22

Conclusion

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In less than 30 years of organized activity, the autism rights branch of the neurodiversity movement has progressed from the fringe to the edge of the establishment. As it has matured from a mainly socio-cultural scope to an active part of a cross-disability rights coalition, the neurodiversity movement has shifted increasing focus toward not only what it opposes, but also what it supports. Increasing engagement on practical issues from the balance between safety and autonomy to reproductive and parenting rights have made the boundaries of activists' positions clearer and offered practical support in areas, such as through toolkits and multiple book presses owned by autistic and other neurodivergent people. Autistic people (and our organizations) have become increasingly included and recognized

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in autism advocacy, for example we have been consulted (alongside parent-led organizations) on matters from Hillary Clinton's 2016 presidential campaign [1] to an autistic *Sesame Street* character [2], producing results that pleased the autism community generally.

This concluding chapter will summarize the stories of events told by leaders of the autistic community and neurodiversity movement in this book and provide context to their significance in the broader political and social world. It will also address some of the critiques of the movement and suggest avenues where activists can make further progress.

The Story so Far

The neurodiversity movement has had overwhelmingly positive influence on clinical and scientific directions in the autism field. Interventions and supports have increasingly adopted approaches and goals more aligned with the neurodiversity framework (e.g. building from strengths and interests to develop useful skills rather than normalization; den Houting [3]). A growing number of leading scientists, beginning mainly in the U.K., have become openly interested in the movement and do work with relatively high compatibility with the neurodiversity perspective [4]. Research (e.g. in the U.S.) has moved toward the neurodiversity movement's research priorities, with a much higher proportion of funding awarded for studies on services, adults, and underserved populations [5]. Similarly, studies have increasingly recognized autism's complexity to the point that recognition that traits which may be advantageous have become part of the state of the science, and autistic adults have demonstrated the most expertise in autism according to the latest scientific understanding [6]. Many years after autistic individuals like Temple Grandin (followed by the organized autistic community) influenced the autism field to incorporate atypical reactions to sensory input in the diagnostic criteria, participatory research partnerships with autistic people have finally become a popular trend (especially in the anglophone world; Nicolaidis et al. [7]; Silberman [8]).

Autistic community and neurodiversity movement leaders, especially the contributors to this book, have driven this shift toward inclusion

of autistic people and their goals. Autistic voices have raised the profile of harms against autistic and neurodivergent people and a sense of autistic identity, such as Sinclair's essay "Don't Mourn for Us" (see Pripas-Kapit, Chapter 2) and websites or webpages autistics.org (Tisoncik, Chapter 5), Getting the Truth Out (Baggs, Chapter 6), and "The Autistic Genocide Clock" (Evans, Chapter 9). As an autistic-led scholarly journal within critical autism studies, *Autonomy* has helped to preserve key autistic writings like "Don't Mourn for Us" and demonstrate the expertise of autistic people in shaping academic and lay ideas about autism (Arnold, Chapter 15). Autistic-led organizations that meet in cyberspace such as InLv (Dekker, Chapter 3) and physical space such as Autscope (Bucker, Chapter 8) have provided acceptance for fellow autistic people, further building autistic community. Active efforts to include autistic people who share other marginalized identities, such as who have an oppressed gender (daVanport, Chapter 11) or race (Giwa Onaiwu, Chapter 18), have helped advocates represent and strengthen autistic community and activism. Allies such as Seidel of neurodiversity.com (Chapter 7) and the non-autistic editors working alongside autistic editors of *The Thinking Person's Guide to Autism* (Greenburg and Des Roches Rosa, Chapter 12) have helped the neurodiversity movement gain the credibility, channels, and power to spread the pro-science, pro-autism acceptance agenda to non-autistic relatives, professionals, and researchers. Campaigns led by autistic and other disabled people against medically and legally sanctioned abuses such as chemical restraint through overmedication (Murray, Chapter 4) and institutionalized electric shock therapy (Neumeier and Brown, Chapter 14) have raised awareness of these practices and gathered momentum against them. Meanwhile, organizations and individuals have incorporated the neurodiversity framework into their everyday work outside of formal activism. These include the AASPIRE community-based participatory research project that has attracted federal funding and international acclaim as a model for including lay and scientific autistic people alike in every phase of academic studies (Raymaker, Chapter 10), and Eric Garcia's journalism that positively and accurately publicizes autism and disability in news and analysis (Chapter 17).

Now the neurodiversity movement has arguably arrived at the threshold of the autism establishment. Autistic activists advised the revision of their

own diagnosis in the DSM-5, achieving significant success (although short of our goals), but this happened on an ad hoc basis rather than as part of full and systemic inclusion (Kapp and Ne’eman, Chapter 13). The creation of Neurodivergent Labour in connection with the U.K.’s Labour Party (Craine, Chapter 19) and the National Autistic Taskforce as an outgrowth of the National Autism Project (Murray, Chapter 20) have shown an investment in the neurodiversity movement for research, public policy, and practice in the U.K. for autistic people and beyond, although due to their recentness a fuller assessment of their impact awaits. As the movement has become more mainstream activists have tended to maintain their principles, and abandon counterproductive attempts to moderate activists who antagonize autistic people, as Robison did when he resigned from advising Autism Speaks (Robison, Chapter 16). This action propelled that exceptionally powerful organization to begin to make reforms [9], which suggests the movement may become a more dominant force in autism advocacy while staying true to itself.

Inclusion of Autistic People with Higher Support Needs

While the neurodiversity movement has become more representative of autistic people’s developmental and cultural diversity through autistic members and both autistic and non-autistic parents or relatives, the most persistent critiques about it tend to claim that it only serves the needs of autistic people with low support needs—sometimes inaccurately and offensively called “high-functioning”. As unfortunately this book’s design did not enable autistic people lacking verbal fluency to contribute (although it does have a non-speaking contributor, Baggs), I will attempt to address these concerns in this section.

While the autism rights movement has welcomed autistic people regardless of support needs—as well as non-autistic relatives, support people, or friends as allies—from the beginning (Pripas-Kapit, Chapter 2), the fluidity and complexity of autistic people’s support needs make classifying them by functioning levels or labels inaccurate. Speech, language, and

communication all differ from one another, and verbal tests tend to underestimate the cognitive abilities of autistic people with little expressive language [10–14]. Reasonable accommodations such as allowing extra time [15] and visual supports [16, 17] support many such autistics to reveal their verbal comprehension and cognitive capabilities. Not only do many such individuals perform as “untestable” on standard IQ tests, but they tend to poorly relate to functioning in autistic people generally [18]. Furthermore, the autism field has failed to identify valid subtypes within the autism spectrum, or any consensus on how to measure autism severity or support needs. This contributed to the decision of the DSM-5 workgroup—influenced by the Autistic Self Advocacy Network to oppose the imposition of a severity scale and frame it as about “support needs” to protect access to services (Kapp and Ne’eman, Chapter 13). Many autistics perform well *because* of the social contexts and supports, and struggle when their enabling environments and services disappear (e.g. after leaving high school; Kapp [19]).

These difficulties with conceptualizing and measuring autistic people’s developmental diversity include that autistic people typically have uneven skills (American Psychiatric Association [20]; Kapp and Ne’eman, Chapter 13), and large disparities in our cognitive profiles [21]. The same autistic individuals’ behavior [22] and perception [23] has demonstrated exceptional variability to the same task or stimuli over time. Even so-called talents or gifts (where present) vary in their presentation as strengths or weaknesses [24], depending on factors such as the social context [25]. Autistic-typical strengths such as pattern recognition tend to exist across the spectrum, including in minimally verbal children classified as “untestable” [10].

Autistic people also tend to gain skills across our lifespans (APA 2013), and the same activists parents might claim as unlike their child may have presented more severely as children. For example, Sinclair, the main “father” of the neurodiversity movement through their work with Autism Network International (see Chapter 2), noted of ANI co-founders “we had all fit descriptions of ‘low functioning’ autistic people when we were younger” [26]. All had speech delays as children, such as the onset of semi-reliable independent speech at age 12 for Sinclair, yet their access to speech and functioning continued to vary in daily life as adults [27]. Many

non-speaking autistic people participate in the neurodiversity movement today, including serving on the board of organizations like the Autistic Self Advocacy Network and Autism National Committee, authoring papers in a special issue on the movement in a major disability studies journal, writing blogs, co-editing or contributing to books, and (co-)directing or participating in documentaries. Many members have significant impairments and support needs, such as long-time activist Cal Montgomery, one of the most widely cited autistic leaders in this book (by Laura Tisoncik [Chapter 5], Mel Baggs [Chapter 6], and Shain Neumeier and Lydia X. Z. Brown [Chapter 14]), who said, “I am incontinent and cannot live alone, cannot bathe myself, etc.” (personal communication, February 22, 2019).

From the movement’s beginnings, non-autistic family members have advocated alongside autistic activists to fight for the rights of their relatives, many of whom would struggle to engage as social activists even as everyone self-advocates and communicates through behaviour or other forms of communication [28]. For example, disability rights activist Diana Pastora Carson does not identify as neurodivergent but managed her family’s successful fight to remove her significantly impaired autistic brother Joaquin (Carson) from an institution, led by Joaquin’s expressed desire to leave that she explained. After a life of enforced behavioral compliance training, chemical and physical restraints, and banishment to an institution, Joaquin settled in his own house of his choosing in the community with the full-time support of publicly funded alternating staff, where he has the support of and friendships with neighbors; contributes to events; and walks, runs, and bikes in the peaceful surrounding countryside. He enjoys work, frequent visits from his close relatives, expanded access to communication (through words, typing, and a board), and attending university courses [29].

Nevertheless, movement *activists* arguably do often have skills more developed in key areas than most people in a population, including in communication. The neurodiversity movement is no different in that regard, and all parts of the autism community leave room for improvement in making their organizations, work, and activities more accessible and inclusive. While autistic-led events such as Autreat in the US (Pripas-Kapit, Chapter 2) and Autscope in the UK (Buckle, Chapter 8) have developed tools, activities, and schedules in chosen venues to try to

reconcile competing access needs, they have encountered limits to accommodating everyone. While the movement may underrepresent the most profoundly impaired autistic people with the highest support needs, the broader autism community and autism field share that challenge. Autistic people with ID and high “severity” have become increasingly excluded from autism research [30, 31] .

Serving the Interests of Autistic People with Higher Support Needs

The neurodiversity movement seeks to safeguard and fight for the provision of “the full set of human rights” to all neurodivergent people [32], in all major life domains such as “accessing communication, education, employment, competent medical care, the right to make our own decisions and live on our own terms, friendship, romantic relationships and sexuality, freedom from abuse, or the basic premise of our lives being acceptable” [33]. These rights apply equally to people with higher support needs, and those less empowered suffer the most vulnerability to violation of their rights. For example, autistic people with less recognized or reliable communication may risk greater abuse and neglect from so-called caregivers, with less access to legal recourses. While the right of people with disabilities to exist may strike some as uncontroversial, I have observed even disabled activists express understanding of and advocacy for parents who murder their disabled child, with no one but me speaking to the plight of the child, while serving in the capacity of a public U.S.-based body intended to protect the human rights of people with disabilities. Disabled people would not be tortured with electric shock “treatment” in the Judge Rotenberg Center (Neumeier and Brown, Chapter 14) were it not for protection from parents who influence politicians. These sorts of actions have generally not received the same level of priority from parent-led advocacy organizations, if not condoned by them. When people working for those organizations commit abuse, the workers often experience a metaphorical slap on the wrist rather than prosecution, such as recently a relatively modest fine against a “care” home run by the UK’s largest autism organization [34]. As autistic activist Crow [35] argued, “we should not have

our humanity be devalued on whether or not we are nonverbal or need 24/7 care for rest [sic] of our lives” (pp. 5–6).

Within the autism community autistic adults and the neurodiversity movement place the highest priority on systemic, practical needs such as services, a more immediate and arguably effective focus than the biological and causation studies that consumes most autism research funding [36]. The neurodiversity movement emphasizes increasing literacy and access to reliable communication, as declared by Ne’eman [37], who implemented this priority while serving on the U.S.’s steering body for funding autism research through successfully pushing for research on augmentative and alternative communication. This is echoed in the U.K. where the members of the National Autistic Taskforce exercise their verbal and other privileges to prioritize the needs of more disabled autistic people. A foundational focus on policy for the most politically mobilized autistic people, like the broader disability rights movement, has helped preserve access to hard-won rights and services while extending others. In the U.S., examples include protecting healthcare and community living through developmental disability services, while raising the minimum wage for workers with disabilities (previously paid as little as pennies on the hour) to parity with the raise for other federally contracted employees [33]. A stronger collaboration in the autism community on supporting the right (and funding) for autistic people to live in their own place with the support needed would enable families to not need to serve as primary caregivers for autistic adults, or at least shifting greater priority to family services could provide relief for familial caregivers.

Parental acceptance of their child’s autism helps the parents’ understanding of their child, well-being, and the parent–child relationship. This parental acceptance of autism does not relate to the “severity” of the child’s externally measured “symptoms” (e.g. by trained observers based on coding of elicited behaviors and semi-structured interactions), but only relates to (fewer or less pronounced traits) according to parental self-report [19]. These findings suggest the attitudes against the neurodiversity movement for autistic people with higher support needs only hold for *subjective* perceptions of autistic people’s differences and impairments.

Similarly, external and self-acceptance of autism helps support autistic adults’ well-being [38], as it likely does for younger autistic people. While

the autism research field lacks analysis of autistic people's views on the core claims of the neurodiversity movement according to their supposed level of support needs, autistic people's functioning has a complex relationship with their core traits and abilities, and one should not make the dangerous assumption that more impaired individuals would more likely oppose the neurodiversity framework. While autistic people with higher support needs undoubtedly face greater risks of denial of basic rights such as autonomy and inclusion, research indicates that autistic people with subtler manifestations of autism and higher cognitive abilities experience more peer bullying, distress, internalized ableism, and exclusion from services [19].

Furthermore, while a study reporting that the social factors related to discrimination and stigma accounted for 72% of the distress experienced by autistic adults had a highly verbal sample [39], this may apply across the autism spectrum. For example, statistical studies have failed to explain self-injury, with little to no relationship to IQ and even anxiety [40]; review and research by Dempsey et al. [41]. Yet this may result from the studies' reliance on parent report; only autistic people have direct access to our emotions, and reporting on autistic children's anxiety has fared better by self-report than parent report [42]. Aggressive behaviors (including against the self) may stem largely from failure of the social environment to meet autistic people's needs, as autistic neurodiversity activist Ballou [43] argues.

Final Thoughts

This book has attempted to document the actions of leading autistic activists in the neurodiversity movement, covering the history at a time when it has undergone different waves in its development, yet not too late to attract most leaders from the countries where it has become most established. It has also sought to explain the concepts of *neurodiversity* and the beliefs and work of the neurodiversity *movement*, engaging with critiques at a time when misunderstandings linger. "Neurodiversity-lite" has seeped into autism culture (adopting some of the rhetoric of the movement but not truly implementing the principles: Neumeier [44]), perhaps mainly

due to ignorance but also co-option of the movement's strengthening force (e.g. changing an organization's name but not its practices—"On Autism Orgs" [45]). The movement has made great progress and has begun to enter politics, yet unless the movement further coalesces in a broader coalition in more regions of the globe, its impact on combating the growing austerity in a global competitive economy may be limited. Future books and works of scholarship and activism may further shed light on the current status of the movement beyond its origins (beyond autism and well beyond mainly anglophone countries), and deconstruct paths forward for helping neurodivergent people receive the support and respect we need.

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