, there is a component of the lived experience that may be missing from their interpretation of autistic behavior. As such, listening to autistic adults is a critical step in improving understanding of their autistic child for parents who themselves are not autistic.

While this study provided insight to a newly explored area of the literature, there were limitations. One, this study was exploring the experience of parents who have an autistic child qualitatively. The nature of qualitative studies requires a small sample size, which cannot be generalized to the greater autism parenting community. Additionally, the parents in this study were asked to reflect on presenters they have heard at a smaller autism symposium in a rural area in Northern California. As such, these experiences might not be the same as parents in more rural areas or other parts of the country.

While the idea of autistic people as educators may be simplistic in nature, the concept of having autistic adults share their experiences, expertise and knowledge is not yet mainstream. Organizations and educational institutions should work with autistic adults and autistic research networks to provide spaces where parents of autistic children and autistic adults can come together to help provide support for families who are raising autistic children. One of the parents in the study summarized this need, stating “it’s important to keep offering these experiences to community members because, if we don’t provide the platform for [autistic adults] to speak, we’re never going to hear them.”

Conclusion

In this discussion, we have considered a research study about the opinions and impressions of parents with Autistic children. The qualitative research study analyzed many

questions mothers of Autistic children worry about daily, including what kind of identifying language (person first language or disability first language) they should use about their Autistic children. The research study focused on mothers as mothers often play the most important role in raising a child with a disability. Mothers believe they know what is best for their child and how to navigate a world not set up for their child's disability. However, as the research suggests, mothers of Autistic children often struggle with providing the best environment for their children. Towards this end, this article suggests we need more research from the perspective of Autistic people as most research that is available is not. Additionally, we need to provide more supports for Autistic people to voice their concerns and to direct their lives so they may have the most independence.

Towards this goal, Autistic voices need to be heard and not silenced. This is the only way we will learn more about the lived experience of those with ASD. As the authors continue to create more supports for Autistic children to grow up and to live an independent life, we also hope there will continue to be more opportunities where Autistic children can communicate and learn from Autistic adults. We believe interacting with others with a similar disability will create a supported environment. Furthermore, the issues of the effects of Autism need a greater spotlight. As we continue our work in the field of disabilities, we will create more avenues for those with Autism. We hope to have greater research on the field and the effects of Autism. We will continue the work for those with Autism and all other disabilities and long for a day where people with disabilities are fully included in society at large. Until then, we will redouble our efforts. When one of us is discriminated against, so are we all. Our work will never be done, and we thank all mothers raising children with disabilities. We appreciate your efforts and know that you are trying your best to get the help your child needs. We know this journey may be long and hard but there is hope.

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