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Shifting the System: AASPIRE and the Loom of Science and Activism

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My Introduction to the Autistic Advocacy and Neurodiversity Movement

When I co-founded the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) in the summer of 2006, I was already grounded in my identity as an Autistic person, autistic rights activist, and general troublemaker. That grounding had taken time, however, and struggle. Growing up, I had been the stupid one, the confused one, the damaged, scary, aloof, broken, worthless, lazy, crazy, alone, alone, alone, one-of-a-kind, never-trying-hard-enough, busted, always alone one—and I had made peace with that. I had learned to love it, and worn it for a skin. Then, in 1999, with the tsunami-like smack of a co-worker's incorrect assumption that I already knew what I was, I learned I was *none of those things*. I was Autistic. Even positive, healthy change—as this was—can

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be traumatic if it requires redefining Self. It is the disintegration of the old identity that is terrifying, not the truth of the new one. My journey of redefining Self started with my friends and co-workers presenting me with the truth, reached a climax with a clinical diagnosis during a period of intense crisis, and ended with my embrace of the neurodiversity movement.

When I first encountered the neurodiversity movement in the early oughts through the writings of Jim Sinclair, Mel Baggs, Joelle Smith, and others on the autistics.org [1] site and disability/autistic rights blogs and forums (like the This Way of Life [2] blog and the old LiveJournal Asperger's community group), I was not new to activism, nor to challenging the social order. I'd been radicalized (woke) in the gay (Lesbian, Gay, Bisexual, Transsexual, Queer, and others, LGBTQ+) rights movement of the late 1980s. I'd marched, created, subverted, and put my body at risk for my civil rights back then, starting with basics, like the right to go outside without being murdered. So when I first started exploring Autistic identity, the first thing that struck me was the similarity between being Autistic and being queer. Nothing brought me to the neurodiversity movement, and there was no choice involved: the world needs all minds just as it needs all genders, sexualities, and other vectors of diversity. As a systems scientist I know diversity provides social and ecological systems with flexibility, resilience, innovation, and a greater chance of optimal survival. As a human rights activist, I know all humans are to be valued. I always have, and always will fight for my communities of identity, and for other marginalized communities, because the empowerment of one benefits us all. I will always pay it forward from the activists who came before me to those who will come after; we are connected in a lineage of social justice.

Individuals and Organizations Critical to My Contribution to Neurodiversity and Autistic Activism

In the summer of 2006, I met AASPIRE's co-director, and my mentor and now long-time collaborator, Christina Nicolaidis—a physician-researcher

and parent of an autistic child who also has experience in feminist and queer activist spaces. Christina, adorably, invited me to an autism scientific journal club because she wanted to meet me (apparently, my postings to the parent-focused Portland Aspergers Network e-mail list were helpful to her), and knew I would never say yes to unstructured social time. We read maybe three research articles, all of which provoked outrage, before deciding not to complain but to do something about the problem we were seeing. "The problem" being autism research that was poorly designed, stigmatizing, offensive, useless if not downright harmful, unethical, or otherwise failing to be of practical benefit to actual autistic people or the A/autistic community.[1] This is the very problem an approach to science called Community Based Participatory Research (CBPR) has been developed to solve.

CBPR is an approach to scientific inquiry that includes people from communities of identity as co-researchers in all phases of research that impacts their community, starting with deciding what to research in the first place [3]. The approach grew out of the field of public health in response to inequities experienced by communities defined largely by race or ethnicity [3]. CBPR has since been used with communities defined by many other identities; however, at the time of AASPIRE's founding, it had never been used with the A/autistic community. CBPR is an emancipatory approach to research, which explicitly acknowledges the connection between knowledge and power, and attempts to return power to communities that experience oppression. CBPR makes no attempt to decouple science and activism; instead, it seeks to use the rigor of science to disrupt the ways that science contributes, both directly and indirectly, to institutionalized oppression. Science can then become both better at answering questions about the world (i.e., be better science), and a vehicle of empowerment.

Coincidence of timing and circumstance is as much a factor in successful activist work as skill, and when Christina and I met at that autism journal club in my living room in the summer of 2006, she was using CBPR

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[1]Capital "Autistic" is used to denote people who culturally identify as Autistic (but may or may not have an autism diagnosis) and lowercase "autistic" to denote people who may have a diagnosis but not culturally identify as Autistic. A/autistic is intended to be inclusive of both overlapping and interconnected communities of identity.

with communities of color to conduct culturally responsive depression care and interpersonal violence research. She'd had the same conversations about problems with traditional approaches to research with her African American and Latina partners that she was having with me about autism research. I was already an activist deeply committed to civil rights and grounded in the neurodiversity and disability rights paradigms. Thus, AASPIRE was born of a deep need for autism research that is driven by the A/autistic community, a recognition of the potential of science to empower the A/autistic community, and a once-in-a-lifetime collaboration between an Autistic activist (who grew up to be an academic researcher) and an academic researcher (with a history of activism) who ended up being best friends.

However, two individuals and a handful of friends do not make a research group, and so Christina and I went looking for additional collaborators, a process which took some time. CBPR typically forms partnerships between community-based service or policy organizations and academic institutions to co-conduct research, drawing on the strengths of their respective networks. The problem was there were so few Autistic-run organizations at the time, and those that were well-established, such as Autism Network International (ANI) and the Global and Regional Asperger Syndrome Partnership (GRASP), had missions focused elsewhere from service provisioning or policy change. The only community-based organization with a service or policy focus we knew of that was run by actual Autistic people was some brand-new thing called the Autistic Self Advocacy Network (ASAN) that we thought (in our own fledgling ignorance) may or may not even have been a real thing. Initial conversations seemed promising though, and by 2007 we had decided to collaborate. I met ASAN's co-founders Ari Ne'eman and Scott Robertson at the very first talk AASPIRE did at a scientific conference (the 2008 meeting of the American Association of Intellectual and Developmental Disabilities [AAIDD] in Washington, DC). At that time, AASPIRE had yet to complete a research study and didn't have any business, really, presenting at a research conference other than that we were the only people in the country doing community-engaged research with the A/autistic community. I remember sitting in my hotel with Ari and Scott as they asked me how I felt about the medical (deficit) model of disability. I fell out my chair—as

I am wont to do when not restraining my hyper-kinetic tendencies, hence my general mistrust of furniture—and proclaimed with the semi-echolalia I was relying on more heavily at the time, "Better dead than med!" They laughed, and I laughed, and we were all relieved that we were on the same neurodiversity page. They asked me to be on their board and ASAN was the first community-based organization to partner with AASPIRE; we've helped each other out ever since. In more recent years, AASPIRE has also developed a strong relationship with the Autism Society of Oregon; however, Autistic voice always has been, and always will be, privileged above organizations that are not self-advocate led. I am happy that there are now many more Autistic-led organizations serving a wide variety of missions.

Intended Goals of My Neurodiversity or Autistic Activism

Over the years, I've contributed to the neurodiversity movement and autistic activism in various ways, always with a goal of social justice. Some contributions have been successful: I yelled through a speech device at a town hall meeting, resulting in the governor adding a role for a self-advocate to the state's Autism Commission, and then serving in that role for two years. Others have been less successful: I blogged on autism issues for Change.org and mostly succeeded in getting death threats and paralyzing anxiety. The success of some contributions remain to be seen: I have several works of fiction published by Autonomous Press (autpress. com), a neurodivergent-run publisher, that center queer neurodivergent characters and attempt, as with pretty much all things I've ever done, to subvert systems of oppression [4, 5]. But out of all of the neurodiversity activism I've done (see dorarraymaker.com), my work with AASPIRE and in the sciences is both what I am most proud of, and what I feel has been the most successful.

My book chapter (written 2010) in *Worlds of Autism*, "Participatory research with autistic communities: Shifting the system" [6], details—in a wide-eyed, fresh-out-of-my-Master's-program way—the dynamic I still believe is at play between science, society, and community. Regardless of the struggles scientists may have in 2018's political climate, scientists still

have more power than many people in oppressed communities. Because of the power society has to marginalize or center communities, empowering communities to influence science—and encouraging scientists to be influenced by communities—is, I believe, a point of leverage. In other words, if we think of behavior in a complex system (like human society) as generated by its structure, then changing the structure will change the behavior. Change the dynamic between scientists and autistic people, and the behavior of the entire system shifts.

Also, I'm a much better scientist than I ever was policymaker or politician, and far more suited to the calm of the lab than the drama of social media. There are plenty of peers in the movement who have those areas covered. What my scientific activism is intended to accomplish can be summarized in AASPIRE's mission statement [7]:

- To encourage the inclusion of people on the autism spectrum in matters which directly affect them.
- To include people on the autism spectrum as equal partners in research about the autism spectrum.
- To answer research questions that are considered relevant by the autistic community.
- To use research findings to effect positive change for people on the spectrum.

Steps to Meet the Intended Goals

AASPIRE conducts autism services research for adults. This is an area in which there continues to be a paucity of academic attention. The topics we focus on are an intersection of what the Autistic community prioritizes, and what we have the scientific expertise on our team to fund and successfully carry out. To date, this has primarily been in the field of health and mental health services, though recently we have branched out into employment, and are open to any type of research that meets our mission.

A lot has been written in the academic literature about how AASPIRE operates [8–10]. To summarize, we meet and communicate in ways that

equalize power. We include a majority of autistic people on the team, and the whole team makes decisions about the research together. We respect each other's expertise and work hard at building trust and a safe—though not always comfortable—space for co-learning between autistic community members and academic allies. We have always had some members with intersecting identities in the group, for example, our co-directors include an autistic academic and a parent academic—which I think helps us translate respectfully between each other's cultures, and find effective ways to share power. We try to select new team members for people who prioritize getting the work done.

We also go through the steps typical of health and social services research: come up with an idea, obtain funding to realize it, carry out the research, disseminate the results to both the scientific community and the public (which, for us, includes the A/autistic communities). Part of the basic business of research also involves participation in professional meetings and conferences, engagement in academic and popular science forums like Reddit, and working with policy and scientific entities like the Interagency Autism Coordinating Committee (IACC) to shape research priorities and the direction of future funding.

It is through this normal business of science that I feel I, and AASPIRE, have had the most success in shifting the system. In a way, this book chapter is a "ten years after AASPIRE's founding" companion to my position in *Worlds of Autism* as it asks me to reflect: Have we shifted the system? Has engaging autistic people in autism research made any difference in the way society and public policy views the A/autistic community? Have we generated a behavioral change through our small influence on the broader structure of science? Have we made life any better for people in the A/autistic community?

Between 2006 and this writing in 2018, AASPIRE has obtained funding to complete a series of five healthcare studies, one employment study, start cutting-edge research on autistic burnout, and create an online, interactive Healthcare Toolkit for autistic adult patients, their supporters, and their healthcare providers (autismandhealth.org). Science moves slowly, and it can take a lot of time to see change from research and practice. However, our results indicate that both patients and healthcare providers found the Toolkit to have positive impact on their healthcare interactions [11], and

we are continuing to find ways to implement the intervention effectively. In the community, numerous autistic people, parents, and clinicians have told us the Toolkit has made a positive difference in their lives. As we complete preliminary steps of learning how best to serve autistic people in employment and other aspects of well-being, we hope to continue to create interventions that directly help the community. Simply participating in CBPR can also help the community; an evaluation of a study which included many members of AASPIRE found that being a co-researcher is empowering and may enhance self-advocacy skills [12].

Members of AASPIRE have spoken on a variety of topics at the IACC, the US government body that sets federal priorities for autism research; people with close ties to, or then-collaborators with, AASPIRE successfully pushed that body to include autistic voice on their board—and sat on their board. I have witnessed multiple "a-ha" moments from scientists and students at my talks when they realize inclusive research is both possible and desirable. We have given our data to ASAN to use for making policy points. Both Christina and I have done highly attended Reddit Science Ask Me Anythings (AMAs) [13, 14] about AASPIRE's work, which has enabled us to reach the broader public with both neurodiversity ideas and the practical results of our research. We have been invited speakers at multiple conferences and events, either to discuss our findings or to discuss how to conduct inclusive research, more and more as time goes on. Our publications on neurodiversity have been loudly cited, while our publications on our research have quietly infused the next generation of academics interested in conducting research in collaboration with the A/autistic community (see aaspire.org for an ongoing list of AASPIRE's publications and activities). Recently, due in part to AASPIRE's visibility in the field, Christina was asked to start a new journal *Autism in Adulthood* (https://home.liebertpub. com/publications/autism-in-adulthood/646) that includes A/autistic people (both scientists and not, including myself as Associate Editor) in all aspects of its editorial processes. The power that I, and my colleagues, have as peer reviewers in other journals to reject articles that are disrespectful, stigmatizing, or poorly designed is significant. Strangers have told me how AASPIRE's work has impacted community—recently, an Autistic counselor at a medical training I did told me they had been using AASPIRE's Healthcare Toolkit for years with their clients. I have obtained

my Ph.D. and become the first openly Autistic person to get funding from the National Institute of Mental Health (NIMH) to conduct autism services research; I recently returned from an NIMH meeting where I was able to discuss inclusive research with colleagues and policymakers. My existence is an act of resistance.

Ten years ago, any one of these things would have been unthinkable.

Ten years ago (or thereabouts), AASPIRE was receiving comments on its grant proposals like "there is not adequate evidence that the self-reports of individuals on the autism spectrum are valid or reliable" (Anonymous, 2010). Ten years ago, we in the autistic rights movement were fighting to get people to believe autistic adults existed at all. Now our work is the leading edge of a new movement of inclusive, participatory research with autistic people worldwide [15].

It is neither AASPIRE's nor my work alone that made change possible—it is the whole of the autistic, neurodiversity, and disability rights movement chipping away at the status quo, being relentless in its march toward social justice, and transmuting its collective rage into sacred anger to burn down everything in its way in order to build a more just and inclusive system. Nothing about us without us.

My Work's Place in the Broader Movement

AASPIRE works within the sphere of academic health and social services research to conduct projects the A/autistic community wants done. I have been capacitated by that work to extend more broadly into the wider neurodiversity and disability communities. I've worked with the developmental disabilities community on research examining connections between violence, disability, and health with the Partnering project [9, 16]. I've worked with women with intellectual disabilities and autistic women to understand their experiences with pregnancy and pregnancy decisions, and develop peer-led informational videos [17]. I've worked with the broader disability community on a peer-developed abuse awareness and prevention program [18]. I've worked with young adults who have experienced first episode psychosis on developing peer-created interactive online tools to

reduce stigma and increase self-determination for others in their community [19]. I am the faculty advisor for my university's Disability Alliance student group, and they are doing important activist work at a local, university level [20]. Because, again, we are nothing if not a collection of intersections of our identities, and the empowerment of one benefits us all.

There is no wrap-up for this chapter, no succinct "lesson learned." AASPIRE, and my intersectional positioning as a neurodivergent, queer, and gender queer activist and scientist remains an active, ongoing experiment in whether or not restructuring the way science is conducted can shift the system toward justice for all.

What Neurodiversity Means to Me

Neurodiversity, to me, means both a fabulous celebration of all kinds of individual minds, and a serious, holistic acknowledgment of the necessity of diversity in order for society to survive, thrive, and innovate. It means identity, belonging, and community. It means I am not broken, not alone, and neither are my siblings standing with me beneath that huge, multi-colored neurodiversity umbrella: we the autistic, the mad, the weirdly-wired, the queer, the crippled, and the labeled with neurodivergent diagnoses like flowers that glorify our beautiful bodies and minds.

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