

Chapter 7

AUTISTIC ADULT AND NON-AUTISTIC PARENT ADVOCATES: BRIDGING THE DIVIDE

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ABSTRACT

Purpose: Due to the developmental nature of autism, which is often diagnosed in preschool or elementary school-aged children, non-autistic parents of autistic children typically play a prominent role in autism advocacy. However, as autistic children become adults and adult diagnoses of autism continue to rise, autistic adults have played a more prominent role in advocacy. The purpose of this chapter is to explore the histories of adult and non-autistic parent advocacy in the United States and to examine the points of divergence and convergence.

Approach: Because of their different perspectives and experiences, advocacy by autistic adults and non-autistic parents can have distinctive goals and conflicting priorities. Therefore, the approach we take in the current chapter is a collaboration between an autistic adult and a non-autistic parent, both of whom are research scholars.

Findings: The authors explore the divergence of goals and discourse between autistic self-advocates and non-autistic parent advocates and offer three principles for building future alliances to bridge the divide between autistic adults and non-autistic parents.

Disability Alliances and Allies

Research in Social Science and Disability, Volume 12, 155–166

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ISSN: 1479-3547/doi:[10.1108/S1479-354720200000012011](https://doi.org/10.1108/S1479-354720200000012011)

Implications: The chapter ends with optimism that US national priorities can bridge previous gulfs, creating space for autistic adult and non-autistic parent advocates to work together in establishing policies and practices that improve life for autistic people and their families and communities.

Keywords: Advocacy; disability; autism; priorities; autistic adults; non-autistic parents

INTRODUCTION

Autism is the shooting star of the disability advocacy world. Although the condition was considered rare and mysterious through most of the twentieth century, it experienced a dramatic rise in diagnoses and awareness in the 1990s (Gernsbacher, Dawson, & Goldsmith, 2005). Autism advocacy was initially spearheaded by non-autistic parents and professionals, which is common for a developmental disability. Parent-advocacy groups prioritized earlier screening for autism (catching autism as soon as possible) and earlier intervention (intervening against autism as soon as possible), along with research identifying the cause of autism and its cure (Ne’eman, 2010).

However, autistic¹ children grew up to be autistic adults, the increasing number of autism diagnoses included an increasing number of adults being diagnosed, and the rise of the Internet allowed autistic adults who were otherwise geographically dispersed to connect across space and time, with no need to read body language or make eye contact. Thus, was born the autistic self-advocacy movement, which prioritizes acceptance, support, and quality of life (Blume, 1997, 1998; Dekker, 1998; Harmon, 2004).

These discordant priorities – caricatured as find the cure versus increase the quality of life – underlie much of the conflict between autistic adults and non-autistic parents. Tensions have escalated into in-person and online protests (Brown, 2012; Luterman, 2015; Wallis, 2009), Twitter skirmishes (V. Hughes, 2015), boycotts of companies that donate to certain parent-led organizations (Owlia, 2019; WikiHow, 2019), and other publicly aired battles (Dejean, 2017). Entire websites and blog posts, such as “We Are Like Your Child” (<http://wearelikeyourchild.blogspot.com>), have been authored by autistic adults to counter a recurring parental claim that autistic adults “are nothing like my child” and are, therefore, unauthorized to contribute to the discussion (Endow, 2018). Complete dissertations have documented the conflicts between autistic adults and non-autistic parents (J. M. F. Hughes, 2015; Linehan, 2014). Here, we hope to do something more.

In this chapter, we begin by exploring the conflicting principles and priorities that have driven discord between autistic adults and non-autistic parents. We then offer examples of convergent advocacy, drawing from other disabilities and from outside the realm of disability. We end by offering three principles for building future alliances between autistic adults and non-autistic parents to bridge the divide.

NON-AUTISTIC PARENT ADVOCACY

The history of non-autistic parent organizations contributes to the current tension between autistic adult and non-autistic parents.² Although our focus is on US-based organizations, we see a similar pattern in the United Kingdom (Fletcher-Watson et al., 2019), Canada (Orsini, 2012), the Netherlands (van den Bosch et al., 2019; Waltz, van den Bosch, Ebben, van Hal, & Schippers, 2015), France (Chamak, 2008; Chamak & Bonniau, 2013), Sweden (Bertilsson Rosqvist, O'Dell, & Brownlow, 2015), and other countries.

In 1965, Bernard Rimland founded the Autism Society of America, which was the first autism-specific parent advocacy organization in the United States. Rimland, who had trained as an experimental psychologist, turned to the scholarly literature when his son began exhibiting characteristics that Rimland, through his readings, diagnosed as autism. Rimland's subsequent book, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, was instrumental in shifting the then-dominant explanation of autism's origin from Bruno Bettelheim's psychoanalytically based "refrigerator mother theory" to hypotheses based on genetics, biochemistry, and neurophysiology (Rimland, 1964).

In the 1970s and 1980s, the Autism Society of America played an instrumental role in advocating for several key disability laws (e.g., Section 504, the Developmental Disabilities Act, and the Education for All Handicapped Act, which later became the Individuals with Disabilities Education Act) (Autism Society, n.d.). In the early 1990s, the Autism Society argued before Congress against the use of aversives, such as the shock used at the Judge Rotenberg Center (Holden, 1990). However, the Autism Society of America was founded by non-autistic parents and, for the most part, has been run by non-autistic parents, along with non-autistic professionals.

The 1990s witnessed the onset of three new parent-founded and parent-run autism organizations: The National Alliance for Autism Research was founded by two non-autistic parents in 1994 with the mission of accelerating biomedical research and treatment for a "disorder ... every bit as devastating as the worst of the psychiatric diseases" (London, 1997); Cure Autism Now was founded by two non-autistic parents in 1995 with the mission to "cure autism now"; and Talk About Curing Autism was founded in 2000 by a non-autistic parent based on "the hope of recovery" (Ackerman, n.d.). In 2005, Autism Speaks was founded by two non-autistic grandparents (Gernsbacher, 2009). In 2006 and 2007, Autism Speaks quickly absorbed the National Alliance for Autism Research and Cure Autism Now, respectively, along with the Autism Coalition for Research and Education (Autism Speaks, n.d.).

Until 2016, Autism Speaks' mission statement described its organization as "dedicated to funding research into the causes, prevention, treatments, and a cure for autism." Their more recent mission statement disavows a cure, because, as stated in a section of their website titled "For the Record," they believe "there is no single 'autism'"; therefore, "there will be no single 'cure'" (Autism Speaks, n.d.).³ Their website also promises that their organization's "goal is for all people on spectrum, no matter how they self-identify, to be appreciated for whom they are and the contributions they make to society."

Unfortunately, as many scholars have noted, very little of Autism Speaks' outreach has been in the service of "all people on the spectrum"; rather, the majority has been in the service of non-autistic parents of autistic children (Stevenson, Harp, & Gernsbacher, 2011). Moreover, quite a bit of Autism Speaks' rhetoric has been incongruent with a message of appreciation; indeed, much of their public rhetoric has been incongruent with the fundamental tenets of disability rights, including the basic human right, as established by Article 10 of the United Nations Convention on the Rights of Persons with Disabilities, to live life as a disabled person.

For example, in Autism Speaks' promotional video "Autism Every Day," one of the organization's non-autistic board members articulates her desire to murder her autistic daughter and confesses her reluctance to do so hinges only on the existence of her other, non-autistic, daughter (this scene is shot with her autistic daughter in full view; Yergeau, 2010). In another Autism Speaks' promotional video, "I Am Autism," autism is portrayed as a terrifying monster that destroys marriages, bankrupts families, steals children along with their non-autistic parents' dreams, and removes all parental hope (J. M. F. Hughes, 2015; Nicolaidis, 2012; Thibault, 2014; Wallis, 2009).

In full-page magazine and Internet ads (underwritten by the US Ad Council), Autism Speaks has warned parents that the odds of their child being diagnosed as autistic are horrifically worse than their child becoming critically injured in a car crash, contracting life-threatening hypothermia, and suffering other distressing outcomes (McGuire, 2011). Other parent-led autism advocacy groups have used rhetoric less extreme than that of Autism Speaks (Carey, Block, & Scotch, 2019), and not all non-autistic parents endorse Autism Speaks and their advocacy tactics (e.g., the cover of a recent issue of *Autism Parenting* magazine and its accompanying editorial decry Autism Speaks; Burby, 2014). However, Autism Speaks and its brand of parent advocacy have evoked some of the most notable conflict with autistic adults.

AUTISTIC ADULT ADVOCACY

The history of autistic adult advocacy also dates to the 1990s. After feeling excluded in conferences and listservs run by and for non-autistic parents, autistic adults first formed their own listservs and then organized their own in-person conferences (Sinclair, 2010). Although these early organizations (e.g., Autism Network International and Autreat) were motivated more by the desire to socialize and interact with other autistic adults than to advocate and campaign for societal change (Dekker, 1998), their early organization laid the groundwork for later autistic-run advocacy groups.

In 2006, the US-based Autistic Self Advocacy Network was founded with the mission to "advance the principles of the disability rights movement with regard to autism"; the goal of "a world in which autistic people enjoy equal access, rights, and opportunities"; the purpose of "empower[ing] autistic people across the world to take control of our own lives and the future of our common community"; the motivation of "organizing the autistic community to ensure our

voices are heard in the national conversation about us”; and the mantra, “Nothing About Us, Without Us!” (Autistic Self Advocacy Network, n.d.).

In December 2007, the fledgling all-volunteer group of autistic adults gained initial visibility with a well-orchestrated protest of an egregiously ill-conceived publicity campaign promoted by non-autistic parents and produced by the NYU Child Study Center (Kaufman, 2007a). Posted on billboards, subway placards, and kiosks were signs designed to mimic kidnappers’ ransom notes, for example, “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” The ransom notes were signed by the metaphorical kidnapper, “Autism” (Kras, 2010).

The campaign was intended to garner hundreds of millions of impressions over a few months (Ne’eman, 2007a). But the Autistic Self Advocacy Network sprang into action, empowering other autistic adults (and their allies), as well as people with other disabilities, to demand that the campaign organizers remove the signs. The controversy made the pages of *The New York Times* (Kaufman, 2007a) and the *Wall Street Journal* (Wang, 2007a). After a dozen days of protest, the campaign was halted, and all signs were removed, showcasing an autistic advocacy victory that again made the pages of *The New York Times* (Kaufman, 2007b) and *Wall Street Journal* (Wang, 2007b), as well as the *Washington Post* (Shulman, 2007) and other outlets.

The autistic adults’ successful advocacy was driven by the power of the Internet coupled with their cross-disability – and even non-autistic parent – alliances. As Ari Ne’eman reported (2007b):

Twenty-two disability rights organizations came together to ensure the withdrawal of this advertising campaign. Our response to this campaign stretched continents, with e-mails, letters and phone calls coming from as far away as Israel, Britain and Australia. The disability community acted with a unity and decisiveness that has rarely been heard before and we are seeing the results of our strength today.

The successful resolution to the ransom notes campaign and other successes placed autistic adults squarely in what Michael Wehmeyer, Hank Bersani Jr., and Ray Gagne (2000) proposed would be the third wave of advocacy: The first wave had been driven by professionals, the second had been driven by parents, and the last wave would be and must be driven by people with disabilities. As Ne’eman (2007b) warned:

Our success sends an inescapable message: If you wish to depict people with disabilities, you must consult us and seek our approval. Anything less will guarantee that we will make our voices heard. We are willing to help anyone and any group that seeks to raise awareness of disability issues, but those efforts must be done with us, not against us.

No longer were autistic adults relegated to providing only what Sinclair (1994) deemed “self-narrating zoo exhibits.” By this expression, Sinclair referenced the most common reason autistic adults had been welcomed at parent-led autism conferences and listservs: to describe their autistic lives to non-autistic parents who then led “discussion of ways to make us other than what we are, and ... create a world in which we don’t exist at all.” Autistic adults had shown the world

that they not only did exist, but they had allies, they could wield power, and they aspired to the mantle of advocacy.

BRIDGING THE DIVIDE

Despite the past and current tensions between autistic adults and non-autistic parents, we believe avenues for increased and mutually rewarding alliance are viable. We propose that non-autistic parents can best ally with autistic adults by honoring the three requirements Tom [Shakespeare \(1993\)](#) identified as vital to self-advocacy movements: resources, recognition, and autonomy.

Resources

It should come as little surprise that non-autistic parents have accrued more resources for advocacy than have autistic adults, if only by dint of longevity. These resources need to be freely shared with autistic adults. And by resources we mean both the tangible and the intangible.

With regard to intangible resources, a more plaintive appeal could not have been made than that issued, nearly three decades ago, by Jim Sinclair (1993, reprinted in [Sinclair, 2012](#)). When addressing an audience full of non-autistic parents at the International Conference on Autism in Toronto, Sinclair pleaded, “We need you. ... Your world is not very open to us and we won’t make it without your strong support.” The rest of Sinclair’s address, which was titled, “Don’t Mourn for Us,” became the bedrock of autistic advocacy. However, the address is just as much a clarion call to non-autistic parents for alliance as anything. For example, Sinclair encouraged non-autistic parents to reframe their perspective and take action:

Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something. Better than being sad about it, though, get mad about it – and then *do something about it*. (p. 3, emphasis added)

Undoubtedly, one of the most valuable intangible resources that non-autistic parents can share with autistic adults is their activism.

As for tangible resources, all the types of assets denoted by the dictionary definition of tangible resources, namely, money, equipment, land, or buildings, can and should be offered. For example, [Nancy Bagatell \(2010\)](#) described an autistic adult group, going strong since the early 1990s, that is only loosely associated with a non-autistic parent-led group. Nonetheless, the non-autistic parent group provides financial support and meeting space for the autistic adults – and has for years.

Non-autistic parents, Kathleen Seidel and Shannon Des Roches Rosa exemplify the process of garnering resources. In Seidel’s case, she founded, financed, and curated the [Neurodiversity.com](#) website for many years, and then she and her spouse ran the Neurodiversity.Weblog ([Seidel, 2019](#)). Des Roches Rosa procured resources for the website, *The Thinking Person’s Guide to Autism*, which is co-led by autistic adults and non-autistic parents ([Greenburg & Des Roches Rosa, 2019](#)).

The key for each of these parents was observing the quack treatments promoted for autistic children and the societal disdain proffered to autistic adults.

Recognition

Allyship requires recognition, which in the case of autistic adults and non-autistic parents means acknowledging autistic adults' existence, validity, and value. Decades ago, Martijn Dekker (1998) pinpointed the conditions that he considered autistic utopia. Those conditions were simple: non-autistic people who listen, respect, and accept autistic people. That is the recognition upon which fruitful alliance can be built.

A fruitful alliance can also be built on the willingness to address past harm (Rosenblatt, 2018; Taylor-Parker, 2016). Grappling with the past will require humility from non-autistic parents and their organizations, along with an understanding that prior conversations and ongoing tensions have been fueled by fear and anger. We believe bridges can be built, and trust can be restored with effective apologies (Kador, 2009). As social psychologists have noted, an earnest apology "not only renders a transgression less offensive but also...provides evidence that the offender acknowledges the [other's] worth" (Janoff-Bulman & Werther, 2008, p. 19).

Recognition will also require an overt and acknowledged shift in power and roles. Parents of offspring with other disabilities have already modeled this shift. For example, in some organizations, non-disabled parents have moved from working on behalf of people with learning disabilities to working beside them (Ryan & Griffiths, 2015; Walmsley, Tilley, Dumbleton, & Bardsley, 2017). One of the clearest demonstrations of a shift from "working for" to "working with" has been demonstrated by parents of gay and lesbian offspring; indeed, the entire organization of PFLAG (Parents and Family of Lesbians and Gays) was founded on the concept of straight parents walking beside, not in place of, their gay and lesbian offspring (Broad, 2011; Conley, 2011; Starr, 1986). We are now seeing a similar alliance with cisgender parents and their transgender offspring (Wahlig, 2015).

Recognition must be more than tokenism, as it has unfortunately been in the past (Petri, Beadle-Brown, & Bradshaw, 2017; Robison, 2013). And the conditions for recognition must not be set solely by non-autistic parents (Carter & Wilson, 2006). Autistic adults' right to exist as they are, and to be valued as they are, must be the basis of any bridges built.

Autonomy

Bridges of alliance can also be forged by respecting autistic adults' autonomy. Perhaps in no greater way has autistic adults' autonomy been challenged as when debating the issue of representation. Simultaneously, autistic adults have been told they are too autistic to represent other autistic people (and thus, non-autistic parents will represent them), and they are not autistic enough to represent other autistic people (recall the "not like my child" criticism we discussed before). This paradox, which Melanie Yergeau (2018) calls "demi-rhetoricity," must be

abolished if we are to truly honor autistic adults' autonomy and the abolishment needs to remain enacted within the autistic adult community, as well.

Honoring autistic adults' autonomy also means respecting their choice of rhetoric, for example, when they choose identity-first over person-first language (Gernsbacher, 2017); when they decry the use of functioning labels (simply Google "functioning labels" to see why); and when they denounce the use of puzzle piece imagery (see Gernsbacher, Raimond, Stevenson, Boston, & Harp, 2018, p. 119, for links to nearly a dozen autistic adult's essays against puzzle piece imagery, as well as empirical evidence that puzzle piece imagery evokes negativity in the general public). Honoring autistic adults' autonomy means respecting autistic-only space, be it the #ActuallyAutistic Twitter hashtag or an in-person enclave.

CONCLUSION

We began by describing autistic adults' and non-autistic parents' separate histories and their divergent perspectives, here in the United States. Across the pond, we see more evidence of shared priorities. For example, in the UK, non-autistic parents and autistic adults correlate more than they segregate on national research priorities (Gotham et al., 2015; Pellicano, Dinsmore, & Charman, 2014). Both groups agree that identifying the best ways to improve the lives of autistic people and creating the best public services to meet the needs of autistic people are higher priorities than researching etiology or epidemiology (Pellicano, Dinsmore, & Charman, 2013; see also Gotham et al.'s, 2015 study demonstrating tight alignment in research priorities between large samples of autistic adults who do and do not have legal guardians).

We are optimistic that the United States can follow suit and that our national priorities can also bridge previous gulfs. We are beginning to glimpse hints of positive change. For example, a decade ago, the [US Department of Health and Human Services' Interagency Autism Coordinating Committee \(2009\)](#) organized their research funding priorities around six questions, which were clearly written from the perspective of non-autistic parents distressed about their autistic children. The questions included "When should I be concerned?" and "What caused this to happen and can it be prevented?" A decade later, the [US Department of Health and Human Services' Interagency Autism Coordinating Committee \(2019\)](#) organized their research funding priorities around questions relevant to autistic adults, for example, "What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?" and "How can we meet the needs of people with ASD as they progress into and through adulthood?" These are steps that will bridge the divide.

NOTES

1. We use identity-first language (e.g., autistic people, non-autistic people) rather than person-first language (e.g., people with autism, people without autism) because identity-first language is preferred by autistic people (Kenny et al., 2015), is recommended by APA (Dunn & Andrews, 2015), and is less likely to contribute to stigma (Gernsbacher, 2017).

2. We acknowledge that many autistic people are also parents of autistic and non-autistic offspring. See Ashkenazy (2009) for an excellent essay written by an autistic parent.

3. We note also that the parent-advocacy organization Talk About Curing Autism (TACA), founded in 2000, recently renamed their organization The Autism Community in Action (TACA), deleting the mention of cure from their name.

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