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Autism, advocacy organizations, and past injustice

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Abstract

Fruitful connections can be made between Disability Studies and post-conflict transitional justice, two areas of scholarship concerned with human rights and the impacts of violence that have rarely been brought into critical dialogue with one another. For over a decade, one of the world's largest and best-known autism organizations, the US-based Autism Speaks, has been subject to criticisms and boycotts by autistic self-advocates and their allies. This article describes the forms of harm attributed to the organization, arguing that these harms can be viewed through the lens of what transitional justice scholar Jill Stauffer calls "ethical loneliness": "the experience of being abandoned by humanity compounded by the experience of not being heard" (2015b, 1). I argue that Autism Speaks's recent reforms and responses to criticism, in focusing largely on present-day organizational policies and structures, fail to grasp the full temporal dimensions of ethical loneliness or the importance of addressing past injustice.

Introduction

This article explores how past injustice informs contemporary politics in the U.S. autism advocacy landscape, focusing on the longstanding conflict between the organization Autism Speaks, on one side, and autistic self-advocates and their allies, on the other. Theories related to post-conflict "transitional justice" offer insights into claims of harm made by some autistic individuals and communities against Autism Speaks, and the failure of the organization's recent conciliatory measures to help it gain legitimacy with its critics or promote meaningful reconciliation.

To speak of autism and past injustice is to call forth a long legacy including stigmatization, abandonment in abusive institutions, lack of access to education, and "therapies"—many of them still common today—that punish and injure autistic people in the name of behavioral "correction." This article's focus is on a seemingly more banal, yet still painful, piece of autism history: the division between traditional autism organizations founded by parents and caregivers and the growing autism rights/neurodiversity movement. There is no more contentious example of that rupture than the decade-plus history of the largest US-based autism research and advocacy organization, Autism Speaks.

While there are multiple reasons why Autism Speaks has this emblematic status, many of them can be summarized in the fact that the organization has long promoted and been identified with what is called a "medical model" of disability as it applies to understandings of autism. In the medical model, autism is defined as an illness or disorder rather than a difference (see Michigan Disability Rights Coalition 2017); thus, the purpose of autism advocacy is to find ways of "treating" autistic people (by making their behavior more closely resemble that of neurotypical peers) and ultimately cure autism itself. This medicalized understanding of autism, and the way it has long driven the organizational priorities of parent-founded groups such as Autism Speaks, is the subject of sustained criticism and activism by autism rights activists and members of the neurodiversity movement, who argue for accepting autism as a natural form of human difference along the lines of race, gender, or sexuality, and thus fighting for inclusion, equal rights, and public policies that better serve people of many abilities, rather than seeking a cure (see Orsini and Smith 2010; Silberman 2015). These perspectives are in line with a "social model" of autism and other disabilities, elegantly summarized by autistic researcher Richard Woods (2017): "The primary goal of the social model has always been to take the focus from the individual impairment, and to shift the gaze towards societal structures" (2017, 1094).

While the tension between medical and social models of disability impacts many different spheres of disability advocacy (see Waltz 2012, 220-222), opposition to Autism Speaks is distinct in both its scope and its centrality to the autism rights movement. Well-known autistic author John Elder Robison, upon resigning from Autism Speaks' Scientific Advisory Board in 2013, wrote, "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. […] No one says the Cancer Society does not speak for them. No one describes the Cystic Fibrosis Foundation as an evil organization. All that and more is said of Autism Speaks every day." Robison may overstate the case somewhat; other high-profile disability organizations, especially those working through a "charity" framework, have been criticized for chasing cures rather than using their influence and funding to support other ways of making disabled people's lives better and increasing their access to public spaces and institutions (see Weiner 2011). Yet these divisions in the autism world stand out for not only the depth of feeling that Robison underscores, but also the breadth of issues they touch upon—including everything from the terminology used to describe autistic people, 1 to specific interventions such as Applied Behavior Analysis (discussed below), to fundraising and scientific agenda-setting. As autistic activist Larkin Parker-Taylor (2017) describes, opposition to Autism Speaks—especially during the month of April, when the organization engages in major fundraising campaigns to mark Autism Awareness Month (which neurodiversity advocates celebrate, in a form of counter-demonstration, as Autism Acceptance Month)—has become its own tradition in the autistic self-advocacy community, and thus part of the way that community remembers itself and reproduces a culture.

Robison's invocation of the concept of legitimacy is highly significant. Critics regard Autism Speaks not simply as engaging in problematic forms of advocacy, but as fundamentally illegitimate—unfit to speak about autism or for autistic people, and unworthy of funding or support. The specter of illegitimacy connects Autism Speaks to the predicament often facing regimes after episodes of authoritarianism and state-sponsored violence, since one of the central questions of transitional justice is how states can reestablish their (democratic) legitimacy after mass violence. Stephen Winter writes, "a broad spectrum of transitional justice practice embodies legitimating values. These connections are how transitional justice responds to the corrosion of political legitimacy by authorized wrongdoing" (2013, 237).

The controversy surrounding Autism Speaks is bound up with a particular institution's claim to legitimacy amongst the constituents it publicly represents, and how that legitimacy is still "corroded" by past injustices. Transitional justice concepts and scholarship offers useful tools for thinking about the relationship between past injustice and present legitimacy. While some might object to the implied comparison between Autism Speaks' policies and the state crimes most associated with the transitional justice literature (such as genocide, torture, and enforced disappearance), as I will show below, an understanding of these policies as embedded within a history of violence against autistic people—even though Autism Speaks is far from solely responsible for that history—is part of what is at stake for many of the organization's critics.

Transitional justice can be used to indicate a specific set of political and juridical practices, as in Winter's description above. Some examples of these practices are war crimes tribunals, truth commissions, reparations, and official apologies. But transitional justice can also be a way of understanding the relationship between justice and temporality, indicating transformative moments when the present and future hinge, even more than in "normal" times, on grappling with the past (Teitel 2002). In bringing a transitional justice lens to autism's politics, this article looks beyond the specific contexts and practices that have usually defined the field, such as genocide, mass violence, and the dilemmas of war crimes tribunals and truth commissions. It draws on philosopher Jill Stauffer's exploration of the myriad experiences of those who suffer grave injuries and then seek, often against great obstacles, to have those experiences recognized by a wider public. Stauffer joins these temporally separate experiences of harm—the initial injury, and the subsequent struggle for hearing and recognition—into a single concept, "ethical loneliness." She defines ethical loneliness as "the experience of having been abandoned by humanity combined with the experience of not being heard" (2015b, 1).

Ethical loneliness is particularly useful in understanding the Autism Speaks controversy because, unlike much transitional justice discourse, it does not depend upon a shared understanding that there is a clear break between a violent or troubled past and a stable, reparative present. Rather, it allows for more complex continuities and discontinuities, and even for the possibility that people's experiences of harm and marginalization impact what they experience as "past" versus "present." The relationship between time, injury, and personal or institutional conceptions of justice will be central to my analysis of Autism Speaks' conciliatory strategies and their failures. I argue that Autism Speaks assumes a distinction between past and present, and thus the potential to move forward into a future that is imagined as less divisive, without recognizing just how "present" the organization's harms still are to many autistic people. These differences play out not only in divergent discourses but also in concrete practices, such as the organization's deleting controversial videos and fundraising appeals from its website without any comment or apology (thus reinforcing the sense that it wishes to mark off parts of its past as distinct and distant), and autistic advocates' archiving and reposting of those same materials (reinserting the "past" into the unresolved present). Furthermore, Stauffer's decision to use the term "loneliness" in describing what it feels like not to be heard by an institution or the "surrounding society" (Stauffer 2015b, 29-33)—as opposed to other possibilities, such as frustration or marginalization—opens up a new and productively ironic possibility for scholarship about autism. The persistent trope of autistic people as "loners"—which one book of writings by autistic people refers to as "the myth of the person alone" (Biklen et al. 2005)—can be transformed into questions about a different, more politicized conception of loneliness. In Stauffer's view, ethical loneliness—as opposed to the aloneness of solitude or privacy—is imposed unwillingly on people "whose story cannot or will not be heard… [and thus] whose harms have not yet been addressed" (Stauffer 2015b, 32).

While applying ethical loneliness and other transitional justice-related concepts to the very non-traditional human rights context of the Autism Speaks controversy, this article nevertheless shares with much transitional justice scholarship the broader purpose of using conceptual tools to answer a concrete set of questions about how institutions gain and lose legitimacy, especially after histories of violence. Its central questions are as follows:

What are the sources of tension between Autism Speaks and many autistic self-advocates/neurodiversity advocates?

What has the organization done to address this history?

Why have these steps largely failed to promote reconciliation or greater legitimacy for the organization?

How might an understanding of ethical loneliness help inform a new approach to one of the deepest divisions in the autism world?

Before addressing these questions, I offer a brief history of Autism Speaks in order to provide some context for the following section, which categorizes the harms autistic self-advocates and their allies accuse the organization of perpetuating during the nearly fifteen years of its existence. The fourth section describes the potential contributions of a transitional justice approach to the Autism Speaks controversy, and the particular relevance of the idea of ethical loneliness. The conclusion examines steps taken by the organization to repair relationships with its critics and others in the autism community, and argues that these strategies will not meet with success when they continue to exclude explicit engagement, let alone a full reckoning, with the past.

Autism Speaks, Past and Present

While the United States is home to many autism research and advocacy organizations, none compares in stature, budget, or global profile to Autism Speaks. In 2014 alone, the organization raised close to US$60 million in grants and contributions, and spent over US$42 million on its programs (Charity Navigator 2017). Autism Speaks was founded in 2005 by Bob Wright, the chairman and CEO of NBC Universal, and his wife Suzanne (who died of pancreatic cancer on July 29, 2016). The couple's grandson, Christian, was diagnosed as autistic in 2004, prompting the organization's founding in 2005 (Autism Speaks 2012a).

Though Autism Speaks appeared on the scene relatively recently in the history of autism advocacy, the Wrights' networks of media elite and their fundraising might—starting with a kickoff donation of $25 million from their friend Bernie Marcus—allowed them to enter into the field with a show of force. Furthermore, Bob Wright's answer to the divisions that had already plagued the autism world for decades was to seek to unify the field. The group did this largely through takeovers (sometimes friendly, sometimes hostile) of other, less well-resourced autism organizations (Donvan and Zucker 2016, 466-470). 2

Autism Speaks funds research "into the causes, prevention, treatments and a cure for autism" (Autism Speaks 2012a), providing resources for autistic people and their families, as well as public awareness campaigns (for example, the annual "Light It Up Blue" campaign to mark Autism Awareness Day on April

2, and the ubiquitous puzzle-piece logo that the organization adapted from previous groups). In fact, because of its media literacy and connections, "awareness raising"—meaning bringing autism to the attention of a wider public, but also creating brand awareness of the organization as a source of help for the "problem" of autism (see Waltz 2012, 221)—is something Autism Speaks has been able to do perhaps more effectively than any other autism organization. The emphasis on speech in the group's name is thus appropriate, in the sense that speech and messaging are among its great capacities; but it also dramatically heightens tensions over whether Autism Speaks actually speaks for everyone affected by autism or represents the condition, and their lives, accurately.

The focus here on controversies and harms does not do justice to the complexity of an organization as large and multifaceted as Autism Speaks—or of an autistic community in which not all members share the same view of the organization (see, e.g., "'Autism Speaks' Response to autistic input" 2011). Even some longtime critics are now arguing that too much focus on one organization is not constructive, and that Autism Speaks' brand dominance in the autism advocacy world is fading, making the energy devoted to critiquing it of questionable utility (Anonymous 2017; Taylor-Parker 2017). As the organization evolves, it increasingly offers resources on uncontroversial issues such as back-to-school transitions and anti-bullying strategies. Thus no single, monochromatic view of Autism Speaks would be fair.

Yet the persistence of critical voices, and calls from autistic people to boycott the organization, cannot simply be brushed aside. The 2013 departure of Robison—a self-described "voice of moderation" (Robison 2013) who has put considerable energy and authority into finding a pro-neurodiversity, pro-science "third way" in autism advocacy—was one sign of how deep the fault lines had grown.

The harms Autism Speaks has been accused of perpetrating against the community for whom it claims to advocate—autistic people—are categorized and explained below. This is a simplified list constructed out of a long, contentious history; its purpose is not to log every single complaint made against Autism Speaks (for an attempt at a complete catalogue of this sort, see The Caffeinated Autistic 2017). Rather, it organizes the major claims of injustice into coherent categories in order to help readers understand what might be required in the name of justice and even "reconciliation," to the extent that ambiguous and troubled phrase is an appropriate goal for any process that seeks to repair both specific harms and ongoing relationships (see Stauffer 2013).

As I proceed, I am conscious of my own role as a non-autistic scholar and the parent of an autistic child. I know that I am now part of a history where 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. I seek, in this and other works (see Rosenblatt 2015), to analyze stakeholders in the context of violent and contentious histories, and to do so in ways that do not reduce them to victims and perpetrators, or demons and saints. This article does not spend a lot of time editorializing, whether to affirm or raise objections, about the longstanding criticisms of Autism Speaks; though in paying intentional, sustained attention to texts written by individuals who identify as autistic (and who are often excluded or marginalized, by design, in the kinds of academic spaces I inhabit daily), 3 I do attempt to correct for the power imbalance that characterizes any clash between a wealthy mainstream charity and its far less widely recognized critics. As a scholar, I treat both Autism Speaks and autistic self-advocates as key and complex stakeholders in a contentious landscape of autism advocacy. Yet as an "autism parent," as well as a teacher and activist who supports the neurodiversity paradigm, I openly wish that the organization so many Americans associate with autism was better at listening to the voices of autistic people, more earnest in its engagement with a painful history, and more committed to the kinds of activism and policy work that center mutual care, radical inclusion, and the transformation of our deeply ableist society.

Categories of Harm

The focus on finding a cure

Autism Speaks is far from the first or only organization to describe its highest purpose as finding a cure for autism. In fact, one of the organizations that Autism Speaks absorbed in its early years was Cure Autism Now, which had existed since 1995. Autism research pioneer Bernie Rimland's organization Defeat Autism Now! was started in the same year (Donvan and Zucker 2016, 559). No one issue pits large numbers of parents and caregivers, especially those with loved ones whose intellectual and/or social challenges require high levels of support, against neurodiversity advocates in the way that the fight over curing autism does. As Dana Lee Baker writes, "Taking pride in the presence of something is difficult to do while simultaneously attempting to eradicate it" (2011, 191). Ari Ne'eman, the founder of the Autistic Self Advocacy Network, argues, "The object of autism advocacy should not be a world without autistic people—it should be a world in which autistic people can enjoy the same rights, opportunities and quality of life as any of our neurotypical peers" (2010). Autistic self-advocates frame the search for a cure as, quite simply, a form of eugenics (Taylor-Parker 2016). Yet for many parents and caregivers, the challenges facing their loved ones seem too great, and the neurodiversity project too utopian, to cease searching for medical interventions that would make autism itself, at least as currently experienced by the people in their lives, go away (see Donvan and Zucker 2016, 521; Lutz 2013). Though it is beyond the scope of this work to address in depth, the 2012 decision to eliminate a separate diagnosis of Asperger's Syndrome, in the DSM-5, had major political as well as clinical ramifications; some parents and caregivers now accuse the neurodiversity movement of being made up largely of "high-functioning" autistic people with no intellectual impairments and Asperger's-type autism, who (according to these parents) have now been empowered to speak across the spectrum in the voice of all autistic people (Lutz 2013).

Having long framed its mission as a quest to cure autism, Autism Speaks has recently responded to sustained criticism by eliminating the word "cure" from its mission statement (Dahl 2016). Crucially, it has replaced the goal of "Funding global biomedical research into the causes, prevention, treatments and a possible cure for autism" with language about "promoting solutions […] for the needs of individuals with autism and their families" as well as "increasing acceptance and understanding of autism spectrum disorder" (Jones 2016). NeuroTribes author Steve Silberman and some neurodiversity advocates have been cautiously optimistic about the new mission statement reflecting a real shift in Autism Speaks' culture (Dahl 2016). A more skeptical self-advocate, Maxfield Michael Sparrow Jones, points out that the prominent use of the word "solutions," put together with a reference to "advancing research into causes" of autism spectrum disorder, still amounts to a cause/solution sequence that is consistent with the pursuit of prenatal screenings, cures, and other strategies for eliminating autism as a part of the human condition (Jones 2016). They also claim that unless the priorities, messaging, and expenditures of the organization are radically altered, changes to the organization's mission statement are merely cosmetic (Ibid.).

Messages of stigma, fear, and erasure

Autism Speaks's long-standing search for a biomedical cure for autism has been expressed in a specific discourse about the condition itself and about autistic people—a discourse the organization did not invent, but which in the US context it has done more than any other group to promote and spread. In 2009, Autism Speaks debuted a video campaign called "I am Autism." Though reminiscent of earlier ad campaigns, such as the NYU Child Study Center's "Ransom Notes" ads that helped galvanize the neurodiversity movement (see Kras 2010), the video takes scare tactics to a new level. It begins with ominous music, as a voice intones, "I am autism. I'm visible in your children, but if I can help it, I am invisible to you until it's too late. I know where you live. And guess what? I live there too." The voice goes on to make a series of increasingly dark threats: "[I]f you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain"; "I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up you will cry, wondering who will take care of my child after I die?" (Autism Speaks, 2009).

Most critics focus on the scare tactics of these first, brazenly manipulative two minutes of the video. Equally significant, however, is the upbeat and seemingly more benign second half of the advertisement, in which the triumphant families of autistic people voice their strength and their promises to fight autism. Not only does the video's language cast autism as a hostile enemy rather than part of the self; it also excludes autistic people from its vision of living together in strength. Every voice in the second half of the video is that of a family member or caregiver pledging to do things for an autistic person or against autism: "You have not properly been introduced to this community of parents and grandparents, of siblings and friends and school teachers and therapists and pediatricians and scientists. Autism, if you are not scared, you should be" (Ibid.). Never is any agency, preference, or desire to live a satisfying life accorded directly to an autistic person.

When not imagining autism itself speaking in the voice of a predator, the organization has also used a metaphorical language in which autistic people are "missing" (see Wright 2013), their true selves absent or locked away. The message still echoes in the organization's "MSSNG" program that supports autism genetics research. Though Autism Speaks states that the title and missing letters "represent the missing information about autism that the research program seeks to deliver" (2017), they also reference a long tradition of seeing autistic people as changelings that are somehow less than the original person they were born to be, "empty fortresses" (Bettelheim 1967) devoid of an interior. As in the second half of the "I am Autism" video, the issue here is not simply one of embracing a medical versus social model of disability, but rather one of erasing the very personhood of the autistic subject.
"Speaking over" while claiming to "speak for"

The messages of stigma, fear, and erasure described above cut even deeper because of Autism Speaks' assertion, encoded in the organization's name, that it speaks for autism, autism families, and the best interests of autistic people. As Silberman says:

> [T]he disability rights movement is predicated on people speaking for themselves and gaining their own voice in the formulation of public policy, while the original autism parents' movement was predicated on parents speaking for their children, because many of their children couldn't speak. That's one reason that some parents and self-advocates are at odds; now people who communicate through keyboards and other forms of assistive technology are demanding the right to speak for themselves and to set their own priorities. The very name of a parent-run organization like Autism Speaks implies erasure of their voices (Brooks 2016).

Since its inception, Autism Speaks has faced criticism for failing to include any autistic people in decision-making roles, attending hearings and setting agendas for autism funding without autistic people present ("nothing about us without us" 2012). The resignation of Robison, the most prominent autistic person

involved with the organization, was a low-water mark. In 2015, two autistic people were appointed to the 31-person Board of Directors, a change greeted lukewarmly, at best, by major voices in the US self-advocacy community (Autistic Self Advocacy Network 2015).
Misrepresenting its mission and diverting funding:

One of Autism Speaks' official "four pillars" is "family services" (Advancing Futures for Adults with Autism 2014). Yet analyses of its spending consistently show the vast majority going to biomedical research, media awareness campaigns, and fundraising. While there may be reasons why these kinds of calculations are too simplistic a way to measure the organization's priorities or impact, 4 autistic self-advocates have mobilized them as evidence of the organization's fundamental commitment to efforts to cure/fix autistic people, and "raise awareness" about the condition amongst non-autistic people, over supporting programs for the inclusion and support of autistic people based on needs they express themselves. According to a critical analysis of its 2014 Non-Profit Tax Exemption Forms, only 4% of its budget was spent on services directly benefiting autism families (Autistic Self Advocacy Network 2016). Given the ways in which Autism Speaks has absorbed a heterogeneous set of other organizations, consistently attracted a lion's share of donations, and "occupied the field" (Kennedy 2014) of autism advocacy, some critics accuse the organization of misrepresenting its priorities and re-directing money that was donated in the hopes of helping families, in the present moment, to biomedical research with controversial, and often distant, outcomes (see Jones 2016).
Supporting controversial therapies and vaccine panics:

Autism Speaks supports Applied Behavioural Analysis (ABA) and other therapies to which many neurodiversity advocates object. ABA approaches have evolved since the "adversive"-heavy, often physically abusive techniques promoted by pioneers such as Ole Ivar Lovaas (Donvan and Zucker 2016, 191-223; Silberman 2015, 304-323); though it still exists in its worst form in the Judge Rotenberg Center, a "school for special needs" in Canton, MA and the target of sustained activism by autism and disability rights activists. Staff members at the Center regularly administer electric shocks as a disincentive for "unwanted" behaviors, and have been accused of beating and spitting on their "patients" (see Smith 2018). Even in less heavy-handed forms, many variations of ABA involve forcing eye contact and eliminating certain behaviors, such as the repetitive motions sometimes called "stimming" (short for "self-stimulation"), that self-advocates say provide an outlet for sensory overstimulation and help them remain focused. Some autistic people who have experienced ABA therapies say that forcing eye contact, and penalizing behaviors such as stimming, actually increases their stress and lowers levels of functioning in social and educational environments (see Bascom 2011; Devita-Raeburn 2016).

During the peak years in which British gastroenterologist Andrew Wakefield created panic by alleging that the ingredients in the MMR (measles-mumps-rubella) vaccine cause autism in children—research that has since been ruled fraudulent and retracted by its publisher, The Lancet—Autism Speaks attempted to maintain a "big tent" philosophy that avoided any official position on the controversy. The Wrights' daughter, Katie, publicly feuded with her parents after making various public declarations that her son's autism had been caused by immunizations. Still, throughout much of the period, the organization funded vaccine-related research (Donvan and Zucker 2016, 485-6).
Focusing on "awareness" messages rather than standing for rights and denouncing violence:

The final category of harm in this list is not the best known of the criticisms of Autism Speaks; yet it is key to this article because it sheds light on how the past informs the present. Furthermore, it gets to the heart of the controversies surrounding the organization because it exposes how, under the surface, what is at stake here is not only the divide between medical and social models of disability, or cure vs. celebration (see Baker 2011, 191-214) but also different constructions of "advocacy," based on different conceptions of what it means to be a political and historical subject within the frame of autism.

Many neurodiversity advocates see violence as a fundamental and salient part of autism's history (see Brown 2016). In Autism Speaks's discourse, in comparison, violence is not prominent. The organization provides resources related to the bullying and stigmatization of autistic people, especially children; and broaches the topic of violence obliquely. It has addressed questions such as whether video games make children more violent, and joined in the important work of publicizing research that debunks the link often made in the media between autism, violence, and mass shootings (Autism Speaks 2013b).

One of Autism Speaks's most controversial public service videos (shown at the Sundance Film Festival in 2007) features the organization's then-president, Alison Singer, confessing that in a moment of distress over the options available for her autistic daughter, she once contemplated driving off of the George Washington Bridge with both herself and her daughter in the car. The reason she chose not to do so, in her telling, is that she also had a non-autistic daughter in need of her care (Autism Speaks 2006). Though Singer intended the statement as an indictment of the inadequacy of services and educational options for autistic children, and an honest expression of the panic and abandonment some parents feel, many autistic people (and other parents and caregivers) heard it as a plain-spoken admission that Singer thought her daughter would be better off dead. Moreover, she seemed to suggest that the needs of her neurotypical child were the only relevant moral considerations. Critics were particularly angered by her choice to voice these feelings right in front of her autistic daughter, with a camera recording (in fact, most of the confessional interviews in the film are conducted with an autistic child present). The assumption—a perilous one, as many nonspeaking autistic people have illustrated when empowered with computers and other assistive technologies—is that the child cannot understand what is being said, that lack of speech is equal to lack of comprehension.

The research-centric, medical charity model of Autism Speaks, however—along with, perhaps, a narrow construction of what it means to be "political" (see Hendrix 2012)—has meant silence about institutionalization and torture-style treatments, alternative therapies that injure and kill, police violence, and "mercy killings" by distraught parents and caregivers. 5 Yet for autistic people these forms of violence are markers of the everyday, as well as central facets of what constitutes autism history: they are the ties that bind today's autistic self-advocates to the mostly voiceless generations that have gone before.

In the summer of 2016, disabled people around the world and their allies responded with horror to the police shooting of caregiver Charles Kinsey by an officer who reportedly was aiming at Kinsey's autistic companion (Rosenblatt 2016), as well as the brutal knife murder of 19 people at a care center for people with cognitive disabilities in Sagamihara, Japan (BBC News 2016). Autism Speaks released no official statement on either event.

"Extreme Autistic Aloneness" and Ethical Loneliness

Autism Speaks has gradually reconfigured aspects of its approach in response to criticisms, which have likely been internal as well as external. There have been a few major turnovers in leadership, including the Wrights both stepping down from the Board of Directors. The organization has recently highlighted the work of autistic volunteers and its new board members (Robison 2015). Despite dropping the word "cure" from its mission statement, it does not yet show signs of significantly shifting its focus from genetic and biomedical research; though it would also be too simplistic to say that all of this research is directly aimed at a cure or prenatal test. Some studies have more complex potential outcomes, such as those looking at the relationship between environmental factors and autism rates (see, e.g., Autism Speaks 2013a). While still often framed in stigmatizing terms of autism "risk," and thus politically fraught (see Baker 2011, 210-211), research of this sort might also help debunk popular (and poorly researched) theories such as vaccines or pesticides causing autism, while offering the public a more complex understanding of how environmental and genetic factors interact in the production of various manifestations of both diversity and disease.

At the time of this article's writing Autism Speaks still hosted on its website the "Autism Every Day" video and an op-ed by Suzanne Wright referring to autistic children as "missing." Both have been taken down since, and are preserved only on other sites, usually with critical responses from neurodiversity advocates. The organization rarely acknowledges its uniquely controversial status within the autism world, and seems not to have incorporated an understanding that its rhetoric in these advertisements and public statements, for many in the autistic community, were not simply bad branding: they were forms of violence.

The problem of past injustice—and especially violence—is at the heart of the practice and study of transitional justice. In an influential early work of transitional justice scholarship, Ruti Teitel defines the term as indicating moments when the "conception of justice" is "contingent and informed by prior injustice" (2000, 6). The question of transitional justice, in its starkest terms, is: because of then, what now? It is a question that is relevant to the politics of autism in ways that popular accounts often fail to recognize, and its role in the prolonged crisis of legitimacy for Autism Speaks is particularly overlooked.

When it comes to autism, however, what "transition" is there? We have no story of an authoritarian regime finally being ousted by its democratic opposition, or of peace accords being signed. 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. As the field of transitional justice scholarship has evolved, however, it has begun to offer conceptual tools that address these more complex timelines and more iterative projects of justice and injustice. Philosopher and legal scholar Jill Stauffer's concept of "ethical loneliness" is one such tool.

Stauffer defines ethical loneliness as "the experience of having been abandoned by humanity combined with the experience of not being heard" (2015b, 1). The term thus denotes the mingled effect of two events that are temporally separate: some form of violence and abandonment, and then also a compounding of that abandonment through the refusal of the outside world to listen or hear about that harm on the survivor's own terms. Stauffer identifies the harms inflicted on survivors during an atrocity and afterwards not as necessarily morally equivalent, but nevertheless important to understand in terms of their continuity within an individual's story of injustice—that person's unique experience of ethical loneliness.

The idea of transitional justice is generally premised on the existence of some events in the past, which now become relevant to the building of a shared future (see Teitel 2000). However, as Stauffer points out, we do not all share the same temporalities; and the experiences of trauma and harm can impact what we experience as "past," and what remains present. She writes, "only some conditions allow the past to be past" (2015b, 123). A person or community experiencing ethical loneliness cannot always accept the terms in which dominant projects of transitional justice or reconciliation are offered, because their "past injury" is still part of their present. Crucially, for Stauffer, the answer to this dilemma is not to focus exclusively on the individual victim's need for psychological healing or on the designation of individual responsibility through criminal law (though these things may be important too); but rather to understand the complex layers of shared responsibility in an unjust, "cooperatively authored" world (Stauffer 2015b, 140). Acts of listening and recognition are the first step in rebuilding a world that "make[s] hopeful revisions possible" (Stauffer 2015b, 137-141). As she summarizes in another work, "survivors want the harms they have undergone to be heard, and the wrongness of them affirmed in a lasting way not only by the perpetrators but by the surrounding society. They seek the help of others to reassure themselves that they are living in a world with others, one in which they will be protected when they are under threat. They seek meaningful human rights" (Stauffer 2013, 44).

Ethical loneliness is a provocative lens for understanding the history and politics of autism for at least three reasons. First, it is a source of unexpectedly fruitful ironies regarding how the rhetoric of "loneliness" has played out in autism discourse since the condition was first identified in the 1940s. Second, and more crucially, Stauffer uses the concept of ethical loneliness to cut across traditional divisions between transitional justice discourse—with its emphasis on mass violence and radical evil—and the everyday harms people experience in "ordinary" settings (for example, victims of sexual assault). Third, she shifts the focus from the traditional triad of victim/perpetrator/bystander to the role of institutions whose practices can allow for hearing or close off that possibility. Stauffer does not believe that institutions, alone, can guarantee all of the forms of hearing, affirmation, and rights protection listed above without more everyday and "anarchic" forms of solidarity (Ibid.); but she does seem to think that institutions bear a particular responsibility for hearing survivors' real needs, and that special forms of violence and harm ensue when the institutions charged with all or part of this task do not do their job adequately. So, again, if an organization is to be called Autism Speaks, it seems to call upon itself a particular form of responsibility for hearing autistic people—especially if one of the central things those people have been expressing is their desire to be recognized as survivors of widespread, widely accepted violence.

Some unexpected power and potential hazard in using the term "ethical loneliness" to analyze autism's history comes from the long history of "loneliness" being used as a trope in portraying autistic people. Stauffer's book tells the stories of people who survived the Holocaust, Apartheid-era violence in South Africa, sexual assault, and other violence. All of these people are rendered alone by outside forces and failures, and yet—with a few important exceptions (Stauffer 2015b, 97-105)—are largely able to persist in speaking about their own desire to connect and to be heard (through writing, sharing testimony in courtrooms, or oral histories, for example). Autistic people make for unique subjects of ethical loneliness precisely because popular conceptions of autism have, for so long, hinged on the idea that autistic people cannot or do not desire this kind of connection or storytelling—that they prefer to be alone, or know no other way to be. The word "autistic" comes from the Greek for "self"; according to autism pioneer Leo Kanner's original description of the condition, "Profound aloneness dominates all [autistic] behavior" (Kanner 1943, 247). In a letter to the mother of his famous "Case 1," a boy named Donald Triplett, he elaborated, "The main distinction [of autistic behavior] lies in the inability of these children from earliest infancy to relate themselves to other people" (qtd. in Donvan and Zucker 2016, 37). Kanner later labelled this trait "extreme autistic aloneness" (Kanner 1944, 211).

The understanding of autism has evolved so that the "loneliness" of autistic people is no longer seen as evidence of infantile psychic damage (traditionally blamed on insufficiently affectionate mothering) or a preference for solitude, but rather of impairments in communicative abilities and understanding of social cues. Nevertheless, the idea of autism as an "empty fortress" that walls the autistic person off from the world persists. It is present in the threats delivered (supposedly in the voice of autism itself) in Autism Speaks' "I am Autism" video (2009), as well as in the exclusion of autistic people from the triumphant chorus of voices vowing, in the second half of the video, to fight autism and create a better (defined as autism-free) future.

To look at the ethical loneliness of autistic people, rather than the problematic theories of psychological and cognitive loneliness ascribed to them, is to flip the script. In keeping with the insights at the heart of the social model of disability, it provokes us to ask not "how does autism isolate people?" but rather "how do features of the social world isolate autistic people?" In fact, one of the ways in which autistic people have been made ethically lonely, per Stauffer's description, is precisely through the trope of their supposed psychological loneliness. In other words, loneliness can become self-enacting: when the dominant culture promotes a notion of a group of people as having a "preference for aloneness" (Wolfberg 2009), it thrusts loneliness, and failures to be heard, upon them. It is difficult to understand the depth of the anger at Autism Speaks without grasping this broader dynamic.

Autism Speaks has its own special history with the "injustice of not being heard" because of the ongoing practices with which it has insisted on speaking for autism, on the largest stage to which any organization has had access, largely without engaging its many autistic critics. Stauffer notes, in the history of international transitional justice, a pattern of "institutions designed for hearing [that] fail to hear well" (Stauffer 2015a)—institutions that thus become participants in ethical loneliness rather than sites for its undoing. Autism Speaks's problem may be related but distinct: with its emphasis on speaking, its design for hearing did not simply fail. Rather, it was never constructed in the first place, because the organization did not originally identify hearing autistic voices as part of its mission.

Yet the concept of ethical loneliness also offers a small bridge across the troubled waters that lie between parent-led charities and the neurodiversity movement. The injustices experienced by caregivers, especially mothers in the era when Bruno Bettelheim and others were blaming them for causing their children's autism (Bettelheim 1967), can also be described through the lens of ethical loneliness. Caregivers found themselves responsible for children whose unique minds and challenges had not been (are still not) well understood, or accepted, by the society in which they lived. Until the anti-institutionalization and public education activism of the 1970s through 1990s began to have major successes (see Donvan and Zucker 2016, 147-187), it was possible to commit one's child to a prison-like institution for life, but not to enroll her at the local public school. Parents who resisted consigning their children to institutions were then faced with having them home at all hours, often with no outside assistance and little integration with their surrounding communities or feasible access to public space.

On both sides of this terrible choice, which Kristin Bumiller aptly describes as a shift in "the location of care […] from public institutions to the isolation of the household" (2013, 144), lie forms of being "abandoned by humanity." Either the child was abandoned in an institution, or the family retreated to the home and remained abandoned by most other key institutions of society: schools, sports teams, clubs, and so on. The first part of ethical loneliness, abandonment by humanity, was thus inescapable. On top of that original injustice, for decades the "experts" and most of the public demanded that these caregivers, mostly mothers, think of all of these problems as their own fault.

In the era of the "refrigerator mother," a narrative of parental/maternal culpability occupied the field where any other narrative, such as one of human diversity and common responsibility to care for one another, might have been voiced. Caregivers became unhearable, because these mothers, like their children, could only be seen as objects for corrective intervention and never as sources of knowledge or ethics. The "injustice of not being heard" thus completed a circle of ethical loneliness drawn almost as firmly around caregivers as it was around autistic people. If Autism Speaks and similar organizations were more able to think historically, about histories of voice and histories of violence, they might focus on these similar dynamics that still impact caregivers and autistic people. 6 In doing so, they might better perceive that challenging unjust and uncaring structures—politics, beyond lobbying for more research funding and beyond "charity"—should be the central and unifying thread of autism advocacy. But this perspective, of course, requires seeing autistic people as subjects: paying the same attention to their suffering and their agency as one does to that of (other) caregivers.

Conclusion: Autism History and Retrospective Justice

The recent boom in attention to autism and autism history is important in many ways. To many, it is a fascinating chapter in the history of science, featuring emergent understandings of the diversity of the human brain, moral panics about "refrigerator mothers" and vaccines, and now a new, neurodiverse chapter in the politics of identity and difference. A clear telling of autism's history, however, would also allow for the detailing of specific and complex injustices, and thus for answers—theoretical and practical—to the question of repair. Just as transitional justice casts the future legitimacy of the political order as bound up in its full recognition of violent histories, the building of a neurodiverse future must incorporate a project of revisiting the past.

The allegations that Autism Speaks has seemed least able to address are the very ones that make transitional justice a relevant framework for analyzing its history. Added up, these allegations illustrate how the injuries of the past, through the layered experience of ethical loneliness, are still present for many in the autistic community—and thus impact the institutional landscape shared by everyone in the broader "worlds of autism" (Davidson and Orsini 2013). The organization has made reforms in its present structure and mission statement without seeming to realize that what may seem like "the past" to its board, staff, and many stakeholders is still actively present for those who experience autism's socially produced forms of ethical loneliness. This divergent temporality is most evident when Autism Speaks attempts to make isolated reforms and move forward; these are met with repeated requests for backward-looking acknowledgement, such as autistic activist Lei Wiley-Mydske's reply that she is still waiting for "over a decade's worth of apologies" (qtd. in Boycott Autism Speaks 2016). She is waiting, in other words, to be able to let the past become past.

In the long-term, it does not seem constructive for autism advocacy to be framed as a war between two paradigms: the parent group and the self-advocacy community. As powerful as the self-advocacy movement has been, furthermore, it may not be possible for a group such as the Autistic Self Advocacy Network simultaneously to serve as a pioneering, rights-based builder of autistic community and as a broad umbrella under which multiple stakeholders—autistic self-advocates, scientists, families and caregivers, therapists and educators, and so on—come together. Gil Eyal et al. write, "Ultimately, both sides need each other… deinstitutionalization has saddled parents with the task of representing, advocating for, and translating their children for neighbors, teachers, and many others on a daily basis. The self-advocates provide them with the language, confidence, and support to make these translations" (2010, 233). Eyal's metaphor of "translation" is problematic, as is his casting of self-advocates as serving a utilitarian purpose of lending "support" to parents (who thus, in this formulation, are granted unquestioned authority as advocates for their children). But the rest of his point has merit. Parents, self-advocates, and autistic parents advocating for both themselves as caregivers and their autistic children—

all are permanent stakeholders in the politics of autism, and best thought of as interdependent, and thus responsible for listening to one another.

Autism Speaks has the funding, stature, and capacity to be the "big table" where people meet to sort out these complex issues of autonomy, voice, and care. It cannot do so with legitimacy, however, until it addresses its past—until there is "an appreciation of the damage done" (Autistic Self Advocacy Network 2015). The exact means by which the organization addresses its past can only be the result of conversations and negotiations, and is difficult to prescribe in advance of that political process.

Nor should one assume that addressing the past would lead, immediately, to a repair of the rift between Autism Speaks and its large, heterogeneous group of critics. Stauffer argues that the act of creating spaces for addressing past injustice must be untethered from the expectation of forgiveness (2015b, 122). Autism Speaks can neither demand forgiveness nor guarantee its legitimacy in the eyes of people it has alienated while representing itself as their advocate. What it can do, in acknowledging past injustices, is place itself back on the same timeline—acknowledging that the past does not simply disappear along with links that are removed from its website, but rather stays present to those who feel harmed by it. The first step in achieving its stated mission of "bring[ing] the autism community together" (Autism Speaks 2012b), it seems, is to replace a politics of erasure with an honest dialogue about its place in a "cooperatively authored" (Stauffer 2015b, 140) autism world—a world that, like any other, cannot plan its future without grappling with its past.

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