SCHOLARLY REVIEW

# Centering Autistic People in Awareness and Fundraising Campaigns: How to Empower and Enable

By Anaiya Nahar

## Author Biography

Anaiya Nahar is a senior at The Bolles School in Jacksonville, Florida. She intends to study public policy and continue advocating for autistic and neurodivergent groups. Inspired by a personal relationship with the cause, she organized a Golf for Autism charity event and worked directly with autistic children to increase their representation in the community.

## Abstract

Autism organizations characterize autism according to their mission. Corporate, medical, research, advocacy, family support, and other organizations create distinctive images of autism to promote their values and efforts. For this research paper, Autism Speaks, Autistic Self Advocacy Network, and The Autism Society of Florida are evaluated. It is worth observing that many organizations promote these representations without autistic individuals in top-level positions, suppressing any contribution they may have. As a result, many autistics have criticized how organizations have portrayed autism in an inaccurate, inhumane, and disrespectful manner. Autistics have advocated for their involvement in organizations by requesting compensation for their efforts in organizational advocacy and better access to disability justice group conversations. However, this inclusion ultimately results in the exclusion of alternative groups: non-verbal autistics. To incorporate them in professional and advocacy spaces, a form of non-electoral representation, surrogate representation, and funding for assistive communication technology are imperative. To further improve autistic self-advocacy, an allyship must be made between autistic adults and autistic parents/caregivers. This allyship can be taken to the next level and be made between major autism industries and autistic advocates as well.

## Introduction

Autism Spectrum Disorder (ASD) is a condition that results in repetitive actions, issues with social communication/interaction, and limited interests. However, this is just a generalization; when the disorder begins in the early childhood ages, it affects each child differently. Initial symptoms of autism include struggles in two groups: communication and behaviors. Issues with communication include a lack of eye contact, facial expressions, and a delay in speech. On the other hand, issues with behaviors include trouble adapting to a routine out of their normal one, sensitivity to changes in their sensory system (smells, tastes, feelings, sounds, or imagery), and repetitive body movements. The causes of autism are still not completely understood, but recent studies and tests have shown that ASD is caused by genetic reasons after the brain has developed. This is when many genes are activated by environmental factors, causing the relationship between the cells of the brain to change (Autism Spectrum Disorder - Symptoms and Causes, 2018).

As of May 2024, 1 in 36 children of all racial and socioeconomic groups is diagnosed with autism spectrum disorder in the United States of America. The disorder is almost four times more common in male children than female children nationwide (Maenner, 2023). Most states have autism diagnoses from 2% to 3.9% of the population. Specifically, Florida holds the highest percentage at 4.88%, and Texas holds the lowest percentage at 1.54% (51 Autism Statistics, 2023). With 1,602 autism organizations currently operating in the United States, in total, they have generated over $2 billion in revenue and assets annually (Autism Organizations | Cause IQ, 2024).

The prevalence of autism gave rise to thousands of autism organizations ranging from medical, research, adult care, childcare, to corporate-based organizations. Despite all having different missions and goals, all organizations want to spread awareness about ASD and motivate the public to support the cause through volunteering their time, money, and more (Nieto et al., 2015). Some organizations are more "cure-based" and focus on research and scientific methods to find a cure for autism. Others follow a "disability-rights" model and focus on the strengths autistics currently have and work on improving them (Saunders, 2018). These organizations were initially led by parents/caregivers of autistic children. But once the autistic children became adults, they decided to pioneer their own movement: the autistic self-advocacy movement. With the help of the Internet, autistic individuals from different regions, time zones, and backgrounds were able to connect and create this movement that encourages the integration, appreciation, and advocacy of ASD individuals (Rottier & Gernsbacher, 2020).

## Methods

### Literature search strategy

Using Google searches and published papers from Google Scholar, this paper evaluates the missions, actions, and rhetoric local and national autism organizations have promoted. Using local and national organizations provides an overview of the similarities and differences grassroot initiatives and corporations have and how both can work towards creating an improved society for autistic and neurodivergent individuals.

The following key terms were used in searches: neurodiversity fundrais-ing/ers, autism fundrais-ing/ers, autism/neurodiversity philanthropy, autism/neurodiversity advocacy/awareness/campaigns, ethical fundraising, autism trainings, autistic jobs, and nonverbal autism advocacy. Relevant organizations' (foundations, nonprofits, corporations, institutes) websites were found using Google search. These websites provided videos from YouTube on autism education and their organizations' efforts.

Many articles were chosen that expressed a critique of current autism organizations' lack of effectively representing autism or including autistics in policy-making, leadership, and campaigns. Additionally, when autistics were included in these areas, the need for this representation to be ethical and accurate was presented in other articles. Finally, the demand for even more autistic inclusion in society was advocated. Strategies, financial opportunities, and restructuring disability groups to promote this inclusion were shared as well. When this inclusion still resulted in exclusion of certain autistics, a new form of representation for this group was offered.

## Results

In Table 1, 15 autism organizations in the United States are represented to show their different focuses. Despite their differences, all organizations can be categorized in five ways based on their framework: advocacy/legal assistance, family assistance, support resources, research development, and housing. State organizations have an emphasis on creating change in the community by focusing on localized concerns. Alternatively, national organizations focus on large-scale changes in research, policy, support, and more. Still, both types of organizations rely on the public's support to further their mission and pursuits in the autism movement.

Table 1. US-Based Autism-Focused Organizations

| Organization Name | Geographic Coverage (United States) | Framework/Approach |
|---|---|---|
| Autism Speaks | National | Autistic parent- led organization focused on research on autism genomics, childhood screenings, and early intervention |
| Autistic Self Advocacy Network | National | Facilitating legal advocacy, educational resources, advocacy tools, leadership trainings for autistic self-advocates |
| The Autism Society of Florida | National-Florida Specific | First autism organization led by parents that monitors federal policies to ensure they support autistic employment, education, health care, housing, and more |
| The Project HOPE Foundation | State-South Carolina | ABA-based non-profit providing services for autistics through its four programs: therapy, education, adult services, and community engagement |
| Autism Research Institute | National | Advancing the health of autistics through research, cooperative efforts, and outreach |
| Autistic Women & Nonbinary Movement | National | Committed to transformative and reformative justice for autistic women and individuals of all or no genders in organizations |
| The Color of Autism Foundation | National | Ending the stigma of autism in African American families through early intervention and empowering families |
| Els for Autism Foundation | National | Parent-founded organization supporting the goals of autistics through early intervention, collaborative partnerships, recreation services, and adult services. |
| Heart of Texas Autism Network | State-Texas | Dedicated to the inclusion, self-reliance, and participation of all individuals and ages with ASD by providing parent advocacy trainings, therapeutic activities, internship programs for adults, and more |
| Advocates for Autism of Massachusetts | State-Massachusetts | Ensuring the human and civil liberties of all autistic individuals by working with policymakers and other advocates to create more support and resources for those with ASD |
| National Autism Association | National | Providing life-saving resources, training to first responders, safety toolkits to schools, and free educational webinars to support and protect autistics |
| Mary Sunshine House | State-South Carolina | A non-profit organization that houses and enriches the physical and emotional growth of autistic and neurodivergent adults |
| Autism Science Foundation | National | By funding scientific research, the non-profit organization is dedicated to understanding the biological causes of autism to provide families with treatment |
| Illinois Center for Autism | State-Illinois | Educating and serving autistic adults with mental health and educational treatment to help them achieve the highest level of self-reliance |
| Washington Autism Alliance | State-Washington | Nation's only legal advocate for those with ASD and intellectual disability regardless of the ability to pay for services. Through legislative advocacy, affected individuals are ensured their rights. |

## Discussion

### Autism Campaigns

#### Rhetoric and Perspective

Local and national autism campaigns are committed to raising awareness about the condition through fundraisers, advertisements, and other rhetoric. Therefore, it is vital that organizations don't just simply inform the public about autism, but rather advocate for the integration of autistic individuals into society. On the national and local level, autism organizations have employed different fundraising and branding tactics and have ultimately created two different representations of autism. The way an organization chooses to characterize autism is reflective of the mission of the organization (see Table 1 for a representative sample of major US-based autism-focused organizations). For example, Autism Speaks, one of the largest autism organizations in the United States, presents autistic individuals as people who are plagued by a disease and desperately need financial support in finding a cure (Saunders, 2018). Thus, the organization brands itself as the necessary cure for autism that can only function with funds and resources from the public. Autistic Self Advocacy Network (ASAN) is another national-level disability organization but utilizes a different rhetoric. Committed to mobilizing the autistic community in order for them to become a part of society, ASAN draws from a disability rights model. They believe in empowering autistic people to self-represent on a large platform with acceptance from the public (Saunders, 2018). These two national organizations present a different approach to representing autism and gaining funds. Similarly, various local and state organizations also differ in how they market autism. The Autism Society of Florida (ASF) is one of the many autism organizations in Florida, the state with the highest rate of diagnosed individuals with autism. ASF is a

non-profit organization that uses the disability rights rhetoric. The organization crafts legislation to ensure their needs are legally represented. Additionally, they believe self-advocacy is a vital practice autistic people should have the opportunity to enact. They teach these self-advocacy skills to parents of autistic children and autistic adults (Donate | Autism Society of Florida | United States, 1988). Overall, these three organizations resort to different interpretations of autism to brand their organization; however, there is concern whether these interpretations are the best way to ethically represent autistic individuals in society.

## Autistic Individuals in Leadership - or Not

Ever since autism campaigns arose in the United States, the leading idea was that relatives, therapists, mentors, and neurotypical individuals were the best representatives for the boards of autism organizations. Unfortunately, many charities restrict autistic adults, those who they claim to serve, from having a position in governance or policy-making. The lack of perspective from autistic people inherently limits charities from the unique insight into the needs and desires of those living with autism. Charities should allow autistic individuals to self-represent to ensure organizations are benefitting autistic people and not hindering them (Waltz, 2012). Additionally, in order for this change to be notable, nonverbal and verbal autistic individuals must be represented (Chapman & Veit, 2020). The concept 'third wave of advocacy' also supports this suggestion that it is problematic that autistic individuals are not part of the boards of autism-focused organizations and that they should be included more. The first 'wave' was dominated by parents, the second by professionals, and the third and final 'wave' should be led by those with disabilities. This comes at a time when the self-advocacy movement is more focused on acceptance, guidance, and a quality lifestyle (Rottier & Gernsbacher, 2020).

The variance of autistic and non-autistic representation on leadership boards of Autism Speaks, ASAN, and ASF makes this case clear. Autism Speaks' leadership committee consists of members who are familiar with autism, but lack a sufficient number of members that have autism. Specifically, Stephen Shore is the only individual on the board of 28 directors that is on the spectrum (Board of Directors | Autism Speaks, 2005). However, ASF does this better even though the organization only has two board members with autism. ASF ensures autistic individuals are involved at every level in decision-making to create a diverse and effective leadership committee (Board of Directors | Autism Society of Florida | United States, 1988). But even more than Autism Speaks and ASF, ASAN's governance includes six neurodivergent and autistic members. The organization has effectively provided a platform for autistic individuals to self-represent their own interests and message to the public ("Who We Are - Autistic Self Advocacy Network," 2021). Still, these inconsistencies in inclusion across the three leadership boards show how more effort can be taken to include autistic individuals in organizations which seek to serve and advocate for them.

## Fundraising Tactics and Image of Autistic Individuals

Autistic self-advocates have recently expressed taking offense to autism charity advertisements because organizations lack the comprehension of the social model of disability, and more importantly, they lack involvement from autistic individuals in the creation of them. Autistics have pushed for the social model of disability to be the leading idea in autism efforts. It is an idea that says society's lack of services and resources for disabled people is what prevents them from being involved in communities (Bampi et al., 2010). For example, self-advocates have criticized campaigns that have used dialogue parallel to the post-9/11 "War on Terror" time period and positioned parents as the warriors (Waltz, 2012). Specifically, in 2007, before being taken down, the NYU Child Study Center initiated the "Ransom Notes" advertisement campaign that employed this rhetoric. The fight from autistics to end this campaign represented their fervor to be accurately and humanely represented ("Victory! The End of the Ransom Notes Campaign - Autistic Self Advocacy Network," 2007). These ideas created about autism are misleading and impose even more stigma on autistics. Organizations begin to portray autism through certain words and phrases, creating cultural understandings. In order to present an accurate understanding of autism to the public, autistic adults must be involved with charities to help improve their advertisements and campaigns. This way, charities can move away from improper awareness and focus more on ethical autism awareness (Waltz, 2012).

Autism Speaks, ASAN, and ASF show a variation of awareness in their campaigns. Autism Speaks has been said to create a negative image of autism and presents the organization as the answer to the injustices faced by neurodivergent individuals. They use fear rhetoric to invoke an emotional response in the public in order to receive donations. For instance, the "I Am Autism" video that Autism Speaks featured in 2009, which was later removed, faced backlash for portraying autistic individuals as harmful to their families and communities. Autism is personified in the commercial, and narrates the scenes of distressed families. "I derive great pleasure out of your loneliness" and "I will fight to take your hope away" are two of the many inaccurate phrases the campaign has used to characterize autism ("Horrific Autism Speaks 'I Am Autism' Ad Transcript - Autistic Self Advocacy Network," 2009). Autistic advocacy by Autism Speaks is inconsistent with the essential tenets of disability rights, including the right "that every human being has the inherent right to life." This violation of the United Nations Convention on the Rights of Persons with Disabilities has created immense conflict with autistics (Rottier & Gernsbacher, 2020; Article 10 – Right to Life | United Nations Enable, 2006). On the other hand, ASAN follows the strategy where information about autism is shared with the public in order to create social change and an opportunity for autistic people to self-advocate. They fight against the notion that autistics are not capable of representing themselves (Saunders, 2018). ASF is committed to creating social change but, in this case, with political action. The nonprofit supports and actively creates legislation to improve the quality of life for autistic individuals. Specifically, their "1 in 36 - The Connection Is You" campaign video focuses more on how the organization can support autistic individuals through various programs rather than focusing on the limitations autism brings to them (Donate | Autism Society of Florida | United States, 1988). However, these variations in awareness create more tension between the autism community and the rest of the public. Thus, it can be concluded that organizations must align more with ethical autism awareness to enable the integration of autistic people in the community (Saunders, 2018).

## Strategies on How to Incorporate Autistic Individuals in Campaigns and Philanthropy

### Economic Barriers to Opportunities

The concept of self-advocacy in autism campaigns and organizations is starting to become an accepted notion, but numerous autistic people are still "locked out" of leadership roles that would allow them to lead campaigns and engage in policy-making. Parents and professionals continue to dominate this sphere. With the little opportunity autistics have, self-advocacy organizations can't operate on their own agenda because they lack sufficient funding and are, therefore, vulnerable to being used to support other organizations' agendas. In order for autistic self-advocates to initiate change collectively, funding is needed to train them in specialist communication expertise, for the salary of support staff, and for transportation. Most importantly, providing autistic self-advocates with specialist communication expertise is vital in contributing to their communication and understanding of affairs. Along with this training, access to augmentative and alternative communication (AAC) devices is dependent on funding as well (Glumbić et al., 2022). To increase autistic self-advocacy, first, opportunities for leadership must be granted, and then support through financial resources and aides must be guaranteed (Petri et al., 2021).

According to Maslow's hierarchy of needs, a person's personal security must be ensured before pursuits of self-advocacy (Maslow, 1943). Jobs which provide equitable opportunities to neurodivergent people can enable them to have financial security. In fact, many philanthropic efforts toward the inclusivity of autistic individuals include employment opportunities. However, autistic people have not traditionally been compensated for their advocacy work - though if they were, they would inherently be empowered towards self-sustainability. Unfortunately, many disability organizations have structured restrictions that exclude autistic self-advocates from holding paid positions. This may happen if professional and parent advocates are still controlling financial resources that would be used for these positions (Petri et al., 2020). Because of this exclusion, more self-advocates pursue their

campaign independently, on a smaller scale, and not in a collective group. As a result, advocates with autism direct their priorities towards their financial security and not self-advocacy. Thus, people with autism should (1) be compensated for their organizational advocacy work, which will (2) enable them to take care of their own financial needs, and (3) be empowered and unencumbered to actively self-advocate as well (Petri et al., 2021).

### "Nothing About Us Without Us"

This disability rights motto has transformed neurodivergent representation and allowed for more inclusion of autistic individuals in decision-making, advertisements, and the community. In fact, digital tools have been successful in creating online areas for advocates to fight against stigma and assert their own claims about life with autism. Creating and supporting digital spaces is a cost-friendly and effective way for autistic people to become involved with their advocacy pursuits.

However, in the disability groups themselves, many neurodivergent perspectives are excluded, especially the ones of autistic individuals. This exclusion can be changed by enforcing certain practices in disability groups to create more inclusion of neurodivergent and autistic individuals (see Table 2).

| Table 2. Jessica M. F. Hughes' (Hughes, 2016) SIX Strategies that Facilitate Inclusion |
|---|
| **#1 Make the meeting spaces and communication accessible to all.** |
| Those with physical disabilities must be accommodated, whether that includes using a space that is wheelchair accessible or near public transit. Additionally, any communication aids should be provided for individuals with verbal constraints. |
| **#2 Presume competence.** |
| This creates a sense of equality in the space and enables self-empowerment because neurodivergent groups feel more pride in their experiences. |
| **#3 Acknowledge neurodivergent people.** |
| The best way to be an effective advocate and mentor for someone else is to fully understand their condition and perspective. Discussion organizers can utilize the internet, conversations, and other literary resources to understand the basics of neurodiversity. |
| **#4 Understand intersectional perspectives.** |
| Value those even more underrepresented within the autism spectrum: people of color and those who are LGBTQ. Involvement from this sphere of people will enhance the type of representation disability groups are capable of. |
| **#5 Initiate connections with underrepresented individuals in the neurodivergent community.** |
| Reach out to intellectually disabled people - this way their voices can be showcased online to strengthen the neurodiversity movement. |
| **#6 Be aware of and challenge "common sense" expectations.** |
| This pertains to organizers and community people understanding their "common sense" expectations and learning how to redirect them. For example, the expectation that group members are capable of the same responsibilities severely limits the range of individuals able to participate in discussion. Having respect and awareness of everyone's capabilities will allow for more participation. |

Overall, to continue the motto of "Nothing About Us Without Us", the public needs to acknowledge the agency individuals with disabilities have in paving their own path in society through organizations and groups. These groups create a sense of autonomy and self-reliance for autistics to create advocacy on their own terms (Scotch, 2009).

## The Fallacies of Inclusion

### Exclusion in Inclusion

Autistic individuals are typically characterized within two groups: self-representing autistics and non-representing autistics. These two groups provide a generalized distinction between autistic people and their abilities. Non-representing autistics are nonverbal and need additional resources for communication. Representing autistics are able to sufficiently communicate verbally. In terms of representation, non-verbal self-representatives are overlooked because their perspective is discredited, even though the majority of autistics are non-representing. However, for verbal self-representatives, they are more easily included in campaigns and other forms of representation. Years of stereotypes and prejudice limit the ability non-representing autistics have, in terms of advocating for themselves on a larger platform (Chapman & Veit, 2020). This type of exclusion results from partial representation. This happens when a person claims to advocate for a group of people, but only engages with a section of that group. In this case, many non-representing autistics are the ones not represented by autism organizations. Many autism self-advocacy organizations are being criticized for not representing this marginalized but majority of the autistic community (McCoy et al., 2020).

### Fallacies to Accuracies

In order to work around communication barriers and ensure the ethical representation of non-verbal/non-representing autistics, a form of non-electoral representation can be imposed. Non-electoral representation "can fill in the gaps in electoral representation" by strengthening the perspectives of non-verbals that have been undermined for so long. In other words, representative deficiencies that are created by electoral institutions are mitigated by non-elected representatives (Montanaro, 2012). These non-electoral representatives must follow two regulations before they can be appointed to the position. First, they must ethically and unwaveringly express the interests of autistic individuals. To do so, they need to take deliberate measures and processes to fully understand them. To understand them, representatives should acknowledge autistic individual's strengths, not their weaknesses. Giving attention to these qualities creates more of an interest to advocate for autistics (Gensic & Brunton, 2022).

Additionally, certain measures to understand their interests include holding forums where verbal self-advocates and professionals who work with non-verbal autistics can discuss different policies. Second, these representatives must request and receive authorization for their plans from constituents. Getting this approval from verbal autistics can be in the form of attending rallies or donating to the representative's campaign. Hence, the question arises for how non-verbal autistics can signal their approval for the candidate. To avoid overlooking their opinion, families, caregivers, and professionals can give their input on who is best fit to lead autistic advocacy pursuits. This is known as surrogate authorization and is an effective way to get approval on behalf of non-verbals (McCoy et al., 2020). Furthermore, representation also needs to extend to the appropriate policies/actions/functions of representatives once appointed (Plotke, 1997). Therefore, it is crucial to recognize that even with these efforts, partial representation can still exist within advocacy spheres. Realistically, non-electoral representation is successful at curbing partial representation, not eliminating it in advocacy spheres (Frith, 2020).

With how diverse autism is, proper organization within the autism organization is necessary. In other words, to limit partial representation and make sure decisions can be made, a "federated model of representation" can be implemented. This means that representatives can be appointed to subgroups to advocate on certain issues on behalf of smaller groups but collaborate under a single entity to advocate for issues affecting a broader range of people. This approach can help bridge the divide between all autistic people and representatives. Applying these changes are crucial to the future of advocacy for not just representing autistics, but also non-representing autistics (McCoy et al., 2020).

The main goal of having non-electoral representation and then using surrogate representation to get authorization from non-verbal autistics, is to work around communication barriers and still provide them representation. However, using surrogate representation indefinitely limits the input non-verbal autistics are able to give (McCoy et al., 2020). Therefore, along with non-electoral representation, funding should be provided by families, caregivers, professionals, and the public for assistive communication technology. ASAN President Ari Ne'eman stresses how if even one-tenth of the funding used to find a cure for autism was put towards this technology, people on the spectrum considered "low-functioning" or non-verbal could communicate effectively. This idea represents a growing objective that instead of fixing autistics, organizations should be doing more to empower and support them (Durbin-Westby, 2010). Surrogate representation is not an ineffective way of respecting non-verbal autistics' interests, but providing communication resources for non-verbal autistics can allow them to express their interests themselves.

## Conclusion

There are two main types of advocacy that are involved with the autistic members and community: "spaces for Autistics" and "shared Autistic space." Major autism corporations, like Autism Speaks, have been accused of following the "spaces for Autistics" type advocacy by centering parents, family, and caretakers in autism advocacy endeavors. As a result, many organizations including ASAN and ASF have been created to follow the "shared Autistic space" type of advocacy to put autistic people on the frontlines of their own movement (Sinclair, 2010). They are in control of the decisions and actions the

organization becomes involved in and make sure their perspectives, not those familiar with autism, are used to create change. Through their involvement, autism is presented accurately and ethically as a way to empower autistics and educate the public (Edidin, 2024). Creating this involvement is vital in creating a future of just autism fundraising, images, and communities. To facilitate their inclusion, financial opportunities in disability/ advocacy groups and other professional spaces must be available. For autistics to be involved in disability groups themselves, their condition, perspectives, and experiences must be recognized and understood by others. However, not all with ASD are represented in advocacy groups as easily. Non-verbal autistics, the majority of autistics, tend to be left out of organizations due to communication barriers. Though non-electoral representation, surrogate representation, and funding for assistive communication technology can bridge the divide between marginalized and mainstream groups in the autism community (McCoy et al., 2020).

Not only is it important to connect members in the autism community, but it is also essential to bring together autistic advocates and parent/ caretaker advocates. To create a more unified future for autism advocacy, non-autistic parents can ally with autistic adults by following three requirements: resources, recognition, and autonomy. Parents can provide resources in the form of activism, money, equipment, or buildings. Recognizing autistic adults means respecting their existence and value. Finally, to continue to uphold this allyship, valuing their autonomy includes allowing them opportunities for representation and respecting their choice of rhetoric to employ (Shakespeare, 1993).

Nonetheless, this allyship is not as common among many corporate businesses and organizations fueled by the Autism Industrial Complex. The AIC is founded on the concept that autism is an issue and organizations must intervene to fix the condition. Autism industries profit from autism by carrying out an industrial-scale commodification of autistic people (SMIL Autism Resources, 2022). It is crucial for national and local autism organizations to not engage in the AIC and instead/continue to promote accurate and ethical advertisements (Table 1). Similar to what autistic parents have done, businesses can also move towards an allyship with autistic advocates. This alliance can mend past harm caused to the autistic community and move towards a future where autistic individuals' advocacy is not only represented but supported by all (Shakespeare, 1993).

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