

A MOVEMENT OF OUR OWN: DIAGNOSTICS, THE INTERNET, AND THE EVOLUTION
OF AUTISTIC ADVOCACY

&

NOTES TOWARD AN ORAL HISTORY OF THE AUTISTIC SELF ADVOCACY
NETWORK

BY

JAY DAVID EDIDIN

THESIS

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Advisor: Michael Busch

ABSTRACT

Unlike the larger disability rights movement with which it is aligned, the history of Autistic-led advocacy is limited to the last thirty years. In this thesis, I use peer-reviewed papers, first-hand accounts, and historical examples to examine how the exclusion of Autistic adults from diagnostic criteria effectively obviated the development of Autistic communities and organizations and paved the way for a parent-dominated movement; and the parallel role of changing diagnostic criteria and a popularly accessible Internet in the subsequent rapid evolution of Autistic advocacy, including the eventual role of Autistic advocates in redefining diagnostic criteria. Following the researched portion of the thesis are preliminary materials and notes toward the development of a comprehensive oral history of the Autistic Self Advocacy Network.

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A Movement of Our Own: Diagnostics, The Internet, and the Evolution of Autistic Advocacy

Academic work focused on the history of disability self-advocacy is somewhat anemic; even more so, Autistic self-advocacy (Petri et al., 2020). Here, I hope to rectify that to at least a limited extent: to examine not only a series of major flashpoints in the history of Autistic advocacy, but also the congruent forces of diagnostic criteria and technology that shaped its comparatively recent emergence. Finally, I explore the ways in which the Autistic advocacy movement has engaged with the same diagnostic criteria that have played a significant role in defining its evolution.

This thesis began as an oral history of the Autistic Self Advocacy Network and an attempt to contextualize its place in both the history of Autistic advocacy and the disability rights movement. As I researched, I was struck by both the paucity of history and analysis of Autistic advocacy and its peculiar estrangement (until recently) from disability-rights advocacy. Why was Autism-focused advocacy so heavily dominated by the non-autistic parents of Autistic children? Where were the intersections with and parallels to intellectual-disability advocates? What factor kept the conversation around Autism so bizarrely siloed—a factor that had changed in the last thirty years, as Autistic advocacy grew into its own?

It is important, I think, to note that this is not a comprehensive history, nor am I an historian. I approach the evolution of Autistic advocacy as a researcher concerned primarily with the relationship between ideas and constructed norms, and the ways in which the evolution of the latter creates spaces for the enlargement of the former—in this case, how broadening diagnostic standards and new information technology opened previously inaccessible conceptual space for

the development of a self-advocacy movement in a field previously shaped primarily by parent and medical perspectives.

Nor do I approach this subject with the pretense of neutrality: I am Autistic, I am involved in the Autistic self-advocacy movement, and I am or have been a small and informal part of some of the conversations I discuss herein. I am not here to debate the validity or efficacy of Autistic self-advocacy—both things I take as read—but to situate it in the larger story from which it has emerged.

We Are Our Language: A Note on Semantics

I capitalize the word “Autistic” when it refers to a person, people, or culture—i.e. “as an Autistic writer,” “the Autistic community”—a usage pioneered by Autistic activists in deliberate parallel to the capitalization of the word Deaf to indicate a term that has grown to describe a unique community and culture as well as a medical diagnosis. I likewise avoid clinical functioning labels in favor of the community-preferred “support needs.” This choice is a conscious reframing of the impact of autism to center Autistic people and the support they need to live full lives as members of communities, rather than their ability to “function”—often shorthand for “pass as non-Autistic”—in an ableist framework. Finally, I contextually avoid the term “neurotypical”—commonly used to describe individuals not on the autism spectrum—in favor of “non-Autistic,” as I find the former usage both misleadingly reductive and problematic in its default erasure of non-Autistic neurodiversity.¹ I do, however, use the word “neurotypical”

¹ Autism is far from the only form of neurodivergence. (Egner, 2022) To describe all non-autistic people as “neurotypical” effectively erases significant vectors of neurodivergence, from ADHD, to mental illness, to non-autistic developmental and intellectual disabilities. To truly advocate for neurodiversity requires embracing its plurality.

to refer to environments or perspectives hostile or antithetical to neurodiversity—i.e. “neurotypical society.”

I make these semantic choices on a number of grounds. First, as an Autistic writer, it’s important to me to accurately reflect the perspective and politics with which I’m approaching the content of this paper. The language I use here also reflects historical forces that have played significant roles in defining the structure of and advocacy within the Autistic community, either as formative ideas or, later, antithetical principles. Autism’s historically troubled relationship with the larger disability community, the functioning-label supremacy that has mediated organizing within the Autistic community, and the future of Autistic organizing have the same roots as and have evolved in close parallel with the language used to define us. To understand the language of our activism is to some extent a necessary step in fully understanding our activism.

Finally, a note regarding the terms “autism” and “autistic” in their diagnostic and historical contexts: the names and descriptions of the conditions currently clustered under the diagnosis *Autism Spectrum Disorder* have changed frequently and dramatically over the last near-century. Throughout this paper, I generally use the terms “autism” and “autistic” in their modern definitions—i.e. I would refer to someone diagnosed with Asperger Syndrome during the lifespan of that diagnosis as “Autistic,” not “Aspergian” unless the latter is directly relevant.

Autism-Focused vs. Autistic Advocacy

For purposes of this paper, I distinguish between two primary types of advocacy related to the Autistic community. These categories are based loosely on Jim Sinclair’s distinction between “spaces for Autistics” and “shared Autistic space.”

Autism-focused advocacy corresponds to Sinclair's definition of "spaces for Autistics"

that are led by non-Autistic people (to whom Sinclair refers as NT / neurotypical). Such spaces:

...are not autistic spaces, even if the majority of people within them are autistic. A good NT teacher, therapist, job coach, life skills trainer, or other service provider can certainly create an environment in which autistic people have positive experiences and learn useful skills. But even such positive and helpful environments still have characteristics of "NT spaces," because NT people are in charge and NTs are making the rules. The very fact that NTs are creating and managing a program or a service, for the benefit of autistic participants, conveys the perception that autistic people are helpless and dependent on NTs to take care of us. (2010)

Likewise, autism-focused advocacy is led and shaped primarily by parents, family members, and caretakers of Autistic people. Autistic people may be involved in autism-focused advocacy, but their voices and perspectives are not central, nor do they define the parameters or priorities of organizations or movements (Robinson, 2020). Overwhelmingly, autism-focused advocacy treats autism as a medical condition and tends to concentrate resources around origins, cures, and therapies with the goal of maximizing Autistic people's ability to comply with the norms of neurotypical society. (Egner, 2022)

Conversely, *Autistic advocacy* corresponds to Sinclair's definition of "shared autistic space," in which "...autistic people are in charge. Autistic people determine what our needs are, and autistic people make the decisions about how to go about getting our needs met" (2010). Autistic advocacy, then, is Autistic-led and defined. It may include parents, family members, caretakers, and non-Autistic allies; but Autistic voices and perspectives are centered, and Autistic needs define the parameters and priorities of organizations and movements. Organization and logistics prioritize Autistic inclusion, not compliance with norms of neurotypical society.

Autistic advocacy is not the inverse of autism-focused advocacy; nor are the two fundamentally at odds, despite their long history of public clashes (Solomon 2008). There are autism-focused groups and publications, like the *Thinking Person's Guide to Autism*, that are

helmed by non-Autistic people but center Autistic voices and draw their priorities from Autistic advocacy. Likewise, there are Autistic people involved in and supportive of even the most cure-centric autism-focused advocacy. No group is a monolith, and no single Autistic person or group of Autistic people can accurately be said to represent every member of the Autistic community.

The Record that Isn't

The nature of the conversations around autism and the voices and movements that define them have led to a deeply lopsided body of scholarly work. Etiology, education, and mitigatory measures—the territory of frightened parents and the medicalization of disability—make up the overwhelming bulk of available literature. (Zuber & Webber, 2019; Egner, 2022; Woods, 2017) Meanwhile, the actual work and organizing of Autistic people has gone largely unstudied outside of informal and first-hand accounts; and those, in turn, are clustered around relatively few sources—an anthology here, a themed journal issue there.² To study this subject in any degree of depth will require time and resources to parse primary and archival sources, conduct interviews, and reframe decades of dialogue to center the voices and accounts of the individuals who have shaped organizations and movements that I discuss here. As such, this thesis is less a comprehensive overview of the history of Autistic organizing than an exploration of the limited perspectives currently available on that subject.

² For instance, a database search for seminal organization Autism Network International yielded a total of eight results, six of which were in English, and only one of which was from a peer-reviewed journal.

Defining Autism: The Clinical Evolution of a Spectrum

The history of Autistic organizing—and particularly the relatively late emergence of Autistic advocacy—is connected closely to the history of autism itself, or at least its place in the annals of psychiatry. That timeline formally begins around 1943, when psychiatrist Leo Kanner described a condition he named *early infantile autism*. A similar condition had been observed a few years before by Austrian psychiatrist Hans Asperger.³ (Silberman 2016)

Kanner’s research was narrow and prescriptive. His definition of autism was limited to early childhood and structured around a long and exacting series of diagnostic criteria that effectively ruled out a large number of individuals who would clearly fit into what is now recognized as the autism spectrum. One of those criteria in particular—Kanner’s initial and longstanding belief that the condition was confined to early childhood—would define not only the following half-century of autism research, but the development of the organizations and advocacy communities that grew in subsequent decades, effectively guaranteeing that the only significant organizations would be controlled by the non-autistic parents of Autistic children.

Kanner’s views on the etiology of autism also primed the pump for parent activism. He blamed autism on parents who were “cold perfectionists,” who, preoccupied with their own careers, mechanically met their children’s physical needs while ignoring their emotional ones (Silberman, 2016). Kanner’s concept of “refrigerator mothers” (Kanner implicated both parents, but it was mothers who bore the brunt of judgment) was popularized via articles in *Time* and the 1967 book *Empty Fortress: Infantile Autism and the Birth of the Self* by psychiatrist Bruno

³ Asperger’s work was effectively lost from World War II until the early 1980s. Kanner never cited or acknowledged Asperger’s research, but it’s immensely plausible that Kanner, who was fluent in German and worked closely with two of Asperger’s former colleagues, was familiar with it. (Silberman 2016)

Bettleheim. While Kanner and Bettleheim's accusations earned the support and funding of a psychiatric establishment still heavily dominated by psychoanalysis, the evidence behind them was slim at best; and they sat poorly with parents struggling to find adequate diagnoses and treatment for their children.

The specter of the refrigerator mother was shattered by the work of Bernard Rimland, a psychologist and disciple of Kanner's who was also arguably the first and most prominent parent advocate. In a book titled *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, Rimland argued persuasively that autism "was an inborn 'perceptual disability' rather than a form of psychosis caused by childhood trauma" (Silberman 2016). Rimland also developed—and distributed, via the appendix of *Infantile Autism*—the first diagnostic questionnaire for autism and the first standardized clinical tool for autism assessment. When parents returned the questionnaires, Rimland scored them using a proprietary algorithm and reported the results by mail.

In the first years of its existence, infantile autism was grouped under the umbrella of *childhood schizophrenia*, a poorly-defined catch-all that included a wide range of childhood conditions that would only later be distilled into distinct diagnoses. It was in this capacity that infantile autism first appeared in the *DSM*—the diagnostic and statistical manual that serves as the backbone of modern psychiatric diagnosis—and remained until the publication of the *DSM-III* in 1980, when *infantile autism* was included as its own discrete diagnosis. (Silberman, 2016; Garcia, 2021)

Infantile autism as defined in the *DSM-III* remained constricted by Kanner's narrow guidelines. The condition was "framed narrowly in terms of [Kanner's] two cardinal signs: 'pervasive lack of responsiveness to other people' coupled with 'resistance to change,'"

(Silberman, 2016) with an age of onset no later than 30 months. Furthermore, diagnosis required a long checklist of nonnegotiable clinical features, including “gross deficits of language development” and “bizarre responses to the environment” (qtd. in Silberman, 2016). Autism historian Steve Silberman describes the impact of Kanner’s diagnostic criteria: “Each of these qualifications increased the likelihood that autism would forever remain as Kanner had described it: a rare disorder. Furthermore, the word *infantile* guaranteed that it would continue to be viewed primarily as a condition of early childhood.” (2016)

For adults who had met the criteria for the full syndrome in early childhood and still manifested symptoms, the *DSM-III* coined the awkward term *Infantile Autism, Residual State*. All other conditions that would later be recognized on the autism spectrum were lumped into the category of Child Onset Pervasive Developmental Disorder. COPDD’s diagnostic criteria included vague or contradictory descriptions including “lack of appropriate social responsivity,” both “inappropriate clinging” and “asociality,” and the catch-all “hyper- or hypo-sensitivity to sensory stimuli” (qtd in Silberman, 2016).

The same year as that the *DSM-III* was published, Eric Schopler and colleagues released the Child Autism Rating Scale (CARS). Unlike previous diagnoses, which had relied on either intensive clinical observations by the small handful of elite specialists trained by Kanner, or Rimland’s checklist with its black-box algorithm, CARS was not only standardized and accessible, but could be administered with consistent and reliable results after a mere hour of training, opening the door to diagnosis for clinicians of all levels. A second edition of CARS, released eight years later, was even easier to use; and, unlike its predecessor, it could be used to diagnose teenagers and adults. (Silberman, 2016)

The *DSM-III* was effectively a working draft; the revised *DSM-III-R*, released in 1987, completely reworked its section on pervasive developmental disorders. Both infantile autism and COPDD disappeared, replaced with *autistic disorder*—now understood to be a lifelong condition. Kanner’s narrow, nonnegotiable criteria were replaced with a far more flexible set of checklists. “The new criteria could be applied to a much larger and more diverse population,” writes Silberman. “Later studies confirmed that the revised criteria were better at picking up cases of autism at every level of ability.” (2016; Garcia 2021)

The *DSM-III-R* also introduced *Pervasive Developmental Disorder—Not Otherwise Specified*, or PDD-NOS, which was essentially subthreshold autism. While researchers expected that PDD-NOS would essentially be a footnote, it quickly became the most common PDD diagnosis. “Like Asperger Syndrome, it was an autism diagnosis that didn’t contain the word *autism* and thus was more readily accepted by parents and health care workers” (Silberman, 2016).

The publication of the *DSM-III* and *DSM-III-R* and the newly accessible CARS diagnostic system corresponded with heightened autism awareness among medical and psychiatric professionals and a surge of public interest in the wake of the 1984 film *Rain Man*. The predictable result was a massive increase in diagnoses, and—from the outside—the illusion of a new epidemic. (Silberman, 2016).

In 1994, the *DSM-IV* expanded autism’s criteria further still, giving new populations access to diagnosis:

“The expansion of the diagnostic criteria in the *DSM-IV* had given large numbers of people access to legal protections, service provision, and a diagnosis and communal identity that helped them make sense of lifelong experiences of social isolation, odd interests, and other common autistic experiences.” (Kapp & Ne’eman, 2020)

The *DSM-IV* also introduced yet another diagnosis: *Asperger Syndrome*, referring back to the work of Hans Asperger, who had described autism several years before Leo Kanner. The first English translation of Asperger's work had appeared in 1991 (Barahona-Corrêa & Filipe, 2016). From the start, Asperger had romanticized his subjects: "they often had extremely original thought, they tended to cultivate abstract and intellectualized interests, and often had, in Asperger's own words, 'a rare maturity of taste in art'" (Barahona-Corrêa & Filipe, 2016). Asperger also rhapsodized on his subjects' physical appearance, their "finely boned features" of "almost aristocratic appearance" (qtd in Barahona-Corrêa & Filipe, 2016). The emphasis on the exceptionality of children with Asperger syndrome had ugly origins: Asperger had been complicit in the Third Reich's *Aktion T4*, a program enacted to kill disabled individuals. His glowing descriptions of some of his subjects were designed to establish them as potentially useful citizens—at one point, Asperger even attempted to convince the government of the utility of his patients as potential code-breakers—while recommending other children for extermination.

Even divorced from its historical context, as it initially was in the 1990s, Asperger syndrome maintained its supremacist and borderline-eugenic implications; and its use as a diagnosis emphasized other social inequities. While Asperger's was diagnostically nearly indistinguishable from so-called "high-functioning" autism to the point of controversy over which of the two should be prioritized in the frequent cases when a patient fit both profiles, white boys were far more likely to be diagnosed with Asperger's, while white girls and all Black children were more likely to be labeled autistic (de Hooge, 2019; Kapp & Ne'eman, 2020). According to Barahona-Corrêa & Filipe, "there is evidence that patients, families, education professionals, and health professionals connote AS with positive features and associate Autism

with strange behavior, learning disability and family dysfunction” (2016). In 2010, Michael John Carley, executive director of the Global and Regional Asperger Syndrome Partnership (GRASP) described his reaction to rumors that Asperger’s was to be folded into the more general diagnosis of Autism Spectrum Disorder in the *DSM-V*:

“I personally am probably going to have a very hard time calling myself autistic,” said Carley in an interview with National Public Radio, comparing the cultural perception of Asperger’s as a diagnosis perceived as associated with major historical figures, like Edison and Einstein, to “somebody who might have to wear adult diapers and maybe a head-restraining device. This is very hard for us to swallow” (Kapp & Ne’eman, 2020).

The *DSM-V* would be notable for another change as well, one that shook the ableist construct on which Aspie (from Asperger) supremacy was scaffolded. It was to be the first edition of the manual where the definition of autism would be directly influenced not only by psychiatric professionals, but by Autistic advocates.

Gathering Places: Autistic Advocacy Online

“The Internet and the disability rights movement have traveled parallel paths,” writes Kras (2009). From its inception, the online world gave disabled people access to conversation and community that they lacked in physical life. So, too, was the case in the Autistic community.

As Egner points out:

While there are some gathering places for autistic people outside of the virtual world, there aren’t many. Like most people with disabilities, we are likely born into families of all able-bodied/minded or allistic people. We rarely have a vertical identity group (or what Goffman (1963) described as tribal identity) from which to learn and build connections. Similarly, it is difficult for autistics to build horizontal community or communities made up of peer groups. We can’t join an autistic club on a college campus or hop down to the autistic bar to meet up with friends. (2022)

Online, on the other hand, there exists “a vibrant and active community of autistic people.” (Egner 2022) In addition to bypassing many of the barriers to organizing in the physical world—distance, cost (to some extent), age (to a greater extent than is perhaps ideal), and a plethora of others—the Internet has served as a platform and forum for nonverbal Autistic people previously cut off from the majority of advocacy conversations (*Directory of NonSpeaker pages, blogs, & media*, 2022). For other Autistic people, it offers a conversational medium far more comfortable for many of us than spoken language (Howard & Sedgewick, 2021). Computer-based communication is “structured in a way that may appeal to and uniquely benefit” (Gillespie-Lynch et al., 2014) Autistic people. The asynchronous, text-based communication allows many Autistic people to converse and connect with the same level of fluency non-Autistic peers enjoy offline (Gillespie-Lynch et al., 2014).⁴ That freedom opens additional doors.

Gillespie-Lynch et al write:

Access to an autistic culture, or online sites such as Wrong Planet where alternative communicative norms to those encountered in neurotypical interactions are encouraged (Davidson, 2008; Jordan, 2010), may provide adults with ASD with the sense that they can express themselves better online. Indeed, contact with similar others online may allow people with ASD to reveal themselves as autistic online and express aspects of themselves that they may try to conceal to appear more normal in other contexts (e.g., Davidson & Henderson, 2010). (2014)

This digital directness not only allows Autistic people to express ourselves online; it allows us to find and connect with one another. Furthermore, it gives us the means to develop our own narratives of collective identity, countering the exclusion of Autistic people from scholarship and advocacy spaces and the medicalization of autistic identity:

⁴ This has certainly been my own experience. In addition to connecting me with the larger Autistic community, social media—particularly Twitter—has functioned as adaptive technology that allowed me to communicate on equal social footing with non-Autistic peers.

Autistic Twitter users reject current cultural narratives of autistic personhood (often embedded with medicalized and stereotypical notions) by employing five resistance strategies: (1) building autistic identity beyond medical conceptions, (2) recognizing shared experiences of marginalization, (3) debunking stereotypes, (4) flipping both negative stereotypes and pathologized evaluations of their “deficiencies” into positive self-stories, and (5) contesting medicalized perspectives that autistic bodyminds should be cured, rehabilitated, and avoided. (Egner, 2022)⁵

Unfortunately, when it comes to the intersection of the Internet and autistic advocacy, the same recurring issue arises with the literature. Database searches yield a scant list of articles examining online Autistic communities, alongside a few dissertations. Those not by the same handful of scholars—most prominently, Steven Kapp—invariably cite them heavily. Fewer than half a dozen address online Autistic advocacy or the relationship between the Autistic community’s ability to organize online and the rise of Autistic-led advocacy.

How, then, to establish the impact of the Internet on the history of Autistic organizing? In 1993, the University of Illinois' National Center for Supercomputing Applications released Mosaic, the first web browser. (Calore, 2010). Mosaic radically expanded access to and interest in the Internet:

With Mosaic, the online world appears to be a vast, interconnected universe of information. You can enter at any point and begin to wander; no internet addresses or keyboard commands are necessary. The complex methods of extracting information from the net are hidden from sight. Almost every person who uses it feels the impulse to add some content of his or her own. Since Mosaic first appeared, according to the NCSA, net traffic devoted to hypermedia browsing has increased ten-thousandfold. (Qtd. in Calore, 2010)

Silberman (2016) establishes that Autistic people had been active online even before the advent of the world-wide web, but the previous iterations of the Internet would have been limited to

⁵ Justine Egner’s “#ActuallyAutistic: Using Twitter to construct individual and collective identity narratives” is both a remarkable primer on the vibrant Autistic community on that social networking platform and an excellently articulated object lesson in the importance of self-narrative in Critical Autism Studies.

early adopters. Mosaic opened the web to a far wider spectrum of users, including—largely for the first time—those not already steeped in computer culture. This new technology “greatly advanced” “the emergence of effective large-scale [autistic] self-advocacy” (Ward & Meyer, 1999). Ward and Meyer directly linked the rise in the Autistic self-advocacy movement to the Internet, writing, “The rapid development of information technology has led to advances in self- and collective advocacy inconceivable less than 4 years ago.”

In addition to connecting Autistic computer users to one another, the nascent Internet democratized access to information that had previously been limited to experts and professionals, arming self-advocates with the means to challenge restrictive social and diagnostic paradigms. (Ward & Meyer, 1999) The prevalence of highly technology-savvy individuals in the autistic community has led to “rapid sophistication” with self-advocacy tools and a significant shift in the power dynamics of expertise and access to information. (Ward & Meyer, 1999)

As critical these technological developments themselves is their timing. The slow evolution of diagnostic criteria and the initial limitation of autism diagnoses to children effectively precluded any Autistic involvement in the early disability rights movement: while Kitty Cole and Judy Heumann were occupying the Federal Building at 50 United Nations Plaza in San Francisco, Autistic adults were a full decade away from qualifying for any kind of diagnosis (Lu, 2021). But by accident of timing, the inclusion of both adults and individuals with low support needs—the latter of whom are overrepresented in the tech field (Silberman, 2016)—in the *DSM* and the subsequent explosion of autism diagnoses corresponds almost exactly with the popularization of the Internet. And it was there that Autistic organizing found its flashpoint.

“Don’t Mourn for Us” and Autism Network International

By the time Autistic advocacy was finding its way online, its foundations had been laid in print. The first two major English-language books by Autistic authors, Temple Grandin’s autobiography, *Emergence: Labeled Autistic*, in 1986; and Donna Williams’ *Nobody, Nowhere*, in 1991 (Pripas-Kapit, 2020). While the Grandin and Williams came from vastly different backgrounds, both works treated autism as fundamentally tragic, the “powerful monster” of Bernard Rimland, who wrote introductions to both volumes, framing each as a fundamentally triumphant story of “overcoming” that monster (Pripas-Kapit, 2020). “*Emergence* and *Nobody, Nowhere* might have challenged the pernicious view that autistic people lacked thoughts and feelings, but the narratives reinforce another idea: that having an autistic child is a tragedy for families,” writes Pripas-Kapit (2020). “Neither writer suggested that autism was anything other than a disability to be mourned.”

Indeed, the theme of mourning an Autistic child—or, at least, the neurotypical child that Autistic child has supposedly replaced—is a recurring theme in the rhetoric of parent-led advocacy (Sinclair, 1993.) And so it is particularly significant that the common rhetorical root of the organized neurodiversity movement, by Autism Network International founder Jim Sinclair (Sinclair, 2010), was titled, “Don’t Mourn for Us.” (Sinclair, 1993)

First delivered as a presentation in 1993 and subsequently published in the Autism International Network newsletter *Our Voice*. “Don’t Mourn for Us” is cited heavily in both popular articles on autism acceptance and by many of the individuals who, in the decades following its publication, would found many of the online gathering points of the Autistic community (Arnold, 2019; Harmon, 2004; Kras, 2009; Pripas-Kapit, 2020; Seidel, 2019; Solomon, 2008).

Above all, “Don’t Mourn Us” is a rebuttal to the lost or stolen-child rhetoric of parent-led organizations like Autism Speaks:

You didn't lose a child to autism. You lost a child because the child you waited for never came into existence. That isn't the fault of the autistic child who does exist, and it shouldn't be our burden. We need and deserve families who can see us and value us for ourselves, not families whose vision of us is obscured by the ghosts of children who never lived. Grieve if you must, for your own lost dreams. But don't mourn for *us*. We are alive. We are real. And we're here waiting for you.

Sinclair goes on to articulate the *de facto* mission statement of autistic advocacy, an ethos that has held up remarkably well through thirty years of reification, organization, conflict, and consensus within the movement:

This is what I think autism societies should be about: not mourning for what never was, but exploration of what is... 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.

“Don’t Mourn for Us” also reflected the template of the organization Sinclair had co-founded the year before with Donna Williams and Xenia Grant. Sinclair, Williams, and Grant had met via a pen-pal list run by an organization for parents of “high-functioning” Autistic children. During a weekend at Sinclair’s apartment, the trio had defined the need for community created by and for Autistic people—previously unable to connect except through parent-run organizations like the one that had introduced them, where their role was something between resource and oddity—and shortly after, launched Autism Network International (Sinclair, 2005; Sinclair, 2010).

Initially, ANI consisted of a newsletter and a pen-pal list, although the latter quickly closed due to the presence of a persistent stalker (Sinclair 2010). For its first several years, the organization would continue to exist in close overlap with the parent-run organizations through

which its founders had met. Lacking the institutional funding of the parent-run organizations, ANI operated on a shoestring budget. It relied on parent organizations' newsletters and listservs for publicity and pitched programming to their conferences, where ANI members generally slept in their cars or, on one occasion, camped in an abandoned building.

Sinclair was shocked by the hostile response ANI received from many of those groups:

Nearly all of us who were involved in the earliest period of ANI had met many parents of autistic children, at conferences and local parent support groups. Almost invariably, the parents were pleased and excited to hear from us. True, their primary interest was in using us as resources for their children rather than supporting us in our own goals; but still, they were not *hostile* toward us. It seems that one autistic person at a time--and preferably a passive one--might be welcomed as an interesting novelty or an amusing diversion or possibly even a valuable source of information and insight. But autistic people organizing together, autistic people pursuing our own interests rather than furthering the interests of parents and professionals--suddenly we were perceived as a threat (2005).

Some organizations banned ANI from their newsletters. The central autism forum at the time objected to an influx of Autistic participants, blaming them for "wasting bandwidth." The Autism Network of America blacklisted Sinclair's proposals from conferences and began to spread rumors that he wasn't actually Autistic (Sinclair, 2005). It was only via a partnering organization unaware of the ban that Sinclair was able to present "Don't Mourn for Us" at the International Conference on Autism in 1993. Later, Sinclair would contextualize this backlash as typical of the opposition faced by disability advocates and organizations who dared "to challenge the status quo—to dispute the presumption of their incompetence, to redefine themselves as equals of the empowered class, to assert independence and self-determination" (Sinclair, 2005).

Pripas-Kapit writes:

By choosing to take this radical stance, Sinclair sacrificed much. A friend of mine who conversed with xem on the subject said that Sinclair was on track to become a professional autistic speaker akin to Grandin and Stephen Shore. After taking more radical stances on autism and neurodiversity, those opportunities were no longer open.

For a time, Sinclair was homeless. He never found a full-time job in his chosen profession as a rehabilitation counselor despite obvious knowledge and qualifications. (2020)

Still, ANI persisted, moving from the forum to its own dedicated listserv in 1994. Two years later, Sinclair launched Autreat, a physical answer to the “By autistics for autistics” ethos of ANI’s online community. Initially a two-day retreat and conference, Autreat grew into a four-day event and ran annually through 2013.

The evolution of Sinclair’s own activism mirrors the evolution of Autistic advocacy itself. ANI was born out of a parents’ network; “Don’t Mourn for Us” existed primarily as an appeal and rebuttal to parents of Autistic children. With ANI’s independence and the creation of Autreat, the focus changed: the conversation was no longer between Autistic adults and neurotypical parents of Autistic children, but among Autistic people.

Whose Voice? Parent Advocates and Autism Speaks

Autistic advocacy is a movement defined as much by what it is not as by what it is. In particular, it represents a hard break from the parent-led autism-focused advocacy that dominated discussions of autism into the 1990s. Indeed, until Sinclair and ANI, parent-led organizations overwhelmingly controlled the conversations and advocacy around autism. The first autism parents’ group, the National Society for Autistic Children, was founded in 1965; others soon followed (Silberman, 2016). Their impact has been sweeping and tremendously mixed:

Parents' speech and advocacy has contributed greatly to some of the most important victories regarding de-institutionalization, access, and education, but has also been implicated in paternalism, pseudoscientific theories and treatments, and violence (both psychological and physical) against autistic people. (Rosenblatt 2018)

For the last seventeen years, the most prominent and by far the best funded such organization has been Autism Speaks. Founded in 2005 by NBC chairman Bob Wright and his wife Suzanne after their grandson was diagnosed with autism, and launched with a \$25 million donation from Home Depot owner Bernie Marcus, Autism Speaks quickly elbowed its puzzle-piece logo into the spotlight, structurally absorbing other advocacy organizations on the way (*About Us*, 2012; Rosenblatt, 2018).

Autism Speaks' budget, connections, and media and marketing-savviness have allowed it to disproportionately shape the global conversation around autism. In doing so, it perpetuates a long tradition of parent advocates and the medical establishment effectively barring Autistic involvement and self-advocacy in conversations and policy that intimately affect Autistic people. "With its emphasis on *speaking*, [Autism Speaks'] design for hearing did not simply fail," writes Rosenblatt. "Rather, it was never constructed in the first place, because the organization did not originally identify hearing autistic voices as part of its mission." (2018) In its seventeen-year history, Autism Speaks had had only three Autistic board members, the first of whom (John Elder Robinson) publicly split from the organization in 2013, writing:

Autism Speaks says it's the advocacy group for people with autism and their families. It's not, despite having had many chances to become that voice. Autism Speaks is the only major medical or mental health nonprofit whose legitimacy is constantly challenged by a large percentage of the people affected by the condition they target.

The absence of people with autism in governing or oversight roles has crippled Autism Speaks in its efforts to connect with the community. Any group that hopes to be accepted in service to autistic people must make autistic people its #1 priority, with no exceptions. The priority cannot be autism parents, or autism grandparents. It's got to be actual people with autism. (Robinson, 2013)

In 2014, twenty-six autism and disability advocacy organizations, led by ASAN, collectively condemned Autism Speaks for a number of transgressions: its lack of Autistic leadership; its

support of dangerous fringe science, including the myth that autism is the result of vaccinations; its promotion of borderline and outright abusive behaviorist techniques, including those of the infamous Judge Rotenberg Center, which were condemned by the U.N. Special Rapporteur on Torture⁶ (Pilkington, 2012); its misallocation of resources away from communities and Autistic people; and its perpetuation of “offensive and outdated rhetoric...designed to present the lives of autistic children and adults as little more than tragedies” (2014 joint letter to the sponsors of *Autism Speaks*).

While its policies and practices have slowly shifted in apparent response to years of vociferous pushback from Autistic advocates (Rosenblatt, 2018), Autism Speaks has for the most part failed to answer to the accusations against it or the allegations of harm it has caused, including complicity in the murders of Autistic children by their caretakers (Ne’eman, 2007, December 8). Rosenblatt writes, “Autism Speaks’ own relationship to its troubled history is, as we have seen, more one of halting and partial acknowledgement than of crisis and transformation.” (2018) Rosenblatt likens Autism Speaks’ reputational challenges to those faced by states following episodes of authoritarian violence, centering his theory on the corrosion of the organization’s perceived legitimacy following past injustices (2018).

While its scale distinguishes it from its peer organizations, Autism Speaks serves as a fairly representative case study of the ongoing tension that exists between modern Autistic advocacy and parent-led autism-focused advocacy. The question of who speaks for whom—

⁶ By 2012, two U.N. Special Rapporteurs on Torture, Manfred Nowak and Juan Mendez, had called for investigations into the Judge Rotenberg Center’s use of electric shocks on disabled children and adults as a behavioral aversive, and the school had been subject to multiple lawsuits regarding the use of electricity as well as other allegations of physical abuse (Pilkington, 2012). In 2020, the FDA banned the use of shock devices in several contexts—including those used at the JRC—but that ruling was voided by an appellate court the following year (Setty, 2021). In 2023, the Judge Rotenberg Center continues to use electric shocks on its students and remains subject to large-scale protest from the disabled community (*#stoptheshock*, 2023). Since its opening in 1981, six students have died in the JRC’s care (Davies, 2014).

whether, for instance, Autistic advocacy adequately addresses the needs of Autistic people with intellectual disabilities and high support needs, or whether Autistic adults have the right to challenge the parenting choices of non-Autistic parents of Autistic children—remains hotly contested (Lutz, 2013).⁷

Some of the conflict is a matter of priorities and perceptions: Autistic advocates frame neurodiversity in terms of a social model of disability, while parent advocates argue that the language of “medical/deficit-based discourse” is necessary to navigate often-hostile school systems and gain necessary accommodations (Woods, 2017). To those parents, use of medicalized language may be a distasteful means to a necessary end, but to Autistic advocates, it reinforces stigma and amplifies the language of cure-oriented autism-focused advocacy. In this context, both Autistic and autism-focused advocates have the same end goal—securing necessary educational accommodations for Autistic children—but approach it from such radically different paradigms that compromise has been difficult to reach.⁸

Nothing About Us Without Us: ASAN and the *DSM-V*

In 2007, NYU’s Child Study Center released its “ransom notes” campaign, a series of advertisements intended to raise awareness of a range of childhood psychiatric disorders, including autism and Asperger syndrome. The campaign consisted of pasted-up “ransom notes”

⁷ This particular conflict is currently centered around ABA, or Applied Behavior Analysis, a behaviorist “therapy” based on the work of Leo Kanner. Embraced wholeheartedly by autism-focused parent advocates, ABA is largely condemned by Autistic adults—many of whom experienced ABA firsthand—as an abusive practice that prioritizes the subjects’ ability to conform to non-Autistic social standards at the expense of genuine communication and understanding. (Rosa, 2022)

⁸ A rare exception is *The Thinking Person’s Guide to Autism*, a digital publication founded by parent advocates to counter the prevalence of misinformation in the parent-advocacy community. While *TPGA* grew out of parent advocacy, its founders are vocal allies to and supporters of Autistic advocacy and center Autistic voices and perspectives in their work while urging their peers to do the same. (Rosa & Greenberg, 2020)

on billboards and kiosks and at construction sites in New York City, as well as full-page ads in *Newsweek* and *New York* magazine. The notes were oblique and threatening. The autism note read,

We have your son.

We will make sure he will no longer be able to care for himself or interact socially as long as he lives.

This is only the beginning.

Autism

The Asperger note was similarly bleak:

We have your son. We are destroying his ability for social interaction and driving him into a life of complete isolation.

It's up to you now.

Asperger Syndrome (Kras 2009)

The language of kidnapping and disappearance was not new to autism-focused advocacy. For decades, parent groups had leaned into metaphors of disappearing children and changelings. In 1965, parent-scholar Bernard Rimland wrote, “This was war. I envisioned autism as a powerful monster that had seized my child. I could afford no errors” (qtd in Silberman, 2016); in the years since, other parent-run groups had seized on the same provocative language (Kras 2009, Silberman 2015).

Autistic advocates—“missing” only in the sense of their exclusion from autism-focused advocacy—had had enough:

From a social constructionist standpoint, NYU CSC's so-called "public service" campaign constituted yet another huge disservice to people with childhood psychiatric disorders, such as autism, Asperger syndrome, depression, and ADHD. A campaign to ostensibly raise awareness and understanding, created by an organization whose "mission

[is] to improve the treatment of child psychiatric disorders by eliminating the stigma of being, or having, a child with a psychiatric disorder" (http://www.aboutourkids.org/about_us/overview_history), instead served to perpetuate a stereotype of those with mental health issues as isolated, markedly abnormal, and incapable of ever functioning in society (Kras, 2009)

At the head of the response to the Ransom Notes campaign was the infant Autistic Self Advocacy Network, "a national grassroots disability rights organization for the autistic community" (*About ASAN*, n.d.), and one of the first Autistic organizations to frame itself as part of the larger disability-rights movement. 20-year-old Ari Ne'eman had cofounded the organization barely a year before with graduate student Scott Michael Robertson, frustrated by the lack of Autistic voices in autism-focused advocacy: "When the organization was formed, there was an unprecedented amount of public discussion about autism but no representation of autistic people in that conversation" (qtd in Opar, 2021).

ASAN's response to the NYU ransom notes was swift, coordinated, and blisteringly effective. As news of the ads spread through the network of disability blogs, Ne'eman and colleagues coordinated twenty-two disability rights organizations and thousands of emails, phone calls, and letters (Ne'eman, 2007, December 19). Soon, word of the campaign had migrated from the blog network to the *New York Times* (Kaufman, 2007; Kras, 2009). On December 19, two weeks after the launch of the ads, the NYU Child Study Center canceled the Ransom Notes campaign and committed to developing their next campaign with input from community advocates (Ne'eman, 2007, December 19; Kras, 2009).

Ne'eman and ASAN had taken on a significant force in the world of psychiatry. In 2009, they decided it was time to tackle the backbone of the entire field: the *DSM*. "Because autistic people are shaped by the diagnostic process," wrote Kapp and Ne'eman, "one of the Autistic Self Advocacy Network's priorities—as the leading organization run by and for autistic people—was

to shape that process in return” (2020). The upcoming *DSM-V* represented the first such opportunity: “...during the development of the DSM-IV, an organized community of autistic adults did not yet exist in significant numbers. The DSM-5 was the newly organized autistic community’s first opportunity to weigh in on the criteria that governed who the medical community considered autistic.” (Kapp & Ne’eman, 2020)

Led by Ne’eman and Dr. Stephen K. Kapp—then a doctoral student—ASAN spent three years lobbying and collaborating with the *DSM-V* Neurodevelopmental Disorders Workgroup. While Kapp and Ne’eman were the faces of the work, they drew on ASAN’s wide network of Autistic activists and scholars, from Network interns to bloggers, and formed an “uneasy détente” with the parent-led organization Autism Society of America. (Kapp & Ne’eman, 2020)

The results were mixed. Ultimately, only some of ASAN’s goals were realized in the *DSM-V*, but this represented a clear milestone:

ASAN’s effort to lobby the DSM-5 is historically significant in that it represents the first successful effort of the autistic community—and as far as we are aware, any disability community—to successfully influence the modification of their own diagnostic criteria. While communities have successfully advocated to eliminate a diagnosis from the DSM (i.e.: homosexuality) or to incorporate one, we are aware of no prior example of successful advocacy to refine and improve diagnostic criteria from the community subject to it. (Kapp & Ne’eman, 2020)

Conclusions and the Future of Autistic Advocacy

Kapp and Ne’eman’s role in shaping the diagnostic standards for autism brings a conversation full-circle: Autistic advocates have played a role in the evolution of the very body that informed the development of their movement. This is not to signify that the conversation is over. While Autistic advocacy has grown into a force that shapes both diagnostic standards and national

policy, it remains in its relative infancy compared to the larger sphere of disability advocacy, and while it has proven itself a force to be reckoned with, its relative youth makes it vulnerable to both externally shifting norms and loss of critical infrastructure.

So, too, must Autistic advocacy continue to evolve to confront a new range of issues. While many fights—lack of school inclusion, subminimum-wage sheltered workshops, absence of funding for home and community-based support—are frustratingly perennial, other challenges have arisen more recently, particularly along lines of intersection with other marginalized populations. In the last year, for instance, the significant overlap between autistic and gender-diverse populations (Warrier et. al, 2020) has been increasingly weaponized by anti-transgender campaigners, who cite the high rates of autism in the transgender community as a rationale to limit access to gender-affirming care.⁹ At least one law, Georgia’s *SBI40*, cites autism and gender dysphoria as “often comorbid,” (Garcia, 2023), and an emergency order by Missouri Attorney General Andrew Bailey bans doctors from providing gender-affirming care to anyone who has not been screened for autism (Rosenbaum, 2023). This framing simultaneously implies that Autistic people are incapable of discerning their own gender identities and denies them the agency to pursue gender-affirming care.

At the same time, the diagnostic and technological forces that have shaped the rise of Autistic advocacy continue to evolve. Parent and medical groups are popularizing a new pseudodiagnostic label, “profound autism,”¹⁰ which ASAN director Julia Bascom and parent

⁹ These arguments—first introduced by notable transphobe (Romano, 2023) and erstwhile children’s author J. K. Rowling (Garcia, 2022)—claim that Autistic youth—in particular, Autistic female-assigned youth—are uniquely vulnerable to the spread of transgender identity via “social contagion,” a hypothesis with a pedigree about as valid as Wakefield’s connection between Autism and vaccine injury (Serano, 2023).

¹⁰ That this new label was proposed by *The Lancet*—the same journal whose negligent review process popularized Dr. Andrew Wakefield’s fraudulent paper linking autism to childhood vaccines—is not lost on Autistic advocates (Bascomb & Perry, 2022). Despite the Wakefield catastrophe and the subsequent and still-rising death toll of vaccine-preventable illnesses, *The Lancet* still considers itself mandated to speak with authority on the well-being of Autistic people while dismissing both Autistic researchers and the entire landscape of Autistic advocacy whole-

advocate David M. Perry characterize as an attempt to lend credibility to the false dichotomy of functioning labels and effectively divide the community based on an artificial measure of who really counts as Autistic, essentially recreating the Aspergers's Syndrome-Autism dichotomy revised out of the *DSM-V* (Bascom & Perry, 2022). If this label makes its way into the next iteration of the DSM—or even gains sufficient traction among scholars and mental-health practitioners—it may create a further barrier between Autistic and autism-focused advocacy.

Furthermore, the technology that has enabled Autistic advocates to network so effectively continues to change. While Twitter is currently a nexus of Autistic community online, its recent acquisition by Elon Musk and subsequent deterioration raises questions about where the future of the movement will make its homes. The ground-shaking advent of social media leads us to ask what other unforeseen paradigm shifts may follow.

The future of Autistic advocacy, then, depends on the movement's ability to shift nimbly alongside technology and cultural and medical norms while reifying the social and political influence it has so far amassed—without losing sight of its driving principle: “Nothing about us without us.” Its development will likely continue to be asynchronous, driven by necessity, evolving external circumstances, and, increasingly, internal momentum, as the conversations it has redefined continue.

cloth, a fact that vividly illustrates the relative perceived authority of Autistic and nonautistic voices in conversations that determine the future of the autistic population (Pukki et. al., 2022).

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Notes Toward an Oral History of the Autistic Self Advocacy Network

The following document is assembled from interviews with Autistic Self Advocacy Network executive director Julia Bascom, edited and organized thematically. Long-term, I hope that these interviews will serve as the foundation for a comprehensive oral history of ASAN. For now, they're essentially a skeleton, which I've used to develop a preliminary set of organizing categories (with the understanding that these will grow and change as the project continues).

I chose to look at ASAN because it represents a rare hybrid in both scope and approach. The advocacy landscape surrounding autism is heavily dominated by child-centered, parent-and-family-run organizations that have consistently earned animosity from neurodiversity advocates and the larger disability community for stances ranging from anti-vaccine lobbying; promotion of abusive behaviorist “therapies”; and broad support of institutionalization, sheltered workshops, and other inhumane and exploitative practices. In contrast, ASAN is an adult-centered autistic advocacy organization founded and run by adult Autistic self-advocates. Its politics and approach to advocacy is rooted heavily in the tradition of disability activism. In addition to direct policy advocacy, much of its work entails providing grassroots self-advocates with the tools to engage with policy, public institutions, and communities. ASAN is also centrally committed to making those tools accessible to and inclusive of nonspeaking Autistic people and those with intellectual disabilities, who are frequently sidelined in both parents-and-family activism and self-advocacy from neurotypical-passing Autistic people.

As is often the case with preliminary research, the wrinkles and warts here will be in full view. Of the sources I contacted, only two were ultimately able to schedule interviews by my deadline; and we had time to touch on only a limited selection of the topics I hope to explore in

the final project. Both interviews were plagued with audio issues—you'll see a bad phone collection reflected in [inaudible] tags in the text—and equipment malfunction rendered a further interview with ASAN co-founder Ari Ne'eman entirely unusable.

Nonetheless, Bascom's interview and the notes from Ne'eman's provide sufficient context and structure for the development of a framework for the larger history, as well as copious background material for future interviews; and I am optimistic about the future of this project to continue even outside of an academic context.

A COMMUNITY IN CRISIS

[Personal histories of founders Ari Ne’eman and Scott Robertson; landscape of autistic advocacy and community pre-ASAN; early criticism of Autism Speaks; early neurodiversity movement; passage of the first Combatting Autism Act]

A QUIXOTIC ENTERPRISE

[Grassroots growth and organization; resources and staff; development into a NPO; expansion of mission; developing philosophies of self-advocacy]

JULIA BASCOM:

I remember the first day we did an organized office supply order. It felt like, “We’re a real organization now!” It was really exciting.

I think that--when I talk about our early days, I tell people that the secret to being a national grassroots organization is that that can mean five people in a couple different states with laptops. And the fact that we’re now--we’re still people in a few different states, but we’re many more people. We have 14 paid staff. We have a home base. We have an office. It means that we’re able to meet a lot more of our community’s needs, while certainly not enough. It means that we’re able to be more organized and deliberate about what we’re doing, that we can step back and have a strategy that spans not just whatever issue we’re currently in the middle of, but how that connects to the other things we’re working on and what our next steps are [inaudible]. It

means that we're in a better position to [inaudible] our community than [inaudible]. [inaudible] chaos, or what have you. It means [inaudible] workspace every value that they have in a place where I can come to work every day where I can move my body the way it needs to move, and it doesn't change how other people see me. Or I can pause and have trouble finding my words, and it doesn't change the perceptions people have about my competence. I think that's really valuable.

And the fact that we exist has now made it harder for other organizations not to hire self-advocates. I think it makes us more real and more effective, and we're able to use that to do what we want to do.

JULIA BASCOM:

I think another thing that differentiates us from other autism organizations, aside from the fact that we are a self-advocacy organization, and there are only really a couple of us in the U.S. at the national level, is that we focus primarily on Autistic adults. Most autism organizations in the U.S. focus mainly on kids. That's changed a little bit over the last ten years, as there's been more recognition that Autistic people grow up, and continue to be Autistic as adults; and, indeed, are adults for most of our lives and need support during that time. But the focus is still very much on children, especially because, you know, kids are cute! It's easier to raise money off of kids, especially if you're talking about curing something or preventing something, or changing [inaudible]. And we've taken a very, very different approach.

We do some work focused on kids, related to ending restraint and seclusion in school [inaudible], or making sure that nonspeaking people have access to communication, but 95% of

our policy advocacy focuses on Autistic people over the age of 18. [inaudible] still really uncommon. An organization doing that work--it tends to be sort of an add-on as opposed to the core of what they do.

NOTHING ABOUT US WITHOUT US: BRINGING DISABILITY JUSTICE TO AUTISTIC ADVOCACY

[ASAN's first successful advocacy campaign against NYU Child Studies Center's "ransom notes" ad campaign; in coalition with ADAPT and other disability advocacy orgs.]

JULIA BASCOM:

One of the reasons I was comfortable becoming a part of ASAN was because... we were given lots and lots and lots of opportunities to say that neurodiversity or disability rights was really about people who could talk, or about people who could live independently, or people without intellectual disabilities. A sort of [inaudible] definition, right? And that we would just focus on those people, and the other autism organizations would just kind of do what they want with the people they considered low-functioning. And that would be fine. And those choices came with a lot of opportunities for social capital attached, lots of opportunities for support attached, lots of opportunities for funding attached; and over and over and over again, Ari and ASAN, and then myself when I joined, turned them down. That's not a bargain that we're willing to take.

We got a lot of support from the rest of the disability-rights movement, from self-advocates with other disabilities, like intellectual disabilities, from people who had been part of the deinstitutionalization movement, who were part of really shifting the way the rest of the disability community talks about inclusion, because we turned those offers down. But they still continue to be made.

And I think that was a really important decision point. Something you see sometimes now from folks who are newer to neurodiversity or newer to autism advocacy is this tendency to try to distance themselves from the concept of disability, and especially from the concept of intellectual disability. And the self-advocacy movement, which was created by people with intellectual disabilities who were institution survivors.

They made a very conscious political choice in those days that we were not going to do that--that we were going to build ourself as a continuation of that self-advocacy movement. And I think that's influenced everything we've done since then. It's why I was drawn to this organization.

JULIA BASCOM:

I think the other thing that really differentiates us from other autism organizations is that disability rights-based language, which says specific things about our values. ASAN is an organization that believes that civil rights are for all Autistic people, regardless how intense their support needs are, or how they appear to others, or how many other additional disabilities they have. We don't think there's an IQ test or a behavioral presentation you have to have to be treated with dignity and respect. We think inclusion is one of those--we're very focused on making sure that Autistic people can live in the general community with everybody else, not in

special places that are set aside for us; that we can work, do jobs in that community and be paid a fair wage, as opposed to being, again, sequestered away in sheltered workshops and paid less than minimum wage. We think we should go to school with everybody else--again, we think that's true of all Autistic people. We think that [inaudible] seclusion [inaudible].

We have this rights-based framework. And that's very common in other disability-based organizations. It's even very common in other organizations that aren't run by disabled people and don't necessarily consider themselves part of the disability rights movement [inaudible] people with intellectual disabilities at the ARC.

It's much less common in organizations in the autism [inaudible] aren't led by Autistic people, but family members or professionals.

That's a [inaudible] process in and of itself. It has to do with the way the autism diagnosis has evolved historically, and the fact that those organizations are representing family members of Autistic people weren't often a part of organizations representing the needs of people with intellectual disabilities and so didn't go through the same process that that community went through to come down on the side of inclusion. So in a lot of ways, that broader autism community--not Autistic people, but the people associated with us--still lag behind the rest of the disability community and the disability-rights movement. And what that means is that ASAN has policy positions that are often seen as very radical by other autism organizations, like our belief that Autistic people have the right to live in the community, or shouldn't be under guardianship, or should have the same kinds of jobs as everybody else.

But those positions aren't radical in other disability organizations, including organizations that focus on people with [inaudible] intellectual disabilities. It's just in the autism

[inaudible] that we're really perceived as this, like, fringe group. That's been interesting to work with.

SOURCE HISTORY - JULIA BASCOM

JULIA BASCOM:

I got involved in the online Autistic community when Autistic activism was pretty much something that just happened on blogs. I was 15 years old, so this would have been back in 2007ish. I got connected because I googled "autism," looking for people letting me know I was going to be okay, and there were other people like me out there, and that things that were hard weren't because we were broken. So that was really important to me at that point in time.

I think that was one year after ASAN was founded or conceived of. I was reading a lot of things other people were writing and starting to write about my own thoughts [inaudible], and I was spending a lot of time with friends in high school who had intellectual disabilities and were in segregated special education classrooms. We were similar in a lot of ways, but we were treated very differently based on how we appeared to other people, how we were [inaudible]. And after a couple of years, one of my friends who didn't have a disability traveled with some mutual friends who did have disabilities to the national Special Olympics. He met Ari there, and he came back and said, "You really need to email this person. I think you guys have a lot in common."

So Ari and I started talking--it must have been, like, 2009, I guess? And we did have a lot in common. We had a lot of thoughts about what the [inaudible] community needed. And I had

[inaudible] At this point, ASAN was just a handful of people. It didn't have nonprofit status, it didn't have offices or bank accounts or anything [inaudible].

We talked a lot about the [inaudible] and then in college, after a couple of years, I had to take a medical leave. And while I was on medical leave, Ari and I kept talking, and ASAN had reached the point where it had a bank account. And so I decided to do [inaudible] [project] as opposed to a project of my own. That's when I sort of formally became a part of ASAN.

And at the same time, I was still--I was interning and volunteering in a self-contained classroom for middle-school students with intellectual disabilities--in this case, who tended to be survivors of our state institution, which had been shut down the year before I was born. [inaudible] that process.

And then, toward the end of 2012, ASAN, again, had a bank account, had an office, had been an official organization for a year or two at that point, recruited me to come down to DC and do that full-time [inaudible]. And that's what I did.

SHAPING POLICY

[ASAN's early efforts at shaping legislation; early major victories beginning in 2010.]

DISABILITY DAY OF MOURNING

JULIA BASCOM:

The first Disability Day of Mourning happened in 2012 following the murder of George Hodgins, who was an Autistic young man, by his mother. And following that murder, every [inaudible] who was seeing these kind of murder cases, they were threatening [inaudible] saw them. And at the time, really sympathetic press coverage to the murderer, talking about it's really hard having a family member living with disability. Who could imagine what she had been through? Et cetera, et cetera. Very little coverage about the victim--about his life; about the fact that he was a murder victim, as opposed to someone who was really responsible for his own death.

And, pretty notably, the Autism Society of America released an article about this where they talked about, I think it was titled, "The Tragedy of Elizabeth Hodgins." Didn't talk about her son at all. Talked about how this is something understandable and that every parent of an Autistic kid has been there. And we thought that was really alarming and really unacceptable. We don't buy that most families of people significant disabilities think about killing us. We don't think there's evidence to support that. We think that's a really offensive thing to say about disabled people and about our families. We also know that this particular family had disproportionate access to services and access to supports, and they had turned away services. So, many folks tried to argue that this could have been the stopped with more services, and we just, again, don't buy that argument.

We were really disturbed by the focus on the murderer and the way that this was being talked about. Zoe Gross, who was a volunteering attorney with us at the time, organized the first vigil. I think there were a few sister vigils that spoke on that nationwide to honor George and also to honor--there was originally a short list, just a couple of other victims that we were able to find through some internet research, who had died in similar ways. It's become much bigger

since then. At our last vigil, I think we have between 30 to 50 states, and we usually have a few international sites. Obviously, the last couple of years have been challenging with the pandemic and it not being safe to meet in public, but folks have still also organized local virtual vigils in addition to the virtual vigil we hold as an organization.

When ASAN started this, we were pretty much on our own. At this point, we're now joined by most other disability-led organizations, as well as by some other major organizations like The Arc of the United States, which has really changed their messaging around these matters and really joined us and focused on the fact that the way the media often talks about these things is not helpful. It's harmful that these are acts of domestic violence that are being perpetrated against disabled people and that we need to be showing it that way, and talking about it that way, and talking about the value--that disabled people have a right to be alive.

The list is over a thousand names long. At the annual vigil, we would read the whole list. At this point, we just can't. It takes hours and hours and hours. So we read the new names that we found in the last year. And it's not that over a thousand people have been killed between 2012 and now. It's that we've gotten a lot better at finding these cases, both retrospectively and in the current year.

It still takes us a long time to read the new names. It's usually a couple of hundred new names for each vigil. We really use these vigils to mourn folks who might not have anyone else mourning them, but also to push for changes in terms of how these cases are covered and how these cases are prosecuted. So I've sort of described the issues with the media coverage before, where people really sympathize with the murderer, even though what we see is that when the victim is not disabled, the press coverage is often very different and very, very horrified.

A lot of disability organizations want to use these murders to talk about the need for more services. And there is a need for more services, but that's not a helpful conversation to have here because these murders are not linked to the lack of services. They're linked to ideas that our society teaches about disability. They're linked to the high rates of domestic violence that people with disabilities face. We're talking about [inaudible 00:06:26] in this context is really... And really [inaudible 00:06:26] people hostage. We've had some success in terms of changing how these cases are covered and how other disability organizations talk about them. Certainly not perfect, but I think the fact that we had The Arc as a major participant [inaudible 00:07:05] very significant, along with the national [inaudible 00:07:09]. And we have seen improvements overall in terms of media coverage.

Our other big focus has been on how these cases get prosecuted. It's tricky because ASAN believes, as a matter of policy, that mass incarceration is wrong and is harmful, and that the criminal legal system often does not advance justice for the disability community or most communities. At the same time, we're really troubled by the discrepancies that we see, where parents and caregivers who commit these kinds of murders often aren't prosecuted or don't receive sentences that are commensurate with what other caregivers who commit this kind of murders receive. I remember, really vividly, a case that happened a number of years ago where a judge told the mother that he wouldn't be sentencing her to see any jail time because, and I quote, "You've suffered enough." You know, raising her kid. Whom she had then killed.

So we have, again, really pushed for these cases to be treated like other filicide cases. They should be treated that way by the press, they should be treated that way by courts. And we have seen a number of improvements in that as well. We were really involved in the trial for [inaudible]. She tried to murder her daughter and her daughter actually survived. It was an extremely high-

profile case. And it was horrific, but we were able to get--we went to the prosecution, and they were able to get an equitable sentence from another murder case, which was also very well publicized. There we saw major improvement in how the media covered this case, focusing much more on the kid and on how she was loved, she was--she had value and then [inaudible 00:09:24] commensurate [inaudible] other mother.

So we've seen improvements like this. This is a cultural event that we organize, but it has led to concrete changes in terms of media coverage and in terms of policy. And it's something that had a very small start but it was, again, very significant.

[Disability Day of Mourning] was also frequently used to paint ASAN culturally as anti-parent. Which again--we do not believe that if we criticize the parents of disabled people who murder their children, that we are criticizing the vast majority of Autistic parents. We do not believe that this is actually a common thing, or an understandable thing, or a thing that most humans contemplate. And we've gotten some support from different families--often not publicly, but they've reached out privately--and we've gotten some support, again, from other parents and family organizations who appreciate not being painted with that brush.

We also maintain the website, with the help of a volunteer, Disability Memorial, that has profiles of everybody who's on the list, and often links to coverage, and so forth.

FAIR PAY: THE FIGHT AGAINST SUBMINIMUM WAGE

JULIA BASCOM:

I think one of our first really big moments was in 2014--it's a moment that's burned into my memory because it was so fast and so intense. In the President's State of the Union at the beginning of 2014, he announced an executive order that all contractors working for the federal government would be paid at least \$10.10, or maybe it was \$10 an hour. This was a big deal, because a lot of federal contracts are with people with disabilities who are paid subminimum wage.

So, by chance--the way this stuff works is, the President gives his big speech to the nation, and then the next day, there are a bunch of phone calls with different White House officials, where they assemble a large group of community representatives, and they brief you on the speech and read out the highlights. We got invited to one of those, a phone call, and I think it was with Tom Perez, who was the Secretary of Labor at the time. He was going through the highlights, and he talked about the executive order for contractor pay; and Ari was able to get a question in, and he asked if that order would apply to workers with disabilities being paid subminimum wage. And the Secretary said, "We don't think we have the authority to do that," which was wrong.

And so, over the course of about a week, ASAN led a coalition of a few other disability organizations, including the National Federation for the Blind, the Collaboration [inaudible], which was a group of organizations [inaudible] people with significant intellectual disabilities, a few others. And we also did worked quite a bit with SEIU to convince the White House to change their mind.

So, our legal director, Sam, wrote a legal memo in, like, 52 hours, laying out that they did have the authority to do this, and here's how they could do it. We sent that off [inaudible] to the White House. We organized action [days], asking people to call in and write in, telling the

federal government to do the right thing. And we [inaudible] bombed the Secretary of Labor. So, he was on a bunch of talk shows and news shows for the next several days, promoting this executive order, and the other things the President outlined in his plan, so we found out when all off those were going to be, and we called in to all of them. It actually got to the point where--it was Ari, and it was a couple of other people who were doing these phone calls. And at one point, I remember Tom Perez saying, "Hi, Ari," because he recognized Ari's voice when he was calling in to ask the question.

We had a lot of press coverage--it was a very intense week--and at the end of the week, the Department of Labor announced that contractors who were earning subminimum wage would be included. It was very intense, and it was very exciting, and it was really the first time that I think we were able to sort of flex our muscles on that level and have that kind of impact.

And it's been sustainable. So, the Biden administration has an executive order now that contractors will be paid at least \$15 an hour, and they made sure to specify that it would include the workers we had been talking about, through certain federal programs, who were already included in the \$10.10 and are now included in the \$15.

THE SETTINGS RULE: HOME AND COMMUNITY-BASED SERVICES

JULIA BASCOM:

People with disabilities who are low-income who need support tools in the community get what's called home and community-based services, or HCBS, through Medicaid. These people also qualify for institutional services through Medicaid. A problem emerged, which was

that before 2014, before this regulation, there wasn't a federal definition as to what differentiated home and community-based services from institutional services. So, what we saw was a lot of people leaving institutions or being on waiting lists for services in the community for years and years and years because they didn't want to go into an institution, finally getting services in the community, and it being living in a group home with a bunch of other disabled people-- sometimes in a cluster of group homes--and they were spending their days at a sheltered workshop or at a day center. And they were just in smaller institutions. The quality of life in that setting, the experience in that setting, was really the same as it would be in an institutional setting.

But the providers and the state were getting Medicaid dollars that were marked for community services to provide these really institutional services. So, when President Obama was elected in 2009, there was a huge multi-agency effort that lasted for five years to write a regulation that said "these are the standards that home and community services have to meet. These are the things that distinguish HCBS from institutional settings. And that was called the HCBS Settings Rule.

We were really involved in the creation of that rule from the beginning. We had to get lots and lots of public comments, which we contributed to. We did a lot of behind-the-scenes work. We were actually commissioned by a federal agency to do one of our first reports ever, which we called "Keeping the Promise." It was a report we did about people with intellectual disabilities talking about what community really meant to them, and what principles should be in policy to make sure that people were actually living in the community. And that informed a lot of the regulation.

So, in 2014 this rule came out. We were really, really excited about it. It's not perfect--we did not get everything we wanted--but it sets really basic things in place that had never been in place before. So now, under this rule, for example, people have the right to lock their own doors. They have the right to eat when they're hungry, not when they're [inaudible] mealtimes are. They have a right to have visitors. They have a right to have visitors overnight. Really basic things--and if you don't have those things, you're definitely in an institution.

So, we submitted [inaudible] implementation on this rule, which means it should have been five years to transition services, because a lot of states needed to make a lot of changes and come into compliance. So that would have been 2019 when the rule became effective. The Trump administration pushed that back to 2022, so that means March of next year is when this rule will be effective. I really don't know--it's possible that Biden is going to push it back again. But we're still extremely focused on implementation.

We worked with a coalition of a lot of other disability rights organizations where we, like--every state has to submit these hundreds of pages plan about what they're changing and how they're changing it, and we [inaudible] the problems with the plan, we try to help advocate in individual states, [inaudible] states to push for things that are important [inaudible] questions that come up, or [inaudible]. It's just been a huge focus of work for us, and it's going to continue to be a focus of work for us in 2022, because that's when it actually [inaudible], there are going to be a lot of [inaudible] still that aren't truly compliant with the rule that need to be held accountable. And [inaudible] a very tangible way to make sure that people are getting the benefits they're supposed to be getting, that they're actually living in the community and spending [inaudible] living in the community.

It's also become a huge flashpoint for other advocates, mostly from autism organizations, a few holdouts among family members who have relatives with intellectual disabilities who support institutional models and who see this regulation as a threat and have really tried to undermine it or push it back or [inaudible] to comply. So, we see, actually, a lot of vitriol that was associated with the antivaccination movement when it was particularly strong, particularly focused on autism, has now sort of moved to opposition of this regulation, which has been an interesting shift.

SELF DETERMINATION AND SUPPORTED DECISION-MAKING

JULIA BASCOM:

The first guardianship case that we were ever asked to get involved in was actually an Autistic trans woman in Texas whose family got guardianship of her in order to prevent her from transitioning. So, we [inaudible].

In 2013, we got involved--we were involved in a case in Virginia, the Jenny Hatch case. Jenny Hatch is a woman with Down's syndrome who was suing to be released from a guardianship. It's very, very hard for anyone to [inaudible]. What Jenny was asking for was pretty much unprecedented. With a lot of work from some disability rights centers we were involved with, she won her case, which was incredible. And started this new wave in the United States around supported decision-making, which is an alternative to guardianship where people with disabilities--usually people with intellectual disabilities or mental-health disabilities--can still get help making decisions, but retain the final say. They make the final choice. So, it might

look like somebody who needs help understanding their options for medical decisions, for example, their doctors have permission to talk to their support people, their support people help make sure they understand the information, that they can process it, they might help them remember things. Their support person might help with communication back to the doctor. But the person with the disability is still making the medical decision, even if they're getting a lot of support.

This is something that didn't start in the U.S. It started about a decade before, mainly in Europe and Canada, and then the UN Convention on the Rights of Persons With Disabilities identified guardianship as a human rights issue. And so different countries started experimenting with supported decision-making models, with Canada being the first [inaudible] United States. After that trial, which we put out statements on and watched very closely, we got really involved with a group of disability rights organizations in the United States who really wanted to figure out, "How can we [inaudible] this?" We were subcontractors on a federal grant [inaudible] to create a national center for supported decision-making and provided technical assistance to different [inaudible] who wanted to try this, and helped craft model legislation that's actually been implemented in several different states to formally recognize supported decision-making. We put out toolkits for self-advocates about alternatives to guardianship [inaudible] American Bar Association [inaudible]. We've done just a ton of work on getting folks out of guardianship and [inaudible]. I think that and community living have probably been our two biggest policy issues over the past ten years.

We've gotten really focused now on how to [inaudible] folks who are at the heart of [inaudible]. So, Jenny, you know--Jenny could talk, Jenny had lived independently before her guardianship. It was relatively easy to demonstrate that Jenny could make her own choices. It's

harder to demonstrate that when someone doesn't have a reliable way to communicate, when someone's never been given a chance to make their own choices before, when someone has a disability that means that their needs and their preferences can change drastically from day to day, they have really serious memory issues. It's still doable; it just requires more specialized support, and it can be harder to get other people on board. [inaudible] on how to expand supported decision-making to really account for everybody. We haven't figured out what to do about people who are in comas yet, but we think [inaudible] everybody up to that point. It's just going to take a lot of time and a lot of effort.

We submitted an amicus brief in Britney Spears' court case, talking about supported decision-making. It's been a big year for that. But I think that's another [inaudible] involved in.

SHAPING PRESIDENTIAL PLATFORMS

JULIA BASCOM:

2016 was really the first time we were ever asked to consult with a campaign on their autism plan. We were asked to give input on the Clinton campaign's autism plan, which was exciting because [inaudible] very bad. And so we were able to shape things within that plan and include a lot of things, like a focus on [inaudible] and competitive [inaudible] employment and other very positive things, as opposed to just more and more ABA for everybody.

And then we had to figure out to what extent we were doing this as ASAN, as opposed to what extent I'm doing this as Julia, a private citizen, and negotiate some of the legal stuff there. But we can do it as ASAN [inaudible]. And then in 2020 we had a number of different

presidential campaigns [inaudible] specifically on disability plans, broadly, which was really, really exciting. We gave a lot of advice to the Warren campaign, the Klobuchar campaign, to [inaudible] when he was running, to the Biden campaign, and I know I'm forgetting a couple. And through that, we actually saw for the first time--

I should say--it wasn't just ASAN being asked to give input, but it was significant that ASAN was included in the disability organizations being asked to give input. It was the first time that we actually saw campaigns that were competing for the disability vote, which had really never happened before, and multiple campaigns coming out with disability plans, which was really good to see. Hillary Clinton had a disability plan in 2016, in addition to an autism plan. I believe President Obama had a small plan when he ran in 2008 that focused on disabilities. Not much before that. This past year, we had many different candidates with disability plans competing.

And it was cool because--obviously a lot of presidential platforms never actually come to fruition because so much depends on congressional action. But it's a way to articulate a vision and set a standard for what our community expects, and it's important that the disability community gets the same kind of consideration that other communities get, and the same kind of attention. We are able to use those conversations once the president is elected to hold them accountable, to drive engagement with them, to introduce them to our policy priorities, which hopefully they've already considered, and then to work with the different federal agencies implementing those priorities. So that was very significant.

FIGHTING FOR OUR LIVES: PROTECTING THE AFFORDABLE CARE ACT

JULIA BASCOM:

In 2017, a lot of different things happened sort of all at once. The Trump presidency began, which was a very scary time for any marginalized community, any organization representing a marginalized community, any civil rights organization. I became the executive director of ASAN at the very end of 2016, and the Republican-controlled congress immediately started trying to repeal the Affordable Care Act. And not only repeal the Affordable Care Act, but [inaudible] Medicaid, which would have just destroyed the program. And these are extremely significant programs for people with disabilities.

Obviously the Affordable Care Act protects [inaudible] a huge deal for the Autistic community, and it's very difficult not to include that in their medical records, even though it can be very relevant for a doctor to know, because [inaudible] insurance company. Autistic people also tend to have co-occurring mental health and medical conditions, so, it's a huge deal for us and for the disability community in general. And then so many Autistic people, especially because people with disabilities are so much more likely to live in poverty, and if you depend on benefits such as home and community-based services, you have to live in poverty, at least if you have Medicaid, which is a health-insurance program for people who live in poverty, so people with disabilities are much more likely to use Medicaid than other people. And so the threats to that program were absolutely overwhelming, especially because they were talking about cutting significant Medicaid funding [inaudible]. And home and community-based services for people with disabilities are what's called "optional services." They aren't required to provide them. Every state does provide some of them in some form, but they don't have to. They can stop providing them. They are not optional services for people with disabilities--they are life-and-

death essential services, but there was an extremely high likelihood that if Medicaid funding was cut so drastically, many states would stop covering home and community-based services, which would result in increased institutionalization and increased death for disabled people. So this combination of policies was just an enormous existential threat to our community, and [inaudible] poured this unprecedented amount of organizational energy into fighting this. That year is a blur.

We did our first sort of comprehensive easy-read toolkits, one about the Affordable Care Act and one about Medicaid, so that our grassroots could understand what was going on. This was particularly an issue with Medicaid, because every state calls their program something different. And because the services that people get are often called waiver services, and so people would hear the news and say, “I don’t get Medicaid. I get PennCare,” or, “That doesn’t matter for me; I’m on a waiver.” And those are the programs that are being talked about, so we really needed people to understand that this was about them [inaudible] what was going to happen.

I spent most of my time most days doing congressional office visits with other disability-rights advocates, just saying over and over again, “This is what will happen. These are the choices that you’re making. These are the people you’re going to hurt. This is what life was like before the ACA; this is what life is like when people don’t get Medicaid. Don’t do this.”

We built a whole sort of grassroots operation that we hadn’t had before. We invented something that we called “proxy calling,” which is--we had a lot of Autistic people write, who can’t use phones either because they use a speech-generating device and if people get a call from them they think it’s a robocall so they hang up; or because they have phone anxiety, or--auditory processing, or just, communication on the phone is harder. And unfortunately, the reality is,

phone calls to elected officials still matter more than emails, and they matter a lot more than tweets. We needed people to make phone calls, but it wasn't accessible for a lot of our folks, so we also had a lot of non-Autistic allies asking how they could help. So we developed a matching system where people can sign up to be volunteers, and Autistic people can write the messages that they want read to their elected officials' office for a certain campaign; and then the volunteer calls in, identifies themselves as a volunteer, and reads that message, so it still functions as a phone call.

It was an enormous amount of energy and work. And it worked. And it really wasn't supposed to work. It was just this massive effort from the disability community, from lots of different marginalized communities, to stop what was supposed to be a done deal, and what for all reasons should have been a done deal. There's really no reason this bill shouldn't have passed, [inaudible]. But it didn't, and the fact that it didn't made a lot of other things that the Trump congress and the Trump administration wanted to do harder. It showed people that we were more powerful than we had thought. It really put the disability community on the radar of other civil rights communities in a way that I don't think we'd been since the passage of the Americans with Disabilities Act, which was important to us in terms of having [inaudible] and the tables we got invited to, the [inaudible] we were able to be a part of, it created some of that change that we talked about in terms of 2020 campaigns taking us more seriously.

From a policy perspective, it also meant that basically after we spent all of 2017 working on stopping ACA repeal, there were several different Democratic congressional offices that wanted to introduce different versions of universal healthcare. And so ASAN, with a handful of other disability-rights groups, went to those offices, and said, "We think we've set an expectation that whenever health [inaudible] happens, it has to be inclusive of disabled people. So we would

like to review these bills and be involved in their drafting and give input to make sure disabled people are included. That's number one. Number two, any expansion of healthcare needs to include an expansion of home and community-based services. Because Medicaid was such a huge part of the issue [inaudible] because Medicaid is the only payer of these services and because it's such an inadequate system and we have so much unmet need. This needs to be addressed just like other forms of healthcare that are not being adequately met.”

And so we had input into the Medicare for All bill that was introduced in the Senate, and the one that was introduced in the House, as well as the Medicare for America, which was a very similar bill that was introduced in the House, and a couple of other [inaudible]. So, we did that work in 2018. We did it again in 2020, because, remember, Congress turns over every two years, so we reintroduced it in 2020. We did it again. And by that point, we'd spent a lot of time working with these offices, writing bills about [inaudible] for the home and community-based services provisions. So we also drafted a bill called the Home and Community-Based Services Access Act, or HAA, which was introduced as a draft bill this past March by Representative [inaudible] and Senators Warren, Casey, and Brown, and [inaudible]. And this is a bill that would basically vastly improve the Medicaid system for home and community-based services and would make these services much easier to get and much higher-quality. And that's a major legislative focus. We got some important home and community-based services provisions in the Build Back Better Act, which we're still pushing for.

As a result of all that work, that'll help lay the groundwork, and then we'll return to getting this bill that we drafted through Congress. It's going to take a number of years. But all of that work builds on itself, builds on the relationships and credibility we established and then the ideas that we tested and then [inaudible]. And that system [inaudible] supported decision-

making. None of the things that we talk about that relate to inclusion or self-determination or just good lives [inaudible] is possible without the right support. What we've seen, forty years after the passage of the ADA, is that many, many promises of the ADA have not been realized for people who require support because the services [inaudible] isn't what it's supposed to be. So these are major areas [inaudible] at this time.

AWARENESS TO ACCEPTANCE: CHANGING THE CONVERSATION

JULIA BASCOM:

I think it's very hard for people to admit when they were wrong or that they've harmed people that they're supposed to represent. I also, in the sort of disability space broadly, and I guess when I say that I'm talking, I think, mostly about intellectual disability and I'm talking about, again, parents, educators, professionals, not so much self-advocates. But in that space where there's been a lot of momentum towards inclusion, you still see a much bigger focus on focusing on points of agreement and trying to increase best practices and inclusion, which is good, and much more hesitancy to denounce bad things, to take a stance against segregation. Like if you look at, for example, the work to end subminimum wage. In disability, a lot of organizations, like ASAN, like Self-Advocates Becoming Empowered, which is the national self-advocacy organization of people with intellectual disabilities, and the National Federation for the Blind, groups like that, we are very focused-- Like, we will say we want to abolish subminimum wage. We want to close sheltered workshops. And yes, we would also like to increase competitive, integrated employment, people being paid fairly and working integrated

jobs, but our main goal, and something that we think is an important and rewarding fight in and of itself, is ending a dehumanizing and exploitative practice of [inaudible] people with disabilities and paying them subminimum wage. In groups that are also fighting to increase competitive integrated employment, like The Arc, like the Autism Society of America, for example--for them this is very different. They talk about increasing competitive integrated employment. They might support bills that technically would abolish subminimum wage, but they're very focused on making sure that those bills increase resources to scale competitive integrated employment, and to help sheltered workshop provider change their practices. And that's not a bad thing, but it's a very different focus. And I've had some really blunt conversations with some leaders from those organizations when we've been working on coalition language and ASAN has included language about ending subminimum wage, who have said, well, we don't really use that language. It's really divisive. If we increase the minimum, if we increase competitive integrated employment, we're going to achieve that anyway. Why would we make that a point in and of itself?

And I think that overall approach... Sometimes we're meeting with folks who have really strong values and who we're aligned with on a lot of different policy issues, it's still a focus on, again, "how can we increase good things?" And not so much a willingness to drop all these bad things or to take a strong, moral stance against those things. And I think that culture then permeates and impacts how organizations deal with the fact that their own practices need to change. That they haven't included self-advocates meaningfully, that they have done things that have harmed Autistic people. We have seen some progress and increase in self-advocate involvement at the board level, at a staff level, on advisory committees and things like that. But there's a real

resistance to acknowledging that there's a problem that needs to be addressed or that these changes are good. That there are changes, which means that the past is not so good.

And I think this is particularly important when we're talking about Autism Speaks. So, the Autism Speaks of today is different from the Autism Speaks of 2006. They still advance a lot of really harmful research and policy priorities. They're still very, very, very strong supportive of ABA, which is very, very harmful to Autistic people. But they have changed their aesthetics so much and changed their language so much, and they have watered down some of their original stances. And it makes it much harder for ASAN to refuse to work for them. We still do, but we face a lot of pressure from other organizations for taking that stance. They don't understand what we're so upset about.

And one of the issues that I think the self-advocacy community broadly, not ASAN, but if I'm looking at Autistic Twitter and things like that, one of the huge issues is that Autism Speaks has never apologized. They've never acknowledged the fundraising video they had where their vice president at the time [inaudible 00:30:55] talked about fantasizing about killing her Autistic daughter, and that the only reason she did it was that she had this nondisabled daughter she needed to live with. And she talked about that in this video while her Autistic child was in those room. That's abhorrent. They've taken that video down, but they've never acknowledged that that was wrong. They've never apologized for that. And that's just one example out of dozens. And I think that, so long as that continues, even if Autism Speaks was to completely update their position statement and abandon their support for ABA, I don't think that would change the relationship to the self-advocacy community because those wounds are so deep.

I think other autism organizations don't necessarily face that level of bad blood and just historical horror, but they have that same unwillingness to acknowledge that there might have been issues in the past, or even that there could be issues now and areas for them to improve.

JULIA BASCOM:

I think another cultural victory was that we saw that in 2015, Autism Speaks appointed two Autistic board members. And then in 2016, they updated their mission and removed the word “cure” from it. And these are very aesthetic changes. Like I want to be really, really clear about that. And they don't reflect a change in terms of the research that Autism Speaks funds, or the policy priorities that they advocate for, legislatively. It doesn't change their focus on ABA, doesn't change the beliefs that they actually have about autism. But it does reflect the mounting quantity of pressure they feel as self-advocates and ASAN have changed the conversation about autism out there. So now if you go on the Autism Speaks website, the language they use to talk about autism is very, very different from what it was 10 years ago. They talk about neurodiversity, which is a little bit infuriating, but they do use that language. They don't talk about curing your child or helping your child become indistinguishable from their peers, they talking about helping your child become the best that they can be. Which again, what they mean by that, is the way to do that is sending your child to ABA. So the underlying things that they do haven't changed, but they felt that pressure to change their language and to change the aesthetics.

And it's frustrating, because what we'd like to see is actual substantive change. And until we see that kind of substantive change ASAN's relationship with Autism Speaks is going to remain as it is. An [inaudible] relationship. But I think that it indicates that we're able to exert the kind of pressure that we were before, where even if we can't get the substantive changes, we

can still change what's acceptable to say about Autistic people. And that's a really important thing. That's the first step towards the kind of substantive change that we want.

We had an early, I think, harbinger of that when the Combating Autism Act was being authorized in 2014. This is the bill that authorizes federal autism research spending, most of which goes towards researching the causation of autism and potential ways to either prevent Autistic people from existing or to explore [inaudible 00:13:44] treatments to remove autistic traits. Self-advocates have voiced our ethical concern, which is that the aims and the results of this bill... I don't know if self-advocates really deliberately--it's not just ASAN.

But ASAN has been able to achieve very small, often largely symbolic, but important changes to this bill and the first success that we saw, really, was in 2014 when it was up for reauthorization. And we were able to change the name from the Combating Autism Act to the Autism CARES Act. I am looking up what Autism CARES stands for. It stands for Autism Collaboration, Accountability, Research, Education, and Support. Which is nonsense, but it does mean that the federal government is no longer officially in the position of combating autism, which we saw as an important change. In the last reauthorization, in 2019, we weren't able to achieve policy changes in terms of the overall balance of research spending, but we were able to secure more self-advocate representation on the governing body that oversees that research spending, which we thought was very important, and we were able to get a special research project commission to focus on autism and health and wellbeing.

So, they were very small changes every time. We would like them to be bigger changes, but we see it as a way for us to build power and also to test how much power our grassroots had built. And when I say "building power," I don't mean as an end in and of itself, but towards ultimately having enough power and having enough influence and changing attitudes about

autism enough that we can change the substance of the bill. I think we get closer every authorization, although we still have a long way to go. And again, that sort of symbolic change that we secured in 2014, in changing the name, that made it harder for Autism Speaks to continue using the language they were using. And they really opposed that change to the name. It was a really bloody, awful, difficult fight because they knew that it was signaling a cultural change and that that was going to make things harder for them. And it has.

JULIA BASCOM:

This year was the 10th anniversary of Autism Acceptance Month, which was started at ASAN 10 years ago. And a really interesting thing happened this past year, which was that the Autism Society of America, who heavily criticized ASAN when we came out with the autism acceptance language--said it was anti-parent, said it was offensive for people who had members with significant disabilities. We invited them to be a part of updating their language and everything else, and they were not about that.

But this year, I had a bizarre conversation with the president of the Autism Society who told me they were doing a whole new rebranding effort around Autism Month, and they were shifting to Autism Acceptance, and had I heard about this? They thought it was really, really important. They thought it would be much more positive and much more in line with the values that they wanted to espouse; and I had to explain to him that, yes, I was very familiar with it. It was our idea. It would be nice to see self-advocates being credited for that. And if you look at their material, they very much bring it as something that the Autism Society came up with. Which is very, very frustrating on a personal level. But, also again, I think it's a reflection of how we've changed that cultural conversation. How we've changed the language that is acceptable to

use about autism and the gains that we've seen in moving away from this awareness mindset, which is really focused on the idea of autism as this scary thing that you need to be aware of and keep track of and it's going up and we don't know why. And more towards valuing and including Autistic people.

We put out a statement on Autism Acceptance Day, this past year, recognizing the 10th anniversary, acknowledging the history of Autism Acceptance Month, and calling on autism organizations to change, not just the language that they use when they talk about autism, which we think is important, but also the policies that they advocate for and the practices that they employ.

So we're very glad to see these aesthetic and symbolic changes happen. We think they're important. We think they reflect real progress. We think they do influence how people think and how broader society and the messages that society shares about autism. But the work isn't done until autism organizations have policies that reflect that affirming language. Policies that focus on inclusion, that advance the lives of people of disabilities. Until they have practices that include self-advocate leadership and meaningful self-advocate input and direction into what the organization does. We still don't have the Autism Society, for example, as a participant in [inaudible]. They're not interested. So it's been back and forth and I think it's been slow progress, but it has been progress. And we have seen the little changes, even though those changes are insufficient. But I think they represent real traction and real movement.

JULIA BASCOM:

The United Nations has a couple of different observances organized by different parts of the UN. World Autism Day. And several years ago, we were contacted by one of those groups,

the groups that really focuses on the Convention on the Rights of Persons with Disabilities and they asked us to help them plan their annual observances. So every year we work with them. We advise on the theme that they're picking and they always try to pick a theme that ties through the Convention on the Rights of Persons with Disabilities, which we think is really good. We think that whenever we can tie autism to disability rights more broadly, we tend to be in safer territory because of some of that stuff I talked about earlier about where the disability rights movement is in comparison to the sort of broader autism community.

And because again, when we have a disability rights focus, they're much more likely to talk about things like an Autistic person's right to access education or communication or employment, as opposed to, "Why are the numbers going up? Autism is so scary. How can we prevent Autistic people from existing?" And we'd rather have that productive focus.

In 2018 we'd been invited, before, in previous years, to speak on panels at this event. And we'd also helped coordinate finding a lot of different speakers for these panels. In 2018, I was invited to address the UN in a speech about women and girls and autism. And the focus that year was on gender equality in the context of autism. And that was a pretty significant event in terms of it... It's certainly not the first time an Autistic person had spoken before the UN, but there hadn't been an address quite like that. That got a lot of attention, and, again, really drove some cultural conversations about autism in a different light, which I thought was really, really positive.

And since then, we've continued, not to address the UN, but to work with that group to coordinate themes and speakers and what the panel should focus on, and so on and so forth. And we've tried to focus on making sure that they're recruiting more diverse people for speakers, that they've got speakers who [inaudible 00:19:29] have [inaudible], speakers who are people of color, who are [inaudible 00:20:13], who are LGBT, et cetera, et cetera, et cetera. So I think

that's been really positive. One point of tension has been that the ASAN talks about autism acceptance, and autism acceptance goals, and Autism Acceptance Month. And the UN, traditionally, have used the awareness language from Autism Speaks and other autism organizations. Now, I think, they sort of use both, which we refer to the middle stage before an organization gives that amendment to acceptance language. So, as a compromise, we actually end up just calling it World Autism Day at the UN, which, I think, they've been using.

TOOLS FOR EVERYONE: INTRODUCING EASY-READ

JULIA BASCOM:

Working on easy-read materials is very much something that I wanted to do since I got to ASAN, and I think we sort of approximated it for a lot of years. We had to get the staff people in place first to actually be able to write long materials at the right level--and that just takes a lot of time--and then do the [inaudible] and initial supports, which takes even more time and real skill. So we have some products that you can probably still find on our website if you search, from 2013-2014 that say that they're plain language--and they're definitely an attempt at that, but they're not written in what we'd consider plain language now.

We still can't do everything we produce in plain language or easy-read, because we just don't have the time and we just don't have the staff capacity, but we're working towards that. I think potentially [inaudible] is that especially in our early days, ASAN, I think, got a lot of credibility in the policy circles we worked in by sounding like everybody else in those policy circles: using the right jargon, striking a very professional and academic tone, showing that we

could do that kind of work. And we still use that language, we can still do that kind of work. In easy-read, because the language is so much simpler, sometimes it can feel like it's [intention] without professionalism. And it's not, really. But sometimes, if we're putting out a statement for Congress or writing a letter to a federal agency, we have to code switch, we have to use that kind of language. And the issue is that we don't necessarily have the staff resources to then translate that into easy-read to have both versions available.

So, ideally, we'd do everything [inaudible] into easy-read. We just need a little more staff capacity for that, but I think we're getting closer. But then we're still dealing with this reality where some materials still have to code switch and be in the right register in order for them to be taken seriously by [inaudible] people. So, we're still trying to reach our goal there.

TOMORROW'S LEADERS: FROM CAMPUS INCLUSION TO PUBLIC OFFICE

JULIA BASCOM:

There's the Autism Campus Inclusion Leadership Academy that we run every summer. It's a week-long training for Autistic college students who want to do advocacy on their campuses around disability rights. It's a basic community organizing training--there's not a ton of special content. We talk about the history of the self-advocacy movement and some disability history, but most of the stuff is what you would find at any community-organizing leadership development program for students from a marginalized group. But we've made a lot of adaptations for accessibility. Often our students couldn't necessarily attend those other trainings

because they wouldn't be accessible, because they would expect students to mask or to use speech, or they would have [inaudible]. It's a really cool training. The feedback we get from the students is like, "Yeah, the training's great, I learned a lot, but my favorite part was spending a bunch of time with other Autistic people and building that community." Often those students are having, for the first time, an experience where they weren't alone and they weren't being pathologized.

And then after that week-long training, we provide follow-along technical assistance and mentoring to those students while they're in college and afterwards if they want to stay involved with us; and we have a Facebook group and an online community where they can support each other. And we see [inaudible] things come from members of that program, like groups being started on campus, policy being changed, students running for office, students bringing self-advocacy skills to wherever they move on to in their careers.

We take that slogan "Nothing about us without us" very seriously. But we also think that that doesn't mean just sort of throwing an Autistic person in the room and being like, "Okay, represent the community." People need support. People need the right skills and the right information for whatever situation they're being placed in. Otherwise, it's just tokenism. And so we're very [inaudible] whether it's through [inaudible], whether it's through ACI, making sure people have that information and have those skills so they can truly not just be present, but lead the conversation and have an active role.

...

With ACI, we reach a lot of Autistic students, which is really exciting. We're trying to get more students with intellectual disabilities who are in different college programs for students with intellectual disabilities and to get more nonspeaking college students, who are attending

college more and more. But those numbers are still lower. And [our funder] still really wants us to focus on college students, so we're kind of constrained by that. We're trying to get more students of color to participate in the program, and we've been more successful there. So, we're still trying to perfect what we're doing and live up to our core values [inaudible] and that's still an ongoing process.

JULIA BASCOM:

Jess[ica Benham] was a participant in our Autism Campus Inclusion Project several years ago, I think in either 2015 or 2016. And she went on to found the Pittsburgh Center for Autistic Advocacy, which is, I think, our strongest affiliate group. They do really amazing things for the local Autistic community in Pittsburgh. And then, in 2020, she ran for state representative. So, in the Pennsylvania state legislature. And she was elected.

She's not the first openly Autistic person to serve in a state legislature, although there are only a couple before her. But she was the first to run for her first race openly Autistic. She had chaired our board in 2020, she had to step off our board after she won her election. And she just gives me so much hope for the future that someone we had worked with could go on to become an elected official herself. Obviously her policy positions are really sound. She's always been really conscious and really deliberate, when she talks about her autism diagnosis and her Autistic identity, about how she wants to see more and more Autistic people and people with disabilities being able to be open about who they are and run and [inaudible 00:41:35].

We've seen a couple of other [inaudible 00:41:37]. [inaudible 00:41:59] move, and she served in the New York state assembly. And after she had won her election, a few years ago, she

came out about her Autistic identity and it's, again, it's been incredible to watch her. She also does really great work and is really impacted by her constituents. And just like Jess, she takes a very intersectional approach to policy making and very much focuses on how any given policy impacts a whole wide range of different marginalized communities. We've seen a couple of Autistic people run for school board, we've seen at least two people win their school board races. We helped one person who then had to sue the school board because they wouldn't give really basic accommodations.

It's just the start, and I think this is a really exciting new chapter for our community. And we're really trying to think about how we can support this, how we can encourage this. And also how we would deal with self-advocates running who might have really dangerous policy positions, because the Autistic community, just like the disability community, has a wide range of political positioning and ideological positioning. And it's not unheard of, just like with any community, to have an Autistic person who has beliefs that will harm our community. And I'm not talking about wanting to use person-first language or little things like that, but like wanting to cut Medicaid, that kind of thing. So that will also be a problem for us to think about in the future. But it's really exciting to see more and more Autistic folks taking that stand of Nothing About Us Without Us and bringing it to the halls of power.

LOOKING FORWARD: THE FUTURE OF ASAN

JULIA BASCOM:

I'm very focused, I think, I've passed that [inaudible 00:32:28] on increasing access to home and community-based services. Whether that's through regulation, whether that's through trying to pass this goddamn, Build Back Better Act, which is just [inaudible 00:32:48] so much energy. And the investment is so much smaller than it was originally, but it's still the largest ever federal investment in expanding home and community-based services. So we're very focused on getting that through the senate, and then on implementation and looking at how they use that money. The next step then would be the HCBS Access Act, which would just really change how Medicaid works with regards to these services, and make them available to many more people. That's a huge focus of ours. The work on supported decision making, again, remains a very significant focus and on access to communication for Autistic people who can't rely on speech. [inaudible 00:33:39].

We've got things that we're looking at around ending restraint and seclusion in schools, ending subminimum wage. We've got a focus on making sure that we're explicitly integrating racial equity into all of our policy and our programmatic work, which is something that we've cared about before, but I don't think we've always been as deliberate and systematic about it as we could be. So we've been working on a project for the last couple of years to just literally make sure that, at every decision point that we face as an organization on a daily or weekly or yearly basis, that we're really looking at that closely and making sure that that's reflected. In some areas, we've gotten more involved in the work around the criminal justice system and around police violence and mass incarceration.

We still do a lot of work around trying to shift the balance of research funding and making sure that Autistic people have a much greater say in terms of what research has done about us, what therapies are practiced on us. To let self-advocates have the [inaudible 00:34:59]

in conversations about autism. And then we're really focused on building our grassroots and making sure that our members have access to information they can understand. They have access to tools, to support their civic engagement, and to support their leadership and their ability to organize locally and on a state level, as well as their ability to participate in big national campaigns so that we can actually shift some of these conversations when they happen on Capital Hill.

We're still in this fight with the Judge Rotenberg Center to get to end the electric shock that they use. So the FDA approved the ban on that, it was a huge victory. And then the Judge Rotenberg Center sued and the FDA lost in court. They just had a last ditch appeal offer and they just lost it, like we just [inaudible 00:35:52] this week about it. So now we have to work with FDA to reissue an updated ban that should comply with the court and also [inaudible 00:35:59] a number of different legislative [inaudible 00:35:59]. And that's another matter, actually, we've been working on this for so long and it's so soul-destroying and it's absurd that we have to talk about this at all.

And it's such a good illustration of what our society believes about people who have significant disabilities. And to what extent elected officials, the court, regulators, that really [inaudible 00:36:39] all different actors who aren't necessarily a part of the disability community. And some members of the disability community are willing to let evil happen instead of taking a strong stance about this and saying, this is obviously wrong. So we'd really like to finish that work. And then we've always tried to be really clear about this in terms of our statements about the Judge Rotenberg Center, even when a ban is finally, fully, permanently implemented, our work isn't done until that center is closed and tons of survivors have the support they need to live good lives in the community, and then care institutions everywhere are closed. No other

institution does quite like the Judge Rotenberg Center does, but every institution is a horrific place to live and plenty of them abuse disabled people in very literal and very physical ways.