

CHANGING CONVERSATIONS AROUND AUTISM: A CRITICAL, ACTION IMPLICATIVE  
DISCOURSE ANALYSIS OF U.S. NEURODIVERSITY ADVOCACY ONLINE

by

JESSICA M.F. HUGHES

B.A., Boston University, 2000

M.A., Lancaster University, U.K., 2004

A thesis submitted to the  
Faculty of the Graduate School of the  
University of Colorado in partial fulfillment  
of the requirement for the degree of  
Doctor of Philosophy  
Department of Communication

2015

This thesis entitled:  
Changing Conversations Around Autism: A Critical, Action Implicative Discourse Analysis of  
U.S. Neurodiversity Advocacy Online  
written by Jessica Marie Fridy Hughes  
has been approved for the Department of Communication

---

Robert T. Craig

---

Karen Tracy

---

Lisa A. Flores

---

David Boromisza-Habashi

---

Amy C. Wilkins

Date 5/6/2015

The final copy of this thesis has been examined by the signatories, and we  
Find that both the content and the form meet acceptable presentation standards  
Of scholarly work in the above mentioned discipline.

IRB protocol # 13-0600

Hughes, Jessica M.F. (Ph.D., Communication)

Changing Conversations Around Autism: A Critical, Action Implicative Discourse Analysis of  
U.S. Neurodiversity Advocacy Online

Thesis directed by Professors Robert T. Craig and Karen Tracy

This dissertation offers a critical, action implicative discourse analysis of neurodiversity (ND) advocacy online. The neurodiversity movement is a contemporary disability rights movement aimed at autism acceptance grounded in an understanding of autism as natural neurological variation. ND advocacy is a site of discursive struggle where advocates work to redefine autism and combat stigma. This study takes a novel, hybrid discourse analytic approach in an effort to understand why ND advocacy is needed and how its emancipatory potential might be developed. Using a critical discourse analytic lens the author first examines dominant autism discourse in order to better understand how oppressive discursive mechanisms disadvantage autistic individuals in the U.S. Next, ND advocacy practices are reconstructed using action implicative discourse analytic methods to foster normative reflection about what ND advocacy ought to look like. The author finds that, while ND advocacy is making important strides in changing public conversations around autism, the young movement has yet to address its own problems of exclusion. The concluding chapter offers some ideas for ways in which advocates might work to include disenfranchised members of the autistic community and more parent advocates.

## Acknowledgements

I feel very lucky to have found my way to the smart and supportive community of scholars that I've had the pleasure of working with the past five years. In particular, I'm deeply indebted to my mentors, Bob Craig, Karen Tracy, and David Boromisza-Habashi, for pushing me as a scholar, writer, and teacher from the beginning. I'm also grateful for the support, valuable feedback, and tough questions I received from my committee members and professors, Lisa Flores, John Jackson, Amy Wilkins, and Pete Simonson. To Jerry Hauser and the members of the dissertation writers' workshop: Thank you so much for your insightful comments and your immeasurable support during the dissertation slog. To my CU cohort, especially Megan Morrissey, Christy Sims, Susana Martínez Guillem, Rex Parks, Marc Rich, Pascal Gagne, Bing Xiong, Elizabeth Eger, Kristina Ruiz Mesa, Meghan Dunn, and Jenna Hanchey: Our conversations have made me a stronger thinker and a better friend. Finally, to my family born and chosen, especially Joe and Jean Fridy, Goat and Ellis: I could not have done it without you.

## Table of Contents

### Chapter

1	Analyzing Neurodiversity .....	1
2	The U.S. Disability Rights Movement and Communicative Approaches to Autism and Neurodiversity .....	16
3	Metatheory: Integrating GPT and CDA .....	27
4	Methods and Materials .....	53
5	Dominant Depictions of Autism as Tragedy .....	84
6	Divides in the Autism Community .....	130
7	Dilemmas of Neurodiversity Advocacy and Concluding Thoughts.....	190
	References .....	221

## Tables

Table 1: Autism Speaks case study corpus overview .....	61
Table 2: DDM case study overview .....	65-6
Table 2: Self-advocate/parent divide case study corpus overview .....	71

## Chapter 1

### Analyzing Neurodiversity

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. The tragedy is not that we're here, but that your world has no place for us to be. (Sinclair, 1993)

[T]he focus of the conversation has been on placing the blame for autism, and on trying to make autistic people something we are not and never can be: normal. This focus on a cure has prevented us from actually helping people. There's been a lot of progress in the disability rights movement over the past 20 years, but people on the spectrum haven't benefited from it because those representing us at the national level have been focused on causes and cures. (Ne'eman, quoted in Silberman, 2010)

Only when the many shapes of personhood are recognized will justice and human rights be possible. (Baggs, 2007)

Neurodiversity advocates like those quoted above “represent the disability rights perspective within the Autistic community” (ASAN, 2013a), a perspective characterized by counter-discourses working to change dominant conceptions of autism and disability. The neurodiversity movement is a “new kind of disabilities movement” (Harmon, 2004, p. 1), one that advocates for autism rights in part by redefining autism and other cognitive disabilities as natural, neurological differences, ways of being ‘wired’ (Blume, 1998).

Neurodiversity (ND) advocates orient toward a model of disability rights grounded in acceptance for all ways of thinking and being. The concept of neurodiversity draws on the idea that “everyone has a different mind, a different way of being” and that one should not “suppress

these differences [but] accept and support them” (Camley, 2005). According to ND advocates, “neurodiversity [is] a natural and valuable form of human diversity which should be considered as similar in many ways to other forms of human diversity, such as racial diversity, sexual and gender diversity, and cultural diversity” (Walker, 2014a). From this point of view, curing autism is not a desirable goal.

We need to stop making autism advocacy about trying to create a world where there aren't any autistic people, and start building one in which autistic people have the rights and support they deserve. That's the goal . . . of the neurodiversity movement as a whole. (Ne'eman, quoted in Silberman, 2010)

### **Autism, Autistic Identity, and a Note on Terminology**

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) provides criteria for identifying autism spectrum disorders (ASD) that are organized around a triad of impairments, namely “deficits in social communication and social interaction . . . [and r]estricted, repetitive patterns of behavior, interests, or activities” (Centers for Disease Control and Prevention, 2015a). Autism is characterized as a spectrum disorder because symptoms occur across multiple contexts and can vary significantly in terms of how pronounced they are. Symptoms of ASD can include delays in or failure to acquire spoken communication, difficulties understanding and reciprocating typical non-verbal communication such as body language and eye contact, difficulties developing and maintaining relationships, and tendencies to engage in repetitive movements or self-stimulatory behaviors, commonly called ‘stimming.’

For ND advocates, these ‘symptoms’ are simply differences related to autistic neurology that must be accepted rather than fixed or cured. Autistic first-person accounts often relate “significant differences in information processing, sensory processing, communication abilities



or styles, social skills, and learning styles” (Brown, n.d.). Some relate difficulties learning or interpreting pragmatic or metaphoric meaning. Many discuss inability to engage in small talk. Many describe being unable to read facial expressions or to produce expected facial expressions themselves. Some autistics write about losing the ability to speak, having difficulties speaking, and being unable to speak at all. Many autistics describe hypersensitivity to sensory stimuli, and using stims such as hand flapping, pacing, or even self-injurious behaviors to help them manage painful feelings of over-stimulation. The Autistic Self Advocacy Network (2015b) lists seven common characteristics of autism, including 1) “Different sensory experiences” like heightened sensitivity and synesthesia, any combination of mixed perception (e.g., hearing color, seeing words and letters as particular colors); 2) “Non-standard ways of learning and approaching problem solving;” 3) “Deeply focused thinking and passionate interests”—what autistics commonly refer to as ‘special interests’ and diagnostic literature calls ‘perseveration;’ 4) “Atypical, sometimes repetitive, movement;” 5) “Need for consistency, routine, and order;” 6) “Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal,” and in particular, difficulties expressing emotions or feelings in words; and 7) “Difficulties in understanding and expressing typical social interaction.”

Within the neurodiversity movement, autism is both a difference and a disability. As autistic activist Lydia Brown emphasizes, “[a]ccepting our autism does not mean ignoring or denying disability” (quoted in Silberman, 2012, p. 364). The differences in neurology described above can pose significant challenges for people on the spectrum, the severity of which can vary greatly from autistic person to autistic person and within an individual over time. While the ND movement is ultimately aimed at changing society to be more inclusive and supportive of autistic

individuals, ND advocates stress that this goal cannot be achieved without acknowledging both challenges and strengths. As Judy Endow (2014) notes

[a]s an autistic person when I am asked to choose one—either “disability” or “difference”—I feel like I am being asked, in essence, which part of me I would like to ignore. When I choose “disability” it means my talents, strengths, abilities, and preferences are ignored. When I choose “difference” my very real needs and difficulties are not only ignored, but I am often blamed for what others consider my stubbornness in hanging on to negative “character flaws.”

Autistic self-advocates stress that their neurological differences and the challenges that come with disability are intrinsic parts of their identity. They describe autism as pervasive, “a way of being . . . [that] colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence” making it impossible “to separate the person from the autism” (Sinclair, 1993). Neurodiversity advocates signal their orientation toward autism as an important part of personhood by using identity-first rather than person-first language. Person-first language (PFL) involves putting the noun *person* before disability signifiers as a way of emphasizing personhood and conveying the idea that a person is ‘not defined by’ their disability. Terms like *person with ASD* or *person with autism* follow linguistic conventions first espoused by self-advocates in the early days of the disability rights movement who argued that others’ inability to see past disability and its attributed stigma obscured their personhood. PFL has since become a preferred normative practice—a ‘politically correct’ way of referring to disabled people in everyday discourse that is also used, officially endorsed, and institutionally required by federal policymakers, media agencies, and disability advocacy groups.

According to many autistic people, however, “[i]t is impossible to affirm the value and worth of an Autistic person without recognizing his or her identity as an Autistic person” (Brown, 2011b). Many autistics—particularly those within the ND movement but also many who

do not identify as ND advocates—prefer identity-first language (IFL), that is, linguistic formulations like *autistic person* or the collective noun *autistics* that highlight autism as an intrinsic part of identity. Some—like ND activist Lydia Brown, quoted above—capitalize *Autistic* as a way of representing autistic community identity in the same way that the capitalized adjectives *Deaf* and *Black* do. Some switch between PFL and IFL for the sake of stylistic variation, and autistics are often explicit in voicing respect for all people’s individual preferences with regard to their own terminology. However, many ND advocates also critique PFL for perpetuating stigma toward disability in that insisting on putting personhood first

betrays the assumption that disability renders one less of a person. If that assumption were not present, there would be no reason to foreground the fact that we really, really, *really* are people, and that one has to put the disability aside in order to see how really, really, *really* human we are. (Cohen-Rottenberg, 2014, author’s emphasis)

### **What is Neurodiversity?**

The word *neurodiversity* was first coined in the late 1990s as a way of categorizing the kinds of neurological diversity associated with ‘high-functioning’ autism (Blume, 1998; Singer 2002[1999]), that is, the “not intellectually impaired” (Singer, 2002[1999], p. 62) end of the autism spectrum. The term was first used to describe autism as a “kind of brain wiring” characterized by a propensity for “[c]ybernetics and computer culture” (Blume, 1998) alongside “qualitative impairment[s] in social interaction” (Singer, 2002[1999], p. 63). According to this early understanding of neurodiversity, autism was an evolutionary upgrade in neurological software, a vital adaptation to an increasingly technological world.

While neurodiversity was first defined around ‘high-functioning’ autism, it has since been expanded to describe any kind of cognitive processing or way of making sense of the world that deviates from ‘typical’ ways of thinking and being, including attention deficit hyperactivity

disorder (ADHD), dyslexia, Tourette’s syndrome, anxiety, and obsessive-compulsive disorder (OCD) (Hendrickx, 2010), as well as ‘low-functioning’ or “severe” autism (Robison, 2013c). This broader definition of neurodiversity has been taken up by education specialists who advocate for “positive responses to specific learning differences” (Pollak, 2009) and fully inclusive classrooms where “the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences” (Armstrong, 2010) can be fostered.

Neurodiversity is often defined against neurotypical (NT) ways of experiencing the world. This distinction rests on the recognition that “NT is only one kind of brain wiring” (Blume, 1998), one that, like any other kind of wiring, has its own affordances and constraints. Neurodiversity discourse “rewires conventional thinking about brains” (Silberman, 2013) that says that anything outside of ‘typical’ cognitive processing is disorder. Some neurodiversity advocates go farther than others to critique dominant conceptions of typicality that position autism as an undesirable medical condition. For instance, the Institute for the Neurologically Typical (ISNT), a parody site for people on the autism spectrum and their allies, critiques the ways in which medical discourses equate ‘normal’ with healthy and atypical differences with disease by turning the relationship between typicality and difference on its head. “[D]escrib[ing] the neurotypical—‘normal’—person as if they are diseased . . . to illustrate the way that . . . medical researchers can portray autistics . . . as defective individuals and genetic mistakes” (Muskie, 2002), ISNT offers a conception of autism as normal neurological variation and neurotypicality as a delusional “obsession with conformity” (Muskie, 2002):

Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity.

Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. . . NTs are often intolerant of seemingly minor differences in

others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum. (Muskie, 2002)

Here and in other autism discourse, the distinction between neurodiversity and neurotypicality is a kind of inside-outside relationship, a juxtaposition of social and communicative behaviors taken to be normal and those perceived as disordered. By arguing against seemingly arbitrary definitions of normalcy and pushing back against pathologizing discursive practices that position deviations from the norm as medical problems, neurodiversity advocates like Muskie work to expand conceptions of normal to include autistic ways of thinking and behaving.

Characterizing autistic differences in terms of neurodiversity is a way of highlighting the value of autism as a development of human evolution that “may be every bit as crucial for the human race as biodiversity is for life in general” (Blume, 1998). This premise positions autism as evolutionary advancement, as an “experience of life [that] is not inferior, and may be *superior*, to the [neurotypical] experience of life” (Muskie, 2002). “[T]he value of [such] biological diversity is resilience: the ability to withstand shifting conditions . . . In a world changing faster than ever, honoring and nurturing neurodiversity is civilization’s best chance to thrive in an uncertain future” (Silberman, 2013).

### **Neurodiversity: A “New Kind of Disabilities Movement”**

The autistic self-advocacy movement began in the early 1990s, before neurodiversity was given a name. Once the term was introduced, neurodiversity “[became] the rallying cry of the first new civil rights movement to take off in the 21<sup>st</sup> century” (Silberman, 2013).

In spite of making up the most prevalent disability category, people with mental and cognitive disabilities have been historically underrepresented in the disability rights movement

(Charlton, 1998; Driedger, 1989). Since the disabled self-advocacy movement began in the early 1970s, people with physical disabilities have been the ambassadors and icons of disability rights in the U.S. With the rise of neurodiversity, “the disability movement [has turned] to brains” (Harmon, 2004), drawing a new and growing tide of disabled advocates to the disability rights movement and a stronger emphasis on cognitive disability issues to disability rights advocacy.

While neurodiversity has become an umbrella term encompassing all kinds of neurological differences, politically speaking the term still carries strong associations with autistic advocacy and autism acceptance. Several groups explicitly equate neurodiversity with autism rights. The Autistic Self Advocacy Network (ASAN) defines the neurodiversity movement as “represent[ing] the disability rights perspective within the Autistic community” (ASAN, 2013c). The Neurodiversity Symposium at Syracuse University (NSNSU) describes neurodiversity activism as

reject[ing] the idea that autism should be cured, and advocating instead for celebrating autistic forms of communication and self-expression, and for promoting support systems that allow autistic people to live as autistic people. (NSNSU, n.d.)

These descriptions reveal how neurodiversity has been taken up by the autistic self-advocacy movement that began in the early 1990s. Jim Sinclair is often referred to as the first neurodiversity self-advocate (Boundy, 2008). In his 1993 address at the International Conference on Autism in Toronto, Sinclair sparked “a self-advocacy movement for social acceptance and self determination” (Boundy, 2008) by “directly challeng[ing] the ‘autism as tragedy’ paradigm<sup>1</sup>” (Sinclair, 2005, p. 17). In his address entitled “Don’t mourn for us,” Sinclair (1993) argued that searching for a cure for autism is tantamount to wishing that “one day [autistic people] will cease to be.” Sinclair’s treatise called upon parents of autistic children to stop

---

<sup>1</sup> “[A] paradigm upon which the conference—and its sponsoring organizations—was based” (Sinclair, 2005, p. 17).

mourning for “the non-occurrence of the expected relationship with an expected normal child” and to instead open up to an “exploration of what is.” Appealing to non-autistic parents about the need for “autism societies,” Sinclair stressed

We need you. We need your help and understanding. Your world is not very open to us and we won't make it without your strong support. Yes, there is a tragedy that comes with autism: not because of what we are, but because of the things that happen to us. . . . The tragedy is not that we're here, but that your world has no place for us to be.

Sinclair's early challenge to dominant conceptions of “autism as a great tragedy”

(Sinclair, 1993) came at a time when autistic people in the U.S. were just starting to network with one another and to confront neurotypical portrayals of autistic experience. Jim Sinclair first started corresponding with a handful of other autistic advocates using a penpal list compiled by an organization for parents of autistic children (Sinclair, 2005). In 1992, they formed Autism Network International (ANI), the first organization run by and for autistics aimed at

form[ing] a mutual aid-self help group for autistic people . . . [in order] to share first-hand experiences to counter the uniformly gloomy and pessimistic (and often offensive and insulting) portrayals of autism in the existing literature; and to advocate for improved support services for autistic people. (Sinclair, 2005, p. 7)

After Sinclair's 1993 Toronto conference keynote, interest in ANI spiked. The organization offered many autistic community members their first opportunity to meet other autistic people and to engage with them in autistic-friendly spaces where “it's okay to be autistic . . . and it's not [a] goal to become (or to learn to emulate) NTs” (Sinclair, 2005, p. 15). After the Toronto conference, autistic conversations continued on an autism listserv forum for parents, and by 1994, ANI started running its own listserv, the first online autistic community run by autistics. Other listservs—e.g., ISNT and wrongplanet.net—soon followed.

Since then listservs, bulletin boards, chatrooms, blogs, and now Twitter, Facebook, and other Internet sites have continued to enable community networking for autistic advocates worldwide, many of whom lack access to autism conferences or could find face to face interactions difficult. “Increasing use of internet technology has played a key role in allowing autistic people who would otherwise be unable to meet, speak, and form a cohesive movement to gather and make their views, wishes and ways of perceiving themselves and their differences known” (Boundy, 2008). Importantly, many of these online forums are spaces that are “designed and structured by [autistics] for [autistics]” (Ne’eman, 2013, personal communication). These autistic spaces “[facilitate] . . . first contact and homecoming experiences for autistic people” (Sinclair, 2005, p. 12) in which autistic communication is not only encouraged, but understood. Messages may have “lots of perseveration on details of things . . . lots of echoing each other’s messages, lots of autistic humor that few . . . non-autistic people could understand or appreciate” (Sinclair, 2005, p. 18). Freed from expectations that they communicate in NT ways, autistic community members online often feel it’s “an amazing and powerful experience to be able to communicate with someone in [their] own language” (Sinclair, 2005, p. 3).

What started as a way for autistics to make their voices heard and build autistic community has evolved into a strong autism and disability rights advocacy network. A lot of ND advocacy occurs online in blogs, Twitter, Facebook, online petition sites like change.org, and active comment threads. Here, ND advocates work to spread autism acceptance, advocate for neurodiversity, and protest against organizations, practices, and discourses that they see as oppressive to autistic and disabled individuals.

### **Analyzing Neurodiversity Discourse**



The ways in which neurodiversity advocacy practices online are working to advance autism rights in the U.S. bear further study. As described in more detail in chapter 3, critical discourse analysis and grounded practical theory offer particularly useful perspectives with which to reconstruct and critically analyze neurodiversity advocacy practices. In the present study, I employ ethnographically-informed, critical discourse and action implicative discourse analytic methods in order to reconstruct a grounded practical theory of neurodiversity advocacy practices guided by the question of what neurodiversity advocacy ought to look like.

Mobilizing counter-discourses in order to further a disability rights agenda focused on autism, the neurodiversity movement is a site of struggle where advocates fight against social stigma. From the perspective of neurodiversity advocates, stigmatizing discourses that position autism and disability as undesirable attributes are the biggest barrier to autism rights.

Neurodiversity discourse pushes for social inclusion, acceptance, and support—goals that are positioned as incommensurate with the idea that being disabled, autistic, neurodivergent, or ‘low-functioning’ is less desirable than experiencing an able-bodied, ‘normal,’ or ‘high-functioning’ way of life. Changing society to be more inclusive and accepting of autistic people requires ‘changing the conversation’ around autism in order to challenge stigmatizing perceptions of autistic individuals.

Neurodiversity advocacy practices are thus rich sites in which to investigate contemporary disability rights issues from autistic perspectives. Examining the problems faced by ND advocates, the discursive techniques that advocates employ to address problems, and the ideals to which advocates orient in advancing their disability rights agenda offers a view of the neurodiversity movement that’s useful for reflecting on how disability rights advocacy and

disability rights themselves might be improved. The present study looks to rationally reconstruct neurodiversity advocacy practices in this way.

My approach to situated practices draws on a grounded practical theory (GPT) perspective that conceptualizes practices in terms of three interrelated levels: practical problems (problem level), the techniques that practitioners use to attend to problems (technical level), and the ideals that practitioners orient to in addressing problems (philosophical level) (Craig & Tracy, 1995). Within this framework, by rationally reconstructing practices—that is, by offering somewhat idealized accounts of each level of practice—analyses can contribute to normative theories about what practices ought to look like (Craig & Tracy, 1995).

This approach also lends itself to a critical orientation focused on stigma and other social realities that negatively impact people with disabilities. Neurodiversity advocacy practices are emancipatory, that is, they are aimed at advancing disability rights and eradicating stigma in order to make life better for autistic people and others with disabilities. Theorizing neurodiversity advocacy practices is thus also an emancipatory project, one that takes seriously the problems that impede civil rights for people with disabilities and works to expose and critique the social mechanisms that perpetuate these problems, goals that are compatible with taking a critical discourse analytic (CDA) approach to ND advocacy discourse.

By focusing primarily on autistic perspectives, the reconstructions that follow also serve the important function of signal boosting ND advocacy messages to new audiences. Signal boosting is typically a form of online advocacy, but the term is also apt for describing the kind of advocacy-through-scholarship I'm aiming for here.

Signal boosting is when someone else shares a link or another's writing either on a blog or on some other form of social media. It's the single most appreciated and important

tool, those of us who are not Autistic, can use to help amplify the words of those we support. (Zurcher, 2013b)

This dissertation is a project that looks, in part, to faithfully represent autistic perspectives to academic audiences that are, for the most part, allistic (non-autistic)<sup>2</sup>. Increasing the visibility of these underrepresented perspectives is sorely needed in order to push back against dominant, stigmatizing conceptions of autism in which autistic perspectives are often erased, silenced, ignored, and dismissed. Incorporating autistic perspectives here also has the potential to facilitate open engagement between readers and autistic others by disrupting neurotypical assumptions. Experiencing such disruption is necessary, I believe, for understanding disability rights from an autistic point of view.

Reconstructing autistic perspectives is also important because—as autistic ND advocate Julia Bascom stresses in comments on her blog *Just Stimming*—“\*Autistic\* people need to be the ones telling our stories. They’re ours.” (Bascom, 2011, author’s emphasis). However, in recontextualizing autistic perspectives, I am also aware of the risk of positioning autistic advocates as ‘self-narrating zoo exhibits,’ that is, persons expected to share their experiences “only for the purposes of educating [others] and without reciprocal sharing on [others’] part” (Sinclair, quoted in Ellerman, n.d.). Such objectification “treat[s] an autistic person not as a person but as a dehumanized information source or a ‘walking autie textbook’” (Zifendorf, 2002). This is certainly not my intention here. Just as I strive to critically examine the dehumanizing effects of stigmatizing discourses in my analysis, so, too, I work to critically evaluate my own practices to avoid inadvertently dehumanizing autistic others myself. By

---

<sup>2</sup> A further note on terminology: *Allistic* is an adjective coined by autistics that means *non-autistic*. This term is more precise than *neurotypical*, an adjective that is the opposite of neurodivergent, not the opposite of autistic. Autism is only one of many forms of neurodivergence, so there are many, many people who are neither neurotypical nor autistic. Using neurotypical to mean non-autistic is like using “white” to mean “not black.” (Walker, 2014b)

reflecting on my own research and writing practices, curating autistic stories willingly published online and elsewhere (often with the explicit intention of teaching non-autistic people about autism), and contributing scholarship that may be practically useful for ND advocates as well as communication scholars, I hope to avoid these pitfalls.

### **Overview of the Dissertation**

In the chapters that follow, I aim to contribute to neurodiversity and disability rights practices, amplify marginalized autistic discourses, and expose stigmatizing ideologies. This study is both practically and theoretically motivated. At a practical level, I'm interested in the impact of neurodiversity advocacy online, and in advocating for neurodiversity and disability rights through scholarship. At a theoretical level, I'm interested in the potential of neurodiversity discourse and conceptions of disability and communication employed by ND advocates to inform more formal social, disability, and communication theories.

In order to address these aims and interests, I begin by providing a review of existing literature in chapter 2. This chapter provides background on U.S. disability rights history and a brief survey of studies of autism and neurodiversity in communication studies in order to help situate the neurodiversity movement within the broader U.S. disability rights movement, and place the present study in conversations with existing communication studies literature.

After laying this groundwork, I address the metatheoretical stances that inform my own synthetic approach in chapter 3. Here, I describe the primary theoretical frameworks that I bring together in this study. Then, I outline the affordances of integrating GPT and CDA.

Chapter 4 describes the materials and methods at the heart of the study, starting with an outline of the three case studies around which primary corpora are organized. All of these case studies involve contemporary online controversies in which ND advocates are active, including

1) neurodiversity advocacy against Autism Speaks, a prominent autism advocacy organization; 2) Disability Day of Mourning and ND advocates' responses to cases of autistic people and others with disabilities being killed by caregivers; and 3) ND advocacy addressing the self-advocate/parent divide. This chapter also provides a description of my ethnographic methods, as well as an overview of the primary analytic constructs which formed the starting point for analyses across case studies.

Chapters 5 and 6 are analysis chapters, both of which attend to sites of controversy where neurodiversity advocates are working to 'change the conversation' about autism. Chapter 5 focuses on ND opposition to dominant discourse. Here, I offer a critical discourse analysis of Autism Speaks advocacy and media discourse around cases of filicide that perpetuate the autism-as-tragedy paradigm, paying particular attention to the ways in which these dominant discourses build stigma around autism and silence autistic voices. In chapter 6, I examine the conflict between parents and self-advocates within the autism community. Here, I use an action implicative discourse analytic framework to reconstruct prominent discursive strategies that autistic advocates use in arguments with autism parents, as well as normative beliefs about advocacy practices they orient to in speaking out.

The concluding chapter revisits the practical aims of the overall study and explores some directions for future study. I start by reconstructing tensions between neurodiversity ideals in order to foster normative reflection about neurodiversity advocacy. In these reconstructions, I also offer my own normative suggestions for ways in which the ND movement might become more inclusive. I close with suggestions for future research.

## **Chapter 2**

### **The U.S. Disability Rights Movement and Communicative Approaches to Autism and Neurodiversity**

In order to contextualize the present neurodiversity movement within the broader U.S. disability rights movement and put the proposed study in conversation with other communicative approaches to disability studies, it's helpful to start by sketching these historical and disciplinary frameworks. This is the aim of the literature review below. I start by providing a brief introduction to the history of the U.S. disability rights movement. This overview lays necessary groundwork for understanding the rise of the neurodiversity movement and the similarities and differences between autistic and otherwise disabled perspectives on disability rights. I then examine existing communication studies of autism and neurodiversity. This survey makes a strong case for the utility and necessity of taking a communicative approach to disability while introducing the primary areas of study in communication studies to which the proposed study would contribute.

#### **U.S. Disability Rights History**

Taking stock of the history of the disability rights movement in the U.S. is a way of understanding the evolution of conceptions of disability in U.S. culture, public policy, and within the disability community. The fight for civil rights for people with disabilities, like other civil rights movements, has largely been a struggle of identity politics, a fight that is not only waged by those united by a minority identity, but one that is concerned in large part with redefining what it means to be disabled. Disability rights history is therefore tied to the history of discourses of disability, and its milestones can be marked in terms of changes in the cultural assumptions, beliefs, values, and discursive practices associated with disability. Taking a historical perspective

is thus useful for understanding how contemporary disability rights movements like the neurodiversity movement have come about, and the semiotic evolution of stigma and disability rights discourses over time.

Histories of the disability rights movement in the U.S. often start with the rise of the first Centers for Independent Living (e.g., Charlton, 1998) and the nascent self-advocacy movement (e.g., People First West Virginia, 2015) in the early 1970s. Before this time, most disability advocates were doctors, educators, and parents—nondisabled people speaking *for* people with disabilities (Eyal, Hart, Onculer, Oren, & Rossi, 2010). The League of the Physically Handicapped (LPH), founded in New York in 1935, was a rare disability rights group in its time, one of the few organizations run by and for people with disabilities prior to 1970. This “seminal precursor to the disability rights movement” (Disability History Project, n.d.) was one of the first groups to protest employment discrimination on the basis of disability (Fleischer & Zames, 2001). Though the LPH was unsuccessful in changing perceptions of disabled workers and significantly increasing access to employment for people with disabilities, the League did make some gains by simply mobilizing disabled advocates and helping them to “[face] the public for the first time, not with self-consciousness, but with honor” (Haskell, quoted in Fleischer & Zames, 2001, p. 7).

The LPH was largely forgotten after it disbanded in 1938, but subsequent social changes helped lay the groundwork necessary for other self-advocates to start a disability rights movement that would last. World War II and the polio epidemic brought a rise in the number of people living with disabilities in the U.S. Advances in technology enabled more disabled individuals to survive, but these advances also brought an expansion in rehabilitation and

institutionalization (Driedger, 1989) as disabilities were treated primarily as medical issues and the purview of doctors and other specialists.

It was the growth of the parents' movement in the U.S. that began to gradually undermine the authority of doctors and rehabilitation professionals over disabled individuals. Parents of disabled children began organizing in the 1930s. By the 1940s, parents groups began using litigation to fight for more adequate therapies and services for their children with disabilities, many of whom were institutionalized (Barnartt & Scotch, 2001). In the 1950s, parents were instrumental in pushing for the establishment of comprehensive clinics that expanded on earlier institutional models by offering more extensive interventions, day programs, and vocational training for people with disabilities (Eyal et al., 2010). By the 1960s, parents' attitudes toward institutionalization were starting to change. As parents groups educated members and developed intervention strategies, parents established disability expertise that rivaled that of medical and educational professionals. While institutionalization had previously been seen as good for families, parents began to frame the family as the most appropriate environment for detection and intervention (Eyal et al., 2010). By the 1970s, most parents were opposed to institutionalization and pushed for normalization—the improvement of social competence and adaptive skills—over rehabilitation or cure (Eyal et al., 2010). This sea change contributed to a protracted process of deinstitutionalization in the U.S. during the 1970s and 80s. After rates of institutionalization peaked in 1967, admission rates gradually declined, community residency facilities began replacing hospital facilities, and parents showed an increasing reluctance to place their children outside the home (Eyal et al., 2010).

The U.S. civil rights, women's liberation, student protest, and anti-war movements of the 1950s, 60s, and 70s provided models for social activism that were taken up by early disability



rights advocates as the idea of community integration for people with disabilities started to take hold. The U.S. independent living movement began in Berkeley, California, in 1970, when Ed Roberts, “the father of independent living” (Independent Living USA, n.d.), began “a consultation business for anyone needing help with problems with cripples” (Roberts, quoted in Independent Living USA, n.d.) with the help of a grant from the University of California. Roberts, severely disabled from polio, and The Rolling Quads, a group of other severely disabled Berkeley students, started the “program run by cripples for the education of cripples” (Roberts, quoted in Independent Living USA, n.d.) in order to spread “dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy” (Independent Living USA, n.d.) for people with disabilities. It was “the start of something big—cripple power” (Roberts, quoted in Independent Living USA, n.d.). Roberts’ program became the country’s first Center for Independent Living (CIL) in 1972. Other CILs soon opened in cities across the U.S. The first self-advocate convention, the People First Convention, was held in Oregon in 1974 (People First West Virginia, n.d.). By the mid-1970s, there was a large and growing movement of disabled activists in the U.S., U.K., and Canada.

Drawing on the tenets of civil rights that demanded that public places be accessible to all groups and that all people be able to influence political processes, activists with disabilities used protests to establish disability politics as minority politics (Barnartt & Scotch, 2001). When the movement started, “apply[ing] the label of discrimination to the disabled was unheard of” (Thoben, quoted in Barnartt & Scotch, 2001, p. 20). Through boycotts, actions, sit-ins, and marches, self-advocates demanded the removal of social and physical barriers that worked to exclude them from full participation in society.

Though it entailed demanding protests over two decades, including a near month-long sit-in—the longest in U.S. history—and numerous civil disobedience actions resulting in hundreds of arrests, the movement was successful in making gains in accessibility and public policy. Transit Authorities were pressured into making public transportation systems more accessible. City planners started installing curb cuts in sidewalks. The Rehabilitation Act of 1973 prohibited discrimination in federal programs. The Education of All Handicapped Children Act of 1975 (later renamed the Individuals with Disabilities Act (IDEA)) ensured free public education to all students with disabilities and helped expand integrated classrooms. And the Americans with Disabilities Act of 1990,

the most sweeping disability rights legislation in history . . . mandated that local, state and federal governments and programs be accessible, that businesses with more than 15 employees make “reasonable accommodations” for disabled workers and that public accommodations such as restaurants and stores make “reasonable modifications” to ensure access for disabled members of the public. The act also mandated access in public transportation, communication, and in other areas of public life. (Equal Rights Center, n.d.)

Alongside these federal policy changes, perhaps the most fundamental shift brought about by the U.S. disability rights movement has been the evolution of attitudes toward and conceptions of disability. The movement has helped to shift perceptions of people with disabilities as pitiable poster children in need of charity to self-determined citizens deserving equal rights (Zames Fleischer & Zames, 2001). This recategorization of disabled identities has been integral in building the disability community over the last four decades. The disability rights movement can be understood as a kind of collective consciousness-raising for people with disabilities, a push to “[replace] the false consciousness of self-pity and helplessness with the raised consciousness of dignity, anger, and empowerment” (Charlton, 1998, p. 16). The rise of

self-advocacy was the start of “a self-help movement that would radicalize how people with disabilities perceived themselves” (Independent Living USA, n.d.).

The same transformation can be seen in the rise of the autistic self-advocacy movement. Like others in the disability community, neurodiversity advocates are also drawing on civil rights frameworks to advance their own minority politics. The present study is useful in helping to extend disability rights histories to account for the contemporary neurodiversity movement. Most disability rights histories stop at the early 2000s. Newer historical perspectives that take neurodiversity into account are necessary. There a need to document the effects of the ND movement’s prioritizing cognitive disability in a movement historically defined around physically disabled perspectives, as well as the impact of disability culture and disability pride, movements within the disability community that have developed as a result of radical consciousness-raising and that have gained significant momentum among autistic self-advocates.

### **Autism and Neurodiversity in Communication Studies**

Taking stock of communicative approaches to autism, neurodiversity, and disability rights within communication studies scholarship shows a need for more academic perspectives on these topics as well. Generally speaking, disability tends to be underrepresented in communication literature when compared to literature addressing other dimensions of difference like race and gender (Grue, 2011). Discourse analytic approaches to disability are particularly scarce (Grue, 2011). Given disability studies’ concern with models of disability and conceptions of normalcy (a concern I address in more detail in chapter 3), communicative and discourse analytic approaches to disability studies offer particularly useful perspectives that address the ways in which conceptions of disability, normalcy, and stigma are discursively constructed (Grue, 2011). Given the prevalence of autism—the Centers for Disease Control and Prevention

(CDC) (CDC, 2015b) currently estimate that 1 in 68 children (1 in 42 boys and 1 in 189 girls) is on the spectrum—and the potential impact of neurodiversity in workplaces and university classrooms, more studies of autism are also warranted, particularly those that take a critical perspective in working to expose and dismantle stigmatizing conceptions of autism and disability. Further, considering the unique aspects of autistic communication, communication studies on autism have strong potential to inform communication theory as a field. Finally, studies of the neurodiversity movement have the capacity to inform social movement studies within communication and to complement historical perspectives in disability studies. In short, autism, neurodiversity, and disability rights are rich and relatively untapped topics in communication studies that have a lot to offer the fields of communication and disability studies.

Communicative approaches to autism tend to focus on communication competencies in autistic children and the impact of autistic communication on social interaction. For example, in a special issue of *Discourse Studies* devoted to discourse and autism, authors examine question-answering (Kremer-Sadlik, 2004), positive politeness (Sirota, 2004), narrative introduction sequences (Solomon, 2004), and rule-violation (Sterponi, 2004) in children with Asperger's Syndrome and other classifications of high-functioning autism. These studies and others (e.g., de Villiers, 2011; Dean, Adams, & Kasari 2013) contribute useful analyses of linguistic formulations that characterize some autistic communication, and also highlight ways in which communication competency and rules of conversation are defined in terms of neurotypical ways of communicating and interacting.

Other communicative approaches to autism attend to representations of autism in media discourse, thereby providing insight into the features and social effects of dominant discourses of autism. Billawalla and Wolbring (2014) offer a longitudinal analysis of almost forty years of

*New York Times* coverage of autism, revealing the ways in which newspaper discourse reproduce damaging medical narratives without providing substantive information about what autism is. Clarke (2012) examines the contrasts between framing with regard to autism in magazines directed at women and those directed at mixed audiences. Here, frames characterizing autism as tragedy were more prevalent in magazine discourse directed at women, while discourse directed at general audiences composed of both women and men framed autism from a more scientific and biological angle. Holton (2013) analyzes discourse from the U.S. television show *Parenthood* to investigate the depiction of autism in popular culture, finding that representations in the program reinforce the association of isolation and fear with autism. Others have examined media discourse around the autism-vaccine controversy, addressing the potential for balanced reporting to undermine medical experts' consensus that no autism-vaccine link exists (Clarke, 2008; Dixon & Clarke, 2013), and the impact of blame-pointers in media discourse about the autism-vaccine link on public behavior (Holton, Weberling, Clarke, & Smith, 2012).

Other scholars investigate the communicative dimensions of autistic identities. Lester and Paulus (2012) analyze how parents and therapists perform (ab)normality in order to frame conceptions of autism for different audiences. Koppers (2008) looks at more artistic performances of autism—including a dance performance and Mark Haddon's novel *The curious incident of the dog in the nighttime*—as a way of analyzing how autism is constructed in different communicative modalities. Such studies of autistic identities suggest implications for autistic identity-politics, a topic which is taken up in studies of neurodiversity. For example, in a first-person account addressing her own experiences as a mother of an autistic child and as an undiagnosed autistic child of an undiagnosed autistic mother, Singer (1999/2002) links autistic identity and self-awareness to the politics of neurodiversity, arguing for a minority politics that

recognizes that “[t]he ‘neurologically different’ represent a new addition to the familiar political categories of class/gender/race” (p. 64). Others take a similar political stance, for instance by using first-person descriptions of autistic identity to support principles of self-advocacy (Savarese, Baggs, Burke, Kochmeister, Rubin, Schwarz, Shore, Sibley, & Thresher, 2010).

A special issue of *Disability Studies Quarterly (DSQ)* on autism and the concept of neurodiversity provides a range of useful and diverse perspectives on autism, autistic identities, neurodiversity, and disability rights that—while not all written by communication scholars—can all be read from a communication studies perspective. Like the communicative approaches described above, several authors here attend to features and social impacts of autistic communication (e.g., Baggs, 2010; Chew, 2010; Donnellan, Hill, & Leary, 2010; Park, 2010; Pentzell, 2010; Prince, 2010; Savarese & Savarese, 2010; Savarese, 2010). However, unlike the discourse studies highlighted earlier, articles in the *DSQ* special issue explicitly question assumptions around communicative competence rather than take them for granted. For instance, Murray (2010) traces the shifting meanings of functioning, drawing on early diagnostic and contemporary cultural discourses “to argue that the notion of function is a fundamental and dangerous simplification of the ways in which autistic presence and intelligence actually manifest themselves.” Baggs (2010) laments the narrow, neurotypical conception of language, likening linguistic barriers to physical barriers that exclude people with disabilities from participating fully or easily in society:

Like counters, stairs, and drinking fountains, language was built mostly by non-autistic people, with the obvious results, and my biggest frustration is this: the most important things about the way I perceive and interact with the world around me can only be expressed in terms that describe them as the absence of something important.

The absence of speech. The absence of language. The absence of thought. The absence of movement. The absence of comprehension. The absence of feeling. The absence of perception.

These and other perspectives on autism in *DSQ* espouse a critical stance characteristic of disability studies while attending to aspects of autistic communication that are of interest to communication scholars.

Other authors in this special issue take a historical approach in linking the neurodiversity movement to the broader disability rights and civil rights movements in the U.S. (e.g., Little, 2010; Ne'eman, 2010). These studies model a social movement perspective on autism and neurodiversity, providing insights on the parallel communicative strategies and social implications across key social movements that have not yet been taken up by communication scholars elsewhere.

Of particular relevance to the present study is research that examines discursive representations of autism and the ways in which these discourses position autistic people within society. Biklen (2005) offers a qualitative study incorporating interviews with autistic individuals labeled 'low-functioning' that push back against prevalent narratives about what it means to be autistic, intellectually impaired, and non-speaking. In a volume edited by Mark Osteen (2008a), communication scholars build on conversations conducted at the 2005 "Representing autism: Writing, cognition, disability" conference. Here, authors engage with representations of autism in clinical contexts, autistic communication, autistic biographies, and popular culture. Extending ideas introduced in her contribution to Osteen (2008a), Nadesan (2005) examines the history of "cultural practices, values, and frameworks for interpretation" (p. 5) that have shaped clinical representations of and approaches to autism.

While the contributions outlined above provide useful perspectives on the communicative dimensions of autism and neurodiversity, they comprise a small and relatively recent corpus of studies within the body of disability literature in communication studies. Because of the general inattention to disability, autism, and neurodiversity within communication studies, there is strong need for more scholars to attend to these topics. The present study looks to do some part in helping fill this gap by providing a study of discourses of autism and autistic discourses that is empirically grounded and critically motivated.



## Chapter 3

### Metatheory: Integrating GPT and CDA

My goal here is to sketch a critical, grounded practical theory of autistic advocacy communication that can contribute practically to autistic advocacy and disability rights more generally. Starting from a strong problem orientation informed by GPT and CDA, the present study aims to foster normative reflection about practical and social problems faced by disability rights advocates. This GPT of emancipatory communicative practice implies both methodological and theoretical stances. Methodologically, it entails a positive reconstruction of the practice aimed at advancing its emancipatory potential along with a negative critique of stigma and inequality informed by critical disability studies. This will be achieved by integrating CDA and action implicative discourse analysis (AIDA), the methodological arm of GPT. Taking such a critical GPT approach enables me to identify practices with emancipatory potential and to interrogate the social mechanisms that negatively impact people with disabilities. Theoretically, this reconstruction and critique are informed by critical and phenomenological theories of disability and communication that are maximally compatible with conceptions of autism, disability, and disability rights evident in neurodiversity discourse.

In this chapter, I describe these metatheoretical stances in more detail. I start with an overview of GPT and the affordances of AIDA. Next, I describe the general aims and assumptions of CDA. Finally, I reflect on the utility of integrating GPT and critical discourse studies.

#### Grounded Practical Theory

Grounded practical theory offers a heuristic for understanding situated practices that is useful in fostering normative reflection about how practices ought to be. According to Craig

(2006), practices are distinguished by three interrelated components: 1) coherent, meaningful activities; 2) normative reflection, including evaluative, aesthetic, and ethical stances that help practitioners plan, coordinate, and perform activities; and 3) normative discourse about activities that help give meaning to action and steer practical conduct (e.g., through instruction, praise, or critique). The term *praxis* captures this conception of practice as “reflectively informed, morally accountable human action” (Craig & Tracy, 1995, p. 249).

GPT studies build practical wisdom by presenting reconstructions of communicative practices, that is, somewhat generalized descriptions that attend to the three interrelated levels of practice introduced above: 1) the technical level, made up of the communicative strategies and discursive resources that actors employ in attending to problems in practice; 2) the problem level, made up of the practical dilemmas that speakers address by communicating in particular ways; and 3) the philosophical level, composed of the normative principles and ideals that speakers use to rationalize actions and weigh trade-offs in practice (Craig & Tracy, 1995). Within this three-dimensional model of practice, problems are pivotal. Practical problems are the catalyst that bring about strategic action and elicit normative reflection. This heuristic thus brings together the discursive and reflective components of meaningful activities in a way that is especially useful for interpretive approaches to the problems inherent to situated communicative practices.

**Action implicative discourse analysis.** Within a GPT framework, discourse analysis is a method for theory building, a means of systematically analyzing the interrelated levels of situated communicative practices in order to elicit normative reflection about how practitioners ought to act in such situations. Action implicative discourse analysis (AIDA) is the methodological arm of GPT (Tracy, 2005). As a method, AIDA involves reconstructing situated

communicative practices at the problem, technical, and philosophical levels. In order to do this, scholars using an AIDA approach first work to understand the situated practice at hand by taking an ethnographic perspective. AIDA researchers use observation, field notes, interviews, and analysis of documents to gain “extensive knowledge” (Tracy, 2005, p. 309) of communicative practices in context. Such knowledge is particularly important for understanding the normative stances that participants use when reflecting on problems in practice.

Next, AIDA studies attend to problems in practice from participants’ points of view, working to understand how different categories of participants in the same practice frame problems from different perspectives. Because problems are so pivotal, identifying and naming problems is a consequential analytical move, one that impacts choices about what discourse should be analyzed and affects where analysts direct blame and attention (Tracy, 2005). AIDA studies focus on moments of conflict in transcripts and texts, and pay particular attention to the ways in which participants name problems in practice.

Developing normative claims grounded in the discursive techniques that participants use to address and understand problems requires that analysts also explore participants’ situated ideals, “beliefs about good conduct that can be reconstructed from discursive moments in which they praise and criticize” (Tracy, 2005, p. 314). In any practice, multiple and often conflicting situated ideals may come into play, so that drawing normative conclusions about future action depends on understanding how participants prioritize different ideals and rationalize acting in ways that may go against explicitly espoused ideals.

The end result of an AIDA study is a rational reconstruction, that is, an idealized model of communicative practice that describes problems, discursive techniques, and beliefs from a range of participant perspectives in general terms. Such reconstructions help analysts to develop

normative models that highlight a broad set of rational and moral principles that are action implicative, that is, useful for normative reflection about how one ought to act in similar situations (Tracy, 2005).

The proposed study aims to present a model of online neurodiversity advocacy communication. To do so, I will analyze the discursive moves that advocates use to attend to problems in three sites of online controversy in light of the situated ideals that inform neurodiversity advocacy. Writing rational reconstructions of neurodiversity advocacy communication in these three conflicts allows me to investigate problems specific to each case, and to consider the problems, discursive strategies, and ideals that characterize online neurodiversity advocacy more generally.

**Expanding the scope of GPT.** Considering different sites of controversy side by side gives a wide-angle view of neurodiversity advocacy communication from which to reconstruct the problem, technical, and philosophical levels of such disability rights practices. Taking this more holistic view of neurodiversity advocacy widens the scope of the present study beyond that typically addressed by AIDA studies. AIDA scholarship generally attends to more micro, situated practices, whereas here I aim to draw connections between related practices. This study also calls for stronger normative principles to be applied than are usually used in AIDA scholarship. Unlike CDA, AIDA does not start with an aim to expose and critique social inequality. Though AIDA studies can account for moral and practical problems that stem from inequality in action, AIDA's participant-focused perspective takes seriously the reasons why inequality is often desirable in practice (Tracy, 2005). For instance, an AIDA study of autism advocacy practices online would likely investigate competing ideals from both self-advocates' and non-disabled advocates' perspectives. Weighing parents' and other non-disabled advocates'

perspectives alongside those of neurodiversity advocates in the cases examined here would highlight ideals around advocacy regarding the value and necessity of normalizing treatments, the need for non-disabled advocates to speak for and act on behalf of people with disabilities, and the value of discourses that position autism as a serious epidemic in fostering awareness and support for educational policies and public health initiatives.

To be sure, understanding these perspectives will also be important to a study of neurodiversity advocacy practices. However, a study of *neurodiversity* advocacy as opposed to *autism* advocacy necessarily prioritizes self-advocate perspectives and neurodiversity ally perspectives over those that are not aligned with the neurodiversity movement. From a neurodiversity perspective, advocacy ideals that position parents, caregivers, educators, and medical professionals as the wards of disabled others go against the disability rights movement ethos of “Nothing about us without us,” and discourses endorsing normalization and characterizing autism as disease position autistic people as less than normal others. From an ND perspective, then, these ideals are part of the problem.

Taking a GPT orientation thus reveals the analytic consequentiality in naming practices. Just as identifying problems leads to particular ways of understanding them, identifying practices impacts how those practices are reconstructed. My rationale in attending to neurodiversity advocacy practices as opposed to autism advocacy practices is linked to my critical approach and explained in more detail below. Because the proposed study prioritizes self-advocate perspectives, it lends itself to a more critical orientation that accounts for social problems that impact the ND community.

### **Critical Discourse Analysis**

While AIDA offers a useful method for investigating situated practices, it does not lend itself to a critical study of inequality at the level of society. Changing the focal scope in this way—moving from looking at situated practical contexts to focusing on wider social problems—involves moving from little ‘d’ discourse to big ‘D’ Discourse (Gee, 2011), from a focus on discursive strategy to a focus on social structure (Fairclough, 2012). This movement is essential to the broad consideration of context within CDA, a perspective that sees context as constituted by communicative practices themselves in addition to the situations, sociocultural and historical circumstances, and ideological and institutional social structures in which they are embedded (van Dijk, 2008). Using AIDA helps me to attend to communicative practices. Combining AIDA with CDA helps me to account for wider discursive, social, and historical contexts as well. While both approaches are grounded in analyses of situated discursive practices, AIDA is aimed at practical theorizing, whereas CDA is aimed at social theorizing.

While AIDA develops normative theories grounded in situated communicative practices, CDA starts with normative assumptions drawn from critical and social theories. Starting from theories of power, ideology, and social inequity “directed at the totality of society in its historical specificity” (Wodak & Meyer, 2009, p. 6), critical discourse analysts aim to understand, critique, and intervene in social processes that perpetuate wrongs in society.

To do this, critical discourse studies investigate how language in use shapes and is shaped by social processes at micro and macro levels of context. Understanding how macro social processes like oppression affect and are affected by semiotic processes in situated communicative practices requires a wide-angle perspective on context capable of accounting for linguistic strategies, discursive techniques, intertextual relationships, and social structures.

Taking such a broad perspective on context positions discourse at local and societal levels and requires tacking between what Gee (2011) calls little ‘d’ and big ‘D’ discourses. At a micro level of context, little ‘d’ discourse is any instance of meaning making in context, including language in use and other non-linguistic semiotic modes like images (Blommaert, 2005). Big ‘D’ Discourse at broader, macro levels of context can be described in terms of the “sets of beliefs that go beyond any individual text” (Tracy, Martinez-Guillem, Robles, & Casteline, 2011, p. 249). These systems of belief are made up of different, interrelated ways of representing the world (Fairclough, 2012)—worldviews that are in turn constituted by semiotic resources that language users employ in little ‘d’ discourses to socially situate themselves and others (Gee, 2011).

Critique is a process of making connections (Fairclough, 1995). Critical discourse analyses trace links between instances of text and talk and the systems of belief that these semiotic practices instantiate, reinforce, and revise as a way of “demystifying ideologies and power through the systematic and *retroductable* investigation of semiotic data (spoken, written, or visual)” (Wodak & Meyer, 2009, p. 3, authors’ emphasis). Like all discourse analytic approaches, CDA studies aim to make explicit connections between the form and social function of communicative practices (Gee & Handford, 2012). However, critical discourse studies distinguish themselves in that they are concerned with the negative social consequences of inequality, that is, the “humanly produced constraints, which in certain respects unnecessarily reduce human flourishing or well-being and increase human suffering” (Fairclough, 2012, p. 10).

Theorizing discourse and society in this way requires that analysts employ an eclectic mix of analytical perspectives. In order to understand the complex connections between discursive forms and social functions, discourse theorists (particularly those engaged in critical

projects) need to bring together whatever tools are useful in attending to different dimensions of discourse (Scollon & de Saint-Georges, 2012). In order to account for such a wide range of contexts, critical discourse theorists bring together linguistic, discourse, socio-psychological, and social theoretical perspectives (Wodak & Meyer, 2009) and employ a variety of different analytic methods (see Blommaert, 2005; Wodak & Meyer, 2009 for overviews of CDA methodologies). Because critical approaches to discourse analysis comprise such a network of various, multidisciplinary, and multifaceted approaches, the term *critical discourse studies* has been suggested as an alternative to *CDA* that emphasizes that CDA is not a single method but a community of scholars who share particular perspectives on discourse and the role of analysis (van Dijk, 2009b). My own methods of analysis continue this eclectic spirit.

While many CDA scholars describe the necessity and benefit of an eclectic approach to critical discourse studies (Wodak & Meyer, 2009; Blommaert, 2005; Fairclough, 2012), there are also difficulties in taking such a varied perspective. It can be challenging for theorists to hold multiple perspectives at once (Martin & Nakayama, 1999), and doing so demands prioritizing some theories over others and critiquing theories in light of alternative claims (Martinez, 2008). At the same time, dialectic approaches that employ multiple and sometimes competing theoretical perspectives are valuable in that they allow scholars to sit with contradictions and tensions between divergent theoretical viewpoints and to cultivate different ways of knowing (Martin & Nakayama, 1999; Martinez, 2008). Taking an eclectic approach also facilitates critical self-reflection, an important component of CDA. Putting different theories and methods in conversation with one another requires that analysts explicitly engage with their own dynamic and shifting stances, a project that can help them to recognize and develop their own analytical assumptions.



**Theoretical starting points: disability studies, stigma, and Levinas' ethics.** Like other CDA studies, mine starts with social theory. More specifically, I'm coming from a critical perspective informed by social theories that are compatible with perspectives espoused by neurodiversity advocates, including disability studies, Goffman's (1990[1963]) understanding of stigma, and Levinas' (1989[1984]) ethics as first philosophy.

***Disability studies.*** Disability studies (DS) is an interdisciplinary field that investigates disability as a social and cultural phenomenon (Goodley, 2011), a complex and central part of the human condition that calls attention to “the ways that the body in its variations is metaphorized, disbursed, promulgated, commodified, cathected, and de-cathected, normalized, abnormalized, formed, and deformed” (Davis, 1997, p. 2). DS takes a critical orientation that recognizes the “ideological and material exclusion of people with labels of physical, sensory or cognitive impairments” (Goodley, 2011, p. xi) as given, and therefore seeks to understand, make visible, and critique ideologies of ability (Siebers, 2011) that position people with disabilities in ways that contribute to such exclusion. This critical perspective is thus highly compatible with a CDA approach.

Understanding disability as a social and cultural construction, DS provides useful perspectives on different ways of understanding disability. Disability theories developed in DS describe models of disability, that is, different conceptions of disability that position people with disabilities in different ways. DS approaches concerned with mapping models of disability (e.g., Goodley, 2011; Grue, 2011; Siebers, 2011) and reconstructing the historical evolution of different conceptions of disability (e.g., Nadesan, 2005; Snyder & Mitchell, 2006) are particularly applicable to the proposed study in that they offer typologies and descriptions of

disability Discourses, that is, classifications and explications of historically situated, cultural conceptions of disability.

Different theorists offer different declensions of disability models, but they generally prioritize medical and social models of disability against other less prominent models like psychological (disability as pathology), cultural (disability as cultural identity), and relational (disability as a relationship between bodies and the environment) models of disability. Medical model conceptions of disability dominate everyday talk about disabilities. Disability categories are primarily constituted in terms of medical definitions that characterize disability as illness or impairment. For instance, like other disabled identities, autistic identities are largely defined by medical diagnoses. While the term “autistic” may signify different things to different people, all ways of being autistic are experiences of autism or autism spectrum disorder (ASD). A Google search for “autism definition” conducted at the time of writing provided two definitions on the page of search results. The first defined autism as “a mental condition . . . characterized by difficulty in communicating and forming relationships with other people and in using language and abstract concepts,” and the second characterized autism as “a developmental disorder that . . . affects the brain’s normal development of social and communication skills.”

In contrast to such medical understandings of disability as “condition,” “disorder,” and deviation from “normal development,” a social model understanding defines disability as a social construct (Oliver, 1996) or way of categorizing human experiences and embodiments in relation to hegemonic conceptions of normalcy (Davis, 1997). Many scholars position the social model of disability as central to a disability studies perspective (e.g., Goodley, 2011; Oliver, 1996). While the medical model defines disability as disease that causes “difficulty” or “affects” individuals, the social model defines disability in terms of “the social barriers, restrictions and /or

oppressions [disabled people] face” (Oliver, 1996, p. 10). From a social model point of view, it is not impairment that prevents people with disabilities from enjoying full inclusion in society, it's society that excludes disabled social actors from full economic, social, and political engagement (Oliver, 1996). This shifts the onus of responsibility for inclusion from individuals with disabilities to society. While the medical model rests responsibility to “get better” on individuals with disabilities and positions them as targets for treatments and rehabilitation, the social model argues that society is responsible for accommodating differences and positions disabled people as agents entitled to equal opportunity to engage in society.

The social and medical conceptions of disability are Discourses engaged in a process of struggle in both theoretical and political practices. They are dominant—and conflicting—models of disability that position social actors in consequential ways. In academic circles, this discursive struggle is evident in debates between social model advocates and scholars who critique the ways in which prioritizing social conceptions of disability downplay and often ignore the embodied experience of disability (Hughes, 2007; Shildrick, 2009). In political practices, discursive struggle is evident in disability rights and policy discourses that push for social model conceptions of disability and explicitly challenge medical model understandings. Social perspectives are central to disability policy discourse in the U.K. (Oliver, 1996) as well as the UN treaty on the Council for the Rights of People with Disabilities (United Nations, 2012), which

takes to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The neurodiversity movement also promotes a social model perspective by placing a focus on acceptance, challenging the idea that autism should be cured, and critiquing social mechanisms that prevent the full inclusion of autistic people in society.

*Stigma.* Stigma constitutes one primary mechanism that marginalizes disabled people in society, and it is a central concern for DS scholars as well as disability rights advocates. Stigma is the construction of deviancy, the attachment of undesirable difference onto particular social actors and ways of being that works to justify discrimination and social exclusion (Goffman, 1990[1963]). As Goffman (1990[1963]) points out, stigma is a relational attribute, one that is constructed alongside conceptions of normalcy and that describes a discrepancy between expected, ‘normal’ identities and actual social identities. Many DS studies interrogate the social construction of stigma and normalcy and point to the material consequences of stigmatizing discourses. For example, Davis (1997) examines what he calls “the hegemony of normalcy” (p. 23) by tracing the modern cultural construction of ‘normal’ categories evident in literature through the rise of modern industry and the power of the bourgeoisie. Here, Davis describes how conceptions of normal came to be associated with conceptions of ‘average,’ and how this in turn shaped industries around average workers. Accommodating the average worker led to the inaccessible construction of industries and workplaces, material instantiations of the ideal of the average that further reinforced the stigmatization of disabled people as deviant in their inability to work or to be ‘productive’ members of society. Other scholars also address how the hegemony of normalcy impacts people with disabilities, for instance by compelling them to pass as nondisabled (Siebers, 2011; Swain & Cameron, 2002).

Interrogating and challenging stigma is evident in disability rights advocacy discourse. Campaigning for equal rights for people with disabilities goes hand in hand with exposing and

dismantling stigma around disability. Self-advocates in the broader disability rights movement and those aligned with the neurodiversity movement offer particularly pointed critiques on how stigma impacts their lives and explicitly challenge stigmatizing ideologies that position disabled identities as less than nondisabled ways of being. For example, People First organizations—organizations of self-advocates who were instrumental in beginning the disability rights movement in the U.S.—position stigma as the primary impediment to disability rights. These organizations take their name from an anonymous self-advocate’s appeal at the first conference organized by and for people with disabilities in 1974. Stressing that “I’m tired of being called retarded. We are people first.” (People First Spokane Valley, 2005), this self-advocate helped to define the inchoate disability rights agenda in opposition to discourse that positions people with disabilities in terms of stigmatized identities capable of obscuring personhood. Neurodiversity advocacy also pursues an anti-stigma agenda by “directly challeng[ing] the ‘autism as tragedy’ paradigm” (Sinclair, 2005, p. 17) and working to “improve public perceptions of autism” (ASAN, 2015a).

*Levinas’ ethics.* Levinas’ ethics as first philosophy (1989[1984]) offers another useful theoretical perspective through which to understand stigma. Levinas takes a phenomenological approach concerned with open and ethical engagement with otherness. The phenomenological tradition defines communication in terms of an experience of otherness (Craig, 2007[1999]), dialogue that transcends the ineffable and insurmountable difference between social actors (Chang, 2007[1996]). In phenomenological terms, stigma impedes genuine dialogue between people with disabilities and non-disabled people. Stigmatizing ideological beliefs position people with disabilities as non-persons (Goffman, 1990[1963]), thereby constituting Discourses that narrowly restrict disabled persons’ ability to engage in dialogue with non-disabled others.

For example, discourses that describe autism in terms of incommunicability rely on stigmatizing beliefs that bar autistic people from interacting with neurotypical others. These stigmatizing discourses position autism at the boundary between communication and “communication breakdown or a malfunctioning communication system” (Pinchevski, 2005, p. 165). This is an epistemological boundary built on a conception of autism as pathology and neurotypical communication as normal, healthy. “[P]redicating normalcy and sociability upon communicability . . . and deeming the incommunicable aberrational and hostile” (Pinchevski, 2005, p. 187), dominant conceptions of autism position autistic others “in a world of their own.”

Neurodiversity advocate Mel (née Amanda) Baggs (2007) describes how she and other autistic and cognitively disabled people are relegated to the realm of incommunicability due to their (occasional or constant) inability to communicate in neurotypical ways. Baggs, a non-speaking autistic advocate who campaigns for autism acceptance and disability rights through YouTube videos and blog posts, describes her way of thinking and interacting with the world as her own language, “a constant conversation with every aspect of [her] environment [through which Baggs reacts] physically to all parts of [her] surroundings.” As shown in her YouTube video entitled “In my language” (2007), this conversation consists of repetitive movements like rocking and hand flapping, humming, pacing, and physically interacting with textures. In her “translation or at least explanation” of her language, Baggs’ describes her language as a form of communication with “everything around [her]” that is more open than neurotypical communication that requires people to “interact with a much more limited set of responses and only react to a much more limited part of [their] surroundings.” Dominant discourses characterize such open communication as being cut off from communicating with others, as “being in a world of [one’s] own.” Baggs points to the irony that it is only by communicating in

“more limited,” neurotypical ways that “people claim that [she is] ‘opening up to true interaction with the world.’” She notes how

failure to learn [neurotypical] language is seen as a deficit but failure to learn my language is seen as so natural that people like me are officially described as mysterious and puzzling rather than anyone admitting that it is themselves who are confused, not autistic people or other cognitively disabled people who are inherently confusing. We are even viewed as non-communicative if we don’t speak the standard language, but other people are not considered non-communicative if they are so oblivious to our own languages as to believe they don’t exist.

The dehumanizing impact of being assumed to be “in a world of [one’s] own” (Baggs, 2007) is great. Baggs describes how, as a non-speaking autistic person, “the way [she] naturally think[s] and respond[s] to things looks and feels so different from standard concepts or even visualization that some people do not consider it thought at all, [though] it is a way of thinking in its own right” (Baggs, 2007). Underscoring the stigmatizing effect of such perceptions of autistic otherness, Baggs relates how “people doubt that [she is] a thinking being and since their definition of thought defines their definition of personhood so ridiculously much they doubt that [she is] a real person as well.” Relegating autistic ways of thinking and interacting outside the realm of “true interaction” (Baggs, 2007)—that is, neurotypical interaction—thus defines personhood in terms of ‘normal’ ways of thinking and acting, and positions autistic others in relation to “real [people] . . . adult[s] . . . intelligent [people]” (Baggs, 2007). Baggs emphasizes the serious effects of such stigmatizing beliefs by calling attention to the violence that accompanies a perceived lack of personhood. “In a world in which [being real, adult, or intelligent] determine whether you have any rights, there are people being tortured, people dying because they are considered non-persons” (Baggs, 2007).

Levinas provides a useful perspective from which to understand and undermine such stigmatizing perceptions. For Levinas, genuine communication is an encounter with incommunicability in that recognizing another's personhood requires engaging with their unknowable alterity. Incommunicability is therefore what makes communication possible (Pinchevski, 2005).

This experience of otherness occurs prior to speech. For Levinas, language marks a move away from true connection in that putting into words constitutes objectification that prevents genuine experience with another. In his view, genuine dialogue occurs when one is simply confronted with the face of the other (an experience that does not require that the other be seen nor interacted with). This is only possible if one is open to vulnerability. In a vulnerable state, a person feels interrupted by the presence of another who calls them to account. Recognizing the other's vulnerability that mirrors their own, the person feels a guiltless responsibility for the other's oppression.

Taking a Levinasian perspective, Baggs' (2007) autistic way of thinking and responding to her environment confronts neurotypical others by way of interruption. Hers is a way of engaging with the world that calls neurotypical others into account. Watching Baggs' (2007) YouTube video open and vulnerable, I recognize that her embodied language is not "non-communicative" and allow myself to be confronted by her face. This causes me to feel myself implicated in the social processes that work to excommunicate autistic others to the realm of incommunicability. This guilt, in turn, leads me to take responsibility for any "incommunicability," rather than expect Baggs to communicate in neurotypical ways. Levinas' (1989[1984]) ethical framework is thus able to account for non-neurotypical ways of thinking, being, and communicating. It also provides an ethical perspective that helps address the question



of inclusion with regard to people with cognitive disabilities, a question that is often side-stepped in DS studies that tend to focus on physical impairment (Harris & Lewan, 1998).

Theories of disability central to disability studies, Goffman's social theory on stigma, and Levinas' ethics as first philosophy provide a theoretical grounding from which I'm able to theorize Discourses and social practices in the proposed study. As I've tried to show above, I'm starting from theoretical assumptions that are maximally compatible with the political practices at the heart of my analysis. Drawing connections between these theoretical and political practices (between formal theorizing and practical theories evident in advocacy discourse) facilitates productive oscillation between theory and data analysis, a movement between theoretical entry points and analytic avenues capable of contributing to formal theoretical perspectives.

**The emancipatory potential of CDA.** All of the theoretical perspectives outlined above help to shape my critical project not only by offering social theory starting points, but by informing my politics as well. Like other critical discourse analyses, mine is a political project, one that "aims to investigate critically social inequality as it is expressed, constituted, legitimized, and so on, by language use (or in discourse)" (Wodak & Meyer, 2009, p. 10). CDA studies are concerned with exposing, understanding, and intervening in processes that impede social justice (Fairclough & Wodak, 1997). By reconstructing the relationships between society and discourse, CDA scholarship works to "produce and convey critical knowledge that enables human beings to emancipate themselves from forms of domination through self-reflection" (Wodak & Meyer, 2009, p. 7). By reconstructing the relationship between stigma and discursive practices, the present study looks to contribute knowledge capable of contributing to the emancipatory potential of neurodiversity advocacy. This project draws on my own political

position as a neurodiversity and disability rights advocate and thus expands on the normative stance espoused by GPT.

Like GPT, CDA starts with a problem-orientation and communicates a normative perspective about what ought to be done. But while in GPT, problems and normative ideals emerge out of participant perspectives in the practices studied, in CDA, the analyst takes a stronger critical stance from the outset, espousing an “[interest] in the way discourse (re)produces social *domination*, that is, the *power abuse* of one group over others, and how dominated groups may discursively *resist* such abuse” (van Dijk, 2009a, p. 63, author’s emphasis). CDA is a form of dissent (van Dijk, n.d.), scholarly discursive resistance to the social and discursive mechanisms that constitute systems of injustice and oppression that impede human flourishing (Fairclough, 2012).

It bears emphasizing that critique of social inequality in CDA focuses attention on both oppression and resistance. Critical discourse analysts recognize that power can have both progressive and repressive social effects (Mills, 2003), and that politics are constituted not only by struggles for power but also by cooperation (Chilton & Schäffner, 2002). Like other critical approaches, CDA is often defined in terms of its focus on power with regard to oppression. And many (if not most) CDA scholars do attend to semiotic mechanisms of dominance and power abuse in an effort to expose hegemonic discourses and their impact on society (e.g., Fairclough’s (2010) focus on capitalism in the neo-liberal era). However, critical discourse analysis is also a means of amplifying marginalized discourses and contributing to discursive resistance.

Texts are often sites of struggle wherein discourses and ideologies vie for control (Wodak & Meyer, 2009). Such struggle is intrinsic to discursive transformation, the processes by which “the reality of discourse and the discourse of reality . . . [is] changed” (Shi-xu, 2007, p. 6). In

order to bring about discursive transformation, it's important that "researchers . . . take the initiative to proactively and creatively participate in changing [what they research]" (Shi-xu, 2007, p. 6), that is, unjust social domination. This requires that analysts attend not only to dominant discourses, but that they also work to "reclaim, valorize, and empower" (Shi-xu, 2007, p. 9) repressed discourses. Amplifying dominated discourses in this way "helps correct biases derived from the dominance of particular perspective[s] over the definition of problems or their possible solutions" (Young, 2000, p. 83).

Shi-xu (2007) is particularly critical of bias due to the dominance of particular perspectives in discourse analysis (DA) and the lack of non-Western perspectives in DA. This point is well taken with regard to CDA scholarship. Most critical discourse studies expose, examine, and critique dominant Western discourses in an effort to help dismantle oppressive social mechanisms. While this is a vital project, it is also crucial that critical scholars analyze, evaluate, and boost non-dominant discourses in order to help resist and overcome hegemonic social structures. Not only are non-Western and marginalized perspectives underrepresented in DA (Shi-xu, 2007), so are disabled points of view (Grue, 2011). To come at discursive transformation from both sides, so to speak, it is necessary that scholars attend more to these discourses of resistance to offset the privileging of oppressive discourses as objects of analysis.

In the present project, I aim to help correct this analytical bias by pro-actively contributing to discursive transformation in sites of struggle. The texts studied are all sites of discursive conflict where non-dominant advocacy discourses and neurodiversity ideologies struggle against dominant autism and disability discourses and neurotypical ideals. Tracing interdiscursive connections between texts and reconstructing situated practices across controversies is a way of mapping an active sphere of resistance. While analyzing the dominant

discourses that neurodiversity advocates oppose will be part of the project, I also analyze the opposition itself in order to contribute a grounded practical theory of neurodiversity advocacy that might be useful for ND advocates and other disability rights advocates. This will entail a rational reconstruction of resistance—an analysis that works to expose, examine, and critique marginalized discourses in order to better understand how they answer to, fight, and reproduce dominant, stigmatizing discourses.

Focusing on neurodiversity advocacy as opposed to autism advocacy is linked to my own political position as a neurodiversity and disability rights advocate. This project looks to amplify marginalized voices by reconstructing practices from disability rights perspectives and critically analyze advocacy discourse in order to grow the emancipatory potential of the neurodiversity movement. This political goal is commensurate with the political aims of CDA, as well as those of disability studies that seek to make visible and critique ideologies that position people with disabilities in ways that contribute to their oppression in society (e.g., Davis, 1997).

### **Taking a Synthetic Approach: Integrating Grounded Practical Theory and Critical Discourse Studies**

Taking a synthetic approach that integrates interdisciplinary and transdisciplinary perspectives can offer new and potentially more useful and apposite insights to examinations of discourse (Blommaert, 2005). Bringing together GPT and CDA with an eclectic mix of theoretical perspectives is a novel synthetic approach that highlights unexplored theoretical complementarities and that combines participant and analyst points of view in useful ways.

Grounded practical theory and critical discourse analysis complement each other in a variety of ways. To start, both approaches are problem-centered. AIDA studies begin by identifying problems in situated practices. CDA studies start by identifying oppressive social

problems. Integrating these problem orientations allows analysts to account for problems in micro and macro contexts, and to intervene by fostering normative reflection, dismantling dominant discourses, and amplifying marginalized voices. Such a synthetic approach also brings together different analytical assumptions that help scholars to address struggles at philosophical and technical levels of practice.

Adopting GPT's understanding of practice and concern with practical problems reveals tensions at the philosophical level. As discussed, GPT studies foster normative reflection by reconstructing the situated ideals that actors orient to in order to attend to problems in practice. This normative approach resists explicitly evaluating the goodness or reasonableness of different situated ideals. Rational reconstructions in AIDA studies offer reflexive perspectives that can be incorporated into practices, not firm recommendations about how act. AIDA studies tend to set competing situated ideals on relatively equal footing in order to suggest trade-offs and strategies for communicators' consideration. While making decisions about how to act by weighing ideological tensions and choosing between competing goals is something that practitioners must do, from a GPT perspective there are no hard and fast rules for how to communicate or what ideals to attend to that can be applied to all contexts.

Adopting CDA's understanding of Discourse and concern with social problems provides insight about discursive struggle at technical and philosophical levels of practice. As mentioned above, CDA frames discursive practices as sites of struggle where dominant discourses exert hegemonic control and marginalized discourses push back. From this perspective, discursive techniques are not neutral, rather "human discourses in the contemporary world . . . are *sites of cultural contest*" (Shi-xu, 2007, p. 4, author's emphasis) that are differentiated according to status, power, cultural affiliation, historical background, form, and function (Shi-xu, 2007).

Discourses exist in dialectical relationships with competing Discourses, and “texts are often sites of struggle in that they show traces of differing discourses and ideologies contending and struggling for dominance” (Wodak & Meyer, 2009, p. 10). Analyzing texts thus requires taking into account the ways in which discursive techniques are bound up with political interests, and engaging in struggles where power relations are not equal. Approaching the technical level of practice from a CDA perspective thus positions some political interests as more valid and desirable than others.

Contentious ideologies and political values evident in texts can also be reconstructed as situated ideals, principled presuppositions that communicators prioritize in practices. However, approaching the philosophical level of practices from a CDA perspective suggests different assumptions about social actors and ideals from those suggested by GPT. Taking a GPT perspective positions social actors as choice-making agents whose actions are imbued with a fair amount of good faith. GPT studies generally assume that communicators weighing ideological assumptions are well-intentioned actors doing the best they can to balance trade-offs in practice. CDA takes a stronger normative stance and attends to practices in which not all ideological positions are morally justified and in which discourses work to oppress and empower social actors whether those actors mean well or not. While CDA studies are concerned with actors’ strategic choices, they also attend to the structural constraints that help to shape actors’ discourse in ways they may have little control over or awareness of (Chilton & Schäffner, 2002). Combining a rhetorical understanding of communication as strategic action with a semiotic conception of communication as “mediation by signs” (Craig, 2007[1999], p. 74), CDA studies position social actors both as agents of social change and pawns of dominant Discourses.

Examining the ways in which GPT and CDA position social actors differently points to the theoretical complementarity of these two perspectives. Both draw on rhetorical assumptions that understand communication as a practical art with powerful social impact (Craig, 2007[1999]). Both are concerned with analyzing discursive strategies, and both approaches attend to the social consequences of discourse. Taking a GPT perspective helps critical discourse analysts to pay attention to the creative, rhetorical force of discourse alongside the constraining effects of signs propagated through discursive processes. Integrating GPT with CDA, then, helps critical analysts to avoid the tendency to privilege structure over agency (Blommaert, 2005). Such a synthetic approach also expands GPT analysts' understanding of the mechanisms that shape the technical level of practices to include both rhetorical impulses and semiotic processes.

Integrating GPT and CDA thus allows me to look at structural problems and political goals in neurodiversity advocacy practices. Utilizing GPT reveals tensions between competing situated ideals that draw on equally legitimate conceptions of autism, disability, and disability rights. Adopting CDA's critical stance calls attention to oppressive ideologies. Analyzing ND advocacy therefore offers a unique opportunity to both break down dominant discourses and amplify marginalized ones. ND advocates' online discourse can be read as a kind of practical CDA itself aimed at exposing and undermining stigmatizing discourses. Neurodiversity advocacy is a form of dissent against oppressive worldviews that impede the well-being of people with cognitive disabilities. However, ND advocacy is also marked by traces of stigma and conflicting Discourses. The present study contributes to neurodiversity's political project and at the same time critiques ND discourse. Reconstructing advocacy practices serves the goal of informing future emancipatory actions by offering accounts of 1) how ND advocates are working

to challenge stigmatizing ideologies, and 2) how ND advocates are also (often unintentionally) reproducing and reinforcing stigmatizing ideologies.

Combining GPT and CDA also brings together complementary conceptions of social influence that help analysts to take into account not only discursive but also cognitive components of social change. From a CDA perspective, ideologies come to shape social structures by being shared across groups of individuals (van Dijk, 2009a). Van Dijk's (2009a) sociocognitive approach theorizes the relationship between discourse and society as a triangle wherein mental models—cognitive models that represent the social structures that participants take to be relevant to the situation at hand—“mediate between discourse structures and social structures at all levels of analysis” (p. 66). From this point of view, “*there is no direct link between discourse and ideology*” (van Dijk, 2009, p. 79, author's emphasis). Rather, ideologies expressed in discourse help to build social cognition, mental representations of knowledge, values, norms, and beliefs that are shared across members of social groups.

Bringing in a GPT perspective provides analysts with a useful framework for understanding the ways in which individuals mediate between discourse and ideology. The philosophical level of practice in GPT's three-dimensional model can be understood as constituting the crucial cognitive interface between discourse and society. Integrating a sociocognitive perspective on discourse with a GPT perspective on practice, situated ideals can be interpreted as elements of social cognition that help to position individuals in society. Taking a CDA perspective while reconstructing situated ideals that impact communicative practices provides some insight into how individual cognitive models connect to larger, socially shared belief systems. Incorporating GPT with CDA thus responds to Van Dijk's (2009a) call for



critical discourse analysts to incorporate an understanding of cognitive models in order to understand the integral cognitive processes that mediate discourse and society, text and context.

Integrating GPT and CDA is also useful for bringing together a variety of participant points of view, including those of both research subjects and researchers themselves. Grounded practical theories of situated practices emerge out of subjects' perspectives. Reconstructing practices from participants' points of view requires that researchers bracket their own perspectives in order to take different, often competing participant positions seriously, and to weigh participants' various situated ideals equally. In contrast, critical discourse analyses start with theoretical perspectives and prioritize analysts' political points of view. Integrating participant perspectives with analysts' theoretical and political points of view can be a productive combination that fosters dialogue between researchers and subjects and between different ways of knowing.

Further, bringing together participant and analyst perspectives in this way builds a strong, nuanced normative stance. While both GPT and CDA are aimed at fostering normative reflection, CDA goes a step further in moving from reflection to intervention. Critical discourse studies recognize "[t]he social embeddedness of research and science, . . . and [the fact] that criticism can by no means draw on an outside position but is itself well integrated within social fields" (Wodak & Meyer, 2009, p. 7). In addition to espousing an unapologetically political stance (Wodak & Meyer, 2009) that allows researchers to 'take sides' in weighing participant perspectives, CDA is a method for intervening in the practices studied. In contrast, grounded practical theories are frameworks for reflecting on practices studied. GPT studies are useful for making visible the equally necessary but not necessarily compatible (and often competing) situated ideals that shape communicative practices. Prioritizing particular ideals over others is a

process of weighing context-specific pros and cons, making choices between equally desirable courses of action, and holding contradictory beliefs simultaneously. By combining GPT and CDA, analysts can engage with this dialectical thought process and sit with different ways of seeing the world that call attention to problems from the point of view of different participants' social realities (Martin & Nakayama, 1999).

Finally, integrating CDA and GPT is a metatheoretical project that allows me to interrogate the epistemological assumptions underlying each approach, and to engage in normative reflection about my own scholarly commitments. This has the potential to move my thinking toward “a genuinely pluralistic and dialectical mindset that may drastically reduce the domination of [my] own . . . cultural preferences as well as proclivities toward a unitary or singular understanding of anything” (Martinez, 2006, p. 294).

## Chapter 4

### Methods and Materials

To operationalize the complementary yet quite different theoretical perspectives outlined in chapter 3, I'm employing a GPT heuristic for elucidating practices and integrating aspects of AIDA with CDA methods. In this chapter, I sketch an outline of these synthetic discourse analytic methods and an overview of the materials at the heart of the study.

My methods involve tracing Discourses of autism and disability rights in neurodiversity advocacy practices in an effort to understand and interrogate the discursive mechanisms that contribute to stigma, inclusion, and emancipatory social change for autistic people. Unweaving conceptions of autism and disability evident in neurodiversity discourse is a process of unraveling colluding and contradictory models of disability and analyzing the ways in which different models are used to reproduce, challenge, and change stigmatizing and emancipatory ideologies.

This (re)constructive critique explicates advocates' emancipatory aims in order to evaluate the extent to which neurodiversity advocacy practices advance and undermine espoused political goals. I am interested in advocates' strategic use of language to dismantle stigma around autism and expand disability rights, and I will also be looking to expose elements of ND discourse that point to, or index, stigmatizing discourses and convey hegemonic ideologies in spite of advocates' orientation to emancipatory ideals. Though I generally view neurodiversity advocates as choice-making agents acting in good faith, I am conscious of the ways in which well-intentioned actors can (often unconsciously and unintentionally) reproduce traces of hegemonic discourses and thereby contribute to the same oppressive social processes they are trying to oppose. Such traces are points of convergence that join Discourses in sites of struggle.

Marginalized and oppressive worldviews evident in discursive struggles exist in dialectic relationships with each other (Shi-xu, 2007). They are “interpenetrated” (Shi-xu, 2007, p. 6) in the sense that they share certain ideological assumptions in spite of their oppositional orientation.

Charting the paths of dominant and marginalized ideologies across situated practices is a way of surveying sites of struggle by “analyzing opaque as well as transparent structural relationships of dominance, discrimination, power and control as manifested in language” (Wodak & Meyer, 2009, p. 10). Explicit ideologies and intentional discursive strategies constitute transparent structural relationships. Implicit ideologies and unintended social consequences constitute opaque structural relationships. In the proposed study, transparent relationships evident in discursive practices include neurodiversity advocates’ explicit opposition to stigmatizing discourses and endorsements of autism acceptance. Opaque relationships are evident in the ways in which hegemonic, ableist discourses are inadvertently reproduced by advocates.

Integrating GPT and CDA involves uncovering, reconstructing, and critically reflecting on competing situated ideals, implicit ideologies, and the Discourses they index. By conducting a close examination of dominant autism discourse and neurodiversity advocates’ resistant discursive strategies, I aim to get at social and practical problems that affect advocacy practices, and to reflect on the ways in which neurodiversity discourse builds and impedes autism acceptance in the U.S. today.

The present analysis offers a unique and valuable perspective on neurodiversity—an ethnographically informed, critical discourse analysis (CDA) grounded in contemporary autism discourse and online advocacy practices. This project answers the need for more discourse-

oriented studies on disability (Grue, 2011) and addresses topics that haven't been much explored in communication or disability studies.

### **Controversy Case Studies**

Starting with the problem level of practice, AIDA studies begin by identifying “moments in which participants seem to be experiencing discomfort, tension or conflict” (Tracy, 2005, p. 310). This study starts the same way, by focusing on controversies of concern to ND advocates. All of these controversies are chiefly situated in virtual contexts.

The three case studies described in more detail below can all be understood as sites of struggle composed of interconnected advocacy practices. In all of the controversies at hand, neurodiversity advocates attend to problems of inclusion and acceptance for autistic people and other people with disabilities. At the problem level, neurodiversity advocacy discourse can be broadly understood as attending to the continued need for disability rights, particularly those that enable accommodation for autism and other cognitive disabilities grouped under the neurodiversity banner. At the technical level, online neurodiversity discourse is characterized by appeals for autism acceptance and rallies against stigma with the ultimate aim of advancing disability rights from autistic perspectives. At the philosophical level, neurodiversity advocacy orients toward emancipatory ideals of full inclusion for autistic and other disabled ways of being, thinking, and communicating. Neurodiversity—the idea that “everyone has a different mind, a different way of being” and that one should not “suppress these differences [but] accept and support them” (Camley, 2005)—is an ideal that informs advocacy practices and also holds interesting implications for disability rights and communication and disability theorizing.

#### **Controversy 1: Opposition to Autism Speaks**

The first controversy is a conflict between the neurodiversity community and Autism Speaks (AS). In this controversy, neurodiversity advocates have used flash blogs, twitter bombs, and online petitions alongside other discursive techniques to protest Autism Speaks' advocacy practices, arguing that AS' characterization of autism, their goal of curing autism, the lack of autistic perspectives in AS, and their budgetary decisions are problems that hurt public perceptions of autism and impede autism rights.

According to their website's *About Us* page, Autism Speaks (AS) is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. (Autism Speaks, 2014b)

AS is a prominent U.S. autism advocacy group with widespread international affiliations and a presence in Washington. Bob Wright—a former vice chairman and executive officer of General Electric and president and CEO of NBC Universal—founded AS with his wife Suzanne a year after their grandson was diagnosed with autism. Since its founding in 2005, AS has established itself as a high-profile autism advocacy organization with considerable “fundraising power” (Robison, 2013b). In its first year, AS raised over \$1.95 million, an amount that Wright referred to as “just the beginning,” stressing that “[w]e need to raise hundreds of millions in order to make a difference” (Autism Speaks, n.d.a).

To accomplish this goal, Autism Speaks has grown into an internationally recognized and well-sponsored organization. To raise awareness about autism and their mission, AS uses “media blitz[es]” (Autism Speaks, n.d.a) and international efforts like the Light It Up Blue campaign, in which “Autism Speaks . . . ask[s] buildings and landmarks around the world to turn their lights

blue” (Autism Speaks, n.d.b)<sup>3</sup> during the month of April—Autism Awareness Month. These high profile campaigns have also garnered significant corporate sponsorship. 48 “Corporate Partners/Friends,” including 36 television networks and several major U.S. business chains, are listed on the Light It Up Blue website (Autism Speaks, 2005-2012). Autism Speaks has also worked to establish an international presence and political influence. AS completed several mergers within its first two years, joining with the Autism Coalition for Research and Education, the National Alliance for Autism Research, and Cure Autism Now to “[create] a powerful national organization devoted to autism with chapters across the United States, Canada, and the U.K.” (Autism Speaks, n.d.c). In 2008, the organization started a Global Autism Public Health initiative to expand partnerships and “[increase] global awareness, services and research collaboration” (Autism Speaks, 2013f) in 42 countries. AS has also hosted several World Focus on Autism events, gathering first spouses and international dignitaries in an effort to “[promote] autism awareness and [highlight] autism as a global public health issue” (Autism Speaks, 2013c).

In the U.S., AS is actively involved with state and national policymaking. Autism Speaks executives have testified before congressional committees (Autism Speaks, 2012a) and traveled the country building local coalitions including influential “autism stakeholders” like state representatives and national disability and education organization chapters (Unumb, 2013). In November 2013, the organization held a national policy and action summit in Washington, D.C., including speakers House majority leader Eric Cantor and “several other top lawmakers and experts in the field of autism advocacy and research” (Autism Speaks, 2013c). The summit, Autism Speaks to Washington, introduced AS’ state and federal advocacy strategy and involved a “take over [of] the nation’s capital with lobby visits to all 535 members of Congress, delivering

---

<sup>3</sup> The Light It Up Blue flyer for April 2, 2013 shows pictures of the Empire State Building, the Christ the Redeemer statue in Rio de Janeiro, and Niagra Falls lit up blue. (Autism Speaks Light It Up Blue, n.d.)

petitions from every state in the nation and a unified call to action on the national plan to address autism” (Autism Speaks, 2013c).

Autism Speaks is organized around “four pillars: awareness, advocacy, science research, and family services” (Advancing Futures for Adults with Autism, 2014). Research programs comprise the largest percentage of the organization’s budget. “In the area of science, more than \$200 million have been donated to researchers all over the nation” (Autism Speaks, 2013g).

Research initiatives include a National Autism Database, a

national online autism database [meant to] serve as a shared resource to centralize registration of families and individuals with autism spectrum disorders and connect them with researchers, parents and other individuals with autism throughout the country and the world. (Autism Speaks, 2006b);

clinical programs like the Autism Treatment Network, “a place for families to go for high quality, coordinated medical care for children and adolescents with autism and associated conditions” (Autism Speaks, 2013d); the Autism Genetic Resource Exchange (AGRE), “a repository of biomaterials and phenotypic and genotypic data to aid research on autism spectrum disorders” (AGRE, 2013); the Autism Tissue Program (ATP), a repository of brain donations started in 1998 (ATP, n.d.); and the Interactive Autism Network (IAN), “a unique source of information about autism and autism research based on the latest scientific findings” (IAN, n.d.).

While AS is arguably one of the most prolific autism advocacy organizations worldwide, neurodiversity advocates argue vehemently that “Autism Speaks does not speak for autistic people” (e.g., Gardiner, 2012). For the last several years, the neurodiversity movement has actively worked to counter AS claims about autism, critique AS initiatives, and inform the wider public and AS’ corporate sponsors about why they should “boycott Autism Speaks” (Boycott Autism Speaks, 2013). The neurodiversity community takes issue with the ways in which AS



discourse characterizes autism, AS' explicit orientation to a medical model understanding of disability and its search for cures for autism, the ways in which AS allocates its budget, and the lack of autistic perspectives within AS. Critiques of AS ad campaigns like the 2009 Autism Speaks ad "I am autism" focus on "Autism Speaks' choice to use fear, stigma, misinformation and prejudice against Autistic people" (ASAN, n.d.c) in its appeals for support. Many neurodiversity advocates refer to the organization as "Autism \$peaks" or "A\$" (e.g. Ianthe, 2014) to call attention to "the huge sums of money Autism Speaks raises from local communities as compared to the miniscule sums it gives back" (ASAN, n.d.c). Because the neurodiversity movement stands in opposition to medical model approaches oriented toward finding a cure for autism, neurodiversity advocates also critique the fact that AS spends the majority of its funding on biomedical research and efforts to find genetic causes and cures for autism. Many ND advocates also argue that Autism Speaks "claims to advocate for autistic people without inviting [them] to speak" (Gardiner, 2012).

Because Autism Speaks is so high-profile and well-funded, it's able to shape conceptions of autism in ways that neurodiversity advocates find particularly problematic. In addition to likening autism to a disease in need of a cure, AS positions itself in a "battle against autism" (AS, n.d.a), fighting a rising "autism crisis" (Wright, 2013). This crisis is often characterized by tragedy and hardship. AS' video "I am Autism" (AS, 2009b) presents this battle as a struggle between autism itself and those who fight on behalf of children with autism. Neurodiversity advocates argue that this discourse perpetuates misunderstanding and stigma rather than autism awareness. ND advocacy around Autism Speaks thus consists of counter-discourses that push back against AS claims and work to spread awareness about autistic perspectives and autistics' opposition to Autism Speaks.

**Corpus 1: AS discourse and ND counter-discourse.** In chapter 5, I offer a critical discourse analysis of dominant discourses in an effort to expose the ways in which mainstream representations of autism position autistic people in public discourse. This analysis draws from a large corpus of AS online discourse and neurodiversity advocates' online counter-discourse. This corpus consists of two data sets: 1) background data on Autism Speaks and the neurodiversity community's opposition to AS, and 2) data pertaining to the neurodiversity community's ongoing protests against AS' recent summit in Washington D.C. The first data set is built primarily around Autism Speaks' website and affiliate sites, neurodiversity advocates' blog posts against Autism Speaks, online petitions, and online actions against AS coordinated by the Autistic Self Advocacy Network. The second data set emerged out of a closer investigation of AS discourse about the Washington summit along with the neurodiversity community's responses. The neurodiversity movement's opposition to the AS summit began before the summit took place and continued into 2014. In addition to AS ads, flyers, blog posts, and promotional articles, this data set incorporates a wealth of neurodiversity advocacy discourse including online petitions, tweets, and blog posts protesting Autism Speaks and the Washington summit, as well as the sustained #BoycottAutismSpeaks Twitter campaign targeting AS sponsors, and its affiliate blog (Boycott Autism Speaks, n.d.) and Facebook pages (Boycott Autism Speaks, 2015). The table below provides an overview of text types and totals from the AS case study corpus. These totals reflect the number of texts that comprised the core corpus, but snowball text sampling conducted during analysis and writing increased these numbers somewhat as I followed links and references to other texts that were not subsequently added to the corpus archive.

Table 1: Autism Speaks case study corpus overview

Description	Text types	Total number of texts
<b>Data set 1: Background information on AS and ND opposition</b>		
Autism Speaks' documents	AS website docs, AS blog posts, AS Google+ and Wikipedia pages	45
AS affiliates	Research initiative web pages	5
AS financial docs	AS budgets, Better Business Bureau Charity Report	3
AS Campaigns	Light It Up Blue web pages, commercials, promotional videos, AS news items	18
Media Coverage of AS and ND opposition	Online news articles	7
Opposition to AS	Advocate blog posts	88
Autistics Speaking Day	Advocate blog posts	1
Flash blog: Autistic people are/should...	Advocate blog posts	29
Flash blog: Autism Speaks, I want to say...	Advocate blog posts	3
#MSSNG hashtag take-over	Advocate tweets	30+ tweets
#AutismSpeaks10 hashtag take-over	Advocate tweets	50+ tweets
<b>Data set 2: ND opposition to Autism Speaks to Washington Summit</b>		
AS docs on Washington summit	Wright's letter, AS press releases, AS news items	4
Media coverage of ND opposition	Online news articles	2
ND responses to Wright's letter	Advocate blog posts	19
ND responses to Washington summit	Advocate blog posts	10
Flash blog: This is autism	Advocate blog posts	246
Flash blog: Love not fear	Advocate blog posts	56
Boycott Autism Speaks	Advocate blog posts, online petition, facebook pages	10
#BoycottAutismSpeaks	Advocate tweets, twitter bomb 1 (Dec. 9, 2013), twitter bomb 2 (Jan. 14, 2014)	200+ tweets

This case is useful for understanding disability rights advocacy online in that it exemplifies the ways in which neurodiversity advocates use online discourse to mobilize quickly and effectively around disability rights issues. Autism Speaks discourse and neurodiversity advocacy counter-discourse also offer rich data for mapping intertextual connections and examining Discourses of autism and disability in a site of discursive struggle, ideas I return to in more detail below.

### **Controversy 2: Disability Day of Mourning and Protests Against Filicide**

The second case study involves the neurodiversity community's protests of cases of autistic children and others with disabilities being murdered by caregivers. In this controversy, ND advocates have used online actions, blog posts, Twitter, Facebook, and media articles to address the problem of domestic violence against disabled individuals and to protest media coverage that they describe as being sympathetic to murderers.

Disability Day of Mourning (DDM) is a day of remembrance organized by the Autistic Self Advocacy Network, Not Dead Yet, and the National Council on Independent Living. For the last four years, on March 1, participants have attended online vigils, tweeted, and stopped to remember disabled people murdered by caregivers. 26 vigils were held in cities across the U.S., in Canada, the U.K., and Hungary, and online in 2015. The rationale behind the Day of Mourning is based on media coverage of cases of filicide, which advocates see as contributing to systems of dehumanization that perpetuate abuse.

Far too often, when a disabled person is murdered by a caregiver, journalists write as though it is the disabled victim who has perpetrated a crime simply by existing. In discussing the killing, people say that we should feel sorry for the murderer, because they had to live with a disabled relative. When a disabled person is murdered, many people act as though the murder victim's life, not their death, was a tragedy. (San Francisco Vigil, 2013)

To organize DDM, the Autistic Self Advocacy Network (ASAN) partners with two cross-disability advocacy groups to address a cross-disability issue. "Not Dead Yet is a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia as deadly forms of discrimination against old, ill and disabled people" (Not Dead Yet, 2013). "The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities" (NCIL, 2013). ASAN is described in further detail below.

While the problem of disabled people being murdered by caregivers is an issue that affects the disability community as a whole, autistic and other cognitively disabled people are overrepresented on the roster of those murdered. In the months after DDM 2013, there were two prominent cases of murder and abuse of autistic individuals that highlight this disparity. On June 10, 2013, Alex Spourdakis, "a 14-year-old boy with severe autism" (Autism Media Channel,

2013, my transcription) was stabbed to death by his mother Dorothy Spourdalakis and godmother Jolanta Agata Skrodzka. After they failed to kill him with sleeping pills, Alex's mother stabbed him four times in the chest and cut his wrist before handing the knife to Skrodzka who killed the family cat (Gorski, 2013; Willingham, 2013). Both women then attempted suicide by taking sleeping pills but survived. On September 3, 2013, Kelli Stapleton attempted to kill herself and her 14-year-old autistic daughter Issy by filling their van with carbon monoxide with the two of them inside. Police found them unconscious after Kelli shut herself and her daughter in the van with a lit charcoal grill. Issy was in a "coma-like state" for four days before she woke up and started to recover with some brain damage (Agar, 2013). Kelli Stapleton was jailed (Walsh, 2013).

There are many parallels between these cases and the ways they were covered online by news outlets and bloggers. Both cases were framed as actions committed by "desperate" mothers. National news reports described Dorothy Spourdalakis as an "autism mother desperate to get help for her child" (CBS, 2013), and Kelli Stapleton was described as "hopeless and at the end of [her] rope" (Cook, 2013). Both children were described as "violent" teenagers. "[Alex] would kick, thrash, bite" (CBS News, 2013), and Issy was prone to "attack" her mother and younger sister. Interestingly, both mothers were building a public presence prior to each incident. Dorothy and Alex Spourdalakis were taking part in "an autism reality series" (Autism Media Channel, 2013). Kelli Stapleton started a blog called *The Status Woe* chronicling life with Issy and fundraising for Issy's treatments. The blog was a success, and her decision to "[go] public with her struggle to help a violent daughter" (Stephan, 2013) was covered by Stapleton's local National Public Radio station. Finally, coverage of both cases placed blame on the "system." Alex Spourdalakis' death was blamed on "a system—doctors, hospitals, social services, public

health, government, and media—that is broken” (Autism Media Channel, 2013). Similarly, bloggers wrote about how “Kelli and Issy were (and are) victims of the same system, and that system made them victims of each other” (Jones, 2013a).

Both of these cases evoked responses from the neurodiversity community that echoed sentiments expressed on Disability Day of Mourning. Neurodiversity advocates reacted to the acts themselves and responded to other published reactions that cast Kelli Stapleton’s and Alex Spourdalakis’ caregivers in a sympathetic light. The Autistic Self Advocacy Network published condemning statements responding to both cases. The Thinking Person’s Guide to Autism—“a one stop source for carefully curated, evidence-based information from autism parents, autistics, and autism professionals” (TPGA, n.d.)—published blog posts responding to coverage of both cases, and organized a petition on change.org asking that CBS News remove its video coverage of the Spourdalakis murder (TPGA, 2013). Several other neurodiversity advocates wrote blog posts decrying the violence and addressing problematic discourse in coverage of the events.

This case offers another example of discursive struggle, one that highlights stigmatizing discourses and their potentially lethal consequences. In their responses to murder cases, neurodiversity advocates draw connections between problematic features of discourse around filicide and continued violence and abuse against people with disabilities. Some also link the preponderance of autistic deaths at the hands of caregivers to the kinds of “[a]wareness’ as interpreted by A\$ and Light It Up Blue” (thatfeministdyke, 2012), arguing that “fearmongering . . . [about] what an epidemic [autism] is, and posturing [autistic people] as diseased, broken, unwanted burdens” creates a climate in which it’s “understandable . . . to want to murder your Autistic child, because they’re such a burden, and autism is so terrible” (thatfeministdyke, 2012). Others condemn the ways “media coverage has consistently attempted to excuse and justify . . .

murderer[s] and paint [them] . . . as the ‘real’ victim” (ASAN, 2013b). Ari Ne’eman, the founder and president of ASAN, points to stigmatizing discourses, saying, “I think an ideology, a dangerous ideology that preaches that people are better off dead than disabled is what led to Alex Spourdalakis’ murder” (Ne’eman, quoted in CBS News, 2013).

**Corpus 2: DDM, murder media coverage, and ND responses.** This case study corpus consists of two data sets: 1) data collected on Disability Days of Mourning 2013-2014 and 2) media coverage of murders and ND advocate responses to media coverage and protests against filicide. Each DDM was publicized through organizer webpages and mailing lists, Twitter, Facebook, blogs, and online articles. A website and Virtual Vigil was set up for DDM 2014 that included 16 readings and a list of 96 names accompanied by age and manner of death, “some of the people with disabilities murdered by caregivers [being remembered]” (DDM Virtual Vigil, 2014). The first data set will be composed of these data. The second data set is primarily comprised of online newspaper articles and news videos and ND advocates’ blogs, Facebook posts, and tweets responding to murders that occurred between DDM 2013 and DDM 2015, though some data pertains to cases prior to 2013.

Table 2 provides an overview of the texts that comprise the DDM corpus.

Table 2: DDM case study overview

Description	Text types	Total number of texts
<b>Data set 1: Background on Disability Day of Mourning</b>		
Background on organizers	National Council on Independent Living, Not Dead Yet, and ASAN web pages	3
DDM 2013	Facebook event pages, ASAN publicity	11
DDM 2014	Facebook event pages, ASAN publicity, ASAN member mailings, Virtual Vigil pages	23
Media coverage of DDM	Articles covering vigils	1
ND opposition to filicide	Blog posts, anti-filicide tools	9
<b>Data set 2: Murder cases</b>		
Cases prior to 2013: Jude Mirra, 2/2010	Media coverage	18
Robert Gensiak, 3/2013	Media coverage, ND advocate	6

	responses	
Alex Spourdalakis, 6/2013	Media coverage, ND advocate responses	18
Matthew Hafer, 7/2013	Media coverage	6
Marian Roberts, 8/2013	Media coverage	5
Jaelen and Faith Edge, 9/2013	ND advocate response	1
Tamiyan Audain, 9/2013	Media coverage	9
Issy Stapleton (attempted), 10/2013	Media coverage, ND advocate responses, Kelli Stapleton supporter responses	116
Dameian 'Luke' Gulley, 11/2013	Media coverage	7
Randle Barrow, 12/2013	Media coverage, ND advocate responses	8
Mickey Liposchok, 12/2013	Media coverage, ND advocate responses	6
Damian Veraghen, 1/2014	Media coverage	4
Vincent Pham, 1/2014	Media coverage	1
London McCabe, 11/2014	Media coverage, ND advocate responses	31

Taken together, the DDM and AS case study corpora offer a picture of how autism is commonly depicted in dominant discourse in the U.S.

### **Controversy 3: The Self-Advocate/Parent Divide**

The third case study addresses conflicts between autistic self-advocates in the neurodiversity movement and parents of autistic children. In-fighting between parents and self-advocates in the autism community might be viewed as a necessary growing pain for the autism rights movement. Leadership in the autism community has shifted over time. While conversations about autism were once the sole province of doctors, parents began to develop expertise that enabled them to impact public debates for the betterment of their children. As mentioned in chapter 2, parent advocacy played a vital role in de-institutionalization, and parents have also been—and continue to be—important stakeholders and vocal advocates in fights for educational inclusion, both at the national level and in local classrooms. The parent-centered organization Autism Speaks and parents are now recognized as leaders in the autism community (e.g., Gardner, 2015). With the rise of the neurodiversity movement, however, autistic self-advocates have started working to gain control over public conversations about autism. Jim



Sinclair’s seminal speech at the 1993 International Conference on Autism sparked the neurodiversity movement through a direct challenge to parental authority and expertise. This challenge—and ongoing conflicts between parents and self-advocates—can be framed as part of a necessary coming of age. As Mitchell (1997) notes, parents often feel anxious and threatened when their disabled children start speaking up for themselves, but self-determination is a crucial part of self-advocacy that enables disabled individuals to exercise their rights and to be included and respected as adults.

The divide between parents outside the ND movement and self-advocates in the ND community is caused by disagreements over what autism is and what should be done about it. Self-advocates argue that

autism is not the problem. Autism is a different way of being, of perceiving. If the autistic person is given the right supports, therapies, and education, and a chance to succeed, then there is no problem. The problem, to the autistics . . . , is with society. (Senator, 2012)

Many parents disagree.

Many parents feel that you should do everything you possibly can to mitigate the autism: education, speech therapy, SI [sensory integration], behavior mod, biomed interventions. . . . To the parents, the autism, the autistic behavior, these are problems that should be fixed to whatever degree possible, because they are getting in the child’s way of a better life. (Senator, 2012)

These fundamentally different viewpoints are often aired in vitriolic confrontations between parents and self-advocates online.

Even parents and self-advocates within the neurodiversity community who agree that the problem is the lack of autism acceptance—and not autism itself—often fight over seemingly irreconcilable differences. The *Thinking Person’s Guide to Autism*, a pro-neurodiversity blogging collective geared toward non-autistic parents of autistic children, has hosted quite a few

blow-ups and attempts at reconciliation, sometimes resulting in community members on both sides of the divide being banned, boycotting the site, and calling for others to boycott it as well.

Conflicts between parents and self-advocates within the ND community often involve fights over centering—that is, fights over whose perspective ought to be positioned as the central locus from which problems are identified and defined. Parents who see themselves as necessary advocates for their children, experts on their children’s needs, and as their child’s ‘interpreter,’ ‘translator,’ or ‘voice’ tend to center parent perspectives. Self-advocates, “tired of being dismissed” (Zoe, 2011a) or ignored in conversations about autism, fight to center autistic and disabled perspectives, often by calling parents out for silencing or overlooking them.

One such conflict precipitated a self-advocate/parent dialogue series at the *Thinking Person’s Guide to Autism* (TPGA). The primary authors who took part in the dialogues—Zoe, self-advocate and blogger at *Illusions of Competence*, and Robert Rummel-Hudson, father of a non-speaking daughter with Bilateral Perisylvian Polymicrogyria and blogger at *Fighting Monsters with Rubber Swords*—“disconnected spectacularly” (The Editors, introduction to Zoe, 2011a) over a blog post Rummel-Hudson wrote to which Zoe objected in a blog post of her own. The ‘disconnect’ started with Rummel-Hudson’s (2011a) critique of a joke from the movie *The Change-Up* in which a character says, regarding a friend’s twin babies, “Are they retarded? This one looks a little Downsy.” To bring home the offensiveness of the joke, Rummel-Hudson wrote a blog post imagining a parent of a child with Down Syndrome,

a mom, one who spends her days, her years, taking care of a child, a very special child in every sense of the word; [who] loves this child the way most special needs parents love our children, which is to say, with equal parts gentleness and ferocity.

In the post, “[o]ur imaginary mom” (Rummel-Hudson, 2011a) goes to the movies for a rare break and

is suddenly confronted with a room full of people, laughing right along with famous faces on the screen, in a multi-million dollar production worked on by thousands of people . . . All those cinema professionals, and none of them, NOT ONE, ever said *"You know, we're making fun of purely innocent, absolutely blameless people here. We're making a shitty joke about people with disabilities, people who are brothers and sisters and sons and daughters of the moviegoers who are going to pay money to see this film. . . . Maybe we shouldn't do this."* (Rummel-Hudson, 2011a, author's emphasis)

Zoe (2011b) took issue with the fact that Rummel-Hudson never considered the perspectives of people with Down Syndrome, writing,

That's right: the R-word is wrong because it's offensive . . . to non-disabled people.

To me, this is as ridiculous as if the author had critiqued the movie's (doubtless plentiful) sexist humor by writing, "Some of the men in that audience have wives and daughters! How do you think they feel?"

Because, what about people who actually *have* Down Syndrome? Don't they go to movies? Don't people with intellectual and developmental disabilities, who have felt the impact of the R-word firsthand, also appreciate edgy humor sometimes? I'm sure that hearing this kind of language disturbs many non-disabled people, but that doesn't mean they understand the experience of being used as a punchline. (author's emphasis)

In comments on Zoe's (2011b) blog post, a polarized debate took shape as the original authors and other parents and self-advocates weighed in. Self-advocates argued that "[o]ur voices need to be viewed as at the center of our national conversations about disability and the tendency of many in the parent movement, despite their good intentions, to leave us out of their thinking indicates deeply held prejudices" (Ne'eman, comment on Zoe, 2011b). Rummel-Hudson and other parents argued that their voices were "extremely valuable" because they needed to "be a voice for [their] kids," and that "[w]hen you try to minimize the voice of any member of the disability community by establishing some sort of hierarchy, you weaken the cause for which we're all fighting."

While many participants used politeness markers to mitigate being “blunt” (Rummel-Hudson, comment on Zoe, 2011b) and show appreciation for the discussion, it ultimately ended with Rummel-Hudson exiting the comment thread because he felt it had “become hateful” and Zoe closing comments because they’d “gotten really messy.” When the authors attempted a “do-over” (The Editors, introduction to Zoe, 2011a) in the TPGA dialogue series, it caused many commenters and readers—including Rummel-Hudson—to express disappointment, disillusionment, and cynicism over parents’ and self-advocates’ abilities to bridge the divide.

**Corpus 3: Self-advocate/parent conflicts, ND advocate push-back against parent misconceptions.** This third case study is built around two data sets: 1) parent and self-advocate discourse that explicitly addresses the self-advocate/parent divide, and 2) ND advocate discourse that addresses points of contention that separate parents and self-advocate camps. The second data set is drawn from the first. After immersing myself in arguments between parents and self-advocates in blogs and on Facebook and Twitter that primarily focused on whether autism ought to be defined according to a medical or social model of disability and over who should speak for the autistic community, it became evident that there were other core ideological issues that parents and self-advocates tended to disagree on that bore further investigation. Specifically, I started gathering additional data around presuming competence, functioning labels, and autism acceptance.

Table 3 provides an overview of the texts that comprise this corpus, with approximate numbers of texts organized by topic.

Table 2: Self-advocate/parent divide case study corpus overview

Description	Text types	Total number of texts
Self-advocate/parent conflicts	Open letters to parents and self-advocates, autism parent and ND advocate blog posts	37
Functioning labels	ND advocate blog posts	39
#FunctioningLabelsMean on Twitter	Self-advocate tweets about functioning labels	100+ tweets
Presuming competence	ND advocate blog posts	18
Acceptance	ND advocate blog posts	45
#AcceptanceIs on Twitter	ND advocate tweets about acceptance	30+ tweets

This case is useful in that it reveals key tensions that divide the autism community and the fundamental ideological values that constitute neurodiversity advocacy.

### Ethnographic Data

Analyses of Internet texts that constitute the technical level of advocacy practices in these three controversies is informed by ethnographic fieldwork in two disability rights self-advocacy groups. In sum, I conducted over 30 hours of participant observation in ADAPT and 15 hours of observation at the Autistic Self Advocacy Network (ASAN). ADAPT is “a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom” (ADAPT, 2015). Founded in Denver in 1983, ADAPT is one of the oldest disability rights advocacy organizations in the U.S. Conducting participant observations in ADAPT meetings and events and informal interviews with ADAPT members allowed me to gather a sense of where the broader U.S. disability rights movement is now, what kinds of challenges it faces, and the kinds of advocacy work going on in pan-disability organizations like ADAPT. These experiences were integral to my understanding of the situated ideals and emotional stances that advocates employ in struggles for disability rights. I also used conversations with ADAPT group members to test my interpretations and invite insider critiques.

Fieldwork was also conducted in the Autistic Self Advocacy Network (ASAN).

According to their website's About page,

ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research, and the development of Autistic cultural activities. (ASAN, 2015a).

ASAN has a strong online presence, and much of their online advocacy work and the work of self-advocates affiliated with ASAN is represented in the discourse analyzed. Observations and a formal interview with Deputy Executive Director Julia Bascom were conducted at ASAN offices in Washington, D.C., in order to gather information about the organization's aims and concerns, challenges to autism acceptance that ASAN and other neurodiversity advocates are working to overcome, and the kinds of advocacy work going on in autistic communities. I also conducted participant observation as a volunteer with ASAN. These observations occurred primarily online, and included my time spent as a member of the email list and my online interactions with ASAN coordinators as the organizer for the 2015 Disability Day of Mourning vigil in Pittsburgh, Pennsylvania. I also participated in meetings and events with the Pittsburgh ASAN chapter. These experiences were vital for helping me to recognize points of convergence and divergence between autistic self-advocacy and broader disability self-advocacy, and for allowing me to observe how neurodiversity ideals are enacted in autistic spaces.

This fieldwork helped me to establish the "extensive knowledge" (Tracy, 2005, p. 309) necessary to contextualize the case studies examined here within larger disability rights Discourses, and to inform my analytical interpretations in light of advocates' experiences. It also served the purpose of making my own research more inclusive (Shi-xu, 2007) of autistic and disabled points of view. Working to build my interpretive stance in dialogue with autism and

disability rights activists enabled me to offer accounts that are faithful to self-advocates' experiences and useful for the practitioners studied.

### **Discourse Analytic Methods**

To make sense of these bodies of data, my data analysis focused on two primary, interrelated constructs: interdiscursivity and identity-work. These constructs helped guide me in building corpora and provided starting points for interpreting texts. My interpretive methods served my overarching goal to reconstruct interconnected practices in order to understand how Discourses of autism, disability, and disability rights position autistic people in U.S. society, and how ND advocates' and others' discursive practices help to elevate and oppress autistics. The constructs outlined below were central discursive mechanisms in the practices studied.

**Interdiscursivity.** Interdiscursivity refers to aspects of discourse that index, or point to, other discourses. Interdiscursive processes are techniques that communicators use when they “inevitably draw on, anticipate and respond to other events and other texts” (Fairclough, 2010, p. 421). Analyzing interdiscursivity is a particularly useful method for making sense of what happened within and across case studies like those described above. Investigating interdiscursive relationships between texts creates a timeline of events, reveals the course of semiotic resources that move through practices, and exposes aspects of social cognition shared by various actors.

Analyzing interdiscursivity is an integral part of discourse analysis. “Analysis of texts comprises both interdiscursive analysis and linguistic/semiotic analysis” (Fairclough, 2010, p. 360). Such analyses trace interdiscursive connections between texts. By identifying communicative patterns that connect texts and practices, analysts account for the inherently

dialogic nature of utterances<sup>4</sup> (Bakhtin, 1999[1986]) and attend to processes of recontextualization (Fairclough, 2010).

Recontextualization is the process by which discursive resources are reproduced in different contexts and thereby “potentially transformed (both deliberately and unwittingly, but often systematically)” (Fairclough, 2010, p. 422). It is an interdiscursive process that connects discursive practices within orders of discourse, that is, within “the totality of [a social domain’s] discursive practices, and the relationships (of complementarity, inclusion/exclusion, opposition) between them” (Fairclough, 2010, p. 93). The order of discourse of neurodiversity advocacy includes not only online discourse, but discursive practices in organizations, public protests, policymaking contexts, and community members’ everyday interactions. Recontextualization is the process that connects these practices and thereby helps to constitute the social domain of neurodiversity advocacy.

Interdiscursive analysis is concerned with mapping orders of discourse. By tracing the trajectories of Discourses that traverse social practices (Lemke, 2012), analysts survey social structures that comprise macro practices. Like accounting for “the totality of society in its historical specificity” (Wodak & Meyer, 2009, p. 6), taking in the totality of discursive practices that comprise the order of discourse of any social domain is an aim that can only be addressed bottom-up. To understand practices in general, analysts must look at patterns that connect particular events. To understand Discourses, we must look at patterns that connect situated discursive techniques.

As with any map, analytic reconstructions like this are always incomplete, including some landmarks and excluding others, and neglecting ground that lies beyond the edges of the

---

<sup>4</sup> Here I’m referring to ‘utterances’ in a very broad sense to include spoken, embodied, and written discourse.



page. However, studying a large corpus of Internet texts and using interviews with neurodiversity advocates to connect online practices with other forms of neurodiversity advocacy does enable me to survey a large part of the order of discourse of neurodiversity advocacy. Ethnographic fieldwork and knowledge of disability rights history also allow me to map connections between ND advocacy in Internet and real-life contexts, and between autism rights and other social domains within the disability rights movement and disability studies.

Reconstructing interrelated communicative practices and the relations between them involves identifying intertextual chains, interconnected series of events or texts marked by parallel linguistic and stylistic forms (Fairclough, 2010). Studying the connections within and between intertextual chains by analyzing the discursive features that characterize them is a way of examining how discursive practices get taken up and evolve (Fairclough, 2010). Genre markers are discursive features that help analysts identify intertextual chains. The linguistic and stylistic techniques that practitioners use to align texts with particular genres connect those texts to others of the same generic type, and help to historically and socially situate texts and authors, addressees, and other social actors referenced in the discourse (Bakhtin, 1999[1986]). Membership categories—interrelated categories for referring to people (Sacks, 1992)—are another feature of discourse that indicate intertextuality. Category terms and the ascriptions and descriptors that come to be associated with particular categories are central to Discourses that connect texts.

Interdiscursivity is a particularly useful construct for analyses of online discourse. Internet texts exhibit interesting interdiscursive features, and researchers conducting online research can easily trace and document intertextual connections. Google searches constitute intertextual chains linked by keywords and other interdiscursive elements. Hyperlinks are

intertextual anchors that connect texts. Hashtags—metadiscursive labels written into tweets and other social media status updates (e.g., #AcceptanceIs)—and flash blogs connect users in forms of online collective action whose power is fundamentally intertextual in nature. That is to say, the power to make a difference often relies on a show of force, and intertextual elements like hashtags and flash blog titles can reveal a critical mass of activist activity with the ease of a search. All of these interdiscursive links also connect online communities of practice in more immediate and personal ways than offline texts do.

Each of the controversies described above plays out through intertextual chains that compose the technical level of advocacy practices. Charting the intertextual series that comprise the three case studies involves attending to the discursive techniques that link the blog posts, tweets, articles, and Facebook pages through which conflicts develop online. The online texts that comprise each corpus are closely tied. Many of the texts analyzed explicitly reference and directly respond to others. Texts are temporally linked as well. Flash blogs and Twitter bombs are comprised of coordinated texts whose messages build on one another by virtue of the use of intertextual elements in close temporal proximity. Petitions, press releases, and interviews are also coordinated in this way to increase visibility for particular events or points of view. Such temporally linked practices generally share intertextual elements like similar or repeated linguistic formulations, topics, and text structures.

An example from the AS case study offers a brief but useful example of the interdiscursive links that connect practices within and across controversies. Suzanne Wright, the co-founder of AS, posted a “Call for Action” to the Autism Speaks web site “[o]n the eve of Autism Speaks’ first-ever national policy and action summit in Washington, D.C.” (Wright, 2013). The neurodiversity community responded to Wright’s descriptions of autism immediately

and angrily. Advocates also organized a “This is Autism” flash blog on Nov 18, 2013 in response to Wright’s post.

In her post, Wright rallies summit participants and emphasizes the need for a national autism plan by describing autism as a “national emergency” and “crisis” (Wright, 2013). More than 200 participants responded to Wright’s post in the coordinated blogging effort organized a week later. In this flash blog, entitled “This is autism,” ND advocates and others opposed to the AS action explicitly countered Wright’s description of autism by blogging about their own autistic experiences. Neurodiversity advocates organized live protests during the Washington summit, and sustained protest online by blogging and tweeting about AS before and after the flash blog. Advocates also coordinated an effort to reach AS corporate sponsors. ASAN (2013a) posted a “joint letter to the sponsors of Autism Speaks” on November 19, 2013 to urge them to stop supporting AS. On December 1, “[t]he Autistic community and those who love and support them” posted a petition to change.org, entreating corporate sponsors again to withdraw support from AS, and notifying them that they had “already introduced an effort to encourage those that are able to boycott [their] company” (Boycott Autism Speaks, 2013). On December 9, advocates participated in a Twitter bomb, a coordinated effort in which participants flooded sponsors’ and others’ Twitter mentions with tweets that entreated them to #boycottautismspeaks. This hashtag has been in consistent use on Twitter since that time.

Reconstructing the technical level of advocacy practices in this and other sites of controversy is a way of describing what happened in terms of *how* participants attended to problems in situated conflicts. In order to get a sense for *why* participants address problems in the way that they do, analysts must move from the technical to the philosophical level. Linking the discursive techniques that participants use to their beliefs about best courses of action is a

way of examining the connection between little-d and big-D discourses. Adopting an ideological interpretation of the philosophical level of practices, Discourses can be understood as situated ideals that people draw on to address problems. Ideologies, identity categories, and normative beliefs shape the discursive techniques that people use in situated practices. Examining these ideals that participants orient to as they respond to and elicit other discursive practices offers a way of tracing the trajectories of big-D Discourses through and across the intertextual chains that comprise situated practices.

In addition to analyzing the ways in which counter-discourses respond to dominant discourses by way of opposition, I am also interested in tracing interdiscursive commonalities between dominant and counter-discourses. As discussed above, the interpenetration of discourses in sites of struggle is such that even discourses that espouse an emancipatory stance have the potential to reproduce traces of stigmatizing discourses and thereby help to reinforce oppressive ideologies. By identifying points of convergence between dominant texts and the advocate texts working to counter them, I expose ways in which semiotic resources can proliferate stigma in spite of advocates' best intentions.

**Identity-work.** Identity-work is the work communicative practices do to construct who people are, including how communicators reveal aspects of themselves as well as how they construct identity categories that pertain to others. Taking a social constructionist perspective on identity as something that is performed and produced through discourse highlights the communicative nature of identity-work. This view relies on a “relational rather than a substantialist logic [of identity]” (Young, 2000, p. 82) whereby identity categories are communicatively constructed in relation to others. The qualities that make one person different from another are “relational propert[ies] existing only in and through [their] relation with other

properties” (Bourdieu, 1998[1994], p. 6) as expressed in discourse. Further, “groups do not have identities as such, but rather . . . individuals construct their own identities on the basis of social group positioning” (Young, 2000, p. 82), a process that happens through communication.

“[W]ho people are to each other” (Benwell & Stokoe, 2006, p. 6) is communicated in a variety of ways. For example, grammatical structures like transitivity (verb structures that vary according to the number and type of direct objects) and modality (the grammatical forms speakers use to communicate certainty, possibility, and doubt) position individuals in relation to other participants and states of affairs (Benwell & Stokoe, 2006; Halliday, 1994). Narratives set up social roles for tellers, audience members, characters, and others referenced in stories (Bamberg & Georgakopoulou, 2008). And membership categorization devices (MCDs)—“collections of categories for referring to persons, with some rules of application” (Sacks, 1992, p. 238)—identify people on the basis of their memberships in and relationships to identity categories that are defined in relation to other identity categories.

As Sacks (1992) points out, “lay theories of social actions are fitted onto these categories” (p. 42). Identity-work can therefore be understood as a kind of social theorizing in everyday practice. “Identity is, properly defined, an epistemological construction that contains a broad array of theories about navigating social environments” (Siebers, 2011, p. 15). By virtue of its relationship to identity-work around non-disabled identities, identity-work around disability constructs practical theories about “locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism” (Siebers, 2011, p. 14).

Autism is one such epistemological construction built around everyday theories about communicating in social environments. The identity categories *autistic person* or *person with autism* mark an epistemological boundary between communication and incommunicability that

positions the latter outside ‘normal’ social engagement (Pinchevski, 2005). These terms are membership categories defined around a “triad of [communicative] impairments . . . [including] social impairments, verbal and nonverbal language impairment, and repetitive, stereotyped activities” (AWARES.org, n.d.) that help construct and reinforce practical social theories about the relation between normal, neurotypical identities and what it means to experience communicative impairments like autism.

Such practical social theories are of course never politically neutral. Positioning identity categories in relation to each other is a way of doing identity politics, that is, using categories of social difference as political resources. At its root, neurodiversity advocacy—like disability rights and civil rights movements more generally—is a way of calling attention to minority identities and the struggles that characterize minority experiences in order to fight oppression and foster political solidarity (Siebers, 2011). Identity-work is central to such identity politics. Examining how neurodiversity discourse constructs what it means to be autistic and disabled is thus a method for uncovering the ideologies and situated ideals that advocates draw on to understand society and their place in it.

An example of explicit identity-work that counters identity construction in dominant discourse about autism in a reading for Disability Day of Mourning 2014 entitled “I am not a burden.” On her blog *Turtle Is a Verb*, the author echoes Person First advocates in the disability rights community and challenges stigmatizing ideologies and sympathy for abusive parents:

I am not a burden. I need to repeat that, because the opposite is told to me too frequently, and digs in, and catches hold. I am not a burden.

I am autistic. I am disabled. I am not a burden. I am a person.

You were nine years old. You had a life ahead of you. Then you didn't. You were a person. Not a burden.

You were twenty-four, or ten, or fifteen, or forty. All of you, you had lives ahead of you.

And all of you were PEOPLE, not burdens.

None of us are burdens. No matter what's said to us.

It's not okay that you were killed, that you were murdered. That your lives were snatched from you, just because you were disabled, just because you were different.

It's not okay, that people are saying that it is fine that this was done because you were a "burden" and that you made your family's lives too difficult. . . .

Every time someone says that the parents lives are too hard, so its not unexpected for them to do these things, I need to step up and say that autism isn't about the parents, and murders are about those who's lives were taken. Because disabled people are people too<sup>5</sup>.

(tuttleturtle42, 2014)

Interestingly, while this post explicitly responds to cases in which people with disabilities were murdered, the identity-work here also counters discourse that characterizes autism as a threat to and hardship on families.

### **Discursive Struggle and Social Positioning**

As I hope I have made clear, the overarching aim in analyzing interdiscursivity and identity-work across the texts and practices that comprise the corpora at the heart of this study is to lay bare Discourses of autism, disability, and disability rights that impact the neurodiversity community. Understanding the cultural conceptions and ideological belief systems that constitute these Discourses is a way of understanding the social positioning of autistics and other disabled people in U.S. society.

All of the controversies outlined here are sites of discursive struggle where ND advocates work to counter dominant discourses and must also contend with conflicting ideological approaches to advocacy. Though I have focused mainly on opposition between dominant and

---

<sup>5</sup> All text excerpts are reproduced as originally written. Because nonstandard presentations, abbreviations, and apparent errors are common to many genres of online discourse and disabled written discourses, I will not mark these textual elements with a *sic*. Doing so not only distracts from the original text, but it reinforces dominant, nondisabled, neurotypical conceptions of correctness that ultimately undermine my own commitment to neurodiversity.

marginalized discourses in my explication of discourse analytic methods above, it is also important to note how advocates prioritize between competing situated ideals about how best to conceptualize autism and disability to combat stigma. This can lead to trouble at the philosophical level as participants sort out internal contradictions that make neurodiversity advocacy problematic.

Understanding dimensions of discursive struggle through close analyses of texts and ethnographic fieldwork facilitates understanding social positioning, that is, processes by which identities and social relations are discursively constructed and negotiated (Fairclough, 2010). Communicative practices position people within social spaces, the “invisible reality . . . which organizes agents’ practices and representations” (Bourdieu, 1998, p.10). Ways of classifying actions and properties position individuals within social classes, theoretical groupings that “are *predictive* of encounters, affinities, sympathies, or even desires” (Bourdieu, 1998, p. 10, author’s emphasis). Analyzing social positioning is a way of mapping the social world, of apprehending and modeling shifting relations between social classes, changing configurations of social spaces, and evolving mechanisms that (re)produce these spaces (Bourdieu, 1998). This requires analysts to examine “the particularities of different *collective histories*” (Bourdieu, 1998, p. 3).

As the latest inflections of the broader disability rights movement in the U.S., contemporary neurodiversity and disability rights advocacy practices make up collective histories through which scholars can uncover social processes that position autistic people and others with disabilities. Reconstructing these historically situated cases is a way of “constructing . . . a ‘special case of what is possible,’ . . . that is, . . . an exemplary case in a finite world of possible configurations” (Bourdieu, 1998, p. 2). Critically analyzing social positioning in the



exemplary cases studied thus offers a useful perspective on our present social reality along with the possibility of more egalitarian social configurations.

## Chapter 5

### Dominant Depictions of Autism as Tragedy

#### End ableism

Challenge ableism (anti-disability bias and prejudice) everywhere you see it. Challenge the idea that it is better to be dead than disabled, that disabled people are a drain on society, that disability means suffering, and that disabled lives are not worth living.

Promote inclusion, community integration, and acceptance.

– Autistic Self-Advocacy Network, Anti-Filicide Toolkit (ASAN, 2015c, p. 9, authors' emphasis)

Ableism and disablism constitute attitudinal barriers to inclusion and acceptance.

Common beliefs about what it means to be able-bodied and what it means to be disabled are (re)produced in discourses and practices that exclude disabled participants and reinforce the subordinate social position of people with disabilities. The discursive and material “complex of processes that exclude disabled people” (Hughes, 2012, p. 18) draw on emotions, beliefs, and assumptions about disabled others (Hughes, 2012) that are in turn (re)produced in discourse and action.

Of the two, *ableism* is the more familiar term, one that is commonly used to signify prejudice and discrimination against disabled people that is analogous to the kind of racial bias indexed by the term *racism*. The appeal quoted above—taken from the Autistic Self-Advocacy Network's list of strategies to prevent filicide (ASAN, 2015c)—draws on this understanding of ableism. For Campbell (2009), however, the *disabling* processes that “promote the differential or unequal treatment of people because of actual or presumed disabilities” (p. 4) are better termed *disablism*. She introduces a distinction between processes of ableism and disablism that calls attention to both the oppression of disabled people and the establishment of able-bodied norms.

According to Campbell, ableism is

[a] network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human. (Campbell, quoted in Campbell, 2009, p. 5)

Campbell's definition of ableism focuses on the construction of the normate, the valued subject position against which "physical and cultural otherness" (Garland-Thomson, 1997, p. 8) is marked. Though the normate is represented as "species-typical,"

[i]f one attempts to define the normate position by peeling away all the marked traits within the social order at this historical moment, what emerges is a very narrowly defined profile that describes only a minority of actual people (Garland-Thomson, 1997, p. 8).

The construction, maintenance, and enforcement of normate cultural ideals is something that is so commonplace it becomes common sense, something so everyday it's 'invisible.' Like whiteness or heterosexuality, ability is something that's taken for granted, a norm that's presumed by default. Until one is apprehended—accurately or not—as deviant, the dominant cultural tendency in the U.S. is to altercast them as white, straight, and able-bodied. As soon as actual or perceived deviation from these norms is recognized, social differentiation occurs (Bourdieu, 1998[1994]). This othering moves the deviant person away from the normate subject position, a move that shifts relations of power and privilege to the disadvantage of the deviant other (Garland-Thomson, 1997).

[T]hose bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy. Invested with the meanings that far outstrip their biological bases, figures such as the cripple, the quadron, the queer, the outsider, the whore are taxonomical, ideological products marked by socially determined stigmata, defined through representation, and excluded from social power and status. (Garland-Thomson, 1997, p. 8)

The neurodiversity paradigm, that is, the "philosophical foundation for the activism of the neurodiversity movement" (Walker, 2014b), recognizes neurotypicality as a "culturally

constructed fiction” (Walker, 2014b), a normate identity that is narrowly defined around societal standards of normalcy. The construction of this normate identity is evident in dominant discourses that define autism against neurotypicality. From a neurotypical (NT) perspective, autism is a deficit of NT communicative ideals; it is a lack of communication, interpersonal awareness, empathy or theory of mind. Medical model definitions of autism exhibit this neurotypical orientation by defining autism as disorder or disease—improper functioning that is less desirable than normal ways of being and behaving. In dominant discourse—where depictions of disease are often fraught with metaphors of fear (Sontag, 1989[1977, 1988])—such medical model definitions of autism are tied to depictions of autism as tragedy. These representations constitute neurotypicality as ideally communicative, fundamentally relatable, appropriate embodiment—a “perfect, species-typical and therefore essential and fully human” (Campbell, quoted in Campbell, 2009, p. 5) way of communicating and being.

Moving away from ableist notions of disability as suffering, the neurodiversity paradigm takes a disability perspective that sees disability as a source of creativity. According to this disability perspective, neurodiversity offers valuable insights regarding the dynamics of inequality along with ways of seeing, experiencing, and knowing that “bring something new into the world that [would] otherwise go unrecognized” (Mitchell, 2014).

The neurodiversity paradigm . . . boils down to these fundamental principles:

- 1.) Neurodiversity is a natural and valuable form of human diversity.
- 2.) The idea that there is one “normal” or “healthy” type of brain or mind, or one “right” style of neurocognitive functioning, is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one “normal” or “right” ethnicity, gender, or culture.
- 3.) The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of

ethnicity, gender, or culture). These dynamics include the dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential. (Walker, 2014b)

The neurodiversity paradigm thus incorporates understandings of ableism and disableism that answer the need to attend to both. Campbell (2009) calls for increasing attention to the mechanisms that (re)produce normalcy, warning that emancipatory social change based only on recognizing and reforming negative assumptions and practices that constitute disableism can “[re-inscribe] an able-bodied voice/lens towards disability[, which], often quite unconsciously, continues to be examined and taught from the perspective of the Other” (Campbell, 2009, p. 4). Rather than cast disabled perspectives into the role of the other, scholarship that “concentrate[s] on what the study of disability tells us about the production, operation and maintenance of ableism” (Campbell, 2009, p. 4) centers disabled points of view and interrogates implicit, ableist assumptions. This kind of research takes up Tom Shakespeare’s suggestion that disability studies scholars, “rather than interrogating the other, [should] deconstruct the normality-which-is-to-be-assumed” (Shakespeare, quoted in Campbell, 2009, p. 4).

The present chapter looks to do just that by interrogating normal—that is, everyday, dominant—depictions of autism and considering what these representations reveal about ableism and disableism affecting autistics in the U.S. today. The dominant discourses at hand come from two data sets: Autism Speaks’ (AS) autism awareness campaigns and U.S. media discourse about autistic filicide. Tracing the intertextual links and ideological convergences that constitute common ways of depicting autism in AS and media discourse, I expose discursive strategies that cast autism as a “diminished state of being human” (Campbell, 2009, p. 5) and exclude autistic people from social power by silencing autistic voices. By relegating autistic people to the subject position of the non-communicative, unrelatable, and dangerous other, these dominant discourses

impede autistics' ability to contribute to public discussions about autism and make them more vulnerable to discrimination and violence.

The critical discourse analysis below starts with a brief discussion of the power of dominant discourse to “(re)produce *social domination*, that is, the *power abuse* of one group over others” (van Dijk, 2009, p. 63, author’s emphasis). I then move to a description of how AS and media discourse represent autism as tragedy, thereby reproducing stigma and contributing to the subordination of autistic people. I also explore autistic counter-discourses, and consider the ways in which ND perspectives expose and undermine dominant ableist representations. To conclude, I briefly reconstruct the normative subject positions that emerge from discourse that (re)produces autistic otherness. I end with a reflection on the importance of perspective-taking and critical language awareness for exposing everyday ableism, imperatives that are answered by neurodiversity advocates working to center autistic perspectives in conversations about autism.

### **Dominant Discourse and Common Sense Thinking**

Dominant discourses are characterized by common sense representations, widespread ideologies that are instrumental in configuring social structures, such as categories of people and their relative privilege (van Dijk, 2009a). As they are (re)produced in texts and taken up by social actors, these discursive representations help actors to construct what van Dijk (2009a) calls *context models*—mental representations of the “relevant structures of the social situation” (p. 73) that help actors to understand the social world and pursue appropriate action. These context models can be understood as mental maps of social space, cognitive representations that include assumptions about one’s own and others’ subject positions.

Context models constitute the crucial interface between discourse and society. Discourse reflects and (re)produces beliefs that are, in turn, reflected and (re)produced in practices that help

constitute social structures. As van Dijk (2009a) stresses, “context models mediate between discourse structures and social structures at all levels of analysis” (p. 66). To put it in grounded practical theory terms, discursive strategies help shape the philosophical level of everyday practices. The common tropes employed in *Autism Speaks* and media texts (re)produce beliefs about what autism is and what we should do about it that people—particularly advocates, policymakers, parents, therapists, educators, and potential employers—orient to when taking action. Thus, while there is no causal relationship between discourse and action, the dominant discourse examined here has real social and material consequences for autistic people.

The process by which discourse comes to shape practice via context models is well illustrated by dominant discourses about autism. The discourse analyzed below is characterized by common sense ways of seeing autism as a lack of communication and tragic disease. As I work to make clear in my analysis, conceptualizing autism in these ways leads advocacy organizations and media outlets to exclude autistic people from public conversations about autism and to promote eradicating autism as a valuable goal. These dominant discourses are ableist in that they cast autism as a diminished, dehumanized state and project lives ‘untouched by autism’ as desirable, normal, and more fully human. Ableist assumptions implicit in *AS* and media discourse cast normate, non-autistic identities in a position of power in relation to autistic others, thereby granting non-autistics control over conversations about autism that deny autistic people control over their own lives. According to context models (re)produced in *Autism Speaks* and media discourse, autism relegates those on the spectrum to a lower class category of persons—one unable to communicate or engage in political participation. According to this view, it is appropriate for non-autistic people to advocate on behalf of autistic people without their input (since autism makes such input impossible). It is also appropriate that autism advocacy aim

to cure autism, thus alleviating tragic suffering. In some cases, it is even appropriate for autistic lives to be cut short, because the lives of those with ‘severe’ autism are so tragic they’re not worth living.

### **Autism According to *Autism Speaks***

To delve deeper into the ways in which dominant discourse (re)produces mainstream thinking, let me move now to the business of reconstructing dominant conceptions of autism evident in Autism Speaks discourse. Doing so entails mapping silences. Silences are omissions, gaps in discourse where pertinent information is left out (Huckin, 2002). In AS discourse, silences generally involve absent voices and missing perspectives that should be represented but are not. They are the result of discursive processes that exclude counter-discourses and autistic points of view.

Huckin (2002) delineates five types of silences: 1) speech act silences whose implied meanings are interpretable according to Grice’s maxims; 2) presuppositional silences that signal common knowledge shared by speakers and listeners; 3) discreet silences that leave out “sensitive information” (p. 348); 4) genre-based silences whose gaps follow style conventions; and 5) manipulative silences that “deliberately conceal relevant information from the reader/listener” (p. 348). I maintain that silences in AS discourse belong primarily to this last category. They are the result of deliberate exclusion and willful disregard of autistic voices that serve Autism Speaks’ express aims to dominate autism discourse at a global scale.

The critical analysis below is built around AS autism awareness discourse including videos, press releases, and interviews in mainstream media outlets published between 2009-2015. These texts are good examples of dominant autism discourse and typical AS discourse. The conceptions of autism and accompanying silences around autistic people evident in these



texts are also employed in AS discourse elsewhere (e.g., the AS website and AS research initiative discourse). I focus on AS autism awareness campaigns here because I'm interested in dominant definitions of autism evident in AS initiatives that are explicitly aimed at influencing international audiences to take action. The tropes that characterize autism in the focal data are also integral to AS identity-work. The texts examined below are fundamental not only because they show what autism is according to Autism Speaks, they also represent Autism Speaks' public identity. My analysis in the present segment starts with a description of central AS autism awareness texts. I then focus on two primary discursive strategies employed in these texts: silencing and dehumanization.

Autism Speaks is—according to its web site—“the world’s leading autism science and advocacy organization” (Autism Speaks, 2014b). AS ‘autism awareness’ campaigns are well publicized, celebrity-endorsed, global initiatives that shape beliefs—including those in state and federal governments—about what autism is. Defining autism on a global scale is the foundational starting point from which the organization began. This is made clear in the AS promotional video *What is Autism Speaks?* (Autism Speaks, 2013g). Here, the narrator talks about how “Autism Speaks . . . was born out of complete heartbreak and grew out of complete commitment and the sheer force of will” (narrator’s emphasis, my transcription) after “Christian, the first grandson of NBC Universal Chairman and CEO Bob Wright and his wife Suzanne was diagnosed with autism in 2004.”

Where to start? Two of the most powerful people in the media began their communication with the world first by defining autism. And now it’s widely understood as a complex, whole-body, developmental disorder with a variety of symptoms that include problems speaking, communicating, developing social relationships, learning and behaving appropriately, as well as gastro-intestinal issues.

The AS (2014i) web page “What is autism?” echoes this medical model understanding and the importance of defining autism using these terms. Describing “autism spectrum disorder” through characteristics associated with its “diagnosis,” this AS text stresses how “[i]ncreasing autism awareness is a key aspect of [AS’] work [to fund research on effective methods for earlier diagnosis].” Here, awareness of autism as disease supports arguments for “early intervention with proven behavioral therapies [that] can improve outcomes.” “[I]mprov[ing] outcomes” through intervention treatments is just one of the missions of Autism Speaks. AS describes itself in terms of its dedication to preventing, treating, and curing autism as well as to increasing autism awareness and advocating on behalf of “all who struggle with autism spectrum disorders” on their web site’s *Mission* page (Autism Speaks, 2014f):

We are dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism. We strive to raise public awareness about autism and its effects on individuals, families, and society: and we work to bring hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

As is consistently evident across key AS texts, the organization strives to build awareness of what autism is, that is, to dominate discourse about autism by defining it in medical terms. The logical conclusions to defining autism as disease in AS discourse are thus medical intervention, prevention, and cure. As I investigate below, fear discourse surrounding autism as disease in AS discourse support arguments for an urgent response, an exigence that “those who deal with the hardships of this disorder” are unable to answer and that underscores AS’ mission to “advocat[e] for the needs of individuals with autism and their families” (Autism Speaks, 2014b).

AS’ foundational medical understanding of autism as a “whole-body, developmental disorder” characterized by the usual triad of “symptoms” plus “gastro-intestinal issues” is

indexed by references to autism as life-threatening disease in AS awareness campaigns. In much of AS' autism awareness discourse, autism is conceptualized as a dangerous affliction, a disease of “epidemic” (Wright, quoted in Autism Speaks, n.d.c) proportions that makes people—especially children—“gravely ill” (Wright, 2013). The epidemic is an “urgent global health crisis” (Autism Speaks, 2013b), something “that plague[s] children in our country and across the world” (Autism Speaks, 2014g).

In the Autism Speaks' videos “Sounding the alarm: Battling the autism epidemic” (2014g), “I Am Autism” (2009b), and “Autism Every Day” (2006a), understanding autism as disease calls up associations with “lethal metaphors of fear” (Ignatieff, quoted in Sontag, 1989) linked to conceptions of serious illness, particularly cancer and AIDS (Sontag, 1989). In fact, autism is often compared—unfavorably—to life-threatening illnesses in AS discourse. Comparisons between autism and “pediatric AIDS, cancer, and diabetes combined” (Autism Speaks, 2009b) appear in multiple AS texts (e.g., Autism Speaks 2014g, 2012a, 2009b; Robinson, quoted in Unumb, 2014). The fact that autism is now “more common than childhood cancer, juvenile diabetes, and pediatric AIDS combined” (Robinson, quoted in Unumb, 2014) is often pointed to in AS discourse as justification for increased government spending on curbing the epidemic.

The “I Am Autism” (IAA) video (Autism Speaks, 2009b) is illustrative of the ways in which AS' descriptions of autism as disease evoke fear. According to an Autism Speaks (2009a) press release, the short film was commissioned from “Academy Award-nominated<sup>6</sup> director Alfonso Cuarón<sup>7</sup> and Grammy-nominated songwriter/producer Billy Mann” and “unveiled . . . especially for [the *Second Annual World Focus on Autism*]” event, “one of the largest gatherings

<sup>6</sup> At the time “I Am Autism” aired, Cuarón had not yet won an academy award.

<sup>7</sup> Director of *Y tu Mamá también*, *Harry Potter and the Prisoner of Azkaban*, and *Gravity*, for which Cuarón won the academy award for best director in 2014.

ever of First Spouses” in which AS kicked off “the \$100 million ‘Decade for Autism’ initiative challenging nations around the world to fund autism research, awareness campaigns and support services for families in their countries.”

The film includes a two-part poem by Mann delivered over “footage of individuals with autism and their families” (Autism Speaks, 2009a)<sup>8</sup>. In the first part of the poem, autism is personified in a deep, male voice. In the second, family members’, educators’, doctors’, and friends’ voices are represented. The first half of the video shows footage of presumably autistic children and one apparently autistic man standing or sitting alone in a variety of locations. As the shot switches between them, the ominous voice-over 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. . . .I hover around all of you. I know no color barrier, no religion, no morality, no currency. I speak your language fluently. And with every voice I take away, I acquire yet another language.

I work very quickly. I work faster than pediatric AIDS, cancer, and diabetes combined. And if 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 don’t sleep, so I make sure you don’t either. I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don’t have the resources, and I relish their desperation. Your neighbors are happier to pretend that I don’t exist—of course, until it’s their child. I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. 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? And the truth is, I am still winning, and you

---

<sup>8</sup> Autism Speaks (2009a) “ask[ed] supporters to help create the film ‘I am Autism’” by “send[ing] video footage of people from around the world who are on the autism spectrum.” AS requested that videos follow specific filming guidelines and include shots of autistic people alone and with family. According to the appeal to supporters to “become part of the worldwide global autism effort,” the footage would be used to “underscore the gravity of this global health crisis, and inform those in a position to effect a change.”

are scared. And you should be. I am autism. You ignored me. That was a mistake. (Autism Speaks, 2009b)

The mix of metaphors employed here draw on tropes that are commonly used to describe autism in dominant discourses. Gross (2012) discusses four primary metaphors associated with autism in contemporary discourse and all of them—kidnapping, military, barrier, and death metaphors—are linked to the conception of autism as disease in the IAA video. Autism is a life-threatening illness like “pediatric AIDS, cancer, and diabetes” that “work[s] very quickly” and for which there is “no cure.” The illness is personified as a “hover[ing]” threat that’s “invisible . . . until it’s too late.” It is a kidnapper with “no interest in right or wrong” who is “plot[ting] to rob you of your children and your dreams.” Autism is a thief capable of “tak[ing voices] away” and “bankrupt[ing]” families. It is also a shameful affliction, something that neighbors would rather “pretend” did not exist and that “make[s] it virtually impossible” for families to do things together “without a struggle, . . . embarrassment, [or] pain.” The fight against autism is a military engagement. In the second half of the video, a “community of warriors” including “parents and grandparents . . . siblings and friends and schoolteachers and therapists and pediatricians and scientists” talks back, pledging to “spend every waking hour trying to weaken [autism].” Drawing on the autism as barrier metaphor, a mother’s voice counters, “You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands?”

While autistic people are present in “I Am Autism,” they are conspicuously silent. Autistic voices are not represented in the video. *Autism* speaks, but autistics do not. This is a pattern evident in other Autism Speaks videos and Web texts. Autistic activist Alyssa Hillary (2013b) points out that “eras[ing], silenc[ing], [and] derail[ing]” autistic points of view are Autism Speaks’ “usual tactics:”

[W]e don't hear from [autistic people]. We hear from the parents, we hear from the experts. . . . We [autistic people] are objects in our own stories, not participants, and we do not speak.

Representing non-autistic parent and expert perspectives and excluding autistic points of view, AS discourse commonly defines autism as some *thing*—e.g., a disease, a threat, a wall—brought down on children and families.

In many AS texts, it's the incredible burden on families that defines autism. The 2006 video “Autism Every Day”<sup>9</sup> (Autism Speaks, 2006a) shows an “unvarnished portrayal of the 24-hour-a-day challenges faced by families as they confront the heartbreak of autism” (Autism Speaks, 2007). The video includes “[e]ight families, each with an autistic child, [who] permit a camera crew into their houses for 24 hours” (Jhailey, quoted in IMDb, 2014). It opens with footage of children screaming, throwing themselves on the ground, crying, and running away from their parents. In interviews, parents describe how “completely insane” and “exhausting” it is “to have a child with autism.” In one segment, Alison Tepper-Singer—who at the time was a senior executive at AS and is now co-founder and president of the Autism Science Foundation—describes her desperation while her autistic daughter Jodie stands behind her with her back to the camera:

---

<sup>9</sup> According to an AS press release promoting the premiere of “Autism Every Day” at Sundance Film Festival (Autism Speaks, 2007),

[a] twelve-minute version of *Autism Every Day* was first produced for, and screened at, *A New Decade for Autism*, a fundraising event held May 9, 2006 in New York City to benefit Autism Speaks and the New York Center for Autism Charter School. The film was intended to be shown one time only, but was subsequently broadcast by Don Imus on his MSNBC and nationally syndicated radio programs. Word of the film spread quickly on the Internet, first among members of the autism community and then beyond, generating tens of thousands of views on various web sites and blogs.

The tremendous online popularity of *Autism Every Day* led [director and producer] Thierry and Solomon to create a longer, 44-minute version of the film that included additional families and their compelling stories.

I remember that was a very scary moment for me when I realized I had sat in the car for about 15 minutes and actually contemplated putting Jodie in the car and driving off the George Washington bridge. . . . it's only because of Lauren, the fact that I have another child, that I probably didn't do it.

AS co-founder Suzanne Wright's (2013) "Autism Speaks to Washington - A Call for Action" published "on the eve of Autism Speaks' first-ever national policy and action summit in Washington D.C." is a more recent text that emphasizes the seriousness of "the autism crisis" by describing how parents live "moment-to-moment. In despair. In fear of the future." Here, autism is a national threat worthy of "call[ing] out the Army, Navy, Air Force and Marines" whose brunt has been born by families.

We've let families split up, go broke and struggle through their days and years.  
 No more. Tomorrow in Washington, D.C. . . . We will demand a national response.  
 Don't our families deserve it? America has always been about its great people.  
 Yet, we seem to have forgotten our children - and our children are our future.  
 Each day across this country, . . . three million moms, dads and other care-takers . . . wake to the sounds of their son or daughter bounding through the house. That is - if they aren't already awake. Truth be told, many of them barely sleep—or when they do – they somehow sleep with one ear towards their child's room—always waiting. Wondering what they will get into next. Will they try to escape? Hurt themselves? Strip off their clothes? Climb the furniture? Raid the refrigerator? Sometimes – the silence is worse.  
 These families are not living.  
 They are existing. Breathing – yes. Eating – yes. Sleeping- maybe. Working- most definitely - 24/7.

**This is autism.** (author's emphasis)

The 2013 film "Sounding the Alarm: Battling the Autism Epidemic" reiterates AS' focus on the effects of autism on families. This documentary "examines the lives of 12 families who live with

autism, and chronicles the challenges and opportunities they face from diagnosis to adulthood”<sup>10</sup> (Autism Speaks, 2014e).

As in “I Am Autism,” autistic people are silent in these descriptions of what “the lives of those touched by autism” (Autism Speaks, 2013b) are like. Autistic children are discursively positioned as patients, both in the sense of recipients of medical treatments and in the linguistic sense of people being acted upon (e.g., by autism, parents, experts). These autistic children are “like [babies] . . . just bigger” (Autism Speaks, 2006a). They have “gone missing” (Wright, 2013) and the changelings left in their places are out of control to the point that parents must remain ever vigilant against what they’re going to do next. They are burdens on their families who have left their parents “running scared” and “up all night” with “dreams deferred” (Autism Speaks, 2006a). Autistic children are “work” that causes families to “split up, go broke and struggle” and leads mothers to contemplate murder-suicide because they have “nothing left to give” (Autism Speaks, 2006a). The logic behind such desperate acts rests on the idea that having autism is a fate worse than death, a sentiment conveyed by an interviewee at the start of the trailer for “Sounding the Alarm” who stresses that “[t]his thing is climbing and climbing, and you don’t die from autism. You have it the rest of your life” (Autism Speaks, 2014g; speaker’s emphasis, my transcription).

There’s an interesting future orientation in depictions of autistic people in these AS texts that mirrors the organization’s mission to “change the future for all who struggle with autism spectrum disorders” (Autism Speaks, 2014f). For the autistic children depicted, the present is

---

<sup>10</sup> Who is the referent of “they” here? The grammatical structure links “they” to “12 families who live with autism,” thereby centering these *families*’ “challenges and opportunities . . . from diagnosis to adulthood.” While it seems perhaps to be the fault of an editing error—that in fact “they” is meant to refer to autistic children who are the ones to “[face] challenges and opportunities . . . from diagnosis to adulthood”—the awkward construction seems telling. It’s as if the diagnosis and growth of autistic children is something most keenly felt by families, not by the autistic people who experience autism and grow up.



already lost to isolation, embarrassment, tantrums, attempts to “escape,” and pain inflicted on self and family. Autistic children have already “gone missing” or “lost everything” (Autism Speaks, 2014g). It is thus the future legacy and looming fate of autistic children that is made present in AS discourse instead. Wright’s (2013) “Call for Action” equates concern for “our children” with concern for “our future.” “‘Children are the living messages we send to a time we will not see.’ What is our message?’ Wright asks, appealing for a “national autism plan—NOW” (Wright, 2013, author’s emphasis). Planning now is necessary in order to address the “500 thousand” (Wright, 2013) children who will ‘age out’ of the system of educational and therapeutic supports that are available to autistic children “in the next ten years” (Wright, 2013), a commonly cited statistic that is often alluded to by tidal wave metaphors in AS discourse.

This looming “wave of children that are gonna become adults over the next decade” (AS executive VP Peter Bell, quoted in Autism Speaks, 2012b; speaker’s emphasis, my transcription) transforms parents’ “fear of the future” into a “national emergency” (Wright, 2013). Not only parents of autistic children, but “we as a country” (Wright, 2013) must be concerned with “what happens when [those parents are] not here” (Autism Speaks, 2006a).

Close your eyes and think about an America where three million<sup>11</sup> Americans and counting largely cannot take care of themselves without help. Imagine three million of our own – unable to dress, or eat independently, unable to use the toilet, unable to cross the street, unable to judge danger or the temperature, unable to pick up the phone and call for help. This is a national emergency. We need a national autism plan – NOW. (Wright, 2013, author’s emphasis)

In an MSNBC interview promoting the documentary “Sounding the Alarm,” Michael Rosen,

---

<sup>11</sup> Interestingly, Wright (2013) starts with a reference to 500 thousand, warning that

In the next ten years, 500-thousand Americans with autism will be growing up and out of the system which means they will no longer qualify for the services they rely on every day. But then, 22 lines later, she describes the “national emergency” in terms of “three million Americans and counting.” It’s unclear from Wright’s “Call for Action” where this uptick in numbers comes from.

executive VP of strategic communication at AS, describes the problem in terms of a lack of institutional homes for autistic adults.

There's just not enough homes. There's 500,000 people over the next 10 years who are aging out of their school support systems . . . They lose their school supports, where're they gonna go? There's a waiting list of 300,000 for a group home. We need a national plan from the government to help make autism a national priority. (Rosen, quoted in Melissa Harris-Perry, 2014; my transcription)

In several AS texts, the large number of aging autistic children is described in terms of an “autism tsunami that is going to hit . . . state budget[s]” (Autism Speaks, 2014g). In the “What is Autism Speaks?” video, AS is a vital lighthouse, ‘sounding the alarm’ to warn of the impending financial impact:

We at Autism Speaks see the tsunami. . . . We recognize the cost to families and the country estimated at up to \$2.3 million per person for their lifetime. That translates to well over \$137 billion<sup>12</sup> and does not account for new cases being diagnosed every eleven minutes. (Autism Speaks, 2013g; narrator's emphasis, my transcription)

### **Silencing**

It's noteworthy that autistic adults are not represented in the texts described above. There is one autistic adult pictured in “I Am Autism,” but the focus on children in Mann's poem effectively characterizes the man as a child. The only autistic adults present in the AS discourse reconstructed above are those helpless wards who will comprise the ‘autism tsunami’ of the future. Autistic people who are currently adults are silent, nonexistent.

Their absence is not just discursive. Autistic adults are not included in leadership positions at Autism Speaks, nor are they prominent in AS events. As autistic disability rights advocate Lydia Brown (2013b) and many other ND advocates have pointed out

---

<sup>12</sup> This statistic is repeated in Wright's (2013) “Call for Action:” “Financially, we estimate it costs 2.3 million dollars to care for one person with autism for their lifetime, and it will be well over \$137 billion dollars for all our children.”

Autism Speaks . . . has no meaningful representation of autistic people among its several advisory boards. . . There is not now and has never been a single openly autistic person on the organization's board or in the administrative leadership.

Apart from the apparently autistic children pictured walking with their families in photos promoting “Autism Speaks' signature fundraising and awareness event [Walk Now for Autism Speaks]” (Autism Speaks, 2014h), autistic people are generally excluded from AS events as well. For instance, autistic voices were largely absent from AS' Washington summit. The list of keynote speakers included “autism advocates” (Feld, 2014[2013]) from policy, advocacy, and treatment organizations, but only one person “on the spectrum” (Feld, 2014[2013]): AS Social Media Coordinator and national speaker Kerry Magro, who introduced keynote speaker Senator Bob Menendez.

Not only are autistic perspectives not represented in Autism Speaks advocacy practices, AS refuses to directly engage with autistic points of view. Online and elsewhere, many autistic people and allies (both ND advocates and not) have spoken out against Autism Speaks' depiction of autism and failure to represent autistic perspectives. In compiling corpora for this project, I traced opposition to Autism Speaks back to 2009 starting with protests against “I Am Autism.” My primary corpus of online discourse expressing opposition to Autism Speaks—often in blog posts directly addressed to the organization—swelled to over 440 texts (not including tweets or comments).

AS' radio silence in the face of autistic criticism is particularly noticeable on Autism Speaks' web site, where neurodiversity advocates have been very active in comment threads. For example, by February 9, 2014—nearly 3 months after Wright penned the post—comments on Wright's “Call for Action” numbered 1,067 and included many autistic voices taking issue with AS' “offensive” (Muzquiz comment on Wright, 2013) discourse. The first several pages of

comments I printed from the thread in February 2014 are dominated by autistics, parents, and other allies arguing against Wright's depiction of autism. These voices are answered by non-autistic parents pushing back in comments that praise AS' "parents perspective" (katie comment on Wright, 2013) and its effectiveness in rallying support for "more facilities, more trained professionals, more acknowledgement and more help for those with autism and their families" (Matt comment on Wright, 2013). However, I could find no response from AS representatives in this long comment thread. When I revisited Wright's (2013) "Call for Action" posted on the AS website in the fall of 2014, I found that comments had been deleted.

The few responses from Autism Speaks to its opponents I could find occurred in interviews. One example appeared in a *Time Magazine* article covering the controversy over the video "I Am Autism" (Wallis, 2009). When this video came out, many autistics and ND advocates protested it online, and the controversy escalated when ASAN published a press release "condemning Autism Speaks' unethical and offensive 'I Am Autism' advertising campaign" (ASAN, 2009). The ASAN press release pointed out that "[t]his type of fear mongering hurts Autistic people, by raising fear and not contributing in the slightest to accurate understanding of the needs of Autistic adults and children" (Ne'eman, quoted in ASAN, 2009). ASAN also created an online petition signed by over 60 disability rights groups—including ADAPT, the National Council on Independent Living, and the Disability Rights Education and Defense Fund—calling for AS sponsors to end their support. Local ASAN chapters also organized live "protests rallies around the country" (Wallis, 2009). These actions made an impact; AS took down the video. But in comments made to *Time Magazine*, "executive vice president of Autism Speaks" (Wallis, 2009) Peter Bell erased the opposition's influence over Autism Speaks' decision to remove it.

Bell . . . said the video got plenty of positive responses from the autism community. "But we realized it did hurt a certain segment of the population, which is why we removed the video link from our website," he said. (Wallis, 2009)

It seems telling that Bell's comments reduce ASAN, disability rights and neurodiversity advocates, and autistic people to "a certain segment of the population" that remains nameless and set apart from "the autism community." Positioning Autism Speaks as having made the realization on its own that "[the video] did hurt" some people, the AS executive characterizes those belonging to "a certain segment of the population" as an inconsequential fringe element unworthy of response.

These discursive strategies point to an underlying situated ideal regarding who should be involved in making decisions about what to do about the autism 'epidemic.' In ideal autism advocacy, according to AS, the most important perspectives are those of neurotypical autism parents and autism experts. The voices of autistic adults are inconsequential or nonexistent. When they are present in AS discourse or included in AS events like the Washington summit, they serve as token<sup>13</sup> representations that boost Autism Speaks' legitimacy without disrupting the organization's depiction of autism.

---

<sup>13</sup> While AS has never had autistic people in leadership positions, it has made some effort to spotlight autistic AS affiliates, leading some ND advocates to accuse the organization of tokenism (e.g., Brown, 2013b). Until 2013, John Elder Robison, "NY Times Best Selling Author" (Robison, 2013a) of *Look me in the eye* (Robison, 2007), was the organization's most high profile autistic representative. However, he resigned from his position on the AS Science and Treatment Board in response to Wright's (2013) "Call for Action" (see Robison, 2013b). Today, Kerry Magro, national speaker and author of "Amazon Best Seller" (Magro, n.d.) *Defining autism from the heart: From nonverbal to national speaker* (Magro, 2013) is AS' most high-profile autistic employee. A Social Media Coordinator at AS, Magro was the only autistic speaker included in the AS Washington summit. He is also a frequent contributor to the AS blog "In Our Own Words," and his tweets and handle appear regularly in Autism Speaks' Twitter feed. "In Our Own Words" [IOOW] is a rare venue in AS discourse that "highlights the experiences of individuals with autism from their perspectives" (Autism Speaks, 2014d). Magro kicked off the IOOW blog on Dec. 4, 2013, 3 weeks after the publication of Wright's "Call for Action," leading one commenter on the inaugural post to speculate about the impetus behind AS' sudden interest in giving space to autistic perspectives.

Given the realities depicted in AS discourse—that parents of autistic children are “depleted. Mentally. Physically. And especially emotionally” (Wright, 2013) and that autistic people are silent—Autism Speaks positions itself as the most vital expert on autism, a representative for all who are “touched by [it]” (Autism Speaks, 2013b). The slogan that closes the video “What is Autism Speaks?” makes the organization’s goal to speak *for* the autism community explicit: “We are their voice. We are Autism Speaks” (Autism Speaks, 2013g).

In order to position itself as “the voice of these children and these families that [are] struggling . . . with this epidemic of autism” (Wright, quoted in Autism Speaks, 2013g), Autism Speaks engages in manipulative silencing. As Huckin (2002) notes, manipulative silences are marked by deception, intentionality, and advantage, and all of these features are evident in AS discourse. Autism Speaks conceals relevant information by positioning itself as the voice of a united autism community and ignoring opposition from many members of this community. It seems clear that this deception is willful. After all, it is unreasonable to presume that AS is unaware of its critics. My own incomplete corpus built from five years of sustained protest against Autism Speaks includes online petitions with prominent signers, hundreds of blog posts, and tens of pages of critical comments posted to the AS website. If AS is unaware of these texts, surely the organization has noticed opposition on Twitter. In just the last year, ND advocates have directly targeted Autism Speaks in hundreds of tweets and several days of Twitter bombs. The twitter hashtag #BoycottAutismSpeaks has been active since Wright’s (2013) “Call for Action,” and it’s successfully lobbied several AS corporate sponsors to withdraw their support. Recently, when AS asked its supporters to celebrate the organization’s tenth anniversary by

---

Was it the backlash that AS received from self advocates, their allies and other organizations after that horrible letter that Suzanne Wright wrote? And it comes only weeks after JER [John Elder Robison] resigned? Seems a bit ummm fishy...is it damage control? One can only wonder if it is. (Imthatg1rl, comment on Autism Speaks, 2013e)

While it is on the AS website, the IOOW blog is not linked to the AS homepage.

tweeting stories about “how AS has touched your life” (Hughes, 2015) using the hashtag #AutismSpeaks10, ND advocates hijacked the hashtag, filling AS’ Twitter mentions with “hundreds of angry missives” (Hughes, 2015). Given the fact that AS must be aware of at least some of this opposition, the failure to respond to or represent autistic perspectives in AS discourse is evidently an intentional strategy, one that confers the advantage of allowing Autism Speaks to dominate discourse about autism and shape common beliefs about what should be done about it.

### **Dehumanization**

AS engages in “fear mongering [that] hurts Autistic people” (Ne’eman, quoted in ASAN, 2009) by characterizing autism as a fate worse than death and autistic people as “broken, voiceless not-people stranded by huge chasms from the rest of the world” (Bascom, 2012a). Judging from AS’ immense “fundraising power”<sup>14</sup> (Robison, 2013b)—Autism Speaks, Inc. reported over \$12 million in net assets in 2013 (Autism Speaks, Inc., 2013)—“raising fear” (Ne’eman, quoted in ASAN, 2009) is an effective rhetorical strategy for raising monetary support. ASAN president Ari Ne’eman suggests that this is one of the reasons why AS has not veered away from “fear mongering” in spite of the damage it does to the autistic community the organization claims to serve.

“Autism Speaks believes that its bottom line will be helped by portraying autistic people as less than human,” says Ari Ne’eman, president of the Autistic Self-Advocacy Network. “This is really damaging if you’re trying to get your child included in school or if you’re an autistic person trying to find a job or get included in society more broadly.” (Diament, 2009)

By characterizing autistic people as frightening, silent, empty, and threatening Autism Speaks discourse positions them as “less than human,” “[m]onsters . . . who trouble the border

---

<sup>14</sup> This fundraising power is indexed by the acronym used by many AS critics online: A\$.

between human and animal, between living and dead” (Waltz, 2008, p. 15). The vacant embodiments of autism represented in AS texts are erratic, uncontrollable, dangerous bodies. Living with autism is “not living” (Wright, 2013) at all; it’s “existing . . . In despair. In fear of the future” (Wright, 2013). It is a fate worse than terminal illness, worse than death.

These monstrous depictions of autism are grounded in communicative ideals that tie conceptions of humanity to neurotypical interaction. As Waltz (2008) points out, “the impairments connected to autism trouble some very basic ideas about what it is to be human” (p. 14). According to prevalent thinking, to be fully human is to speak. “We [also] hold that there is a standard level of ‘relatedness’ present in all normal humans” (Waltz, 2008). According to these normative communicative ideals, when a person cannot speak or does not appear to relate to others, when they move and look in ways that ‘normal humans’ can’t relate to, they are taken to be less than human. This dehumanization is the crux of stigma.

By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences, such as those of social class. (Goffman, 1990[1963], p. 15)

Autism Speaks helps to construct a stigma theory that explains autistic people’s inferiority by showing them to be incommunicative, broken, threatening, and costly. This “reduce[s autistic people’s] life chances” by casting them into the realm of incommunicability and excluding them from meaningful political participation. Such positioning is “really damaging” (Ne’eman, quoted in Diament, 2009) in that it bars autistic people from inclusion in society and precludes genuine engagement with autistic others (an idea I explore in more detail in chapter 7).



Pinchevski (2005) describes autism as the epistemological boundary between communication and incommunicability. While “communication itself is deemed explicable, knowable and analyzable” (p. 187), its negation is deemed inexplicable, incomprehensible. The boundary between the known (the normate) and the incommunicable is marked by a hierarchical dichotomy between “impassé”—being unable to communicate—and interaction that “renders impassé noxious and interaction remedial” (p. 188). To frame this idea as a situated ideal: It is bad to be autistic; it is good to communicate like a neurotypical.

Drawing on this ableist belief about what communication and personhood ought to look like, Autism Speaks impedes inclusion through its autism awareness discourse. As autistic disability rights advocate Paula C. Durbin-Westby notes, AS discourse “perpetuates a double injury to Autistics” (Durbin-Westby, n.d.) by characterizing autistic lives as undesirable and autistic people as incapable of civic engagement.

Autism Speaks perpetrates a double injury to Autistics, at both the personal and community level. "You don't die from autism, you can have it for the rest of your life" is a threat of personal violence in that individual Autistics are considered not worthy of life as we are. Structural violence is committed against Autistics as a subgroup of citizens\* when we are purposely removed from having the equitable access to national-level conferences that is enjoyed by Autism Speaks. \*Autism Speaks' rhetoric and practices of us erases our citizenship by convincing lawmakers and other decisionmakers that we have nothing to contribute. We are effectively not recognized as being capable of political participation in the public sphere.

### **Consequences**

The discursive strategies outlined above are consequential. They serve AS' aims to define autism and dominate discussions about it. These strategies are effective in convincing autism parents, national policymakers, international politicians, influential endorsers, corporate

sponsors, fundraisers, and donors that autism is an urgent issue that needs to be addressed, and that Autism Speaks is a legitimate authority on autism who is worthy of the task.

In addition, the construction of autism in AS discourse is linked to the organization's decisions about how it ought to address autism. The future-orientation in AS autism awareness discourse is mirrored by the organization's commitment to funding research to reduce future cases of autism. As Suzanne Wright put it in 2006 at the organization's 'New Decade' Fundraiser, "We are walking toward a future of hope . . . a future when autism is not a daily struggle for millions of families, but a word for the history books" (Autism Speaks, n.d.). To achieve this future, Autism Speaks devotes the majority of its research funding to "science and medical research" (Autism Speaks, 2013d) aimed at finding "the causes, prevention, treatments and a possible cure for autism" (Autism Speaks, 2014k). Work toward Family Services—the division of AS that "support autism families . . . with information, advice and easy-to-use tool kits" (Feld, 2014b)—currently makes up 4% of the organization's overall budget (ASAN, 2014a; Ryan, 2014), less than one third the amount devoted to science grants and less than 10% of the total spent on advertising (Ryan, 2014). As ASAN (2014c) argued in its 2014 joint letter to AS sponsors, by failing to "[reinvest] in services and supports for autistic people and [their] families" Autism Speaks actually "pull[s] money away from local communities . . . at a time when state budget cutbacks are making investment in local disability services all the more critical."

As outlined in chapter 1, AS' focus on curing autism is something that positions the organization as fundamentally at odds with ND advocates, who go so far as to argue that Autism Speaks' goals are eugenicist in nature.

Within the autistic community, the concept of a "cure" has been discussed at length. Most autistic people agree—autism cannot, and should not, be cured. Autism is an intrinsic part

of an individual's personality, a neurological configuration that affects a person on a fundamental level. Its removal would mean a disruption of senses, thought structures, behaviors and interests so complete that it is difficult to see it as anything but death. Even assuming, for the sake of argument, that the much-vaunted cure is both possible and desirable, [Autism Speaks'] research into the genetic markers of autism will result not in a cure in the form of medication or treatment, but in the form of a prenatal test that will allow autistic fetuses to be selectively aborted simply for being autistic, something that has already devastated the Down's Syndrome community. (Blaylock & Washburne, 2014)

Taking a social model stance, many ND advocates oppose AS' medical model approach to addressing autism, arguing that AS awareness discourse helps build social barriers that impede autistic people from flourishing.

[A]utistic adults experience considerable economic struggles because of the need to live off of disability, the difficulty finding jobs, the struggles of maneuvering alone, without supports, through a world that refuses to accommodate them, that harkens to the negative and damaging stereotypes that Wright and others like her perpetuate. (Willingham, 2014)

Speaking out against AS' ableist representations of autism, autistic advocates voice their own experiences, a move that counters silencing, reclaims autistics' right to represent what autism is like, and encourages non-autistic audiences to engage with autistic perspectives. As Leah Jane (2012), blogger at *The Quixotic Autistic*, explains, overcoming "the attitudes and societal barriers" perpetuated by Autism Speaks requires taking a disability perspective that recognizes the value of autistic points of view as well as a social model perspective that recognizes the disabling effects of stigma.

[T]here are days when I feel pain, frustration, and stress towards how my brain works- But those limitations are mostly caused not by the functioning of my brain, but instead, by the attitudes of people who believe Autism Speaks' message about my mind and my way of life being somehow inferior, less functional, broken, or a puzzle to be solved.

If you could take away the attitudes and the societal barriers which privilege one way of thinking and being over another, my life would become considerably easier- and it doesn't take millions of dollars in laboratories to do so. All it starts with is a change in perspective. . . . Truly, if we want a better world, the first thing in need of curing is not autism, but ignorance and resistance to the idea that difference can be beautiful, exciting, and valuable.

Autistic advocates also work to personalize the effects of AS' rhetoric, a move that pushes against dehumanizing depictions of empty, uncomprehending autistic children by asking audiences to take these kids' points of view. This shift in perspective is illustrated by advocates who argue that talking about killing your child in front of them—as Alison Tepper Singer did in the AS video “Autism Every Day” (Autism Speaks, 2006g)<sup>15</sup>—is not “gutsy and courageous” (Thierry, quoted in Liss, 2006) but “unconscionable” (Brown, 2013d). In a blog post addressed to autism parents entitled “Your children are listening,” Sparrow Rose Jones (2014b) offers her perspective as a way of reminding parents that fear and stigma can become internalized by children:

I hear how pitiful I am. I hear how frightening I am. . . . All over the internet, people are talking about the great tragedy, the epidemic, the tsunami. . . . People speak reverently about a future time when people like me are never born any more.

The whole world is talking about people like me. I hear it all the time. I hear it even when I try really hard to get away from it. And your children are listening to it, too. When the world talks about us like this, how do we find the path to feel good about who we are? How do we find the motivation to keep working to try to find our way in a world that so clearly doesn't want us here? How do we learn to fit in with people who make it clear

---

<sup>15</sup> Singer (2009) has since distanced herself from these comments, writing that [t]he point I was trying to make in the film was that the lack of appropriate services and the thought of putting her in a terrible school made me want to drive off the bridge; not that Jodie did. If I had the film to do over again, I would certainly try to make that point more clearly than I did. . . . Those thoughts were not rational, although those feelings were real. I am not the only mother to ever experience those desperate thoughts. . . . Please know that those feelings stem from love and desperation. We love our children.

every day that they think we are broken, wrong, undesirable? How do we keep from feeling hated, pitied, feared, despised, and like we should never have been born in the first place? How do we keep from adopting those feelings about ourselves and turning the hatred inward?

Other ND advocates argue that Autism Speaks makes life harder for autistics by helping to make a neurotypical world that's unsafe for neurodivergent individuals. These advocates point to the ways in which AS fear discourse depicts violence against autistic people as sympathetic, even reasonable. Quoting a line from Suzanne Wright's (2013) "Call for Action," Ariane Zurcher (2013b), mother to a non-speaking autistic daughter and blogger at *Emma's Hope Book*, argues that AS discourse portrays filicide as "practically inevitable" by building a damaging "public perception" of autistic people.

"How long before they break?" [asks Wright, referring to autism parents.] Given that several parents have recently attempted and some have succeeded in killing their Autistic children, this language is particularly repugnant. This is not a call for action, it is a call for fear. . . . It dismisses the horror of these crimes against their own children as something that is practically inevitable. It suggests that autism is the reason people would go to such extremes, but nowhere does Autism Speaks suggest it is the public perception, a perception they have had a massive hand in creating, that makes the lives of families and our Autistic children more difficult and yet I can tell you, it does. What they are doing, what they are saying is making my daughter's life harder, not easier.

Several ND advocates go farther and draw a direct line between AS discourse and murder, arguing that AS and its supporters have "blood on [their] hands" (Neurodivergent K, 2012). These 'angry autistics' point out that stigma perpetuated by dehumanizing discourse is a real killer, something capable of "diminish[ing one's] human worth to the point that [their] life could very well be in danger" (Ryan, 2013b). For Bev Harp (2012), Autism Speaks' power to shape public perception makes it a particularly insidious threat, one whose capacity to contribute to grievous violence against autistic people is frequently explained away.

Somebody calls autism a tragedy. Somebody kills an autistic person. Somebody doesn't see how these two events are connected. I try to explain. I try harder. It happens again and again and again and somebody 'splains it away.

The topic here is devaluation. When it becomes commonplace to pair the words autism and tragedy, the pairing seeps deep down into the collective mind. When the puzzle piece [Autism Speaks' logo] becomes the recognized symbol for autism, the message comes over and over that there is something unfinished about the person. Something mysterious that the general public cannot be expected to understand. Now when someone hears "autism," tragedy echoes in the background. Puzzlement reverberates. This one is not like the others. This one is out of our range of understanding and compassion. (p. 256)

### **Connecting the Dots between Discourse and Filicide**

If the connection between Autism Speaks discourse and murder is something that's easily "splain[ed] away," it is because there's no direct connection between discourse and filicide. Ableist context models that position autistic people "out of our range of understanding and compassion" are the intermediary between dehumanizing discourse and violence against autistic people. While some may not see how AS' brand of autism awareness and murder are connected, there are other dominant discourses in which the link between ableist representations of autism and filicide is perhaps more apparent.

As many ND advocates note, there are significant consequences to dehumanization, the most extreme of which is death. Filicide of disabled people—cases in which people with disabilities are murdered by parents or caregivers—is alarmingly common, and filicide of autistic children is unfortunately well represented among such cases. Disabilities—especially cognitive disabilities like autism—are significant risk factors "that may increase the likelihood of child maltreatment" (U.S. Dept. of Health and Human Services, 2013), including abuse leading to death. According to the U.S. Department of Health and Human Services (HHS) (2013), more

than 67,000 children with disabilities were reportedly maltreated in 2012<sup>16</sup>, many of them by parents or caregivers. Children with cognitive disabilities comprised 75% of these cases.

The number of incidences of filicide involving people with disabilities is unknown since no national statistics are tabulated. Those working to document these cases generally rely on newspaper reports. Between October 2013 and 2014, ASAN added 30 homicides to its “running list of people with disabilities killed by their caregivers” (ASAN, 2014b). According to ASAN’s list, in the last five years, more than seventy people with disabilities have been murdered by their parents (ASAN, 2015c). Autism Memorial, a LiveJournal site “dedicated to remembering those autistic people who died because of malpractice, lack of resources or support, or outright murder” (Autism Memorial, 2013) lists 17 autistic people killed by parents or caregivers in 2014. Since June 2013, I’ve followed 13 high-profile cases of attempted filicide of autistic individuals in the U.S., 12 of which were successful. The most recent was the murder of six-year-old London McCabe, who was pushed off of a bridge by his mother Jillian on Nov. 3, 2014.

While ND advocates argue that Autism Speaks’ depiction of autism as tragedy offers an indirect excuse for autistic filicide, media coverage of murder cases portray autism as justification for murder in more direct ways. *NBC News* coverage of London McCabe’s murder illustrates dominant discursive patterns that reiterate context models in which filicide is a rational response to the tragedy of autism. Here, “caring for a non-verbal and autistic child<sup>17</sup>” is an “incredible [challenge]” that caused a “once-stable mother [to suffer] a mental collapse” (Vinograd & Connor, 2014). Jillian’s story elicits “understanding” (Donaldson James & Vinograd, 2014) reactions; one can imagine how someone so “overwhelmed” (Donaldson James

---

<sup>16</sup> Note that this is a count of *reported* cases. The actual number of incidents including uninvestigated cases is likely to be significantly higher.

<sup>17</sup> In Vinograd and Connor’s (2014) article, this challenge is compounded by “a health crisis that left [Jillian McCabe’s] husband fighting for his life, and the death of her father.”

& Vinograd, 2014) might harm their child. In fact, according to the expert quote reproduced below—a portion of which (indicated in bold) is repeated as a large-font, italicized block quote midway through one *NBC News* article—it’s surprising that more mothers don’t murder their autistic children, given these kids’ inability to reciprocate bonding.

Dee Shepherd-Look, a psychology professor at California State University, Northridge, who runs an education group for mothers of autistic children, said “quite frankly, I am surprised this [filicide] doesn’t happen more often.”

“These children are really unable to be in a reciprocal relationship and **the moms don’t really experience the love that comes back from a child — the bonding is mitigated,**” she told *NBC News*. “That is one of the most difficult things for mothers.”

Shepherd-Look said autistic children can also be “rigid and oppositional.” (Donaldson James & Vinograd, 2014, my emphasis)

Media discourse like this constructs a stigma theory according to which autism is justification for violence. Such characterizations are very common; the tropes highlighted above are echoed in most media coverage of disabled filicide. According to these representations of “overwhelmed” caregivers and dehumanizing depictions of “rigid and oppositional,” unloving, and often violent children, it is not surprising that mothers murder their autistic children. What is surprising is that so many parents manage to refrain from doing so. Reading depictions of a mother at the breaking point coupled with mental representations of autism-as-tragic-burden, readers can imagine the grim reality implied by Shepherd-Look’s assertion that “[m]oms [of autistic children] are really on duty 24/7” (Donaldson James & Vinograd, 2014). “[N]ot living . . . [but] working” (Wright, 2013), facing the ‘incredible challenge’ of parenting an autistic child, a hardship that is often portrayed as “exacerbated by lack of social support . . . financial worries, divorce or marital conflict” (Donaldson James & Vinograd, 2014)—insults to injury that are themselves characterized as caused by the burden of autism—it’s no wonder that so many



parents reach a breaking point. According to such discourse, “the unthinkable” (Donaldson James & Vinograd, 2014) is understandable.

Interestingly, in dominant discourse about autistic filicide, depictions of autistic children as impossible to relate to or bond with, as burdens without whom families would be better off, as frightening, incomprehensible and inhuman figures—these mental representations of autistic people override the typical expectations that go along with mental representations of parents. In dominant discourse about autistic filicide, autistic victims are dehumanized to the point that typical reactions to a parent killing their child are silenced. It is not generally socially acceptable for parents to contemplate killing their children. Indeed, “[a]ny person who attempts to murder a [child] sparks in us an outrage, as it should” (Endow, 2013). This typical reaction is disrupted, however, in cases of disabled filicide in which “[d]isabled people are construed as a burden . . . and even thought to be the fault of their own murders” (Endow, 2013). In dominant discourse about parenting ‘severely’ autistic children, it is common to acknowledge parents’ “desperation . . . [and] dark fantasies” (Rosin, 2014), to describe a parent’s thought process as they envision driving their child off a bridge (Singer, quoted in *Autism Speaks*, 2006g) or driving them in front of a train (Rosin, 2014) or letting them drown (Rosin, 2014). When these tragedies do happen, “[s]ympathy starts pouring in for the poor murderer . . . who, in fact, did what any one else would be driven to do in the same circumstances” (Endow, 2013).

Thus, while depictions of parents driven to the brink disrupt common sense expectations that parents not murder their children, they often do not disrupt common sense assumptions that parents love and protect their children. For instance, Jillian McCabe was described as a “devoted” (Quinn, 2014), “otherwise loving mother” (Donaldson James & Vinograd, 2014), apart from the fact that she killed her child. Images of disability as tragedy bolster some parents’

claims to have committed “altruistic filicide” (McKinley, 2014) or “compassionate homicide” (CBC News, 2010), ‘mercy killing’ framings that allow murderous parents to retain some semblance of their loving protector position. For others, like Jillian McCabe, images of the burden of autism support depictions of a parent driven “out of [their] mind” (Quinn, 2014), a framing that places blame on autism-induced mental illness rather than the parent.

These depictions thus facilitate an unusual kind of perspective-taking, asking audiences to ‘walk in the shoes’ of a parent who kills their child. For many, this perspective-taking is marked by withholding judgment. As one ‘understanding’ reader put it in comments on an *NBC News* article, we should “[t]ry living [Jillian McCabe’s 24/7 ‘patient’ load] for a bit before judging her” (Shannon Jackson, comments on Donaldson James & Vinograd, 2014). Imagining parents’ day-to-day struggles supports arguments that one ought to sympathize with parents who kill disabled children. In these arguments, the audacity of suggesting that murderous parents deserve sympathy is often sidestepped with ‘there’s no excuse, but...’ disclaimers like this one quoted by *NBC News*: “There’s no excuse ... But at the same time, you have to wonder what happens that an otherwise loving mother can feel like this is the only option or that this is the best option” (Donaldson James & Vinograd, 2014).

This focus on parents is often accompanied by silences around disabled filicide victims in media discourse. Media coverage typically centers parents’ perspectives and describes the events leading up to a child’s death from the point of view of the murderer. Autistic victims’ perspectives are not represented, and few details about victims are provided. *NBC News* coverage of the McCabe case illustrates how media discourse typically focuses on the parent and their struggles, not the victim nor their death. One *NBC News* article opens with a sentence about “[a]n Oregon mother who had a breakdown while caring for her autistic son and ailing husband

[and] allegedly threw the 6-year-old off a bridge” (Vinograd & Connor, 2014)—details that position the unnamed 6-year-old as the object of his mother’s actions. Another 9-page *NBC News* article includes only two short sentences about London. The rest of the text compares Jillian McCabe’s actions with those of two other mothers—Kelli Stapleton and Gigi Jordan<sup>18</sup>—involved in “recent high-profile case[s]” (Donaldson James & Vinograd, 2014) of autistic filicide, “raising troubling questions about how much a parent who has ‘reached the point of desperation’ can be blamed” (Donaldson James & Vinograd, 2014).

For neurodiversity advocates and others who decry such depictions, there is no question. As Matt Carey—a parent of an autistic child himself—writes at the autism blog *Left Brain/Right Brain*, “When a child is killed by a parent the word ‘but’ does not apply. . . . No one should commit murder. No parent should kill their child. Full stop. Period” (Carey, 2014).

Through blog posts and organized remembrances, neurodiversity advocates work to shift the focus in public conversations about filicide from parents to victims. In 2012, the Autistic Self Advocacy Network began partnering with other disability rights groups to organize Disability Day of Mourning, a national day of mourning held March 1 during which participants read the names of disabled victims of filicide at candlelight vigils around the country and virtual vigils online. ASAN has also dedicated its recent publications to filicide victims, wherein a long list of names, each followed by the age of the victim, the cause of death, and the year the person died fills the first page. Reading the names of murder victims facilitates a very different kind of perspective-taking than that invited by dominant media depictions of filicide. Rather than imagine what a parent must have been going through to reach a point of desperation so dire as to

---

<sup>18</sup> Gigi Jordan fatally poisoned her 8-year-old autistic son Jude in 2010. In text that further suggests authors’ inattention to victims, Donaldson James and Vinograd (2014) mistakenly refer to Jude as Jordan in their *NBC News* piece.

murder their child, these lists ask that we “imagine what it’s like to be a disabled person murdered by someone you love and trust, like your parent” (Gross, quoted in L. Young, 2012).

### **Issy Stapleton, 14 Years Old, Gassed by her Mother, 2013**

The case of Issy Stapleton invites us to imagine what it’s like to be an autistic teenager whose parent tries to kill you, fails and goes to prison, and then becomes the center of ‘high-profile’ media coverage in which you are portrayed as the violent burden that drove your mother to murder. It is also a case that highlights ways in which ND advocates and others have successfully used online discourse to start changing conversations around autistic filicide.

On September 3, 2013, Issy Stapleton’s mother Kelli told Issy they were going camping, then drove her to a secluded hiking trail, gave Issy some s’mores and a double dose of Risperdal, and shut them both in the family van with two lit hibachi grills. When they were found several hours later, Issy was “strapped into the front seat. Her skin was roasting hot, her throat ‘raw as a hamburger,’ according to the police report, her mouth was foaming, and she was unconscious and unresponsive” (Rosin, 2014). After being taken to the hospital, Issy remained in a coma for three days, and doctors confirmed she’d sustained brain damage. When she woke up after being taken off the ventilator, her father called her recovery “nothing short of a miracle” (M. Stapleton, 2013).

National news coverage of the Stapleton case began immediately and continued through Kelli Stapleton’s sentencing over a year after the attempted murder-suicide. Following similar patterns to those outlined above, most news stories focused on Kelli, not Issy. When they did offer depictions of Issy, news stories tended to focus on her “violent, unstoppable rages” (Rosin, 2014) and “physically abusive behavior” (Castrodale, 2014), describing how Issy had hit her mother on several occasions, and knocked her out twice.

Dr. Phil McGraw—“perhaps the most well-known mental health professional in the world [and] host of the leader in daytime talk, *Dr. Phil*” (Peteski Productions, Inc., 2014)—devoted two episodes of his talk show to an exclusive interview with Kelli at the Michigan prison where she was being held. One episode entitled “Kelli Stapleton: A mother’s worst nightmare” asked viewers to imagine “what would possess a mother . . . to do the unthinkable” (Pennington, 2014a). By focusing on Issy’s “aggression,” describing Kelli’s “black eyes” and “fractured cheek” (Pennington, 2014b), showing a video in which Kelli screams and sobs while presumably being pursued by Issy (the shaky home movie pulled from Kelli’s blog shows only the floor and someone’s feet), and highlighting clips of Kelli telling Dr. Phil about being knocked out by her daughter, the episode makes clear that Kelli’s “nightmare” and her “unthinkable” attempt on Issy’s life were caused by Issy’s violence. According to Dr. Phil, Kelli should not have been held criminally accountable since her actions were driven by unstable mental health resulting from abuse.

[Dr. Phil] ended the interview by shaking [Kelli’s] hand and saying, “I wish you the best, Kelli.” He also opined directly to the camera, “In Kelli’s case...I don’t think that serving time behind bars is the best solution. If allowed, we would like to provide the court with some sort of evaluation and a clear mental health plan.” (Picciuto, 2014)

Audience members responded to media coverage of the Stapleton case with similarly sympathetic reactions in comment threads and on Twitter. Live-tweeting the *Dr. Phil* episodes using the hashtag #KelliStapleton, many expressed compassion for Kelli and a reluctance to judge her. “#KelliStapleton did not make the right choice, but she has my sympathy” wrote @acspears (2014). Others expressed how they were “unqualified to judge . . . hav[ing] never walked in [Kelli’s] shoes” (@Teresa\_Fraylick, 2014). Several pointed to a lack of services as the cause of Kelli’s breakdown, and suggested that Kelli’s actions were a necessary ‘wake-up call.’

As @k8lynncutie (2014) tweeted, “It’s sad that #KelliStapleton had to attempt murder-suicide in order to get the help she needed. Michigan has failed her.” Twitter users also employed disclaimers to express the idea that “[m]urder is wrong but this woman was pushed to the brink” (@lopear11, 2014). Others lashed out at “holier than thou types judging” (@lopear11, 2014), urged them to “[h]ave compassion [for Kelli]!” (@Fifi\_flea, 2014b), and reiterated the primacy of parent perspectives with comments like “[u]nless you’re facing [raising a child with special needs], you can’t begin to understand” (@Fifi\_flea, 2014a). Parents also expressed solidarity with Kelli Stapleton. In a comment on *Inspectrum: Reports from the world of severe autism* (Lutz, 2014) that echoed the sentiment expressed by other autism parents online (e.g., Magnusson, 2014), Sue C wrote

I am Kelli, except through the grace of God, I didn't break. I thought about it at times. I felt deep inside me that my son and I would be better off in heaven. My son also has severe, non verbal autism. His problem isn't a "different brain wiring" problem. He is terribly, cruelly sick and with no help or end in sight. . . . I love my son with all my heart and I know Kelli loves Issy. I have lived her life. I can't condemn her, I can only pray for her and all the parents who are living this life.

### **Changing the Conversation**

As soon as media outlets began covering the Stapleton case, ND advocates started pushing to change the conversation by criticizing dominant discourse and working to center Issy’s perspective. ASAN (2013b) “condemn[ed] media coverage of the attempted murder of Issy Stapleton” by calling attention to familiar patterns in news reporting about the attempted murder-suicide.

Both local and national media coverage of Issy’s attempted murder have emphasized her mother’s alleged stress, the “burden” of Issy’s disability, and the insufficient state of autism services today (although Issy had returned home from an intensive 6-month residential placement less than 72 hours previously.) Rather than rallying with sympathy

and support for the child victim of attempted filicide, media coverage has consistently attempted to excuse and justify her murderer and paint the person who tried to kill her—her own mother—as the “real” victim. (ASAN, 2013b)

In a statement submitted to Kelli Stapleton’s sentencing hearing a year later, ASAN (2014b) argued that “[t]his narrative is not only untrue, but can also promote future violence against people with disabilities.” In its statement “calling for zealous prosecution in the attempted murder of Issy Stapleton” (Autism Women’s Network, 2013), the Autistic Women’s Network described the connection between dominant narratives of disability-as-tragedy to violence against disabled people in more detail:

Our work seeks to challenge the dominant narrative of disability as defect, deficiency, and disorder, because this narrative paints a disabled person's life as a tragedy and a burden. This is precisely the kind of attitude that leads to justifications for violence against disabled people, when policymakers and the media alike encourage the public to sympathize with the aggressors rather than the victims.

There is no excuse for murder or any other form of violence directed against disabled people. Lack of adequate supports and services does not lead to murder. The attitude that disabled life is lesser or of less value does. (Autism Women’s Network, 2013)

Others also challenged aspects of dominant narratives portrayed in media coverage. As part of the #IAmNotKelliStapleton #WalkInIssysShoes flashblog, 77 participants took a stance against discourse “[g]eneralizing that all mothers to disabled children are teetering on the edge of murdering them” (Kim, 2014). Among them, several autistic and mentally ill parents pushed back against the portrayal of filicide

as a tragedy caused by a lack of resources. Or, worse, [as something] blamed on a parent’s stress or mental illness, which not only fails to hold the parent accountable, but also promotes the belief that mentally ill parents are unfit to raise children. (Russo, 2014)

Other autistic ND advocates reiterated the connection between dominant discourse and ableist beliefs at the root of violence against autistic people. Nonspeaking autistic advocate Amy

Sequenzia (2014c) noted how sympathetic discourse toward murderers and dehumanizing discourse about victims cast disabled people in the dangerous position of “spend[ing their] lives waiting for the ‘mercy killer’ hero.” Judy Endow (2013) voiced the uncomfortable truth that “[a]t our core, as a society, we hold the belief that a disabled person is better off dead. We don’t actually talk about this belief, but it is what is underneath when so many can read the story and agree with and sympathize with the murderer.” Paula C. Durbin-Westby (2014) agreed, explaining that “[b]ecause of this pervasive societal attitude, tipped toward dismissing our lives in a very concrete way, disabled people are in harm’s way, all of the time. Many of us are at the mercy of family or other caregivers”—caregivers who may not believe that “disabled people, especially the very disabled ones, even know what we want, that we want life” (Sequenzia, 2014c) or who may also “see [disabled] lives as not worth living” (Durbin-Westby, 2014).

Advocates also worked to dismantle Kelli Stapleton’s “‘mercy killer’ hero” status. Several accused Kelli of “using her daughter for cheap martyr mom points” (@WileyAutLibrary, 2014). Some highlighted the fact that Kelli had appealed to *People Magazine*, *Dr. Phil*, and the *Ellen Degeneres Show* on Twitter, looking to “share [her] story” about Issy’s “[e]xtreme behaviors” (@thestatuswoe, 2013) to argue that she cared more about “attention . . . than actually helping [her] ‘problem’ child” (Anonymous, 2014). Others used the hashtag #justiceforIssy to counter appeals to “pray for compassion and leniency for Kelli Stapleton” (@KatiesFowler, 2014). ND advocates also attacked Kelli’s “otherwise loving mother” (Donaldson James & Vinograd, 2014) image, using Kelli’s online discourse as evidence that Kelli “demean[ed] and vilif[ied Issy] on the basis of her disability” (ASAN, 2014b). To substantiate these claims, ND advocates pointed to Kelli’s blog *The Status Woe*, where she described “living with [Issy as] beyond horrific” (K. Stapleton, 2013b), wrote about how Issy belonged “firmly planted in



autism’s ‘hard to love club’” (K. Stapleton, 2013a), posted pictures of injuries inflicted by Issy, and published videos of Issy allegedly attacking her. Contrary to media accounts that referenced Kelli’s posts as evidence of Issy’s aggression, ND advocates used them to censure Kelli for exposing Issy “at [her] most vulnerable” (Monje, 2013) online.

Some advocates read Kelli’s accounts as skewed portrayals of parental abuse that justified Issy’s violent actions. These reactions portrayed Issy’s aggression as a reaction to—rather than an instigation of—mistreatment. In one particularly vilifying blog post, autistic activist Neurodivergent K (2013a) compared Kelli to her own abusive mother, suggesting that Kelli “was [also] violent first.”

I keep seeing "Issy was violent" portrayed as an excuse. Thing is? My mom could have made the same case. I tossed her across the room more than once. I bit her more than a few times in my teens. Pulled her hair once or twice. Kicked. . . *But this was not unprovoked.* My mother's idea of a good time was to provoke a meltdown, then get in my face, try to hold me down. It feels like suffocating, being in a prone restraint. . . . My mother was violent first. And I have no doubt that Kelli Stapleton also did things that made Issy feel trapped, where fight was the option because flight was made impossible. (author’s emphasis)

Using the hashtag #walkinIssysshoes and offering autistic points of view on Twitter, advocates worked to “re-center the conversation about autism to make it more balanced and more inclusive [of autistic perspectives]” (Onaiwu, 2014b), particularly Issy’s perspective. Several ND advocates brought Issy into public discourse by addressing her directly in open letters online, a discursive strategy that characterized Issy as a cognizant, valued member of the autistic community as opposed to a depersonalized, unaware victim. Letter authors often started by reassuring Issy that what happened was not her fault, a move that acknowledged how hard it must be for Issy “to have to live the rest of her life knowing that her mother tried to kill her”

(Crane, quoted in TPGA, 2014) and that so many people sympathized with her mother. Autistic activist Alyssa Hillary (2013a) employed this strategy in a way that reaffirmed Issy's personhood and right to life while explicitly placing blame on Kelli Stapleton and society:

Dear Issy,

I want you to know that *you deserve to exist*. . . . I want you to know that the way you are is *OK*. . . . No matter what anyone tries to tell you, the way you are does not justify what was done to you. You're a person, with all that entails. You deserve to exist. You deserve to live. The problem isn't with you. The problem is with your mother trying to kill you, and the problem is with her thinking that the status woe is a good way to describe raising an autistic daughter, and the problem is with her thinking that she had any right to make a decision about someone else continuing to live or not. It's with a society that encourages the parents of disabled children to take a martyr status. It's with a society that sympathizes with murderers and attempted murderers. Note how none of things are you being autistic or you being broken or wrong. (author's emphasis)

Letter writers also pledged support and love from the autistic community, and welcomed Issy into the community. In a letter to Issy signed "With love, Autistics," Amy Sequenzia (2013a) offered unconditional acceptance as a central tenet of a unified autistic community.

We, autistics, are a community that embraces you just as you are. We do not ask or require that you change in order to be accepted. We know that sometimes some of us react with violence to certain situations. We still embrace you. We want you to feel respected for who you are.

Over time, ND counter-discourse made some impact. While dominant discourse around the Stapleton case exhibited familiar dehumanizing tropes and silence around Issy, ND advocates raised their voices loud enough to start shifting conversations about filicide in meaningful directions. Sustained ND advocate protest online exposed new and important audiences to autistic and ally perspectives. Mainstream media outlets—including the Associated Press (e.g., AP News, 2014; Crimesider Staff/AP, 2014)—finally took notice and included quotes from

ASAN in reports about the case. *The Daily Beast* ran an article (Picciuto, 2014) that focused on ND opposition to Dr. Phil's coverage of the Stapleton case and linked to ASAN's homepage. And for the first time, ASAN's advocacy went beyond "challenging media narratives, . . . blogging, . . . [and] issuing [their] own statements" (Crane, quoted in TPGA, 2014). The organization submitted a sentencing statement to Kelli Stapleton's hearing, action through which they were

able to participate in the actual process, and influence the people who are making important decisions about sentencing, . . . about the kinds of defenses that are acceptable, and about the kinds of defenses that are going to be recognized as straightforwardly anti-disability. (Crane, quoted in TPGA, 2014)

### **Ending Dis/Ableism in Dominant Discourse**

As the critical analysis above makes clear, Autism Speaks autism awareness discourse and media discourse about filicide are two arenas of dominant discourse that have contributed to dis/ableism (both disableism and ableism) by promoting stigmatizing representations of autism. While AS discourse uses fear rhetoric to push for a cure for autism and media discourse enlists sympathy for parents to justify or mitigate killing of autistic people, both discursive threads draw on the same ideological presupposition. "Both strategies [for dealing with disability]—to kill or to cure—transmit the same core cultural message: disabled people represent 'what not to be' and are, therefore, ontologically invalid or 'uncivilised'" (Hughes, 2012, p. 18).

In characterizing autism as 'what not to be,' dominant representations revolve around an implicit normate identity, a taken-for-granted neurotypical standard constructed in contrast to autistic ways of being. According to such ableist discourse, to be normal is to communicate like a neurotypical, to interact in ways that are recognized as relating well, to behave 'appropriately' at home and in social situations, to be able to live 'independently'—that is, with no more than

the usual level of dependence on others for things like food and services. In dominant discourse about autism, these normate subject positions are also bound up with cultural assumptions about civilized families. In these normal families, children are parents' 'pride and joy,' and parenting is a fulfilling journey that ushers children into independent adulthood.

Of course, the normate is an over-simplification, "a culturally constructed fiction" (Walker, 2014b) about perfect people and ideal families that no one lives up to all the time. Adopting a neurodiversity perspective that understands autism as a natural and valuable part of human diversity destabilizes the commonsense social order by emphasizing the normalcy of diversity. This perspective is marked by acceptance of autistic people rather than awareness of autistic otherness. From this point of view, to be autistic is to inhabit "a site of resistance that critiques the 'normate'" (Goodley, 2011, p. 16). Speaking from this site of resistance, autistic ND advocates disrupt ableism using two primary strategies: critical language awareness and perspective-taking.

Fairclough (1992) uses the term critical language awareness (CLA) to describe a component of language education aimed at building "conscious attention to properties of language and language use" (p. 1) coupled with "a critical awareness of the world, and of the possibilities for changing it" (p. 7). While I am using the term to highlight grassroots rather than classroom education, CLA is a concept that captures the goal behind much of the autistic advocacy I've amplified above. "[CLA] highlights how language conventions and language practices are invested with power relations and ideological processes" (Fairclough, 1992, p. 7). It's built on the understanding that language and society shape each other, and that changing discourse is important for changing power relations and identities in society. As Lydia Brown (2012c), blogger at *Autistic Hoya*, explains

Language is imbued with power as it both reflects and shapes the society in which we live by creating rhetorical constructions that we readily transform into objects of presumed fact. . . .

The representation of disability . . . has a profound impact on cultural perceptions and prejudices, attitudinal barriers to equal access and opportunity, service provision, and the individual self-concept of millions of disabled people. Ableism inherent to the language used to represent disability and disabled people readily seeps into attitudes and actions directed toward us, leading to increased stigma, prejudice, bigotry, and discrimination on the basis of disability.

At its core, ND advocacy is about discursive change. ‘Changing the conversation,’ ‘ending misrepresentation,’ ‘rethinking autism,’ ‘reframing’—these catchphrases common to ND counter-discourse all point to a critique of dis/ableist discourse and a push for discursive transformation. By challenging dominant representations of autism and educating people about the power of language, ND advocates build critical language awareness to combat stigma. It’s a process that takes time, but that has started to yield results. “It’s taken years of us being persistent and staying focused and chipping away at the same old story and telling a different one, but progress is happening” (Bascom, 2014b, author’s emphasis, my transcription).

Perspective-taking is another antidote to dis/ableism in dominant discourse. First-person accounts from autistic ND advocates fill silences, belying common presumptions that being autistic means being unable to self advocate or unaware of what’s going on. For autistic advocates, challenging misrepresentations, critiquing oppression, and centering discourse about autism around autistic—rather than neurotypical—perspectives are acts of discursive struggle. Sharing stories, voicing opinions, and representing the voices of other members of the autistic community are ways of reclaiming the right to self advocate and fighting against “the many and terrible things being done to Autistic people and other brethren in the broader disability community” (ASAN, 2012). Asking audiences to take autistic perspectives is a way of

“reclaiming voice” (ASAN, 2012), that is, working to counter silencing and establish control over representations of autism.

We reclaim our voices not just so we can fight back against what is being done to us. We do so in order to take our rightful places as equal members of a society. We do so in order to establish and advance the idea that we are not objects of charity; we are citizens, endowed with the right not just to live in the world, but to help shape it. (ASAN, 2012)

Representing autistic perspectives is also integral to building the movement and dismantling dis/ableism. Helping audiences to engage with the lived experiences and points of view of autistic people helps to make visible the mechanisms and consequences of dis/ableism. ‘Walking in autistic people’s shoes’ is a first step in empathizing with autistic people by recognizing the damage done by dehumanization, silencing, and abuse. The point of this perspective-taking is not necessarily to mourn the plight of those in the autistic community. Rather, it’s a kind of emotional consciousness-raising, one that’s enhanced by the number of autistic perspectives shared. By engaging with multiple autistic points of view, audiences can begin to move beyond sympathy to anger—a move that can facilitate action.

As the first neurodiversity advocate Jim Sinclair (1993) stated, “Be sad about [the things that happen to us], 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” (author’s emphasis). Mourning the dis/ableism that autistic people face does little to move them out of the subject position of objects of pity and charity. Anger is more useful in that it is “powerful energy” that can be “channel[ed] . . . into making change for the greater good” (Roberts, n.d.). It’s an emotion with a strong tradition in the disability rights movement. According to “father of the ADAPT community” (ADAPT, 2010) Wade Blank, “[a]nger is the root of all advocacy efforts” (Blank, quoted in ADAPT, 2010). By engaging with disabled perspectives, listening to autistic voices rail against being “erased,

silenced, derailed” (Hillary, 2013b), reading long lists of names of disabled children and adults killed by parents and caregivers, audiences can begin to appreciate why ‘angry autistics’ and other disabled activists are “irate with inequality and angry at the status quo” (ADAPT, 2010). It might also encourage them to join the fight.

While the case studies above point to the utility of critical language awareness and perspective-taking in neurodiversity advocacy, they also highlight challenges that advocates face employing these strategies. Opposing Autism Speaks and pushing back against media representations of filicide, ND advocates reproduce conflicts with parents of autistic children, infighting that creates divides within the autism community. Endorsing a neurodiversity perspective that aims for acceptance over awareness also has the potential to discount the need for treatments that might mitigate real difficulties faced by autistic people living in a non-autistic world. And what of the ‘severely’ autistic, the ‘low-functioning’ children at the heart of media representations and Autism Speaks awareness advocacy? What makes neurodiversity advocates qualified to speak for those who can’t speak for themselves? In the next analysis chapter, I reconstruct these dilemmas and consider the underlying ideals that guide ND advocates addressing these challenges.

## Chapter 6

### Divides in the Autism Community

Certainly, it is true that many individuals on the spectrum, and their families, face serious challenges on a daily basis. . . .To confront this reality and achieve progress on behalf of and with people with intellectual and developmental disabilities, including autism, the only successful path forward is one which unites, rather than divides. We all must work together.

. . . our power to achieve change is greatest when people with intellectual and developmental disabilities, their parents, brothers, sisters, professionals, colleagues and friends are all at the table. Our voice is even stronger when we make it a priority to listen to what people with developmental disabilities have to say for themselves about their own lives.

– Peter V. Berns, Chief Executive Officer at the Arc (2013)

My objection to [the word “community”] is that it usually- it presumes there’s a single group, um y’know whereas whether you wanna talk about the black community or the autism community or the gay community, there are big divisions within all of those quote-unquote “communities.” And it also bothers me, y’know, are they hangin’ out? . . . What makes them a “community?” . . . We need a new word.

– CAN (Council for Autism and Neurodiversity) Radio, 2014 (my transcription)

References to the *autism community*—a term that’s used to encompass “anyone affected by or having a professional interest in Autism” (Brown, n.d.)—abound in advocacy and media discourse about autism. The term is a valuable political tool that allows speakers to discursively construct a united community with shared goals, a singular entity for whom representatives can speak. Like references to the *disability community*, however, the *autism community* is a monolithic representation that lumps together a diverse and often contending or downright fractious crowd, thereby erasing differences and silencing dissent among the ranks.



There are significant divides within the autism community, many of which stem from a “broader conflict . . . over different ideas about what autism *is*” (Ne’eman, 2011b, author’s emphasis). Defining autism is no small matter. Just as there are multiple and competing models of disability, there are different and contentious ways of defining autism. And different definitions are consequential. How advocates define autism is directly connected to their ideas about what the autism community ought to be striving for.

“[I]n the autism world, what autism is—and what should be done about it—are very much under conflict” (Ne’eman, 2011b). Much of this conflict plays out between those for whom “the medical model need not apply” (Kelter, quoted in *Boycott Autism Speaks*, 2015) and those for whom “biomedical research into the causes, treatment, prevention, and a possible cure for autism” (Autism Speaks, 2014f) is a top priority. Disagreement on this front often sets autistic self-advocates against parents of autistic children. Generally speaking, “[i]n the parent and provider community, there’s more emphasis on trying to cure or fix [autistic people], and that’s not something [autistics] feel is a priority” (Ne’eman, quoted in Heim, 2015). In a survey study, Kapp, et al. (2013) found that most autistic respondents were disinterested in the question of cause, while finding a cause for autism was a priority for most parent participants. As mentioned, within neurodiversity circles, questions of cause and cure are antithetical to the movement’s ideals. From an ND perspective, autism is caused by natural neurological variation and curing autism is tantamount to eugenics.

The “self-advocate/parent divide” (Durbin-Westby, 2011) is talked about a lot within the autism community. Apart from disagreements over the desirability of researching causes and finding cures, other “battle lines” (Brown, n.d.) separate parents and self-advocates. Conflicts over who should represent autistics—especially autistics who cannot speak for themselves,

whether a person can ‘recover’ from autism, the validity of normalization therapies and non-traditional treatments like chelation and shock therapy, and the belief that vaccines cause autism are particularly divisive issues. Disagreements between parents of autistic children and autistic adults are characterized as “fracture[s] in the community” (Winegardner, 2011), even community “implosion” (Jones, 2014a).

These disagreements, which are always personal and deeply emotional for all involved, often result in fighting, nasty exchanges of insults, and hurt feelings on internet forums, blogs, and social networking sites, as well as occasionally in person. No one “side” is entirely culpable for all of the hatred. I have seen other Autistics spew hatred as often as I have seen the parents of Autistic children spew hatred (which is, sadly, a lot.) It is very easy for those of us in the Autism community to be upset, personally offended, and enraged enough to want to go on a personal rampage against the other person. (Brown, n.d.)

“[A]ll this disagreement/arguing/vitriol/tension/hate . . . online” (Brown, n.d.) can be “confusing and uncomfortable” for people “walking into that conversation without prior knowledge” (Winegardner, 2011), particularly non-disabled parents of newly diagnosed children.

The self-advocate/parent divide is a problem for neurodiversity advocates because this entrenched conflict impedes the broader autism rights movement—that is, the realm of autism advocacy that encompasses everyone in the autism community and in which both parents and autistic people are deeply, irrevocably invested. The divide is like a fork in the road of autism advocacy for neurotypical and non-disabled parents. Almost as suddenly as parents enter the autism community, many encounter clashes between parents and self-advocates online. These conflicts are often so polarized—and so inflammatory—that newly-inducted autism parents can feel compelled to take sides early on. Parents seem predisposed to side with other parents—after all, they can easily empathize with other parents and may find the characterizations of autism

common in parent discourse more familiar. After parents join the autism parent community, they may become less and less likely to encounter or be receptive to autistic perspectives over time. Most parents' everyday approach to autism—working toward recovery—diverges so fundamentally from the approach endorsed by self-advocates—working toward acceptance and support—that fighting and talking past one another are much more common than dialogue between these groups.

However, autism parents and self-advocates have a lot of “shared concerns” (Des Roches Rosa, 2014b), and the autism community’s “power to achieve change is strongest” (Berns, 2013) when all community members “work together” (Berns, 2013). Autistic self-advocate Robert Moran (2014) stresses that “[p]arents of autistics are our natural allies, not our enemies. As long as we are at each other[’s] throats we will gain nothing. A house divided is a house that will fall.” Citing differences that set self-advocates and parents at odds, autistic neurodiversity and disability rights activist Lydia Brown (2012a) agrees that “there is no way for the autism and the Autistic communities to move forward without creating some type of group cohesiveness.” As long as parents and self-advocates disagree on fundamental issues—like what autism is and what should be done about it—group cohesiveness is impossible.

The present chapter takes a closer look at fault lines that separate parent and self-advocate camps within the autism community. Here I offer an action implicative discourse analysis that looks at the problem of the self-advocate/parent divide and reconstructs discursive strategies ND advocates use in arguments with parents. The analysis starts with a brief review of AIDA and my methodological aims. Next, I reconstruct discursive strategies ND advocates use to construct a united autistic community. This overarching aim takes shape in arguments over models of disability as they relate to autism, disagreements over who can speak for whom, and

fights about functioning and acceptance—all key issues that separate parents and self-advocates. I conclude by reflecting on the normative ideals of disability, autism, neurodiversity, and communication that advocates orient to as they impact the problem of the self-advocate/parent divide.

Before I attend to that analysis, however, I must first interject some clarifications regarding the membership categories *self-advocate* and *parent*.

### **Self-Advocates and Parents**

Like references to the *autism community*, the *self-advocate/parent divide* is an oversimplification, a term that inaccurately groups all self-advocates and all parents into mutually exclusive, monolithic camps. In reality, there are distinctions within and overlap between these groups, as well as disagreements over terminology that merit mention. To start, there is a fair amount of ambivalence around the term *self-advocate* among autistic neurodiversity advocates, mostly stemming from individualized notions of the category. *Self-advocacy* is often defined in terms of self-determination, that is, “understanding your strengths and needs, identifying your personal goals, knowing your legal rights and responsibilities, and communicating these to others” (Wrightslaw, 2012). Paula C. Durbin-Westby and other autistic ND advocates feel that the term *self-advocate* “dismiss[es], or undermine[s], or diminish[es] . . . the advocacy efforts of Autistic adults, suggesting that we ONLY advocate for ourselves” (Durbin-Westby, 2012a, author’s emphasis). As autistic activist Corina Becker (n.d.) emphasizes,

This is not what I do . . . I am not asking for my human rights; I am demanding them, not only for myself, but for the rest of my community. This is not about ME, this is about my fellow autistic and disabled people, both now and in the future, and making sure their rights are respected. (author’s emphasis)

While there is a strong association between self-advocacy and self-determination, particularly with regard to intellectually and developmentally disabled self-advocates (see Goodley, 1997; 2003), *self-advocacy* is also used to encompass the kind of activism Becker describes. In disability rights discourse, the term *self-advocate* is often used to signify any disabled advocate, and the organization Self Advocates Becoming Empowered (n.d.a) stresses that “self-advocacy is a civil rights movement.” In any case—whether advocating for themselves or on behalf of the movement—self-advocates are marked as disabled.

In the discourse reconstructed below, the distinction between self-advocates and parents seems to hinge on neurodiversity ideals as well as disability status. Fights between parents and self-advocates map a frontier of the ND movement, where “[m]any (but not all) parents of Autistic children (usually non-speaking), and many (but not all) self-advocates” (Brown, n.d.) argue over how autism ought to be defined and what ought to be done about it. Those on the self-advocate side of the divide are neurodiversity advocates who “reject the idea that autism should be cured, and advocate[e] instead for celebrating autistic forms of communication and self-expression, and for promoting support systems that allow autistic people to live as autistic people” (NSNSU, n.d.). Parents are positioned as pro-cure.

It should be noted, however, that not all autistic people are proponents of neurodiversity and not all parents are pro-cure. There are autistic individuals who actively oppose the neurodiversity movement—e.g., Jonathan Mitchell (see Hayasaki, 2015), author of “Neurodiversity: Just say no” (Mitchell, 2007)—and many who are careful to clarify that they do not necessarily align themselves with ND ideals (e.g., Moran, 2014). These individuals may identify as self-advocates, but they often side with parents in fights online.

There are also many non-disabled parents who are neurodiversity advocates and who therefore side with the self-advocate side of the divide. These individuals sometimes signal their allegiance to self-advocates by referring to themselves as *parents of autistic children* rather than *autism parents*, a term that—along with *autism mom* and *special needs parent*—is common to dominant discourse about parenting autistic kids. While some parents of autistic children complain that *autism parent* is simply “patronizing” (Salas, 2015a), others go further in distancing themselves from negative connotations associated with terms like *autism mom*.

“Autism mom” gives the impression that I am parenting a *thing* to be had, not a human. .

..

“Autism mom” simultaneously puts parents on a pedestal. . . . I become “heroic” because I got *the thing* to raise. I got the nightmare. Yet we are still living. Still existing. This automatically proves my fortitude, whether or not it’s true. . . .

“Autism mom” has also, for Autistic people, become synonymous with distrust, with pain. When “autism moms” are taught that their child is something to fear and that they themselves are somehow special, superior, they do all sorts of things that harm. They silence. They erase. They even commit acts of filicide. This might sound extreme but it’s all too real.

**The distrust Autistics have for “Autism Moms” is justified.** (Clark, 2015b, author’s emphasis)

The negative associations with *autism mom* that Heather Clark refers to above are often indexed by scare quotes in ND discourse that highlights the self-advocate/parent divide. This is evident, for instance, in the following text description<sup>19</sup> of a cartoon portraying the “huge double standard when it comes to how we talk about Autistic people” (PACLA, 2015b) recently posted to the *Parenting Autistic Children with Love & Acceptance* (PACLA) Facebook community page:

---

<sup>19</sup> Providing descriptions so that images are accessible to those who use e-readers is a common practice in autistic spaces online.

Image: Black text on white background reads: Autistic person writes about how “Autism Parents” treat them horribly: “YOU BIG MEANIE PANTS!” picture to the left is a crude drawing of an angry face

“Autism Parent” writes dehumanizing piece about how Autistic child ruined their lives: “YOU ARE SO BRAVE!” picture to the right is a crude drawing of a face with wide, sad eyes, crying and clasping their hands over their mouth. (PACLA, 2015b)

Finally, while the dichotomous reference suggests that the categories *self-advocate* and *parent* are mutually exclusive, there are of course self-advocate parents. The unmarked term *parent* and its opposition to *self-advocates* convey the presupposition that parents are non-disabled and not autistic. This presupposition stems from a pervasive cultural bias that evaluates parents against dominant norms of ability (Stevenson, 2008). Parents are assumed to adhere to ableist normate standards, that is, they are assumed to be non-disabled, neurotypical. Indeed, when they reveal themselves as disabled and therefore outside the normate position, their status as parents is often undermined or ignored, as Paula C. Durbin-Westby’s (2011) account below highlights.

I don’t tend to use the word self-advocate for myself, preferring the term disability rights activist, but if I had to make a choice between being on the “side” of “the self-advocates” or being on the side of “the parents,” I would find myself squarely in the camp of the self-advocates. This is because I *always* experience the world as a person with a disability, in this case autism. I can’t *not* be a self-advocate.

Here is the difference that propels me over into the self-advocate camp: When I am communicating with self-advocates in the disability community, even though I am a parent and most of them are not parents, we work together as equals. My competence is never questioned . . . On the other hand, when I am communicating with non-disabled parents (and non-disabled people in general, if they know I am Autistic), too often the fact that I am a parent is not only not taken seriously, it is actually ignored or dismissed. I’d like to be wearing my “parent hat” but people keep knocking it off my head. (author’s emphasis)

I am aware that continuing to refer to the self-advocate/parent divide reifies the idea that such an impasse exists and will persist, and that the very idea of a divide implies a sense of insurmountability. I don't wish to suggest that the divide is inevitable nor insurmountable—indeed, I suggest some ways that ND advocates might work to bridge the gap in chapter 7. All of these caveats aside, inasmuch as the divide does currently exist, I will continue to reference the *self-advocate/parent divide* as shorthand for the present split in the autism community that separates autistic neurodiversity advocates and their allies from many (but not all) autism parents. I will also employ the term *self-advocate* in its fullest sense to mean an autistic advocate who advocates for themselves and is also engaged in the disability rights movement.

### **Reconstructing Advocacy Practices Using AIDA**

As outlined in chapter 3, the present study combines a critical orientation with grounded practical theory, a heuristic for understanding the interconnected problems, discursive strategies, and ideological positions that make up practices. While chapter 5 offers a critical discourse analysis mapping oppressive dominant discourse that impedes flourishing for autistic people, the present chapter offers an action implicative discourse analysis (AIDA) reconstructing the discursive strategies ND advocates use to address divides in the autism community.

As should be clear already, I bring a critical perspective to this analysis that is opposed to tragedy model discourse and in favor of neurodiversity ideals. I also bring a pragmatic orientation that recognizes the self-advocate/parent divide as a problem, one that I hope an AIDA reconstruction can help to address. By mapping key “battle lines” (Brown, n.d.) that separate self-advocates from parents, I hope to better understand the ideological presuppositions that underlie these camps' seemingly irreconcilable differences, and determine where shared



concerns might offer a way forward toward increased group cohesiveness and wider autism acceptance within the autism community as a whole.

AIDA starts with naming problems, since problems are the pivotal level of practice around which discursive strategies and ideological positions revolve (Tracy, 2005). Offering somewhat idealized reconstructions of the discursive strategies actors use to attend to problems in practice and the situated ideals—“beliefs about good conduct” (Tracy, 2005, p. 314)—they orient to in making decisions about how to act, AIDA studies provide rational models that can inform normative reflection about what practices ought to look like (Craig & Tracy, 1995). Throughout, AIDA works to take seriously and faithfully represent practitioners’ points of view.

In this case, I’ve started by attending to the problem of the *self-advocate/parent divide*, a problem identified by self-advocates and allies in the neurodiversity movement. The problem name comes from the two week blog series hosted by the *Thinking Person’s Guide to Autism* (TPGA) in response to Zoe and Robert Rummel-Hudson’s ‘disconnection’ described in chapter 4. TPGA orients toward neurodiversity ideals and includes regular posts from key ND advocates, and their primary audience is parents of autistic children. TPGA’s “Self-Advocate/Parent Dialogues” were built around the idea that the “hard work” of “[b]uilding constructive conversations and creating real social change,” employing “steely listening, forcing ourselves to bench purely defensive reactions, and honestly trying to understand unfamiliar perspectives and direct criticism” “needs to happen” (TPGA, 2011), that “[c]ontinuing the Dialogues is important, no matter how hard it gets or what fractures appear” (Des Roches Rosa, 2011b). These sentiments were expressed by parents and self-advocates alike, revealing common concerns over divisions and a shared value for dialogue as a fix—albeit a slow and arduous one—for fractures within the autism community.

Moving from naming the problem to reconstructing actors' discursive strategies below, I investigate the ways in which ND advocates interact with parents online. Conversations on the Internet can look very different from those off-line. Because the 'Internet is forever'—that is, because something published online soon takes on a life of its own and can be archived and retrieved by anyone, anytime—dialogue need not happen within the space of a blog series or comment thread, though it may. Interactions between parents and self-advocates can occur across years, in direct exchanges, or through listening in ('lurking' on forums or blogs). The reconstructions below are therefore drawn from large corpora that include both ND discourse explicitly directed at parents and ND discourse that may never have been written with parent audiences in mind but that nevertheless speak to issues that contribute to the self-advocate/parent divide. Building these reconstructions, I was driven by the question of whether and how self-advocacy discourse builds dialogue with parents.

From these reconstructions, I work to glean ND advocates' situated ideals, that is, the normative, mental models that advocates orient to as they try to persuade parents to see things from a self-advocate point of view. In particular, I focus on beliefs about disability and autism rights advocacy, and ideas about how people ought to conceptualize autism and communication. These situated ideals emerge out of extensive knowledge of neurodiversity advocacy and in-depth analysis of individual texts. Uncovering the complex, often competing, normative beliefs that actors orient to in practice is a strength that AIDA brings to my critical study. By reconstructing situated ideals, I can begin to engage with the cognitive interface that mediates the dialectical relationship between discourse and society (van Dijk, 2009a). These normative models may also provide philosophical maps that can help us to understand and perhaps unstick entrenched worldviews like the tragedy model of disability.

Discourse analysis is a method for theory building. The present analysis is aimed at building normative theories about what neurodiversity advocacy ought to look like, and, more specifically, how self-advocates might persuade parents to join the ND movement. It's also aimed at building disability theory by interrogating how disability and autism ought to be conceived from an autism rights standpoint. Finally, this analysis is also concerned with social theory in that it looks to understand how a minority social group uses resistant discursive strategies to spread acceptance and equal rights for autistics and other cognitively disabled people.

### **Self-Advocates vs. Parents**

I now turn to mapping discursive strategies that characterize conflicts across the self-advocate/parent divide. What follows are reconstructions of patterns in self-advocate discourse that serve four primary strategies: 1) endorsing a social model view of autism over a medical model view of disability; 2) arguing for self-advocates' right to speak for all autistics; 3) arguing against the use of functioning labels; and 4) pushing for autism acceptance. While these strategies are reconstructed as distinct advocacy practices for the sake of analytical clarity, it should be clear that these four realms of self-advocacy are interdiscursively entangled. Repeated themes and recurrent ideals will become apparent, and I will return to these key ideas in my analysis of situated ideals in the concluding section of this chapter.

### **Espousing a Social Model View of Autism**

“Perhaps the largest consequence of the neurodiversity movement and its associated ideas is the emergence of a community of people on the autism spectrum along the social model rather than the medical one” (Ne’eman, n.d., p. 2). Drawing on a social model understanding of disability and a minority model understanding of community, neurodiversity advocates construct

a united autistic community that is defined over and against the fragmented conception of autism based on a medical model view of disability. This is an important discursive move, one that enables neurodiversity advocates to represent all autistics and to undermine the legitimacy of medical model approaches to autism.

As shown in chapter 5, Autism Speaks defines autism from a medical model perspective by framing autism in terms of disease of epidemic proportions, a conceptualization that supports the organization's goals of curing autism and finding causes for autism spectrum disorders. However, while AS claims to support everyone who is 'touched by autism,' the way the organization defines autism as disease confounds their aim to represent the autism community in its entirety, a fact even AS executive vice president of strategic communications Michael Rosen conceded when responding to the controversy over Autism Speaks co-founder Suzanne Wright's (2013) "Call for action." In comments to the *Palm Beach Daily News*, Rosen attributed disagreement over Wright's post to differences in functioning, an attribute that differentiates 'severe' from more "higher-functioning" autism spectrum diagnoses.

[Rosen] said [Autism Speaks] understands that higher-functioning people with autism may have a different point of view about the issue.

"The people who are not sick, not unhappy, and are totally fulfilled and happy with their differences, we totally support them as well," Rosen said. . . .

"What [Wright's] column had was a lot of empathy for those who are struggling the most."<sup>20</sup> (Nelander, 2013)

Autism parents often draw on the same functioning split, arguing that the neurodiversity movement is "a group of high-functioning individuals opposed to medical research that . . . 'they don't need, but [low-functioning individuals do]'" (Lutz, 2013). From this parent point of view,

---

<sup>20</sup> Wright's apparent intention to speak only for some members of the autism community was obscured by her repeated refrain "This is autism" (Wright, 2013), which suggested instead that she spoke for autism itself and families impacted by autism more generally.

medical distinctions are important and anyone who claims neurodiversity can address the needs of the autistic community as a whole is operating with a “lack of understanding of what severe autism and intellectual disability really looks like” (Lutz, 2014). As autism parent Amy S. F. Lutz (2014) puts it, “[f]or [high-functioning individuals] to identify . . . with any member of this [low-functioning] population is as presumptuous as me identifying with the blind because I need reading glasses.” According to autism parents of kids with ‘low-functioning’ autism (LFA), self-advocates can only “speak for [themselves]” (Jager, 2010).

Since its inception, the [neurodiversity] movement has been lambasted by parents of lower-functioning autistic children for pursuing what they consider to be an exclusionary agenda focused on civil rights, societal attitudes, and support. These [parent] advocates . . . say that this ‘irrational’ mission distracts and draws funding from research on medical treatments and possible cures. (Lutz, 2013)

Many parents propose “separating the high-functioning end of the spectrum—perhaps calling it something else—so that we can focus on the urgent and looming issue at hand” (Myung-Ok Lee, 2014), namely treatments and possible cures for more ‘severe’ forms of autism.

All of this discourse points to a fundamental problem with defining the autistic community around a medical conception of autism-as-disease, namely that autism is a broad spectrum diagnosis that includes a community of autistic people for whom the experience of autism can be vastly different. As Nat, “neurodiversity and transgender blogger” at *Graphic Explanations* writes

We say that autism is a spectrum condition because **there’s a huge amount of diversity among people who are autistic**, so it’s more helpful to consider autism as a wide range of different experiences rather than taking a single *one-size-fits-all* approach.

The cliché is that when you’ve met one autistic person then you’ve only met *one autistic person*, and there’s a lot of truth in this. (Nat, 2013, author’s emphasis)

As Mark Osteen (2008) puts it “there is no ‘autism’ per se, but autisms” (p. 298, my emphasis). Defining community around whether a person has autism<sup>21</sup> groups together people who are “not sick” (Rosen, quoted in Nelander, 2013) with those who experience significant impairments in functioning, that is, more ‘profound’ “functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance” (American Psychiatric Association, 2013). As *Autism Speaks* has seen, relying on a medical definition of autism and claiming to speak for autism itself can spark conflict in the autism community.

Iris Marion Young’s (2000) discussion of difference as it relates to identity politics offers a helpful perspective for understanding why a medical model conception of autistic community falls short. As Young notes, difference can be a resource for social groups, but essentialist logics that define group affiliation around whether or not members have a particular attribute are not very helpful for establishing social group identities. Such rigid ascriptions of group membership distinguish in- from out-group roles in ways that ignore “the experienced fluidity of social relations” (p. 88) and create conflict between camps. Such identity politics also run into problems when some people who have requisite attributes do not identify as group members, or fail to grant their particular difference the political status demanded by group membership. In addition, defining group identity this way implies that common attributes entail common interests and aims, an implication that ignores the fact that people who share differences may have widely divergent viewpoints. Finally, any one person can be different in myriad ways, but

---

<sup>21</sup> A discussion of the ideological stances indexed by person first (person with autism/ASD, person on the spectrum) versus identity first language (a/Autistic person, a/Autistic) is included in chapter 1. The person first descriptor used here—‘has autism’—is *Autism Speaks*’ and autism parents’ preferred formulation. Person first language (PFL) is used predominantly—and often exclusively—across all AS texts surveyed for this study, and parents of autistic children—particularly those who favor a medical model view of autism—tend to use PFL (Benham, 2014).

essentialist logics ignore intersectionality and deny diversity around how people experience difference. Attempts to define group identity in terms of shared attributes “[tend] to normalize the experience and perspective of some of the group members while marginalizing or silencing that of others” (p. 89).

All of these problems are evident in Autism Speaks discourse. Even AS executives must admit that their definition of autism normalizes the tragic experience of “those who are struggling the most” (Rosen, quoted in Nelander, 2013) and silences “different point[s] of view” (Rosen, quoted in Nelander, 2013)—namely those of autistic people in general, not just “higher-functioning people”<sup>22</sup> (Rosen, quoted in Nelander, 2013). Parents, too, face the problems Young (2000) outlines, particularly with regard to defining community goals in terms of curing autism and functioning as a static ascription—an idea I’ll return to below.

Young (2000) proposes that organizing communities according to emergent, relational criteria avoids the problems of essentialist conceptions of community identity.

Considered relationally, a social group is a collective of persons differentiated from others by cultural forms, practices, special needs or capacities, structures of power or privilege. . . . [that] are not explicitly constituted. They emerge from the way people interact. The attributes by which some individuals are classed together in the ‘same’ group appear as similar enough to do so only by the emergent comparison with others who appear more different in that respect. (p. 90)

Defining social groups relationally highlights the structural processes that enable and constrain opportunities for group members. This kind of relational understanding has been particularly important for mobilizing the disability community—a group with an even wider spectrum of difference than that encompassed by autism diagnoses. Awareness about how disabled people

---

<sup>22</sup> To be clear, this last claim is mine, not Rosen’s. As demonstrated in chapter 5, Autism Speaks discourse excludes autistic voices in general, not only those who are ‘high functioning.’

are socially positioned against normative ideals is what allows disabled people to emerge as a unified group of social actors.

“[T]he disabled” is a category of “the other” to the able-bodied, and for that very reason it is also a politically useful and socially meaningful category to those who are in it. Disabled people share forms of social oppression, and the most important measures to relieve that oppression have been initiated by disabled people themselves. Social oppression may be the only thing the disabled have in common; our struggles with our bodies are extremely diverse. (Wendell, 1997, pp. 263-264)

Like those in the wider disability rights movement, ND advocates orient to a social model understanding of disability and autism that enables a relational conception of autistic community identity. “Neurodiversity is a movement that arose out of the social model of disability in response to the medical model of disability and cure culture” (Schaber, 2014c, my transcription). The neurodiversity movement’s orientation to a social model understanding of autism sets self-advocates and allies apart from parents and professionals who subscribe to a medical model understanding of autism as disease. According to a medical model view, autism is impairment to communicative functioning that lessens quality of life for autistic people and their families. From ND advocates’ social model perspective, societal barriers to inclusion—not autism itself—are what impede flourishing for autistic people.

The problem of disability is not located in the body or the mind of the person called “disabled,” but it’s located in a society that disables that person because they don’t function, act, behave, or communicate in the same way as everyone else. (Brown, 2013c)

Defined socially, the appropriate response to disability is making society more inclusive, not helping autistic people assimilate. As the tagline for the blog *Parenting Autistic Children with Love & Acceptance* exhorts parents, “[c]hange the world, not your Autistic child!” (PACLA, 2015a, authors’ emphasis).



Neurodiversity advocates define autistic community according to social relations and structural differences, not diagnoses. For neurodiversity advocates, where an autistic person is positioned along the autism spectrum is immaterial. From an ND disability rights perspective, “the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens” (ASAN, 2015a), no matter how they function, nor whether they’re formally or self-diagnosed (Hillary, 2012b). According to this view, autism is a difference experienced by a minority group who faces discrimination in ableist society. Like race or gender, this difference is not an essential characteristic that leads to discrimination, but a deviation from normative identity that is marked as less than in social interactions.

An ND articulation of autism rights thus draws on a social model understanding of disability that separates impairment from disability and focuses primarily on the latter. Disability is defined in terms of disablement—social oppression—not individual impairment. Embodied limitations in functioning may change the way individuals experience autism, but they do not change autistic individuals’ entitlement to inclusion. Civil rights are not contingent on functioning. “The neurodiversity movement works toward equal rights for those of *all* neurological configurations” (ASAN, n.d.b, p. 6, my emphasis).

From a neurodiversity movement perspective, all autistics—“regardless of neurology” (ASAN, n.d.b, p. 6)—are united in a “common community” (ASAN, 2015a) by the experience of oppression even though individuals’ experience of autism may vary widely. Living a neurodivergent life in a world made for neurotypical people unites all autistics. The neurodiversity movement is built around this *autistic* community, rather than autism itself. As the Autistic Self Advocacy Network puts it—using the capitalized adjective that acknowledges autistic identity in the same way capitalizing the adjective *Black* acknowledges black cultural

identity—“[we view] the Autistic community as one community, and we work with parents and other allies who share our goals” (ASAN, 2015e). From this point of view, it is in being socially positioned outside of normate functioning and personhood that the autistic community emerges, and through sharing goals set by the autistic community that the ally community takes shape.

Importantly, drawing on a social model understanding groups all autistic people together as one autistic community, no matter their politics. Neurodiversity advocates see themselves as “trying to help all Autistic people, all autistic people, and all people with autism” (Hillary, 2013c)—that is, autistics who adopt an Autistic cultural identity and espouse Autistic pride, autistics who see their autism as an intrinsic part of who they are, and autistics who view autism as disease. In short, all autistics are included in the movement, regardless of their stance toward autism and the desirability of curing it. Even autistic people who do not align themselves with the neurodiversity movement are still part of the autistic community and thus part of the ND struggle. Jonathan Mitchell, blogger at *Autism’s Gadfly*—whose tagline reads “we don’t need no stinkin’ neurodiversity” (Mitchell, 2015)—is one such autistic person. He is emphatic that the ND movement does not speak for him.

I long for a cure for autism . . . Somehow I got missed when [ND advocates] took the census. So they are incorrect about all or most autistics. Is this a viable philosophy that will help autistics and their families? Is there a consensus for this philosophy among most autistic persons? (Mitchell, 2007)

For ND advocates, however, consensus is not necessary. Self-advocates’ legitimacy to represent the autistic community as a united front stems from their belief that the neurodiversity movement will help all autistics.

The neurodiversity movement is really about changing society, yes, but also making sure that we change society in a way that gifts people access to the support necessary um to pursue the things they want in their own life. . . .For us [ND advocates], when we do our

advocacy, we try to focus on the kinds of things that will have a positive impact on autistic people of all different kinds. (Ne’eman, quoted in Bambury, 2015, my transcription)

Focusing “on the things that [many autistics] actually want: quality of life, independent living, civil rights, all those other things—the things they’re actually aspiring to, as opposed to . . . the idea of ‘normalcy’” (Ne’eman, 2011b) is viewed as helping all autistics and cognitively disabled others, even those who do aspire to normalcy.

It is noteworthy that autistic opponents of neurodiversity are often absent from ND self-advocacy discourse. When they are acknowledged, they are cast as victims of false consciousness. For example, according to autistic neurodiversity advocate Nick Walker, Jonathan Mitchell is “no different than a black person blaming his race rather than society for his problems” (Walker, quoted in Hayasaki, 2015) due to internalized racism. Self-advocates sometimes describe how they “can relate to [wanting a cure] because growing up, autism made [them] feel broken too” (Ne’eman, quoted in Bambury, 2015) in stories about their own consciousness-raising as a way of suggesting that autistic opponents might yet come around to ND ideals. In these accounts, feeling broken is a response to being cut off from the autistic community and internalizing ableist assumptions perpetuated by parents and doctors. As Amy Sequenzia (quoted in Parker, 2015) relates

I had to unlearn ableism (I internalized all the assumptions about me, that I was broken, incomplete, not good enough) and I had to put myself out in the world. When I was a child, I didn’t know any Autistic adults to have as role models. My parents didn’t know either and they made a lot of mistakes.

All the conversations were controlled by parents and doctors, usually full of pity and dire predictions.

Feeling broken is a ‘before’ state in these stories. ND advocates who sympathize with autistic individuals who “hate [autism]” (Mitchell, quoted in Hayasaki, 2015) couch their understanding

in awakening stories that include an ‘after’ state marked by “unlearn[ing] ableism” (Sequenzia, quoted in Parker, 2015), realizing the social model of disability, “get[ting] access to the supports and to the sense of community [that enable them to] no longer feel broken” (Ne’eman, quoted in Bambury, 2015), and coming to self-acceptance.

### **Speaking for the Autistic Community**

“The [self-advocate/parent] divide is about who can speak for whom” (Senator, 2012). Both parents and self-advocates face the problem of speaking for others. Because of their divergent viewpoints on whether autism is best conceived as disease or difference, self-advocates tend to disagree with parent and autistic opponents to neurodiversity on the question of who should represent the autistic community.

According to a medical model understanding of autism, parents and professionals are the best representatives for autistic people—particularly children and non-speaking autistics who cannot (or may not) advocate for themselves. Within a medical framework, autism is defined from a neurotypical perspective as a lack of neurotypical abilities. This view centers neurotypical autism experts (parent ‘lay experts’ (Langan, 2011) as well as professionals), defines quality of life in terms of neurotypical achievement, and encourages recovery as a process of bringing autistic people as close to the neurotypical center as possible. This often involves changing autistic behaviors so that autistic people look as neurotypical as possible.

[W]hen non-disabled people try to define disabled people’s quality of life[, i]t usually includes “fixing” [disabled people] to be as close to “normal” as possible. Or it is mistaken by a definition of “independence” that has nothing to do with what [disabled people] really want or need. . . . Even when the idea [of quality of life] is full of love and legitimate good intentions, even when the idea comes from people we really trust. It is still a subjective and personal thing and [disabled] perspective[s] will be always different from the perspective of non-disabled people. (Sequenzia, 2014d)

The neurodiversity movement’s social model understanding of autism, on the other hand, centers autistic perspectives rather than neurotypical points of view, casting autistic people as the most knowledgeable experts of what autistic people need, and non-autistic members of the autism community as outsiders. Some advocates separate the *autistic* community from the *autism* community entirely, excluding all but autistics from the former and relegating all allies, parents, family, professionals, and “anyone who thinks they know anything about Autism” (Sutton, 2015) to the latter. For ND advocates, this distinction between communities is important in terms of conferring rights to speak for and with.

Because self-advocates are the people best situated to recognize needs in the community and to define what a better quality of life looks like from an autistic perspective, they are positioned as the best representatives of the autistic community from a social model standpoint. For ND advocates who separate the autistic and autism communities—like mother to two autistic children Michelle Sutton, quoted below—this can mean that *only* self-advocates should speak on behalf of the autistic community.

I keep seeing people who are part of the autism community speaking out as if they have the right to say what the Autistic community needs. I wish they would stop. You don't get to say what a group of people needs unless you are part of that group. The only time it is alright to speak on behalf of a group of people is if they have told you what they want and asked you to speak with them. (Sutton, 2015)

An anonymous author at Autistic Wiki agrees. In a post addressed to parents entitled “You are not your child’s voice” (Autistic Wiki, 2015) they write,

[n]o one can ever speak for another person. Ever. . . . Parents mean well when they try to be the voice of their child, but please understand you do more harm than good. Yes, you know your child better than anyone else. But you can never truly get inside another person’s head.

For other self-advocates, like autistic activist Lydia Brown, centering autistic perspectives in matters that affect the autistic community is part of the disability rights ethos ‘nothing about us without us.’ This motto prioritizes autistic voices and looks to offset the underrepresentation of disabled individuals in advocacy, but it does not mean that allies can’t speak for disabled others. According to Brown (2012b),

[t]he principles of self advocacy are not that *only* disabled people can speak for disabled people, but that they *must* be involved with any advocacy. “Nothing about us without us” has been a motto of disability rights for a long time. There is nothing in that statement that suggests that non-disabled people have no right to be part of advocacy. What is at stake is that the most important stakeholders—the people for whom the advocacy is occurring—are routinely excluded, marginalized, and treated with . . . contempt . . . We, as Autistic people . . . have the right not only to advocate for ourselves individually, but for the rights and needs of Autistic people at large. (author’s emphasis)

Whether self-advocates and their allies take a strong stance that denies non-autistic allies the right to speak for autistic others, or a more measured stance that pushes for recognition of autistic people as “the most important stakeholders” (Brown, 2012b) in public conversations about autism, ND advocates center autistic perspectives and prioritize autistic voices over and against those of non-autistic and non-disabled autism parents.

From an ND perspective, it is “self-evident that autistic people should be *leading* each and every conversation about [the autistic] community” (Bascom, personal communication, author’s emphasis). Any public conversation about autism is viewed as part of a larger movement, one in which self-advocates “need good allies, but . . . [also] need to take charge!” (SABE, n.d.a, author’s emphasis). To be good allies, non-autistic parents need to take a support, rather than leadership, role. “Just as women need to lead their movement and African-Americans need to lead their movement, autistics need to lead their movement” (Winegardner, 2011). As

allies, non-disabled parents must “make some room for [self-advocates] in conversations about disability. [They] can use the platform [they] have been given to help [self-advocates] get [their] voices heard” (Zoe, 2011a). From a neurodiversity perspective, parents must “discover, listen to, and respect the experiences of those who have lived autistic lives” (Des Roches Rosa, 2014b). Allied parents can “speak *with* the Autistic community” (Sutton, 2015, my emphasis), but they should

- . . . not speak over the voices of Autistic people
- . . . recognize that Autistic voices deserve center stage over [the] voices [of] parents of Autistic children
- . . . [and be] open to learning from Autistic adults. (PACLA, 2015a)

Defining autistic community and the role of parents in this way thus empowers children in relation to their parents and caregivers. By claiming autistic children as community members and elevating them as experts, ND advocates position these children as future self-advocates to whom parents should be held accountable. As Sutton (2015) warns in a passage that sets the autism community in opposition to the autistic community,

There is a pretty good chance that your child will agree with the adults of the Autistic community when they grow up.

So before you [parents] go around spouting the truth of what the autism community thinks, and patting each other on the back for your advocacy, you might be wise to first listen to what the Autistic community wants.

Your child is a part of that community.

As they get older, they will know you have actively stood against their community.

(Sutton, 2015)

An ND conception of autistic community thus places non-autistic parents in a subordinate position in relation to self-advocates, an orientation that many parents feel uncomfortable with.

In this sense, being a supportive ally means abdicating some authority to speak for one’s

children, a move that can feel dangerous or untenable to parents who are vital advocates for their kids. Speaking for is an important part of most parents' identity. All children—particularly those who are (severely) disabled—depend on their guardians to recognize their needs and make decisions on their behalf. It's generally assumed that parents—and mothers in particular—know their children and their children's needs intimately (Stevenson, 2008), that they can and should make decisions in their child's best interests. For parents “living for [their children] and doing everything for their autistic children that they can possibly do” (Winegardner, 2011)—especially those who feel like they're in a “ceaseless struggle to engage [their] kids, to teach them, to advocate for the best schools and therapies, to stop them from hurting themselves or others, to maximize their quality of life now and in the future” (Lutz, 2014)—the idea that self-advocates who do not know their children nor their day-to-day challenges can claim to represent their needs can be downright offensive. Many parents would “prefer to make decisions on [their child's] behalf without being unnecessarily challenged or insulted” (Jager, 2010) by self-advocates. As one autism mom commented,

I resent anyone trying to speak for [my daughter]. If anyone will be her voice, it will be the person, namely ME, who has cared for her for 15 years, scraped poop off walls, spent hours on the floor doing DIR<sup>23</sup>, forcing communication, up at 3 am every friggin day. And damn [self-advocates] if they say I should not speak for her. I know her like I know I have a right and a left hand. She cannot speak for herself right now. And frankly, I don't care that they don't like, for whatever reason, that I AM speaking for her. They will come and go, I am the constant ship on the horizon for my daughter. (Penny, comment on Senator, 2012, author's emphasis)

### **“F\*%\$ Your Functioning Labels!”**

---

<sup>23</sup> DIR stands for developmental, individual difference, relationship-based model. Also called Floortime, DIR includes “affective relationship-based intervention strategies” (Interacting with Autism, n.d.) including play between parents and children on the floor.



As seen in the reconstructions above, divisions between ‘high-’ and ‘low-functioning’ separate autistic people according to a linear hierarchy along which individuals are “graded” (Sequenzia, 2014a) as more and less impaired and more and less capable of self-advocacy. Within the autism community, fights erupt between parents and self-advocates over the rightfulness of using functioning labels. Self-advocates in the neurodiversity movement tend to agree with *The Unpuzzled Project’s* (2014) sentiment that

[n]o matter whether we are personally labeled as high-functioning or low-functioning, these labels are detrimental to **all** of us—both individually and as a community. So that’s why I say: **F\*%\$ YOUR FUNCTIONING LABELS!** (author’s emphasis)

This strong stance aligns with self-advocates’ social model understanding of disability in which functioning is inconsequential to the allocation of rights. When they work to delegitimize functioning labels and erase “harmful divisions in [the autistic] community” (@retiredwaif, 2015), self-advocates and allies set themselves in opposition to many autism parents who rely on functioning labels to characterize their children’s disabilities, and who use arguments about functioning to justify their rights to speak for their children.

Functioning labels undermine self-advocates’ efforts to construct “autistic community [as] one big tribe” (Kim, comment on Kim, 2013a) by forcing “a rift within the autistic community” (Rubin, quoted in Bambury, 2015, my transcription) along a linear spectrum. “Functioning labels are labels that people—usually non-autistic people in positions of authority over autistic people—place on people with autism to describe their abilities” (Schaber, 2014a). These labels are often assigned by doctors as part of autistic diagnoses, or by professionals as part of therapeutic evaluations. Whether an autistic individual is labeled high- or low-functioning is generally based on whether they meet developmental benchmarks observed in their neurotypical peers—particularly with regard to speaking and self-care—and the degree to which

they can control autistic behaviors. “In other words, functioning labels are basically another way of saying whether or not you think a certain autistic person can pass for neurotypical” (FeministAspie, 2015); they are designations that categorize autistic individuals against normative standards.

There is “a significant emphasis on functioning labels in the autism parenting world” (Tate, 2014). In articles, blog posts, comments, and discussion forums, parents typically offer their children’s functioning designations as key pieces of information. For many autism parents, these functioning diagnoses are “simple statement[s] of fact” (Lutz, 2014) that reflect the realities of impairment and help them in “determining questions of autonomy and quality of independent life . . . [on] behalf of their young children and in the tricky transition to adult life” (Rummel-Hudson, comment on Senator, 2012). Parents—particularly those of ‘low-functioning’ autistics—often rely on functioning labels to categorize their children’s differences and determine what supports they need. They argue that, while

[m]any advocates assert that these distinctions between high- and low-functioning are unimportant, even insulting[. . .] the parents who are guiding the development of their kids’ lives and futures know better. (Rummel-Hudson, comment on Senator, 2012)

For self-advocates and allies in the ND movement, functioning labels confer a dangerous amount of power to parents, both in terms of their capacity to control their children’s lives, and their ability to dominate public conversations about autism. According to self-advocates, parents use functioning labels to “silence [self-advocates] and disregard [their] advocacy” (Salas, 2015b). From an ND point of view, functioning categories are mechanisms of oppression that enable parents and others in the autism community to exclude autistic individuals from conversations that impact them. As the Caffeinated Aspie (2013) writes, self-advocates face a

“no-win situation” in which they can be discredited as both ‘not disabled enough’ and ‘too disabled’ to participate in public debates about autism.

[Some are] “too high functioning” to deserve a voice in the debate . . . But then again, “low functioning” folks don’t get a voice either, because they aren’t able to have coherent thoughts, and opinions and make decisions about their own lives. (The Caffeinated Aspie, 2013)

As seen above, many parents take issue with ‘high-functioning’ autistics claiming to represent the autistic community. Parents often levy ‘Not Like My Child’ arguments at self-advocates, because the very act of self-advocacy is viewed as a mark of high functioning. “[M]any [self-advocates] have heard this one before—‘well, you’re not like my child, you’re high functioning. My child will never be like you’” (Schaber, 2014a). Perhaps because autistic impairments are often invisible online, Internet self-advocacy in particular elicits frequent “if you can write on the internet/keep a blog/respond to these comments, you are very high-functioning and Not Like My Child” (Brown, 2015a) arguments. As mentioned, these arguments are used to discredit ‘high-functioning’ autistics who claim to speak for everyone on the spectrum. “[T]he term ‘low-functioning’ [is also used] to discredit the voices of non-verbal autistic people” (Schaber, 2014a) when “communication through AAC [augmentative and alternative communication] or pointing to a letterboard or text-to-speech [is viewed as not] as valid as speaking with your mouthparts” (Schaber, 2014a). Some parents are particularly quick to dismiss non-speaking autistics who communicate via facilitated communication (FC)—a method of communication involving typing or pointing in which aides provide physical support or verbal prompts to the communicator—arguing that FC messages come from facilitators, not self-advocates (e.g., Lutz, 2013). Self-advocates also accuse parents and autism professionals of presuming that those labeled low-functioning are incompetent or incapable of self-determination,

arguing that “in many NT folks’ mind, ‘low-functioning’ equals ‘non-thinking’ or ‘incapable’” (The Caffeinated Aspie, 2013) or having “no voice” (Autistic Wiki, 2015), presumptions that preclude ‘low-functioning’ people from participating in public debate.

In some ways, fights over the validity of functioning labels run counter to self-advocate aims to eradicate the “harmful binary” (@FilmSpectrum, 2015a). Undermining assumptions about functioning can lead self-advocates into “debate[s about] ‘which severity of autism is more valid’” (@FilmSpectrum, 2015b) or push them to strategically label behaviors and people according to functioning or claim functioning labels as part of autistic identity. Using functioning labels at all—even to discredit them—is seen by some self-advocates as “[p]articipating in our own oppression” (@retiredwaif, 2015) since these discursive moves reify functioning categories even as self-advocates work to dismantle them. Nevertheless, self-advocates and allies talk a lot about functioning in efforts to push “[p]arents and family of disabled people . . . [and] everyone who is part of their children[‘s] lives [to] stop using functioning labels” (Sequenzia, 2014a).

Autistics stress that “‘high functioning’ and ‘low functioning’ really aren’t the neat little boundaries people would like them to be” (Melissa K., comment on Tate, 2014). A lot of self-advocate discourse about functioning aims to blur category distinctions as a way of undermining attempts to divide the autistic community. For instance, to combat the presumption that all self-advocates are high-functioning, ND advocates often point to the ways in which members of the self-advocate community fall short of high-functioning expectations. As Lydia Brown (2012d) relates,

I know firsthand of not a few Autistic people who cannot consistently perform activities of daily living such as cooking, cleaning, keeping a schedule, traveling, or maintaining hygiene without assistance from a family member, friend, or aide. Yet some of those

same people often face ridiculous assertions that because they must be *so* high-functioning or “just Asperger’s<sup>24</sup>,” their advocacy clearly is illegitimate and unfounded. Self-advocates also frequently spotlight ND activists who “might never be called things like ‘high-functioning’ if you met them in person” (Brown, 2012d), like non-speaking community members Amy Sequenzia, Larry Bissonnette, Tracy Thresher, Dora Raymaker, and Mel Baggs. Others point out parents’ presumptuousness in assuming self-advocates’ lack of experience with ‘low-functioning’ behaviors. As @BabyBloodheart (2015) recently tweeted, “[m]y childhood was meltdowns, self-harm, unable to talk, eat, acknowledge others, etc...but #HighFunctioningMeans apparently it didn’t happen.” The blog collective *We Are Like Your Child* offers another direct challenge to parents who argue that autistic adults capable of self-advocacy don’t “[understand] . . . what severe autism . . . really looks like” (Lutz, 2014). There, autistic adults have written about their experiences with self-injury (e.g., Autisticcook, 2013), severe aggression (e.g., Chavisory, 2014a), and being unable to live without 24/7 support (e.g., Sequenzia, 2013d) with the goal of showing parents that symptoms associated with low functioning do not preclude an autistic person from self-advocating, achieving success—when success is defined in terms of being “comfortable in our own skins [and] having lives we find fulfilling” (Neurodivergent K, 2013b)—nor living independently—as long as “[i]ndependence is about self-determination, about setting my own goals, about knowing what is important to me” (Sequenzia, 2013d).

---

<sup>24</sup> Before the adoption of the newest Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Asperger’s Syndrome was a form of ‘high-functioning’ autism separate from classic autism. The primary distinction between Asperger’s and classic autism was that Aspies (people with Asperger’s) displayed no delays in developing language compared to their neurotypical peers, unlike those with autism (Albert, 2004). An Asperger’s diagnosis also indicated that an individual had an average or above average IQ, though it should be noted that IQ tests are often unreliable measures of intelligence for people with developmental disabilities since they rely on a person’s ability to communicate and move in typical ways (Jorgensen, 2005). DSM-5 removed Asperger’s as a separate diagnosis and now groups together all autism diagnoses.

Self-advocates also work to delegitimize functioning labels by calling attention to the categories' inadequacies. Many self-advocates point out that functioning is a poorly defined attribute, a slippery construct that means different things in different contexts. "Which label is given to the person can depend on a number of arbitrary factors, but often involves verbal ability, ability to live independently, and (especially in children) academic ability" (Feminist Aspie, 2015). Because designations can change based on what factors are most valued in a given context and because functioning is evaluated against normative standards of communicating and behaving, some argue that "functioning labels are arbitrary, ableist, and totally made up" (Tate, 2014). For these reasons, the online community at *Parenting Autistic Children with Love and Acceptance* has banned the use of functioning labels; "[p]osts using them to describe people [there are] deleted" (PACLA, 2015c).

Whether one is labeled high-functioning or low-, self-advocates claim that functioning labels obscure important aspects of autistic experience because *the "false dichotomy"* (Melody, 2014) ignores the ways in which the same autistic individual may be 'high-functioning' in some ways and 'low-functioning' in others.

These binary divisions don't address the wide variety and range of characteristics of autistic people and paint a limited picture of individual autistics, many of whom defy . . . the expectations surrounding their end of the spectrum (Durbin-Westby, quoted in Zurcher, 2012b)

Pointing out the ways in which they themselves move between functioning categories, self-advocates argue that autistic impairments are not in fact rigid attributes, but fluid states that change over time. "One of the central problems of functioning labels is that they presume a uniform set of competencies" (Kim, 2013a) when in fact, functioning "can shift over time,

meaning that [someone] might appear to [be] very competent in one area today and much less so a month later” (Kim, 2013a), or vice versa. And just as

neurotypical people have days when they can handle more things and days that they can handle less. Days when their energy is lower, or they might need some time alone. With autistic people it’s the same. Our brains are not static. Our abilities and limitations are going to fluctuate and change day to day, week to week, in different situations and different environments. . . . Autism is a spectrum, not just for each autistic person and each of their abilities and differences and deficits, but also within each autistic person. So you really cannot categorize an autistic person as low-functioning or high-functioning. At least not if you want to do justice to each individual autistic person’s life and experiences. (Schaber, 2014a)

To combat one-dimensional definitions of functioning, some self-advocates claim both high and low labels. There’s a particular generic form that several bloggers (e.g., Kim, 2013a; ischemgeek, 2014) use to this effect. It includes descriptions of two autistic people, one high- and one low-functioning. Readers are asked to guess which is which, and then it’s revealed that both vignettes describe the author. These blog posts hearken back to Cal Montgomery’s (2012[2001]) essay “Critic of the Dawn,” in which Montgomery describes her “imaginary [companions]” (p. 73), her uncle Bruce and sister Mary.

You’ve seen [Bruce] rocking in the corner, headbanging. He cannot speak, and, people assume, has nothing to say. Sometimes he is a cute, incomprehensible child; sometimes a terrifying, incomprehensible adult. . . . Violence swirls around him: sometimes he is a target, sometimes a perpetrator, sometimes both. . . . He’s no different from me—but he is. Get me in the right situation, and we look exactly alike. Get me in the right situation, and you can see no resemblance. . . .

[Mary is] the daughter my parents wished in my place, pretended they had. . . . Me, but with impairment denied, defused, removed. Me, but with grace, stamina, social skills. She’s no different from me—but she is. Get me in the right situation, and we look exactly alike. Get me in the right situation, and you can see no resemblance. . . .

I am pressured to disown my uncle Bruce, I am also pressured to pass for my sister Mary.  
(pp. 73-4)

As Montgomery (2012[2001]) points out and self-advocate accounts reiterate, “the representations of disability that give Mary and Bruce detailed life are less than reality, are both more and less than truth, . . . two stereotypes, not two realities” (p. 75). Mary’s high functioning and Bruce’s low functioning erase the complexity of autistic experience. As autistic advocate Laura Tisoncik puts it, “[t]he difference between high-functioning and low-functioning is that high-functioning means your deficits are ignored, and low-functioning means your assets are ignored” (Tisoncik, quoted in *The Caffeinated Aspie*, 2013).

In arguments about functioning, some friction between parents and self-advocates can be seen as an extension of ND advocates’ fight against the proliferation of the tragedy model (French & Swain, 2004) view of autism and disability. Parent accounts of

what it IS to be low functioning or what it’s like to have to care for some one 24/7 . . . raising a kid who will need constant care and will never be able to be independent and may never even communicate in a meaningful way (CWA, quoted in *WrongPlanet*, 2015, author’s emphasis).

are examples of little-d discourse that reproduce and are reinforced by the big-D autism-as-tragedy Discourse evident in AS and media texts. In fact, many ND advocates characterize parents’ tragedy model thinking as a kind of false consciousness perpetuated by dominant discourse, a result of “Autism Speaks . . . pitt[ing] . . . parents against [self-advocates]” (@nicocoer, 2015) or “a co-operative and complicit media” (Winter, 2012, p.120) excluding autistic perspectives and repeating “the same hurtful, tired autism stories the media always airs” (Des Roches Rosa, 2014a).

Autistic advocates call attention to the fact that the “assumption that some [autistics] are so ‘severely autistic’ [they] suffer” (Sequenzia, quoted in Parker, 2015) evident in AS discourse



also exists in discourse about ‘low-functioning’ autism with similar dehumanizing effects.

Recently, autistic advocates took to Twitter to offer “first-person accounts of what it is like to be labeled, and how useless those labels actually are in the real world” (Autistic Wiki, 2015). Using the hashtag #LowFunctioningMeans, self-advocates critiqued functioning discourse that casts autistics as “soulless burden[s]” (@Privetine, 2015b) and autism as “a tragedy . . . [and] a fate worse than death” (@FilmSpectrum, 2015c) worthy of “[p]ity” (@FilmSpectrum, 2015c).

Autistics on Twitter also related how low-functioning labels undermine the ideal of presuming competence, a guiding principle in special education for students with significant intellectual and communicative disabilities. Presuming competence entails treating those who “[have] a label of severe mental retardation” (Jorgensen, 2005, p. 1) “as if [they are] smart” (Jorgensen, 2005, p. 4) and maintaining skepticism regarding the validity of evaluations of intelligence based on a student’s ability to meet neurotypical measures. This is also referred to as operating under ‘the least dangerous assumption’ because “[p]resuming incompetence could result in harm to . . . students . . . [whereas e]ven if we are wrong about students’ capacities to learn . . . , the consequences to that student of that incorrect presumption are not as dangerous as the alternative” (Jorgensen, 2005, p. 3).

As self-advocates point out, low-functioning labels presume incompetence with regard to a person’s ability to communicate and live a self-determined life. Understanding ‘low functioning’ to mean that a person “has no voice” (Autistic Wiki, 2015) or that they “will never be able to be independent and may never even communicate in a meaningful way” (CWA, quoted in WrongPlanet, 2015) can harm autistic individuals by “devalue[ing] who [they] are” (Sequenzia, 2014a), lowering expectations, and ruling out the possibility of independence. Speaking from her own experience growing up “listen[ing] to people talk about me as if I was a

stagnant being, unable to learn and grow” (Sequenzia, comment on Tate, 2014), Amy Sequenzia (2014a) relates how others’ presumptions of incompetence can impede an autistic person’s own expectations of themselves.

Self-esteem matters. Being assumed to be competent matters, even if we don’t meet all of our parents’ expectations. As we grow, we develop our own sense of worth and we start to develop our own goals and our expectations for ourselves. . . . If all we hear is that we can’t, that we need to improve, that our future will be not good because we are part of a ‘low’ class of humans, we don’t learn that we can expect to be valued for who we are.

This attitude, coming from our own family, becomes a self-fulfilling prophesy.

According to autistic advocate Cynthia Kim, presuming incompetence is not only bad for children, it’s bad for the neurodiversity movement, since parents operating under the assumption that their children cannot self-advocate often overlook opportunities for them to do so and may ultimately impede their ability to learn how. From her point of view, if the neurodiversity movement seems dominated by ‘high-functioning’ individuals, then parents are partly to blame.

[M]any more [non-speaking activists] could [actively participate in the movement], given the right supports and opportunities. The danger of labeling nonspeaking or low IQ people is that they are then not given the opportunity to even try to participate. (Kim, comment on Kim, 2013a)

According to self-advocates, functioning labels set up a “class” (Sequenzia, 2014) divide within the autistic community whereby ‘high-functioning’ individuals are granted a certain degree of privilege over ‘low-functioning’ individuals. “[H]igh functioning is seen as good. It’s seen as being more normal than not” (Terra, comment on Kim, 2013a) and “not that defective” (Kim, 2013a). Because we “live in a world where people think it is a compliment to tell [autistics] ‘But you seem normal,’ and where [they] are under constant pressure to appear as non-Autistic as [they] can” (Brown, 2011a), ‘high-functioning’ autistics often experience passing privilege. When autistics look neurotypical, non-disabled, non-Autistic—when their disability is

‘invisible’—they can avoid stigmatizing assumptions that those with more visible impairments face. Communicating and behaving in ways that others deem ‘high-functioning’ or neurotypical can make interactions easier for autistics who have the privilege of passing. As Judy Endow (2015) relates

though I am embarrassed to admit this, I would rather be seen as high-functioning than as low-functioning as this somehow has come to mean that others see me as a better human being. I have discovered the more I can look like a neuro-majority person the more opportunities I am given in life.

Many self-advocates describe passing as a “necessary evil” (Schaber, 2014d), a strategy that autistics need to employ in order to avoid the negative repercussions of ableist assumptions—like being infantilized, seen as less than, bullied, or denied employment.

The problem is that passing comes at a price. Acting neurotypical does not come naturally nor easily to most autistics, even those who have “grown up learning all sorts of little tricks to pass and often . . . do it without thinking” (Kim, 2013b).

For every hour that we manage to pass, we spend two or three or five recovering. We pull off a great passing act at work and pay for it by needing the whole weekend to recharge. We juggle a full class load like our typical peers and end up overwhelmed to the point of illness by midterms.

Because passing is a myth. So often what we’re doing when we’re passing is simply keeping a lid on our natural tendencies. And sometimes we’re not even doing it very well. (Kim, 2013b)

Passing renders the effort to pass invisible along with disability. “Ability appears unmarked and invisible because it is the norm, while disability, as an affront to ability, feels the full and persistent force of an ideological impulse to erase from view any exception to ability” (Siebers, 2011, pp. 102-103).

Expectations around passing reinforce an individual notion of disability that positions disabled people as responsible for ‘fixing’ problem behaviors in order to meet normative standards. According to this view, “#HighFunctioningMeans you’re expected to tolerate a world that makes no sense to you” (@chromesthesia, 2015), that “[you] can just get over mental and social issues” (@tykat22, 2015) and “‘learn’ not to be so weird” (ischemgeek, 2015).

If you’re high functioning, you must be fine, right? . . . You can just high function your way around all [your] little problems and get stuff done like a normal person.

Because if you’re high functioning, you’re practically normal! So close to normal. So, so close.

If only you’d work a little harder and get all your functioning ducks in a row, you’d be all set. And then the question becomes, why aren’t you doing that? And why are you suddenly backsliding? We fixed this thing and that thing and the other thing already.

(Kim, 2013a)

“[T]he price of distancing oneself from a stereotype is to reinforce that stereotype, and the related injustice, for those who cannot likewise distance themselves” (Montgomery, 2012[2001], p. 82).

Passing preserves social hierarchies because it assumes that individuals want to rise above their present social situation and that the station to which they aspire belongs to a dominant social group. It stamps the dominant social position as simultaneously normative and desirable. (Siebers, 2011, p. 101)

In this sense, passing reinforces the idea that “some Autistic people are worth more than others” (Tate, 2014), making ‘high-functioning’ autistics complicit in the dehumanization of ‘low-functioning’ autistics and in the stigmatization of autism in general. As @PixelPusher83 (2015) puts it, “#HighFunctioningMeans that if I’ve been given this label to elevate me there is someone who has had the opposite and been devalued.”

Autistic advocates describe high functioning as a liminal state. “High functioning means you’re disabled enough to have real challenges, but not enough to get any help. . . . you’re not normal enough to be normal, but not disabled enough to be disabled” (ischemgeek, 2015). In this sense, ‘high-functioning’ autistics embody the fluid ambiguity of functioning more generally. As self-advocates report, ambiguity is often unwelcome in the neurotypical world. Ambiguity is ‘creepy:’ “[T]he more we look ‘like everybody else,’ the creepier it is for others when we turn out not to be like everybody else” (Jones, 2013b, p. 62). Ambiguity is often denied: “High functioning means you don’t have any of the problems that those low-functioning people do, and if you say you do, then obviously you’re lying” (ischemgeek, 2015). And low functioning means that “[w]henver [you display] things that [cannot] be placed neatly in the deficit box, it [will be] tossed in the ‘splinter skills’ box” (Zurcher, 2013e). Pushing ambiguity too far can also result in a revocation of privilege:

High functioning means you will hide and cover up those ‘low functioning’ problems, lest I decide in my infinite wisdom that you’re not high functioning enough after all, and take away your independence and freedom. High functioning means you will always walk the tight rope between burnout and dehumanization. Don’t fall. (ischemgeek, 2015)

In ND discourse about why parents and others in the autism community should stop using functioning labels, self-advocates often recommend that parents embrace ambiguity and simply describe their children’s strengths and challenges, that they move “towards a more holistic approach of treating autistic people as individuals whose own ‘functioning levels’ may fluctuate day to day, month to month, or year to year, [in order to] foster more understanding and a more accurate picture of what each autistic person’s life and experiences look like” (Schaber, 2014a). Lydia Brown advocates a more radical approach—redefining functioning to include all neurotypes and abilities.

If I could redefine “disability,” I would start with our definition of what it means to be fully functional and able. To be fully functional and able . . . should mean possessing the ability to live a life that is meaningful and satisfactory for oneself, by one’s individual feelings, with the appropriate amounts of support where required to live that life. By that definition, almost no one would be disabled. Nearly every Autistic person falls into that definition—and I only say “nearly” because I try to avoid absolutes. (Brown, 2011a)

### **Autism Acceptance**

In many ways, acceptance has come to signify all of the ND tenets reconstructed above. Acceptance is the ideal that undergirds the notions that parents should change the world rather than their children, that autistic perspectives should be privileged over non-autistic points of view, and that functioning differences should be acknowledged and accommodated. Acceptance as defined in ND discourse is a complex ideological and practical stance. Self-advocates position acceptance as an alternative to awareness and recovery, responses to autism that are commonly endorsed by autism parents. By espousing acceptance as an ideal, centering and celebrating autistic perspectives, and claiming autistic communication and impairments as part of autistic identity, autistic advocates challenge parenting and advocacy practices they see as stigmatizing.

Autism parents in favor of pursuing a cure for autism rightly feel that acceptance is a challenge to their preferred course of action. “In [their] view, Autism Acceptance mean[s] that we’ve given up hope for finding the cause of autism, and that we will just accept that autism is here to stay” (Jeff, 2014). Some “desperate” (Schaber, 2013) parents “believe acceptance is giving up [on their children] and that they have to ‘destroy the Autism and rescue their children’” (Schaber, 2013). Some ND advocates observe that espousing acceptance elicits anger from some parents and speculate it’s because the idea “[t]hat autism is bad is taken as a given, so much so that hearing that someone thinks otherwise can enrage [them]” (Bjornstad-Kelly, 2012). Some autism parents see acceptance as unrealistic, or think that “[p]eople that preach autism

acceptance believe [autism is] all rainbows and unicorns” (Sophie’s Trains, 2015). Other autism parents don’t see acceptance as particularly useful. They agree with Jonathan Mitchell’s statement that “acceptance is a nice thing, we all want to be accepted, but it can only go so far when a, like, an autistic person’s yelling or screaming . . . there are limits to acceptance” (Mitchell, quoted in Bambury, 2015, my transcription). ND advocates’ calls for autism acceptance are also met with resistance from members of the autism community who feel acceptance is too “passive” (Ianthe, 2014) and from autism parents who worry that acceptance “mean[s] no therapy, no education, no intervention, just letting my kid stay where they are forever” (Ianthe, 2014).

It’s perhaps understandable that ND advocates pushing for acceptance would face critiques like “you folks in the Neurodiversity movement just believe in leaving everyone alone, to rot and decay” (Ne’eman, 2011a). In everyday usage, acceptance is a kind of ‘letting go,’ a cessation of striving, and there is some semblance of the serenity prayer in the ND conception of acceptance as it relates to accepting things that can’t be changed, like functioning impairments and neurological predispositions. However, self-advocates clarify that “acceptance is an action” (Autism Acceptance Month, n.d.), that is, “an active process that involves both a shift in thinking and action” (ASAN, 2015d).

In ND discourse, autism acceptance entails a disability perspective that “promotes acceptance and celebration of autistic people as family members, friends, . . . and community members making valuable contributions to our world” (Autism Acceptance Month, n.d.). Many advocates relate autism acceptance to the parenting ideal of unconditional love.

[Neurodiversity advocates] believe everyone should be accepted for who they are. Everyone. The more support someone requires, the more he/she benefits from an inclusive and accepting society. . . . [You cannot] love [your] child but hate autism . . .

[L]ove is unconditional. There are no caveats, no “I love this part of you but not that part,” no “if you do this I’ll stop loving you” and no “I’d love you more if you were different.” . . . The best gifts a parent can bestow upon their child are self-esteem and acceptance. (Sophie’s Trains, 2015)

Acceptance-as-action is a process that involves supporting autistic people to live self-determined lives and “working to make our world a better, more inclusive, safer place for autistic people of all ages and abilities” (Ianthé, 2014). When it comes to education, advocates describe autism acceptance in terms of working with a person’s specific neurology and functioning, and centering their perspective, wants, and needs.

Autism acceptance involves teaching autistic people as we are, accepting that our minds work . . . however they happen to work (that’s not even necessarily consistent over time and between energy levels within a single autistic person . . . but there are some patterns in how autistic minds *tend* to work.) It involves saying, “This person is always going to be autistic, we’re going to work on skills that are compatible with their autistic self, in ways that are compatible with their autistic self, with goals matching *their* goals.”

(Hillary, 2014, author’s emphasis)

Self-advocates clarify that therapeutic acceptance

is not “ignore the difficulties” but rather value your children’s strengths, support them, and help them find, or learn, the best way to deal with their individual difficulties. This includes therapies that value who they are and work with them to make certain aspects of their lives easier to cope [with] (without trying to change who they are), and support with whatever is needed for them to achieve their own definition of independence. (Sequenzia, 2014a)

Cynthia Kim (2015) describes this approach as “equipping, not fixing:”

Learning new skills and building on our strengths equips us to cope with life’s challenges. At the same time, it allows us to continue to be our autistic selves. Fixing often has the goal of making autistic people indistinguishable from their nonautistic peers, creating [a] feeling of brokenness . . . Equipping, on the other hand, promotes



acceptance and builds confidence by reducing day-to-day struggles and improving . . . quality of life. (Kim, 2015)

Self-advocates position acceptance as antithetical to the concept of recovery (Hillary, 2014), the elusive goal of normalization therapies aimed at helping autistic children become as ‘indistinguishable from their peers’ as possible and “therefore . . . ‘less autistic,’ potentially even ‘not autistic anymore’”<sup>25</sup> (Hillary, 2014). Self-advocates are extremely critical of normalization therapies that they argue amount to enforced passing and compliance training that can make children “even more vulnerable to abuse” (Ryan, 2013a) when they are “physically forced to comply with requests” (Ryan, 2013a) as in traditional Applied Behavior Analysis, a common therapy for autism. Starting from the understanding that “[a]s sure as skin color or sexual orientation, [autistics] cannot change being autistic” (Brown, quoted in Silberman, 2012, p. 364), self-advocates argue that normalization therapies “teach [children] that there is something fundamentally wrong and unacceptable about who they are” (Jones, 2014a) and that “down that road leads repression, down that road leads suicide, down that road leads all manner of other very negative things” (Ne’eman, 2011b). “Autism acceptance is recognizing that [autistics] are different” (Jones, 2015), that they’re “not ‘normal’ and . . . never will be ‘normal’” (Jones, 2013b, p. 62), and that “[a] healthy, thriving autistic person looks very different from a healthy, thriving non-autistic person” (Walker, quoted in Silberman, 2012, p. 385).

While acceptance stresses that autistic people are different, this espoused ideal also emphasizes the idea that autistic people are the same as anyone else, that is to say, human.

Acceptance works to normalize the experience of autism as “a natural part of life” (Salas, 2012),

---

<sup>25</sup> There are some accounts of ‘recovered’ children who have “overcome autism” (Padawer, 2014). These rare cases include children who lose autism spectrum disorder diagnoses over time, a change that their parents often attribute to intense Applied Behavior Analysis. Self-advocates argue that these cases do not demonstrate recovery, but extremely effective yet unsustainable passing that will ultimately lead ‘recovered’ children to “breakdowns and burnouts” (chavisory, 2014b).

an existence characterized by “strengths and challenges” (@MattJDever, 2015)—“commonalities we [all] share” (S., 2012). “Autism acceptance is seeing [autistic people] as whole, complete human beings worthy of respect” (Jones, 2015) and “deserv[ing of] an education, access to communication, and a place in society as [they] become adults” (Brown, quoted in Silberman, 2012, p. 364). Understanding autistic people as both the same as and different from anyone else recognizes that “autism [is] part of who someone is, not all of who someone is” (@rsocialskills, 2015a).

Acceptance involves a rejection of tragedy and medical model conceptions of autism common in dominant discourse. This aspect of acceptance is made most clear in self-advocates’ discursive struggle against awareness. Autism awareness is an espoused ideal proliferated by advocacy organizations and many parents, particularly during the month of April, national Autism Awareness Month in the U.S. Some autistics and allies argue that “awareness is not enough” (Bjornstad-Kelly, 2012), that “[i]t’s a start but no means a finishing point” (S., 2012). Many others oppose awareness as it has come to be defined in dominant discourse, arguing that autism awareness campaigns frequently rely on tragedy model discourse that pathologizes, others, and silences autistic people. April is “dreaded by [many] autistic people” (Feminist Aspie, 2015) for whom “anxiety increase is directly proportional to the ‘autism awareness’ marketing strateg[ies]” (Sequenzia, 2015) that “[fill the world] with traumatizing fear and pity based rhetoric about [autistic] existence” (@autistichoya, 2015). Since 2011, self-advocates and allies have rebranded April Autism *Acceptance* Month, and mobilized counter-messages on social media and blogs to combat awareness “misinformation” (Feminist Aspie, 2015) with messages of autism acceptance.

As self-advocates point out, autism awareness discourse typically instantiates all of the problems of Autism Speaks discourse outlined in chapter 5. This is hardly surprising given that Autism Speaks dominates awareness discourse and in many ways defines what autism awareness means. “‘Awareness’ campaigns are usually planned by non-disabled people, with a non-disabled perspective” (Sequenzia, 2014d) and typically “[elevate] the voices of non-autistic parents . . . and professionals, while silencing [autistic] voices” (Sequenzia, 2015), thereby resulting in “amplified misinformation” (Feminist Aspie, 2015). Awareness messages often characterize “autism as tragic burden to be eradicated” (Feminist Aspie, 2015), and generally include “a lot of scare talk” (Jones, 2015) that conveys “a sense of urgency . . . [about autistics] as a problem to be solved” (S., 2012) and “brings an undesired side effect of pity” (Sequenzia, 2014d). Based on my own recent survey of top Google search hits for “Autism Awareness” and “Autism Awareness Facts,” awareness campaigns commonly include statistics about the prevalence of autism diagnoses in children, yearly and lifetime costs of autism for families and taxpayers, and the fact that there is no cure. Most autism awareness discourse focuses on how parents and children “struggle with the challenges of Autism” (@TrishTorz, 2015). As autistic advocate Kassiane Sibley relates

Awareness [tends] to highlight how Other we are and emphasizes the differences and distance between [autistic and neurotypical] ways of being. . . . We are the problem, and . . . the onus is on us to be fixed. Awareness is all about the problems and the difficulties, usually as experienced by the neurotypical majority of folks . . . Awareness makes sure the world knows how difficult we make it for those around us. (S., 2012)

Autism acceptance discourse challenges these dominant depictions by presenting a non-tragedy view of autism. “Acceptance is the brave act of every day saying no to cure culture, no to fear, no to hopelessness, and saying yes to love, yes to acceptance, and yes to your child” (Schaber, 2013). For many self-advocates, “saying no to cure culture” requires that parents reject

medical model assumptions that impede children’s abilities to live self-determined lives. As autistic activist and Mom (Salas, 2015a) to autistic children S. R. Salas (2015b) puts it

[We parents] have a choice to make. We can jump on the Medical Model freight train and treat our children as if they’re broken as we robotically nod our heads and do what we’re told by professionals focused on fixes rather than our children. . . . bending and forcing them into a mold they can’t possibly fit, never once questioning what it is *they want*. And as we do this, we can watch as our words and actions, work to undermine our children making them believe they are broken and eliminating any possibility of success through their own self-determination. **Or** we can advocate for acceptance and nothing less. (Salas, 2015b, author’s emphasis)

Autism Acceptance Month is about “promoting acceptance and inclusion and changing the dialogue from fear, pity, and tragedy to support, acceptance, and empowerment” (ASAN, 2015d). In actions online, self-advocates and allies work to do this by centering autistic people as “the main experts on autism and on their own needs” (@AsanWashington, 2015). For instance, on April 2 of this year—Autism Awareness Day—many ‘#ActuallyAutistic’ advocates took to Twitter to counter Autism Speaks’ #AutismAwareness blitz by offering “[r]eal #autismawareness from the inside” (@AutisticWiki, 2015b). The Autistic Self Advocacy Network ran a selfie campaign and retweeted pictures of autistic children and adults holding template signs that read “I Like Being Autistic Because: . . .” Self-advocates also tweeted about positive autistic qualities like “sensory joy” (@Privetine, 2015a) and “intense interests . . . [that] carry you when others treat you like you’re not a person” (rsocialskills, 2015d). Using the hashtag #AcceptanceIs, self-advocates and allies described what acceptance looks like in everyday interaction.

#AcceptanceIs my housemates checking my communication necklace<sup>26</sup> before talking to me, without impatience regardless of what state it declares (@zymish, 2015)

#AcceptanceIs hubby signing with me on really difficult/nonverbal days.  
(@TealBassoon, 2015)

#AcceptanceIs understanding that my #ActuallyAutistic son repeats phrases to comfort and reassure himself. Not to annoy anyone. (@thinkingautism, 2015)

#AcceptanceIs respecting accommodations – yes, even the ones you’ve never heard of before and currently think are just silly or ridiculous (@FeministAspie, 2015)

Many of these tweets framed acceptance in terms of autistics’ right to communicate.

#AcceptanceIs having the right to communicate in whatever method I prefer and feel most comfortable using! (@AutismDogGirl, 2015)

#AcceptanceIs seeking out ways to listen to autistic people who live in group homes and aren’t allowed to use the internet (@rsocialskills, 2015b)

#AcceptanceIs understanding #No, #Icant, #leavemealone, #DontTouchMe, are complete sentences. #RespectThem (@pgzwicker, 2015)

Others focused on the idea that “behavior is communication” (@AngieGorz, 2015b).

#AcceptanceIs realising that reading body language is of supreme importance in communicating with us. Use your eyes, not just your mouth! (@NuttyNaturalist, 2015)

As these tweets highlight, accommodating autistic communication is a big part of autism acceptance. Calls to respect autistic individuals’ right to communicate using a variety of modalities—including those that may seem frightening or incomprehensible from a neurotypical perspective—are common in autism acceptance discourse. These accounts cast comprehensibility as a responsibility that is disproportionately and unfairly shouldered by autistic people for whom typical communication does not come easily.

---

<sup>26</sup> A communication necklace is a necklace with different colored charms on it to signify an autistic person’s willingness and capacity to interact. These necklaces are based on communication badges commonly used at Autreat, the annual U.S. conference for autistic people. Generally, green means that the individual wearing the necklace is energetic and talkative, grey/white means the person is feeling good and is willing to talk, yellow means that they feel somewhat overloaded or withdrawn and wish to limit interactions to close friends, and red means “Stay away. I do not want anyone to talk to me or interact with me in this moment, please leave me alone.” (SpacerobotStudio, n.d.).

Meeting [autistics] halfway just isn't done. No one considers it as an option. It's a tidbit of ableism that is so entrenched . . . autistics do all the work is just how it is. . . . [Non-autistic people] are perfectly capable of giving more. . . . [It's] just that they don't. A communication problem must have at least 2 sides, yet "I have a communication disorder, so this is my problem" is the way it is. (Neurodivergent K, 2011b)

Accepting autistic communication can mean "listen[ing] to what [autistic individuals] are saying, rather than how they are saying it" (Des Roches Rosa, 2011a) in the understanding that "[s]ometimes it's hard enough [for autistics] to make what [they] mean clear" (Sibley, quoted in Silberman, 2012, p. 372) without worrying about 'appropriate' or 'acceptable' tone. Acceptance also means valuing all forms of communication rather than privileging speaking or only some forms of writing (smith, 2014). Acceptance can mean "being patient enough" (@AutisticWiki, 2015a) to wait for an autistic person to formulate words, communicate through a device, or take time out to stim before responding. Most importantly, accepting autistic communication means recognizing that a person can't *not* communicate.

One thing that everybody should know by now is that EVERYBODY communicates. Words are not the only way to communicate. If a person does not understand, it is that person's deficit, not the fault of the one who communicates without words. (Sequenzia, comment on Tate, 2014)

'Behavior is communication' is "a catchphrase in the autism community" (Kim, 2014) that self-advocates and allies use to push for parents and professionals to recognize the communicability of behaviors typically glossed as 'symptoms of autism.'

Meltdowns. Elopement. Biting. Hitting. Crying. Refusing to eat certain foods. These are not the only autistic behaviors that are communication.

**Stimming is communication.** . . .

**"Lack of communication" is communication.** . . .

**Eye contact (or lack thereof) is communication.** (Kim, 2014, author's emphasis)

Self-advocates and allies stress that parents need to develop "[b]ehavioral awareness" (Des

Roches Rosa, 2011a) by “trying to understand why a person with autism . . . behaves the way they do” (Des Roches Rosa, 2011c) in order to become “truly aware of that [autistic] person's needs” (Des Roches Rosa, 2011c). This requires taking the autistic person’s neurodivergent perspective, not applying NT assumptions to autistic behaviors.

[U]sing a neurotypical “dictionary” to interpret autistic behavior and body language can lead to chronic miscommunication. Understanding that behavior is communication is a good first step. But it’s not enough to look at autistic behavior and guess, based on neurotypical experience, reasoning and cultural norms, what that behavior means or doesn’t mean.

Only through accurate translation of autistic behavior can real communication occur. (Kim, 2014)

Accepting all modalities of autistic communication as legitimate is a first step in building a kind of intercultural competence whereby non-autistic parents can learn to “[u]se [their] eyes” (@NuttyNaturalist, 2015) to interpret behaviors from autistic perspectives. Self-advocates who write about their own experiences facilitate this kind of understanding.

Self-advocates are quick to point out that—while acceptance makes room for “embracing, even celebrating Autism” (@AngieGorz, 2015a)—“[a]ccepting . . . autism does not mean ignoring or denying disability” (Brown, quoted in Silberman, 2012, p. 364). Drawing on the dominant, medical model understanding of disability as impairment, self-advocates acknowledge embodied limitations both as a way of stressing the need for accommodations and understanding, and as a way of community-building. In doing so, many self-advocates work to convey the complex “no nonsense . . . reality” (Sequenzia, comment on Tate, 2014) of living disabled lives which—like nondisabled lives—are seldom perfect. “#AcceptanceIs speaking openly about the aspects of autism that can suck, and still being seen as a full human being with a worthwhile life” (@rsocialskills, 2015c).

Claiming disability is a form of acceptance as a “well-being practice” (C. Kim, 2015) for autistics themselves, one that empowers autistic individuals to overcome internalized ableism and come to terms with their functioning differences. Within the ND self-advocate community, disability acceptance

means seeing yourself as you actually are, without being consumed by either tragedy or the need to focus on overcoming disability. It means accepting where you are, and living now, without putting your life on hold waiting for a cure.

Acceptance creates abilities. Acceptance makes it easier to be happy and to make good decisions. But acceptance does not solve everything, and it does not come with an obligation to love absolutely every aspect of being disabled. (Real Social Skills, 2014)

Self-advocates often acknowledge autistic impairments as a way of fostering self-acceptance and sharing effective “workarounds and self-management strategies” (Tardistic, 2015). For example, first-person accounts of behaviors commonly associated with ‘low-functioning’ autism offer a “body of knowledge that [autistics] have created and . . . can consult, and that can also assist non-autistic parents, educators, and professionals” (Durbin-Westby, quoted in Zurcher, 2012a). These depictions of autistic impairments build awareness about what functioning difficulties feel like from autistic perspectives. Some self-advocates post accounts of what it’s like to lose the ability to speak (e.g., Durbin-Westby, 2012b). Others write about the experience of sensory overload, that is, feeling overwhelmed or in pain due to sounds, sights, smells, tastes, and physical sensations that “the average person can ‘tune out’” (Soraya, 2015). Some self-advocates describe meltdowns, the “physiological fight or flight response” (Schaber, 2014b, my transcription) commonly triggered by sensory overload or prolonged stress that can feel like “an adrenaline rush and a mental breakdown and a panic attack rolled into one” (Schaber, 2014b, my transcription). Others discuss their own self-injurious behaviors (e.g., Bridget, 2012). While many authors preface their experiences with disclaimers that warn others’ mileage may vary,



these first-hand accounts often resonate with other autistic readers who comment to say thanks and “me, too” (Bridget, comment on Bridget, 2012).

These accounts normalize the co-existence of out of control autistic bodies and self-reflective autistic points of view. In self-advocate accounts, impairments in functioning and autistic differences are cast as a simple fact of autistic life, “a natural occurrence, or . . . an uninvited outcome that nonetheless becomes part of who we are” (Sequenzia, 2014a)—something that an individual may or may not love, but that isn’t necessarily “unfortunate, undesirable . . . [nor] tragic” (Sequenzia, 2014a). Accepting embodied limitations is a central ideal that unites the autistic community as one welcoming “support system” (chavisory, 2014b), a network that enables autistic individuals to overcome internalized ableism. As S. R. Salas (2015b) states, “[t]hose of us who accept ourselves as we are, are able to do so because we’ve found community, and within that community . . . we’ve found acceptance for who we are as human beings. We understand that being disabled isn’t *less than*” (author’s emphasis).

### **Can Neurodiversity Ideals Bridge the Divide?**

All of the reconstructions presented above outline discursive strategies that self-advocates use in communication with parents. Out of these communicative models emerge implicit situated ideals—ideas about what advocacy ought to look like and what conceptions of autism ought to entail that self-advocates and allies orient to in arguments that span the self-advocate/parent divide. To conclude, I aim to make these ideals explicit, and to reflect on the extent to which neurodiversity ideals both bridge and deepen the split between autism parents and advocates in the ND movement.

The descriptions below attempt to articulate situated ideals from self-advocate perspectives as a starting point for normative reflection about what neurodiversity self-advocacy

ought to look like. I leave the business of explicitly engaging in normative reflection to chapter 7.

### **Building Autistic Community Is More Important than Bridging the Self-Advocate/Parent Divide.**

One discursive strategy that appears again and again in self-advocate discourse is the construction of a united autistic community. Whether espousing a social model view of autism, arguing for self-advocates' right to speak on behalf of all autistic people, or pushing back against parents' beliefs about functioning and awareness, self-advocates and their allies consistently rely on conceptions of *autistic* community over and against *autism* community that, on the face of it, do more to deepen the divide than to bridge it.

The united autistic community is bound together by the experience of oppression and by autism—a fluid way of being and communicating that enables self-advocates to speak from an autistic point of view. Though self-advocates strongly resist defining what autism is—their accounts of what autism feels like are rife with ‘I can only speak for myself’ disclaimers—and though the autistic community is constituted through autistics being socially positioned as less than, there are some experiential commonalities that unite members of the autistic community. To wit, all autistics are unable to perceive the world through a neurotypical lens, and most—if not all<sup>27</sup>—autistics cannot consistently communicate as neurotypicals do. The autistic community is thus a united social group that emerges out of oppression and in juxtaposition to neurotypicality.

There are many online examples of self-advocates reaching out to educate parents about what it's like to be a member of the autistic community, and many ND advocates stress the need

---

<sup>27</sup> I avoid the absolute here as an acknowledgment that some individuals formerly diagnosed as autistic do themselves report having ‘recovered’ from autism.

for parents to seek out autistic points of view for the sake of their children. “[A]utistic writers so often share their life stories in the hope that today’s children will have a chance at being better understood and accepted, and be able to live comparably better lives” (Des Roches Rosa, 2014b). All self-advocate accounts can be read in this light, but there are many places online that expressly aim to facilitate parents’ exposure to and engagement with autistic perspectives, including the *Thinking Person’s Guide to Autism* (TPGA), Amethyst Schaber’s regular YouTube video series *Ask an Autistic*, and Sparrow Rose Jones’ blog *Unstrange Mind*. In these spaces, autistic authors work to reach out to parents with measured language that acknowledges parent fears and validates parent perspectives, while ultimately espousing a neurodiversity stance. These examples and many others demonstrate that educating parents is a goal of the self-advocacy movement.

However, most self-advocate discourse cited above does not resemble the kind of “constructive [conversation]” (TPGA, 2011) necessary for productive dialogue according to TPGA. The adversarial stance toward autism parents adopted in many of the texts referenced above along with the ways in which the ND movement privileges autistic perspectives reveal that building autistic community is a bigger priority than educating parents for most self-advocates. There is a fair amount of “defensiveness around parent-advocates” (Neurodivergent K, 2011a) on the part of self-advocates, and a sense in self-advocate discourse that many autistics feel that while they can “[present] evidence that [a parent’s] way may be wrong” (Neurodivergent K, 2011a), many parents are never going to “get it” (Neurodivergent K, 2011a). From this point of view, trying to convince parents to see things from a self-advocate perspective is a waste of valuable energy that could be better spent fighting for disability rights. As civil rights protestor DeRay McKesson (@deray, 2015) writes, “The burden of marginalized people is not, can never

be, the moral conversion or salvation of allies. Our burdens are freedom and justice.” ASAN president Ari Ne’eman (2011a) agrees:

[M]ost of us didn’t get involved in the disability rights movement to be a resource for parents, however laudable a goal that may be. We got involved because we have opinions about how this society is approaching disability.

Self-advocates’ primary goal is to build autistic community identity according to neurodiversity ideals. As shown above, the autistic community is positioned as autistics’ most necessary support system. The autistic community is where autistics will find role models, a “place where [they’re] ‘normal’” (Neurodivergent K, 2014), and others who “know what to do when they [have] breakdowns and burnouts” (chavisory, 2014b). Importantly, the autistic community is where autistics will learn self-acceptance and how to undo internalized ableism. So conceived, the autistic community is absolutely vital to the neurodiversity movement. It is a space where autistics will learn how to advocate for themselves and on behalf of other autistics. If parents come to the movement as allies—as many do—that’s great. But on behalf of the children of those who will not, self-advocates prioritize building autistic community both as a form of support, and in the hopes that a critical mass of self-advocates and allies can eventually change society in spite of parent opposition.

One problem with building this critical mass that self-advocates increasingly acknowledge is the lack of diversity and intersectionality within the autistic community. The overwhelming majority of ND leaders cited in this project are white, and many self-advocates have noted the underrepresentation of people of color within the autistic community (e.g., Onaiwu, 2014a; Robison, 2009). Part of this has to do with racial disparities in autism diagnoses whereby children of color are less likely than white children to receive an ASD diagnosis (Mandell, et al., 2009). Another issue may be that neurodiversity ideals are centered on white

autistics' experience of autism. As Louise (Robinson, 2014) notes, black communities and white communities have different ways of talking about autism. In her experience as a black woman with Asperger's Syndrome, autism and other "different abilities" are often "called something different" Louise, quoted in Robinson, 2014, my transcription) in black communities. Relating her experiences 'panicking' and 'hiding' if someone asks her to lunch, Louise also observes that

Caucasian people are always processin' stuff. They always analyzin' things. . . . Now if I [talk about hiding] to someone Caucasian, it becomes this whole thing about overstimulation, not processing, um being uncomfortable. They all become these different kinds of um- and it's actually, it's all the same thing, but I notice when you talk about this on the color lines, it- it's more about how I feel when I'm talkin' to [my black friend] Verna. (Louise, quoted in Robinson, 2014, my transcription)

The lack of diversity in the ND movement reflects fragmentation within the autistic community. While ND advocates may work to define the autistic community around the social experience of autism, this account essentializes a white experience of autism and ignores the intersectional dimensions of oppression experienced by autistic people of color and other marginalized identities. "The intersection of autism and race is a site of thorough erasure. Where does that leave the intersection of autism, race, and sexuality? Autism, race, and gender?" (Narby, 2012). The ND community is starting to address these issues, but given the disproportionate risk of police violence and criminalization directed at young, black, autistic men and boys—as evidenced by the recent cases of Kayleb Robinson (Çevik, 2015a) and Neli Latson (Brown, 2015b)—as well as the increased risk of sexual violence for autistic women who underwent older, intensive forms of ABA (Jones, 2013b)—just to name two pressing concerns—the ND movement has a long way to go before the autistic community reflects all autistic perspectives and acceptance accounts for all dimensions of difference.

### **Autistic Perspectives Are More Legitimate than Parents' Points of View, and Some Self-Advocates' Perspectives Are More Legitimate than Others.**

In neurodiversity discourse, whether an advocate is positioned as legitimate—that is, whether they are seen as credible, authentic, and deserving authority to speak for autistic people at large—is related to the extent to which they are ableist—that is, the extent to which they take on “an attitude that devalues or differentiates disability through the valuation of able-bodiedness[/mindedness] equated to normalcy” (Campbell, 2009, p. 5). According to an ND self-advocate perspective, parents who orient to a medical model view that defines autism in terms of functioning deficits, who wish that their children would ‘recover,’ who view autism as tragedy and autistic people as burdens are operating according to ableist beliefs that devalue being autistic and value neurotypicality. These parents can therefore never legitimately represent autistic perspectives.

Credibility with regard to speaking for autistic people is also based on whether a person can speak to what it’s like to be autistic. In this regard, non-autistic parents are at a disadvantage compared to ‘#ActuallyAutistic’ people, but parent allies who work to learn about, engage with, and amplify first-person autistic accounts can credibly represent autistic experiences and legitimately speak for their autistic children, as long as they don’t espouse ableist beliefs, that is.

While self-advocates who oppose the neurodiversity movement are credible in the sense that they know what it feels like to be autistic, they are not legitimate representatives of the autistic community due to internalized ableism. These autistic opponents are positioned as victims of false consciousness in ND self-advocate discourse. According to a neurodiversity standpoint, an autistic person who wants to be cured or to be ‘normal’ is likely suffering because “someone is doing something terrible to [them], because [they’re] not ‘normal’” (Ne’eman,

2011b), and they wrongly blame their autism rather than the terrible person for this fact because they've adopted the ableist assumption that being autistic is wrong.

While autistic people who do not subscribe to ND ideals are part of the autistic community, it is justifiable for their voices to be silenced in public conversations about autism from an ND perspective. Self-advocates routinely exclude the perspectives of autistic opponents in discourse that portrays the autistic community as a united group. Self-advocates frequently claim to speak to what all autistics want, ignoring the voices of those autistics who disagree. Self-advocate discourse that characterizes autistic opponents as operating under ableist assumptions discredits and discounts those perspectives. Some self-advocates go even farther to try to edge these challenging points of view out of public discourse about autism altogether. Prior to the publication of a recent article profiling autistic neurodiversity critic Jonathan Mitchell, for instance, autistic blogger Philip Gluyas contacted the author “urging [her] not to [write the piece, saying,] ‘That man is a threat to the stability of the autistic community. . . . He’s a hater. He hates himself.’” (Hayasaki, 2015).

Given the fact that autistic oppression often takes the form of autistic voices being “erased, silenced, [and] derailed” (Hillary, 2013b), it is interesting to see autistic neurodiversity advocates engage silencing strategies in order to claim authority to speak for autistic people at large—including those who they discredit as suffering from internalized ableism.

### **Empathy for Autistic Points of View is Vital, but Empathy for Autism Parents’ Points of View is Dangerous.**

Throughout the reconstructions above, empathy is a reiterated ideal and frequent discursive strategy. Acceptance discourse “centers the voices of autistic people in the conversation about us” (Autism Acceptance Month, n.d.) and asks parents to engage in “deep

empathy” (Schaber, 2013) in order to “accept [their] child[ren] for who they are” (Schaber, 2013). A social model understanding of autism also centers autistic experiences of oppression, and demands that parents turn conventional thinking about disability on its head by identifying with what it feels like to be excluded. Functioning discourse that utilizes the second person is another interesting example that highlights how self-advocates employ empathy. Positioning readers in their shoes by using the pronoun *you*, self-advocates cast readers as victims of silencing trapped by the self-defeating compulsion to pass—a powerful discursive strategy that can help non-disabled readers acknowledge their able-bodied privilege.

Empathy is not an unquestioned good in self-advocate discourse, however. While empathy toward self-advocates is a vital part of the neurodiversity movement, empathy toward parents is a dangerous emotional stance that is generally avoided or even actively discouraged. From self-advocates’ point of view, autism parents are part of a “mainstream autism community that is not a safe place for Autistic people to be” (Bjornstad-Kelly, 2012).

The idea that self-advocates “hate parents of autistic kids” (Hillary, 2012a) has become a common stereotype (see also Sequenzia, 2012a). Autistic activist Alyssa Hillary clarifies that the issue isn’t hatred, but mistrust.

[Do I] hate parents of autistic kids[?] . . . Not usually, but I don’t usually trust you unless you earn it first either. . . .And that’s pretty common. We [self-advocates] kind of have reason not to trust [parents], since it is parents who kill their autistic kids and parents who get the sympathy of other parents when this happens. (Hillary, 2012a)

Autistic advocate Savannah Logsdon-Breakstone (2015) also points to self-advocates’ tendency to mistrust parents, explaining that “[y]ou can’t tell . . . merely by looking that the parent next to you is a good parent.” While Logsdon-Breakstone (2015) tends to give parents the benefit of the



doubt and “trust [they] . . . are good people, good parents,” she acknowledges that others “might . . . say that’s too trusting.”

Within this climate of mistrust, empathizing with parents is a dangerous proposition. From an ND self-advocate point of view, humanizing parents who subscribe to a medical model or tragedy model conception of autism—and for many self-advocates the two are so linked that one implies the other—means dehumanizing autistic people. Identifying with parents who long for a cure for autism or who see autism as a “tragedy [that] is to be avoided, eradicated or ‘normalized’ by all possible means” (French & Swain, 2004, p. 34) means identifying with ideological presuppositions that justify murder. While these parents may protest that they’re good people, that they would never consider murdering or abusing their children, from a self-advocate perspective they share an ideological stance with murderers that excludes them from the realm of empathy and trust.

Even potential parent allies with the best of intentions prove themselves unworthy of trust when they dismiss self-advocate perspectives. Zoe (2011a) describes the cynical attitude that many self-advocates have toward parents when she notes,

There is a saying amongst developmentally disabled activists. It goes like this: “Some parents just want disabled children to speak and disabled adults to shut up.” . . . We say this because we’re tired of being dismissed. An act at which some non-disabled parent advocates excel (one could even call it a “splinter skill”) is coming up with reasons to disregard what disabled people have to say about disability. We’re too angry (“You catch more flies with honey than with vinegar”). We disagree with them too much of the time. We’re not properly grateful that they’ve taken a stance as our allies (“I’m putting myself out here for disability rights and I haven’t heard a single thank-you from disabled people”). We’re too idealistic, or else we’re too “small-picture.” We’re too disabled (“You’re autistic, so your perspective is distorted by your black-and-white thinking and lack of empathy and I don’t have to listen to you”). Or we’re not disabled enough

(“You're lucky to be able to write a blog post, but my child is more severely affected so I don't have to listen to you”).

### **Disability Must Be Understood in Terms of Both Social Oppression and Embodied Impairment.**

In self-advocate discourse, adopting a social model understanding of autistic identity while also recognizing the realities of impairment offers a hybrid perspective, one that acknowledges that individual ability differences matter, but that presses for social model solutions to exclusion based on impairment.

Accounts of ‘low-functioning’ autistic behaviors acknowledge autism as disability in the sense of impairment. As Judy Endow (2014) explains, “autism is a ‘disability’ . . . [because] the way our autism plays out in our body means that we are faced with numerous obstacles to overcome every day of our lives.” Acceptance requires that autistics and allies recognize and accommodate embodied obstacles. While self-advocates reject functioning labels, they accept fluctuations in functioning and even a “hierarchy of disability” (Shakespeare, 2006, p. 60) along which “some Autistic people are very severely disabled” (Brown, quoted in Silberman, 2012, p. 364) while some are not.

Thus, while ND advocates draw on a social model understanding that casts impaired functioning as a difference that must be accepted and accommodated rather than fixed, self-advocate discourse also acknowledges limitations located in individual bodies—a conception of impairment that aligns with many autism parents’ medical model understanding. Acknowledging that the severity of impairments can vary also reifies the notions of high- and low-functioning even while locating the responsibility for ameliorating disability within society. As Lydia Brown (2012d) admits, “[s]ome Autistic people might be more disabled than other Autistic people,” but this admission simply means that “[s]ome would benefit from more services and

accommodations, and others would benefit from very few.” This hybrid social-medical understanding of disability recognizes the social nature of medical impairments and brings a consideration of the body to a social model understanding of disability—nuances which expand traditional social model approaches and answer calls to bring the body to bear on disability studies (e.g., Wendell, 1997; Hughes & Paterson, 2010).

## Chapter 7

### Dilemmas of Neurodiversity Advocacy and Concluding Thoughts

I hope by now to have made a strong case for why neurodiversity advocacy is needed and what ND self-advocacy looks like. As I've worked to make clear, autistic people often face dehumanization and silencing in public conversations about what autism is and what should be done about it. Portrayals of autism as tragedy are prevalent in advocacy and media discourse. These representations convey the idea that autism is an affliction and that autistic lives are less than or even not worth living. Such accounts silence autistic perspectives by excluding autistic voices, erasing autistic adults, and positioning people on the spectrum as lost and incapable of communicating. As shown in chapter 5, *Autism Speaks* and media discourse around filicide reinforce a mental model of disability in which autistic impairments manifest in the behaviors of individuals with autism cause suffering that is most keenly and cruelly felt by parents and family members. According to self-advocates, this tragedy model view lies at the heart of parental pursuits of recovery and negative beliefs about what autism—particularly 'low-functioning' autism—entails.

Neurodiversity advocacy is a site of discursive struggle where self-advocates fight to be heard and work to “change the dialogue about autism from fear, pity, and tragedy to support, acceptance, and empowerment” (ASAN, 2015d). Shifting conversations away from medical model and toward social model conceptions of disability, away from awareness of suffering toward acceptance of autistic differences, away from stigma and toward a non-tragedy view of autism happens primarily through opposition. In sustained protests against *Autism Speaks*, coordinated messages opposing media discourse in remembrances like Disability Day of Mourning, and discourse countering parent perspectives, autistic ND advocates and their allies

struggle to disrupt neurotypical misconceptions about autism and promote autistic points of view.

“[T]here isn’t a neurodiversity manifesto” (Schaber, 2014c, my transcription). Though self-advocates work to discursively construct a united autistic community, there are key tensions within the ND movement evident in self-advocacy. These tensions stem from conflicting situated ideals, contrary beliefs about what acceptance ought to entail and what advocacy ought to accomplish. With regard to acceptance, ND advocacy discourse reveals tensions with regard to competence. While presuming competence in the sense of presuming intelligence is a cornerstone of autism acceptance, ‘big tent’ neurodiversity also entails a need for acceptance, support, and accommodation for those whose minds *are* intellectually impaired. With regard to advocacy, ND advocates experience a tension between radicalism and dialogue. While ND activism is marked by a radical disability rights sensibility aimed at upsetting existing power relations by delegitimizing powerful actors, self-advocates also hold value for dialogic exchange of ideas that is inclusive of all stakeholders and for phenomenological dialogue marked by a willingness to take others’ perspectives.

In this concluding chapter, I turn first to an examination of these dilemmas and normative reflection about how neurodiversity advocates might address them. Staying true to my hybrid CDA-AIDA aims, I articulate problematic tensions from my perspective, as a critical researcher, and from ND advocates’ perspectives, as is typical in action implicative discourse analyses. The dilemma reconstructions described below also incorporate a hybrid conception of the philosophical level of ND advocacy practice. Here, I’m drawing on a conceptualization of situated ideals as both beliefs about best conduct—as they are defined in AIDA—and as

ideological presuppositions—components of mental models that are central to CDA. I close with a discussion of limitations in the present study and ideas for future research.

### **Presuming Competence and Accepting Intellectual Impairment**

There is an apparent tension between presuming competence and accepting intellectual impairment that stems from the ways presuming competence is often talked about in ND discourse. According to a ‘big tent’ notion of neurodiversity, all ways of thinking and being are recognized as valuable, regardless of cognitive ability. However, when ND advocates espouse presuming competence as a communicative ideal, they tend to do so in ways that reinforce cognitive ableist biases that value intelligence over a perceived lack of intellectual ability.

Cognitive ableism is a stance that values particular cognitive abilities and those who are perceived to have them (or to be able to cultivate them), and devalues those with an actual or perceived lack of cognitive abilities (Carlson, 2001). ND advocates’ opposition toward the use of functioning labels rests on a critique of cognitive ableism in terms of a value for ‘typical’ neurology over autistic neurology and for ‘high-’ over ‘low-functioning’ cognition. Presuming competence addresses cognitive ableism by disrupting assumptions that position people who are perceived to be ‘low-functioning’ as unintelligent, incapable of understanding, learning, or communicating, and therefore less than.

As education scholars point out, evaluations of cognitive ability are often inaccurate. This is because judgments about intellectual disability are based on performative, not cognitive, criteria (Biklen and Burke, 2006; Jorgensen, 2005).

The very student who has difficulties with performance, including speech, will often be caught in the diagnostic category of severely retarded, not because of any proof about thinking ability, but because of an absence of evidence about his or her thinking ability. (Biklen & Burke, 2006, p. 167)

The same is true in everyday interactions, where a person's capacity to behave in neurotypical ways is judged as indicating cognitive functioning. In other words, in educational and everyday settings, individuals must communicate competence in typical ways in order to be presumed intellectually competent.

As ND advocates point out, presuming incompetence is a damaging self-fulfilling prophecy. If a parent views their child as incommunicative, they are likely to ignore communicative behaviors or simply regard them as symptoms. If an educator believes a child is incapable of learning beyond a certain level—with levels often following developmental trajectories defined around neurotypical development—they will not give students opportunities to advance. “The instant someone is presumed incapable of self-advocacy is the instant that the person is unable to self-advocate” (Bascom, comment on Zoe, 2011b). This sets up a “vicious cycle” (Snow, 2007) wherein “because we presume [people with disabilities] are incompetent, we don't give them opportunities to demonstrate their competence, and this, in turn, is taken as ‘proof’ that they are, indeed, incompetent” (Snow, 2007).

In essence, presuming competence rests on a phenomenological theory of communication that mirrors that of Emmanuel Levinas. In Levinas' terms, presuming incompetence is a kind of knowing that impedes genuine, ethical communication. It is a way of objectifying others in terms of cognitive functioning that “*appropriates* and *grasps* the otherness of the known” (Levinas, 1989[1984], p. 76, author's emphasis), reducing disabled others to narrow representations of personhood that can never account for all that they are. “[T]he more informed one is of the Other, the less one is responsible for the Other” (Pinchevski, 2005, p. 79). The more one assumes about what a disabled person doesn't know, think, or experience, the less responsible one is to

include them. The more certain one is that a person is ‘not there,’ the less responsible one is to find accommodations that may enable the other to communicate.

Within Levinas’ phenomenological framework, presuming competence is an openness to the other that enables ethical communication to take place. According to Levinas, communication depends on the “irreconcilable difference of alterity” (Pinchevski, 2005, p. 71), the insurmountable separation between people that comes from the fact that one can never know another’s mind. As some ND advocates describe it, presuming competence involves just such a recognition of otherness. As autistic neurodiversity advocate Julia Bascom (2014a) stresses, presuming competence means, in part, “*remember what you don’t know*” (author’s emphasis). Ariane Zurcher (2013f)—a writer and neurodiversity advocate who has blogged extensively about her own ongoing efforts to presume competence with regard to her non-speaking autistic daughter—agrees, noting that she works to “[r]ealize that I don’t know. There is just a great deal I don’t understand.” Zurcher (2013c) describes presuming competence as a kind of contemplative practice requiring that she “stay aware, stay present and open to whatever happens without preconceived notions of what should or shouldn’t happen.”

As in Levinas’ ethics, it is this openness to otherness in the absence of knowledge that enables communication in ND advocate accounts. For Levinas, ethical communication occurs prior to speaking. It is a process that involves coming face to face with otherness and allowing oneself to be affected by it. Encountering the face of the other, “the forefront of the Other’s otherness” (Pinchevski, 2005, p. 76) is an experience that “confront[s] and unsettl[es] the self” (Pinchevski, 2005, p. 76) by exposing the other’s vulnerability and calling the self into account. In this communicative moment, “[the self] feels accused, is disturbed without knowing why” (Pinchevski, 2005, p. 77). Suddenly aware of the “nakedness . . . extreme exposure,



defenselessness, vulnerability” (Levinas, Levinas, 1989[1984], p. 83) of the other, the self recognizes their responsibility toward them, an ethical stance marked by a willingness to “suffer [rather] than to commit injustice [toward the Other]” (Levinas, 1989[1984], p. 83). These communicative ideals are also evident in ND discourse about presuming competence. In ND advocate accounts, recognizing the vulnerability of autistic others comes out of awareness that “to presume **in**competence is to actively do damage” (Zurcher, 2013d, author’s emphasis). Seeing that autistic others are exposed to and often defenseless against such damaging presumptions, one feels a responsibility to listen to them, to “examine” and “dismantle” one’s own “preconceived notions . . . ingrained beliefs, [and] prejudices” (Zurcher, 2013f), to be patient, and to do the work of finding the accommodations and supports the autistic other needs in order to learn and grow. The process can be frustrating, difficult, and fraught with unknowns (Zurcher, 2013a)—particularly when the disabled other isn’t able to communicate in typical ways. But presuming competence ultimately enables a connection built on recognition of shared personhood (Bascom, 2014a). Understanding that every person “has intellectual ability . . . [and] wants to learn and assert him or herself in the world” (Biklen, quoted by UNESCO, 2012), that “all human beings are capable of learning if given the right supports and accommodations” (Zurcher, 2014b), and that “not being able to speak is not the same as not having anything to say” (Bascom, 2014a) involves recognizing that the other—no matter the extent of their impairments—is “more like you than not” (Bissonnette, quoted in Biklen & Wurzburg, 2010).

Presuming competence is a vital communicative ideal, “nothing less than a Hippocratic oath for educators” (Biklen, quoted by UNESCO, 2012). It is a foundation for inclusion and an orientation toward disabled others that facilitates self-empowerment and self-determination. It is the starting point for interactions that honor “another human being . . . as a true equal” (Zurcher,

2013d). Seen through a phenomenological lens, presuming competence is an ethical orientation toward an other that enables communication even in the absence of language or neurotypical signification. In stories about presuming competence, moving from presuming incompetence to recognizing others' capacity to learn is a shift that facilitates remarkable growth. In Zurcher's and other's accounts, presuming competence is the necessary first step that enables nonspeaking autistic individuals to finally 'find their voice.'

In neurodiversity discourse, the importance of presuming competence is frequently underscored by stories about people labeled 'low-functioning' or presumed to be significantly intellectually impaired who reveal themselves to be intelligent through communication accommodations that enable them to express their thoughts in words. Ariane Zurcher relates how she was told her child "couldn't and didn't understand most of what was said to her" (Zurcher, 2014a). Since learning to type at the age of 9, "[her] daughter has defied everyone's expectations" (Zurcher, 2014a) by revealing that she taught herself to read and is quite intelligent. Non-speaking neurodiversity activist Amy Sequenzia has written about being labeled "too damaged to learn" (Sequenzia, quoted in Parker, 2015), an evaluation that is clearly belied by the passion and intelligence she exhibits in her extensive writing and advocacy work. Tracy Thresher, non-speaking disability advocate and one of the subjects of the documentary film *Wretches and Jabberers*, writes, "I may appear to be a man shrouded by a cloak of incompetence but if you will take the time to listen to me typing you will understand I am intelligent" (quoted in Zurcher, 2013d).

These stories and others like them help to undermine disabling presumptions of incompetence, but they also have a tendency to reproduce problematic discourse. For example, stories about presuming competence often employ barrier metaphors in which "autism is a

physical obstacle which stands between an otherwise-normal [person] and the world around them” (Gross, 2012, p. 262). Because barrier metaphors call up mental models in which autism is separate from a person’s identity and autistic individuals are waiting to be recovered, they’re “tired tropes” (Yergeau, 2010) that tend to reinforce misconceptions about autism. Zurcher (2013d) stresses that “[t]o presume competence does not mean we assume there is a ‘neurotypical’ person ‘trapped’ or ‘imprisoned’ under an Autistic ‘shell.’” However, self-advocates themselves often support this misconception in neurotypical-sounding descriptions of intelligent minds hidden inside disabled bodies. Just as Thresher describes how autism shrouds his intelligence behind a “cloak of incompetence,” Amy Sequenzia (2013b) employs a barrier metaphor as well in a blog post where she asks, “[w]ho knows in which body the next brilliant brain resides, if opportunities are not equal?”

A bigger problem in ND discourse about presuming competence is that it tends to reinforce cognitive ableist biases in overt and implicit ways. In one explicit example, Thresher argues for the need for parents and educators to “[put] communication to the top of their list of priorities” (Thresher, quoted in Zurcher, 2013f) with regard to autistic children, by stating, “[b]eing able to show intelligent thought is the path to happier futures and true quality of life” (quoted in Zurcher, 2013a). Though his comment reflects Thresher’s own experience learning to type as an adult, his stance supports ableist notions of quality of life that devalue the lives of those who cannot “show intelligent thought.”

More often, cognitive ableism is supported in more covert ways in ND discourse. As seen above, competence is frequently defined in terms of intelligence in ND advocate accounts. Stories about the damage of presuming incompetence invite neurotypical others to take the

perspective of someone who is intelligent but assumed to be intellectually disabled. This can lead readers to

think that the problem was that [people] treated [the autistic person] like they were intellectually disabled, and they weren't. But that's not the problem. The problem is that [people] thought that [the autistic person] was intellectually disabled, *and so they didn't treat them like a person.* (Bascom, 2014a, author's emphasis)

According to cognitive ableist assumptions, intelligence is a marker of personhood. By asserting autistic individuals' rights to be viewed as persons by emphasizing their intelligence—even potential brilliance—ND advocates inadvertently reinforce the link between personhood and intellectual functioning. These accounts have the power to disrupt people's tendencies to “judg[e] intelligence by smooth movements and the ability to speak” (Rubin, 2014), but they support ingrained conceptions of personhood that cast intelligent people as recognizably human and dehumanize intellectually impaired others. In this way, ND advocates undermine the ideal of acceptance in their espousal of the ideal of presuming competence. As Julia Bascom stresses, presuming competence must ultimately rest on a recognition of personhood independent of cognitive functioning in order to apply to all neurodivergent individuals.

These revelations about presuming competence, human dignity, and the least dangerous assumption—they don't apply only to [people] who are secret geniuses. They apply to everyone. They are *the most important* for the [people] who really do have intellectual disabilities, who really *can't* read or use full sentences and who really do need extensive support. . . . These terms don't mean *assume they aren't actually disabled*. These terms mean *assume they are a person, and remember what you don't know.* (Bascom, 2014a, author's emphasis)

The tension between presuming competence and accepting intellectual impairment I've outlined above could be alleviated by increasing the representation of people with intellectual disabilities within the neurodiversity movement. The critique that the ND movement is

dominated by ‘high-functioning’ individuals is accurate when functioning is defined around passing privilege. Most activists in the ND movement enjoy a degree of cognitive privilege that enables them to communicate in typical ways and to access and disseminate valued knowledge. Even those labeled ‘low-functioning’ and for whom communicative abilities may fluctuate often pass as neurotypical online. Addressing such cognitive privilege is a necessary step in disrupting cognitive ableism (Carlson, 2001). By acknowledging their own privilege—that is, recognizing how they, too, are “tied to structures of domination and oppression” (Alcoff, 1998, p. 8)—ND advocates could come to realize how defining competence in terms of intelligence devalues those with intellectual disabilities. ND advocates could then work to find alternative discursive strategies and ways of using their privilege to make space for underrepresented voices in the movement.

In order to disrupt cognitive ableist beliefs that predicate personhood on intelligence, the neurodiversity movement must do more to demonstrate the value of intellectually disabled persons. A primary way of doing so would entail giving these community members more opportunities to assert themselves in the ND movement. Given the nature of cognitive and communicative impairments, such inclusion is a challenge, but it’s one that might be answered in a number of ways. First, the Autistic Self Advocacy Network (ASAN) might engage in more visible partnerships with self-advocacy groups for people with intellectual and developmental disabilities like Self Advocates Becoming Empowered (SABE), the Ala Costa Adult Transition Program (ACAT), People First groups, and other independent living self-advocacy groups. These self-advocacy groups support adults with learning difficulties—including individuals labeled ‘low-functioning’ who aren’t able to reliably communicate what they’re thinking in neurotypical ways—to develop self-determination skills that enable community inclusion and political

consciousness-raising. These skills are often developed in the context of everyday interactions “that might not fit with the public, . . . campaigning forms of activism so celebrated by new social movements, but [they] are resistant nonetheless” (Goodley, 2003, p. 126). Publicized coalition-building between ASAN and other self-advocacy groups might widen participation in public campaigns and bring important grassroots disability rights initiatives—like SABE’s Accessible Voting Project (n.d.)—to the attention of the ND community. Making space in ND advocacy discourse for accounts of intellectually disabled community members’ everyday forms of resistance—like those published in blog posts on the ACAT website (e.g., White, 2014)—would also underscore the value of neurodiversity ideals for those with less passing and cognitive privilege.

Individual advocates might also find ways of increasing cognitive diversity within the ND movement by finding ways to listen to and amplify the perspectives of intellectually disabled individuals. Advocates could do this quite simply by sharing links to SABE, ACAT, and other self-advocacy groups’ newsletters, blog posts, and videos in ND community networks online. ND advocates might also read and share stories about what presuming competence means in interactions where a person cannot communicate in neurotypical ways and may never prove their ‘competence.’ Notable examples include essays by Julia Bascom published on her blog (e.g., Bascom, 2011b; Bascom, 2012b) and in the anthology *Loud Hands: Autistic People, Speaking* (Bascom, 2012a) that describe Bascom’s relationships with students in a life skills special education class.

Finally, ND advocates might find more ways of connecting with individuals with intellectual disabilities and representing their voices in activist spaces online. Building these connections may be particularly important for people who are institutionalized. Autistic blogger

Real Social Skills argues that “it’s . . . not ok that the online community barely knows that [autistic people who live in group homes] exist” (@rsocialskills, reply to @rsocialskills, 2015c). “[S]eeking out ways to listen to autistic people who live in group homes” (@rsocialskills, 2015b) and others who are institutionalized as Real Social Skills suggests is a significant challenge that may require ND advocates to recruit more assistance staff and parents to the movement so that they may listen to and faithfully represent the perspectives of those community members who are currently excluded from ND discourse.

### **Radical Activism and Dialogue**

ND advocacy is characterized by both radical activism and dialogue, two communicative ideals that are at odds with one another. Radical activism is a situated ideal associated with civil disobedience, and in ND discourse this ideal is expressed in accusatory, oppositional discourse aimed at exposing “social evil” (Katz, quoted in Calabrese, 2004) and attacking any action that supports oppression (Loan Trần, 2013b). Dialogue is a situated ideal associated with deliberation, that is, a form of democratic communication in which stakeholders come together to discuss public issues and consider relevant facts and values from multiple points of view in order to make decisions that are seen as legitimate for all involved (Carcasson & Sprain, 2010). Dialogue involves open engagement with others’ perspectives, empathetic, active listening, and a commitment to come to a shared understanding with others who may hold very different values and commitments (Cramer Walsh, 2007). This kind of engagement is incompatible with radical activism that casts particular social actors as illegitimate and undeserving of empathy.

In ND advocacy, the tension between radical activism and dialogue is evident in discourse that switches between confrontational and inviting language. The first post in the *Thinking Person’s Guide to Autism’s* (TPGA) self-advocate/parent dialogue series exemplifies

how these two competing ideals are often negotiated in practice. In her post, self-advocate and author Zoe (2011a) tacks back and forth between inflammatory discourse that positions parents as actively impeding the autistic community and discourse aimed at acknowledging parent perspectives. She starts by calling parents out for “want[ing] disabled children to speak and disabled adults to shut up” and then acknowledges that starting this way might make parents “feel attacked.” She moves from talking about how parents dominate public conversations around developmental disabilities to lamenting public sympathy for parents who murder and abuse their children to trying to “assure [parents] that [she is] not bringing up these cases in order to compare [them] to these murderous and abusive parents.” Next Zoe discusses ways in which parents dismiss and invalidate autistic voices, and follows this accusation by clarifying that she is “aware that parent advocates are Not All Like That.” She then asks parents to “consider whether [they] may have been Like That at some point [because they] probably have.” In this post, Zoe works to incorporate radical discursive strategies in dialogue, moving between calling parents out and drawing them back in in an effort to engage in a productive conversation that conveys her anger with regard to “the context in which [she is] trying to make a difference”—that is, a social context in which parents often contribute to the oppression of autistic individuals. In their reactions to Zoe’s post, ND advocates strongly debated whether Zoe succeeded in using radical impulses in the service of dialogue, or whether she used an appeal for dialogue to serve radical purposes.

Radical politics are a key component of disability rights advocacy grounded in a social model view of disability. Locating disability in society as opposed to within the bodies of impaired individuals is not only radical in the everyday sense of overturning conventional thinking, those that first developed the social model intended it to be radical in the revolutionary



sense as well. As Vic Finkelstein (2001)—one of the authors of the Union of the Physically Impaired Against Segregation’s *Fundamental Principles* document which first articulated a social interpretation of disability—explains,

[o]ur society is built on a competitive market foundation and it is this social system that disables us. From this point of view disabled people are forced to live in a social prison. . . . Nothing less than dismantling the prison and replacing it with a non-competitive form of society can break-down the doors which bar our emancipation. (p. 4)

Most disability rights advocacy in the U.S.—including neurodiversity advocacy—is aimed at civil rights, what Finkelstein (2001) characterizes as a “legalistic approach to emancipation” (p. 4). Changing society by fighting for legal protections and minority recognition may fall short of Finkelstein’s materialist vision, but civil rights goals are also fueled by radical politics aimed at overturning the status quo.

Feeling “angry . . . [and] very frustrated” (Sequenzia, 2012a) and using hostility as a way of “trying to be heard” (Sequenzia, 2012a) are common strategies in radical disability rights activism (e.g., ADAPT, 2010). Like other social movements, the fight for disability rights is characterized by contentious politics whereby actors demand rights through angry rhetoric (Barnartt, Schriener, & Scotch, 2001). Anger is empowering. Through anger, “nam[ing] disability as social oppression is not the defeated wailing of victims, but the clarion call of social change agents” (Charlton, 1998, p. 192). Outrage over oppression is an important part of disabled political identity, a visceral response to “consciousness-raising . . . in which disabled people come to understand that their difficulties arise . . . from the way society has treated them” (Shakespeare & Watson, 2001, p. 548).

For most self-advocates in the movement, hostility is a justifiable response to living a disabled life in ableist society. For ND advocates living in a world where autistics typically face

“years of miscommunication, bullying, rejection and being misunderstood” (Kim, 2012); where autistic children are 28 times more likely than their non-autistic, non-depressed peers to contemplate suicide on the basis of these social factors (Soraya, 2013); where “discrimination against autistic children and adults is more the rule rather than the exception” (Davendas Aguilar & Puras, 2015); where “doctors are more likely to allow [patients with cognitive disabilities] to die” (Bingham, 2013); where people in homes for the developmentally disabled can face abuse and neglect (Bale, 2015); where more than seventy disabled people—among them a disproportionate number of autistic children—have been killed by their parents in the last five years (ASAN, 2015c); self-advocates argue that “[i]f you aren’t outraged, there is something wrong with you” (Brown, 2013d).

Though self-advocate bloggers and other ND activists online aren’t engaging in the kinds of radical civil disobedience protest tactics practiced by ADAPT, much ND advocacy on the Web can be read as a similar kind of “militant struggle from below” (Malhotra, 2001) aimed at empowering autistic people and toppling existing power structures in which Autism Speaks and parents are positioned as leaders of the autism community. According to Chesebro’s (1972) taxonomy of radical rhetorical strategies, ND bloggers, commenters, and Twitter and Facebook users are cultural revolutionaries who target “social values on an interpersonal basis . . . [by] confront[ing], attempt[ing] to subdue, degrad[ing] or symbolically destroy[ing] enemies who reflect the norms and value-orientations of the established power system” (p. 41). For self-advocates, fighting ableism and tragedy model discourse means undermining Autism Speaks’ and parents’ legitimacy to speak for autistic people, and this work is often done in rather hostile opposition against these members of the autism community.

Such contentious politics run the risk of alienating potential allies (Barnartt, Schriener, & Scotch, 2001), and autistic self-advocates often respond to charges of being ‘too angry,’ and ‘hateful.’ When it comes to justifying anger directed at Autism Speaks, ND advocates suggest that hatred is justified, that such vitriol is simply opposition that meets the measure set by an organization that many explicitly refer to as a “hate group” (e.g., Sequenzia, 2014b; Wiley-Mydske, quoted in Sutton, 2014) spreading “hate speech” (e.g., Ne’eman, 2009). When it comes to justifying anger directed at parents, ND advocates typically rely on hate-the-sin-not-the-sinner arguments, claiming that it’s ableism and majority privilege they’re aggressively targeting, not parents themselves.

While ND advocates often use discursive strategies oriented toward radical activism, most also agree that dialogue is needed, particularly when it comes to communication between self-advocates and parents. As autistic activist Lydia Brown (2012b) stresses in an open letter to parents,

[w]e need you. . . . [T]here is no way for the autism and Autistic communities to move forward without creating some type of group cohesiveness. Yes, that means that we will have to enter into painful dialogue and discourse, and yes, that means we will have to accept the validity and legitimacy of the ideas and feelings of people with whom we may disagree.

Brown’s comments echo the words of Jim Sinclair (1993) who started the neurodiversity movement by stressing to parents, “We need you. We need your help and understanding.”

Dialogue between parents and self-advocates is described as a necessary first step “that might start the process of working together better as one larger community” (Roberts, 2011).

One principle bound up with both dialogue and radical activism is the value for inclusion. Dialogue is meant to include all stakeholders (Carcasson & Sprain, 2010). ND advocates use radical activism as a way of fighting for the inclusion of autistic perspectives. However, fighting

exclusion leads to the exclusion of parent perspectives when radical discourse casts parents into the role of the oppressive other.

When ND advocates call parents out for harboring damaging beliefs about their own children and contributing to stigma, when they link cure discourse to eugenics and tragedy model thinking to murder, they employ radical discursive moves that position parents—particularly those intent on recovery—as part of the problem, even unworthy of trust and liable to abuse their children in the name of normalization. Understandably, this radical resistance upsets many parents who feel “insult[ed]” (Sullivan, 2013) by “militant, angry autistic adults” (Sullivan, 2013). Though self-advocates sometimes offer disclaimers like Zoe’s, clarifying that they recognize not all parents are “Like That” (Zoe, 2011a) and that they don’t mean to compare parents to “murderous and abusive parents” (Zoe, 2011a), these disclaimers ring hollow in neurodiversity discourse where ableism is characterized as a slippery slope that leads from silencing to abuse and murder.

This can lead to tribalism, a problem that ND advocates share with other leaders in the disability rights movement. “Rather than building bridges with other groups . . . the vanguard of the disability movement has often been separatist, promoting a notion of ‘us’ disabled people against ‘them’ non-disabled oppressors” (Shakespeare, 2006, p. 80). According to Shakespeare (2006), this tendency stems from identity politics grounded in a social model view of disability focused solely on oppression. He argues that identity politics aimed at social injustice reinforces the otherness of disabled groups, reaffirms disabled people’s social position as victims rather than actors, and encourages mistrust and fear of an “oppressive and hostile” (p. 80) nondisabled world. While building radical political consciousness has been useful for disability rights groups, Shakespeare (2006) warns against the tendency for “[a] strong political identity, which should be

a means to an end, [to] become an end in itself” (p. 80). To offset the effects of social model identity politics, he suggests that disability rights movements find ways of addressing the “poisoned relations” (p. 197) that have come out of separatist politics and build partnerships with nondisabled allies.

One of the primary impediments to productive partnerships between non-autistic parents and self-advocates in the neurodiversity movement is the erasure of parent perspectives in ND discourse. While ND advocates are highly critical of the ways autistic voices are silenced in dominant discourse about autism, they are not above silencing tactics themselves. In addition to erasing or dismissing autistic voices who wish for a cure for autism, ND advocacy discourse also silences parents’ points of view. As evident in my own reconstructions of ND self-advocacy that make little room for parent perspectives outside ND characterizations, centering autistic perspectives frequently means ignoring parent perspectives. When autism parents are represented, ND characterizations are typically unsympathetic and often quite negative, and usually fail to mention the good that parents do or the values they might share with self-advocates. In order to combat the pervasive belief that autism entails suffering or that autistic people are burdens on their families, ND advocates also often dismiss many parents’ lived experiences. It seems that for ND advocates fighting ableism, any recognition of parental hardship with regard to parenting autistic children entails tragedy model discourse and must therefore be avoided.

The fact is, however, that many parents of autistic children do struggle with stress and emotional anguish. Devastation is one of the “most common reactions reported by parents” of newly diagnosed autistic children (Synapse, n.d.). In a study profiling 26 couples with autistic children,

[a]ll of the families experienced despair, sadness, denial, confusion, and anger after [the discovery that their child had autism]. Four couples described the experience as a loss comparable to a death in the family. Every parent wondered if his or her child would ever lead a “normal” life. (Altiere & von Kluge, 2009, p. 145)

Parent discourse online supports these findings. Diagnosis stories prevalent in autism parent blogs often include descriptions of parents’ “confused, angry, devastated, in tears, scared and overall just broken” (Shaw, n.d.) emotions. In forums and comment threads, parents often share fears that their children “will need constant care and will never be able to be independent and may never even communicate in a meaningful way” (CWA, quoted in WrongPlanet, 2015). They worry about what will happen to their children when they are gone. As one commonly cited study notes, many parents of adolescents and adults with autism exhibit cortisol levels on par “with other groups experiencing chronic stress, including parents of children with cancer, combat soldiers, Holocaust survivors, and individuals suffering from PTSD” (Mailick, et al., 2011, p. 466). In addition, “parent-blaming persists in autism culture” (Osteen, 2008, p. 298). Though Bruno Bettelheim’s early theories that unfeeling, ‘refrigerator mothers’ cause autism have long been disproven, discourse about the causes of autism—notable recent examples include discourse around vaccines and genetics—sometimes still position parents as responsible for their children’s disability. Parents routinely report feeling negatively judged, blamed by educators, other parents, and others for being too lenient, too strict, too attentive, and not attentive enough. Self-blame is also common for autism parents, who “constantly feel guilty and inadequate; if they don’t try every possible therapy, diet or medication, they may believe they haven’t done enough for their child” (Osteen, 2008, p. 298), even though the effects of many therapies may be potentially damaging, unproven, or hard, if not impossible, to track.

Parents often use online spaces to ‘vent’ about the challenges of raising children on the spectrum as a way of alleviating stress and finding support, and it is online that they frequently clash with self-advocates. “Let[ting] yourself grieve” (Suszynski, 2010) and seeking out the support of other autism parents (e.g., Synapse, n.d.) are two pieces of advice commonly offered to parents of newly diagnosed children, and parents enact both strategies through online discourse. Researchers note that venting can be “cathartic” (Altiere & von Kluge, 2009, p.151). Many parents feel they “NEED to vent” (DW\_a\_mom, quoted in WrongPlanet, 2015, author’s emphasis) and participants in online autism community forums (e.g., WrongPlanet, 2015)—autistic and NT alike—often agree that parents “have a right to vent and be heard” (OliveOilMom, quoted in WrongPlanet, 2015). Being heard is important for autism parents, who often report feeling isolated, subject to “rejection and disdain” (Altiere & von Kluge, 2009, p. 151), even “dismissed by most of society” (Winegardner, 2011).

“[S]evere ASD mom[s]” (Sarah, comment on Magnusson, 2014) and fathers whose children experience significant behavioral difficulties can feel isolated “even in an ASD support group” (Julie P., comment on Magnusson, 2014), and a significant number use the Internet to find community. Like Kelli Stapleton, some post videos and accounts of their children in meltdown, and YouTube contains many other parent videos of autistic children engaging in self-injurious or aggressive behaviors, stripping, and even smearing feces. Parents often frame these accounts as attempts to reach out to other parents for help or to let other parents know they’re not alone. As Kate Wells (Wells & Wells, 2015) recently posted on Twitter in the midst of live tweeting<sup>28</sup> her son’s “brutal,” “horrifying” meltdown, “This is reality. I’m open about the progress, but the other, darker side, needs to be talked about . . . I would be doing a disservice to my fellow #autismparents if I didn’t open up our full experiences. All our voices need to be

---

<sup>28</sup> Live tweeting involves posting status updates to Twitter about an event in real time, as it happens.

heard.” For Wells and others, venting is not only a way of maintaining “sanity, strength, support & feeling like there’s a chance [of] helping someone else feel not so alone” (Wells & Wells, 2015), talking about “hardcore reality” (Wells & Wells, 2015) is necessary for true acceptance, both for parents and children. As Wells tweeted the day after her son’s public meltdown, “[w]e cannot accept what we don’t understand. We cannot expect understanding if we remain silent” (Wells & Wells, 2015).

Like Kelli Stapleton, Kate Wells was subjected to quick, unforgiving retribution from neurodiversity advocates who accused her and her husband Jason—who also posted some status updates about the meltdown—of “put[ting their] kid’s private struggles on blast” (@WileyAutLibrary, 2015) and “disrespect[ing]” (@K1mmyR0cks, 2015), “exploiting” (@Mom2Rebels, 2015a), “humiliat[ing]” (@UVGKassi, 2015), and “abus[ing]” (Clark, 2015a) their son. Amy Sequenzia was particularly unforgiving, tweeting “Disgusting. You know what I call exposing child’s [meltdown] without their consent? Emotional rape” (@AmySequenzia, 2015). For autism activist, blogger at *The Autism Wars*, and parent to a non-speaking autistic child Kerima Çevik (2015b), the Wells’ tweets were more insidious, a “red flag” indicating “serious problems in the home” and suggesting that the Wells—like the mothers of Issy Stapleton, London McCabe, and Alex Spourdalakis—might move from “digital exhibitionism” to harming their child.

Responses to Wells’ live tweeting enacted a strategy commonly employed in radical social justice activism referred to as ‘call-out culture.’ Calling-out means publicly naming discursive actions that support oppression. It is a way of “punish[ing] people for their mistakes” (Loan Tràn, 2013b) and it is also a public performance (Ahmad, 2015) aimed at exposing the everyday discursive mechanisms by which systems of oppression operate. By calling-out Kate



Wells and her husband, ND activists not only publicly shamed and attacked the couple, they called attention to ableist discourses that position autistic people as frightening and uncontrollable, that ignore autistic people's—and children's—preferences and erase the need for their consent, that prioritize parents' feelings and needs above their autistic children's, and that are used to justify violence.

While call-out culture is useful for drawing attention to mechanisms of power and privilege, radical activists invested in social justice movements concede that calling-out often leads to the kinds of “poisoned relations” (p. 197) Shakespeare (2006) warns against. Calling-out is one way of “defin[ing] the bounds of who's *in* and who's *out*” (Ahmad, 2015), creating “clubs of people who are right and people who are wrong” (Loan Trần, 2013b) in which “[i]ndividuals become synonymous with systems of oppression” (Ahmad, 2015), “as if we are not more complex than that” (Loan Trần, 2013b). Calling-out entails shutting-out, ‘writing people off’ as part of the problem, as ND advocates did with the Wells. But radical activists note that shutting out everyone “who fuck[s] up” (Loan Trần, 2013b) is unsustainable, that community-building is necessary for movements to thrive, and that activists need to employ dialogue—‘calling-in’ instead of calling-out—to “advance the conversation” (Bayetti Flores, 2014) with potential allies. Demonstrating the same ambivalence toward dialogue as ND advocates, other radical activists are also quick to point out that marginalized people “have EVERY RIGHT to get angry when [privileged people] fuck up” (Mia, comment on Loan Trần, 2013b, author's emphasis), and that not everyone deserves dialogue. Calling-in is a discursive strategy reserved for “people who we want to be in community with, people who we have reason to trust or with whom we have common ground” (Mia, comment on Loan Trần, 2013b).

While the ND advocates cited above would disagree, I see the Wells controversy as a missed opportunity for calling-in. This example is one that highlights the complexity of parent perspectives and the ramifications of call-out culture. Kate Wells messed up by publicizing her son's "private struggles" (@WileyAutLibrary, 2015), and many of her tweets portrayed him as aggressive and scary. But she also posted status updates that humanized him by describing him as "funny,sweet,kind&loving" (Wells & Wells, 2015) and "MY hero . . . the strongest person I know . . . pure love" (Wells & Wells, 2015, author's emphasis). She also communicated a desire for acceptance, both in the status update quoted above and on the tagline to her Twitter account where she described herself as "passionate about #autismawareness #autismacceptance" (@aintlifewells, 2015). Starting from a shared value for love and acceptance could have offered ND advocates the opportunity to connect with the Wells and expose them to self-advocate perspectives.

Dialogue would have been a more appropriate response given the public forum as well. Kate Wells currently has over 2,300 followers on Twitter. Local media published some of the couple's "raw, emotional tweets" (PTBOCanada, 2015), widening Wells' audience online. Calling Wells out had the effect of alienating a significant number of audience members, including Kate Wells and other autism parents. Shortly after live-tweeting the meltdown, Wells posted that "[t]he 'block' button<sup>29</sup> is working overtime" (Wells & Wells, 2015). Some of her followers defended Wells in angry replies to ND advocates. One supporter received eight favorites<sup>30</sup> for tweeting, "if you have anything but support for @aintlifewells & @JasonWells72, fuck off" (@PatTrudeau, 2015).

---

<sup>29</sup> Blocking on Twitter prevents blocked users from accessing the blocker's tweets or Twitter timeline when logged in.

<sup>30</sup> Favorites on Twitter show that another Twitter user liked the post and archived it in their favorites, a curated list that is accessible to other Twitter users.

Calling-in is a way of saying “[y]ou’re making mistakes, you need to broaden your perspective, you need to listen to people who can grow your advocacy in a productive way” (Rummel-Hudson, 2011b). It’s an important overture to dialogue that can help parents find the support that they need. In their study of autism parents, Altieri and von Kluge (2009) found that couples were most resilient—that is, most able to manage stress, handle financial struggles, juggle other familial responsibilities, and, importantly, recognize the *positive effects* of raising a child with autism—if they felt recognized and accepted. “*Acceptance and support from the community [are] integral to the emotional well-being of [autism parents]*” (Altieri & von Kluge, 2009, p.151, authors’ emphasis).

Calling-in counters the risk that parents join “a community that, while providing catharsis and emotional connections [parents may not have] found elsewhere, is actually toxic, actually fosters insidious attitudes about parenting children with disabilities” (Des Roches Rosa, 2014c). In a world where “almost everything works against parental understanding and acceptance of Autism” (Ryan, 2014b), “it all comes back to finding the right community” (Des Roches Rosa, 2014c). For many parents who are struggling, Autism Speaks and other tragedy model discourse may feel supportive in that it recognizes parents’ fears and challenges, and creates a safe space where depictions of “hardcore reality” (Wells & Wells, 2015) are accepted. But this “toxic” discourse can damage children’s self-esteem and feed parents’ fears about the future, causing them to ‘lose hope’ and presume incompetence. “[S]evere ASD” (Sarah, comment on Magnusson, 2014) parents who reach out to others online may find communities where publicly posting degrading videos of children in crisis is an encouraged form of support. In their desperation to find cures, parents also find their way to communities that support dangerous

interventions, like withholding vaccines, chelation (the removal of heavy metals from the body)<sup>31</sup> or chlorine dioxide (CD) protocols (regular oral or enema administrations of bleach solution)<sup>32</sup>.

Given these risks, connecting autistic children to autistic support networks takes on a significant urgency. As seen in the Wells case, radical activist discourse can impede community building by estranging parents—and thereby their children—from self-advocates. This is damaging for parents in that they are then left “with fear and despair . . . [unaware that] there’s another way” (Zurcher, 2014a). But it’s more devastating for the children whose parents have not yet found “the path of acceptance” (Kim, 2015) and are cut off from finding autistic mentors early on. Kassiane Sibley, autistic activist and blogger at *Radical Neurodivergence Speaking*, advises parents of newly diagnosed children that “[t]he *first thing* [they] need to do” (Neurodivergent K, 2014, author’s emphasis)—before finding a therapist, reaching out to other autism parents, or researching augmentative and alternative communication—is to forge relationships with autistic individuals as a way of providing their children with role models they can identify with and who can connect them to the larger autistic community. In order to be there for autistic kids in this way, ND advocates must find ways of maintaining open dialogue with parents. By “getting the word out” (Kim, 2015) about the dangers of ableism and the benefits of acceptance through constructive dialogue, ND advocates can also help parents embrace

---

<sup>31</sup> Chelation therapy has not been approved for autism, and a proposed study of the treatment was abandoned in 2008 by the National Institute of Mental Health when trials “determined that [there was] no clear evidence for direct benefit to children . . . and that the study present[ed] more than minimal risk” (NIMH, quoted in Boyles, 2008). The U.S. Food and Drug Administration has warned that “[c]helation can be dangerous and can cause serious harm” (Lee, quoted in Tsouderos, 2010). There has been one confirmed death associated with chelation administered for autism. A 5-year-old boy went into cardiac arrest during an intravenous procedure in Pennsylvania in 2005 (CDC, 2006).

<sup>32</sup> The U.S. Food and Drug Administration (FDA) (2010) “warns consumers of serious harm from drinking Miracle Mineral Solution (MMS)”—the other name for CD protocol. Per the FDA

The product instructs consumers to mix the 28 percent sodium chlorite solution with an acid such as citrus juice. This mixture produces chlorine dioxide, a potent bleach used for stripping textiles and industrial water treatment. High oral doses of this bleach, such as those recommended in the labeling, can cause nausea, vomiting, diarrhea, and symptoms of severe dehydration.

neurodiversity ideals. As mother to an autistic daughter Beth Ryan (2014b) notes, remembering her own “turning point” that happened “when Autistic adults reached out to [her]” underscores the need for ND advocates to reach out to others.

People who gently and lovingly taught me about things like the problems with person first language. . . . I don't remember what it was like to not have a community of Autistic adults supporting me. . . . I was given a chance. . . . I need to extend that [same] leeway to other parents . . . the ones who haven't had the opportunity to be supported by the community of people that promote the love and acceptance of Autistic people.

Rather than alienating parents by calling them ableists (or worse), perhaps ND advocates might try to exemplify more of the open acceptance and dialogue they endorse in communication with parents. Two discursive strategies could help in this regard, namely 1) including more parent perspectives in ND discourse, and 2) employing call-in strategies. Including autism parents' points of view in ND discourse might help more ND advocates to “accept the validity and legitimacy of the ideas and feelings of people with whom [they] disagree,” as Brown (2012a) suggests. To include parents' points of view, ND advocates could simply acknowledge parent concerns and critiques more often. In addition, more non-disabled parents in the ND community could share their own ‘convert’ stories highlighting practical, positive differences between acceptance and tragedy model thinking.

The kind of calling-in I'm calling for here is somewhat different from the discursive strategy outlined in radical activist discourse. Calling-in within the context of call-out culture is a discursive strategy that is employed between community members within the movement who share commitments to social justice. To be sure, this kind of calling-in would also be helpful in addressing rifts within the ND community. But I see calling-in as a set of dialogic strategies that

would also be helpful for ND advocates to grow the movement, particularly by reaching out to parents who they see as making mistakes or reproducing aspects of ‘cure culture.’ Calling-in starts by “let[ting] go of treating each other like not knowing, making mistakes, and saying the wrong thing make it impossible for us to ever do the right things” (Loan Trần, 2013b). In this sense, calling-in is like presuming competence in that it involves believing in others’ willingness and capacity to learn.

Opening up dialogue may also mean that ND advocates avoid blaming speech acts.

According to autism parent Mark Osteen (2008),

autism culture needs to move beyond the discourses of blame that divide us and that preserve outdated and damaging views about autistic people and their families. To do so is the first step toward genuine empathy and community. (p. 299)

As mentioned, ND advocates sometimes characterize parents’ tragedy model thinking as a kind of false consciousness perpetuated by dominant discourse. They also acknowledge that when parents dismiss autistic perspectives,

[i]t’s not because [they’re] bad [people]—it’s because [they] live in a society that teaches [them] that the voices of neurotypical folks are more important than the voices of disabled people. It’s because [they’ve] been given privilege, and that affects the way [they] think. (Zoe, 2011a)

Doing more to recognize the ways in which parents are socially positioned may help ND advocates recognize their humanity and capacity for change. In this light, parents can be absolved of some blame for reproducing (dis)ableist discourse or silencing autistic perspectives.

One of the primary problems with calling-out is that radical, inflammatory discourse positions targets as “representations of the [system]” (Ahmad, 2015) rather than individuals. Seen from a phenomenological perspective, casting others as “manifestations of the worst of society’s slights” (Rummel-Hudson, comment on Roberts, 2011) is a way of representing or

objectifying them that impedes genuine engagement. To enable dialogue, ND advocates must “[center] all of us who are involved as ever changing, ever evolving people who are complex and complicated” (Loan Trần, 2013a).

Calling-in is not ‘tone-policing.’ ND advocates rightly dismiss such demands for civility as discursive strategies that often silence marginalized actors (e.g., Brown, 2013a). Calling-in is simply a set of discursive strategies that may help reconcile ND advocates’ commitments to both dialogue and radical activism in interactions with parents. This is not to say that parents should not be held accountable for what they say and do. And I wholeheartedly agree with ND advocates who argue that sympathy for parents who murder or abuse their children is “dangerous and irresponsible” (Des Roches Rosa, comment on Des Roches Rosa, 2014c) and grounded in deplorable victim-blaming. But when it comes to parents in the autism community who are doing the best they can, perhaps recognizing the fact that they, too, are positioned in structures of power and privilege and that overcoming the influence of dominant discourse may take some time can help ND advocates resist blaming and approach parents as potential allies rather than enemies.

### **Conclusions, Limitations, Looking Ahead**

The neurodiversity movement is still in “the early stages” (Des Roches Rosa, comment on Roberts, 2011), but it is gaining momentum. Public conversations around autism are slowly changing. While media outlets still cite Autism Speaks and parents as the leaders of the autism community (e.g., Gardner, 2015), journalists also call upon representatives from the Autistic Self Advocacy Network to offer counterpoints more frequently (e.g., Donaldson James & Vinograd, 2014). Awareness campaigns about issues of concern for the ND community are finding wider audiences. This year, there were 25 vigil sites for Day of Mourning worldwide. ND advocates

have also had some success standing up to Autism Speaks, particularly on Twitter. Recent campaigns to #BoycottAutismSpeaks have led some sponsors to reconsider their support, and the “autistic Twittersphere” (Ne’eman, quoted in Hughes, 2015) take-over of the Autism Speaks’ hashtag #AutismSpeaks10 transformed an online celebration of AS’ 10 year anniversary into a protest that caught the attention of BuzzFeed News (Hughes, 2015). Self-advocates are also making themselves heard at the level of national policy. In 2014, the U.S. Senate and House re-authorized the *Combating Autism Act* as the *Autism Collaboration, Accountability, Research, Education and Support (CARES) Act* in response to autistic opposition to the language of the bill. And people on the spectrum and their allies have created a wealth of resources online aimed at educating parents and building autistic community neurodiversity ideals.

Moving forward, there is a need for ND advocates to address problems of exclusion within the movement, all of which are mirrored in the limitations of the present study. Because of its leadership history, the ND movement and my reconstructions are dominated by the voices of cognitively privileged autistics. In order to spread ‘big tent’ acceptance, ND advocate communities and disability studies researchers must find ways of listening to and working with individuals with more profound intellectual and communicative disabilities. Prioritizing autistic perspectives and fighting against oppressive social structures that implicate parents has had the effect of marginalizing non-disabled parents in ND advocacy and in this project. While the ethos “nothing about us without us” demands that autistics take a central role in the ND movement, parents are vital allies without whom the most vulnerable autistic community members—children and those who cannot reliably communicate in neurotypical ways—will be left behind. Finally, there is a lack of diversity and intersectionality within neurodiversity advocacy and this dissertation. The leaders of the ND movement represented in my reconstructions are



predominantly white, ND ideals are defined in terms white people's experience of autism, and the autistic community's struggles tend to be narrowly conceived around social oppressions on the basis of neurodivergence. In order to represent a united autistic community, the ND movement must do more to include the perspectives of non-white autistic individuals and consider how the experience of disability intersects with other differences—like race, gender, and class—to socially position community members in different ways.

Future research should build on the normative claims I make here and investigate efforts to increase inclusion within the neurodiversity movement. Driving questions might include: How are ND advocates working to include more neurodivergent perspectives, more parent perspectives, more intersectional perspectives? How might critical disability studies scholarship facilitate inclusion? What are the challenges involved for ND advocates and researchers? How does increasing diversity within the ND movement affect conceptions of autism acceptance and autistic community identity? There are some young initiatives that have begun to address problems of exclusion in the ND community that might provide good starting points for this research. The Autism Women's Network is sponsoring an *Autism and Race Anthology* edited by Lydia Brown aimed at "explor[ing] new ground for autistic communities of color whose stories need to be told" (Brown, quoted in daVanport, 2014). Two new blog collectives—*Parenting Autistic Children with Love & Acceptance* (2015a) and *Respectfully Connected* (2015)—now join the *Thinking Person's Guide to Autism* (n.d.) as parent-centric enclaves of neurodiversity online. And though they are not yet affiliated with the ND movement, there are online spaces where intellectually and communicatively disabled individuals are respectfully represented and make their own voices heard, such as sites for the Institute on Communication and Inclusion at Syracuse University (Syracuse University School of Education, 2015), Self Advocates Becoming

Empowered (n.d.b), and other, smaller self-advocacy groups (e.g. Ala Costa Adult Transition Program, 2015).

The value of this research lies in mapping “the early stages of [a] social justice and civil rights [movement]” (Des Roches Rosa, comment on Roberts, 2011) that is pushing disability rights forward online and in U.S. society. The autism acceptance movement is not only a new frontier for civil rights. It’s an expansion of human rights that pushes back against ideologies of ability that define personhood according to neurotypical norms by engaging a disability perspective that values all ways of communicating, thinking, and being in the world. Goodley (2014) argues that “learning disability studies in the academy do challenge attitudes and change lives . . . because they get us to think about this question: what does it mean to be a human being?” I’d argue that autism disability studies do the same.

## References

- @acspears [Christina]. (2014, Sept. 16). #KelliStapleton did not make the right choice, but she has my sympathy as does Issy and the entire family #DrPhil [tweet]. Retrieved from <https://twitter.com/acspears/status/512071039967182848>.
- ADAPT. (2010, Feb. 14). Anger [video]. Retrieved from <https://www.youtube.com/watch?v=AbAStbavOK4>.
- ADAPT. (2015). Welcome to ADAPT! [web page]. <http://www.adapt.org/>.
- Advancing Futures for Adults with Autism. (2014). Autism Speaks. Retrieved from <http://www.afa-us.org/newsroom/our-stories/32-autism-speaks>.
- Agar, J. (2013, Sept. 9). Autistic girl Issy Stapleton's recovery "nothing short of a miracle," father says. *M live*. [http://www.mlive.com/news/grand-rapids/index.ssf/2013/09/autistic\\_girl\\_issy\\_stapletons.html](http://www.mlive.com/news/grand-rapids/index.ssf/2013/09/autistic_girl_issy_stapletons.html).
- Agar, J. (2014, Sept. 15). Jailed mom thankful daughter survived, tells Dr. Phil: "Autism became a deadly condition in our house." *MLive*. Retrieved from
- Ahmad, A. (2015, Mar. 2). A note on call-out culture. *Briarpatch Magazine*. Retrieved from <http://briarpatchmagazine.com/articles/view/a-note-on-call-out-culture>.
- @aintlifewells [Kate Wells]. (2015). wife&mom. writer of run on sentences,finder of lost items.easily amused. Passionate about #autismawareness #autismacceptance [Twitter handle]. Retrieved Apr. 20, 2015 from <https://twitter.com/aintlifewells>.
- Ala Costa Adult Transition Program. (2015). About ACAT. *ACAT: Ala Costa Adult Transition Program* [web page]. Retrieved from <http://alacosta-acat.org/>.
- Alcoff, L. M. (1998). What should white people do? *Hypatia*, 13(3), 6-26. doi: 10.1111/j.1527-2001.1998.tb01367.x

Altieri, M. J. & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual and Developmental Disability*, 34(2), 142-152. <http://dx.doi.org/10.1080/13668250902845202>

American Psychiatric Association. (2013). Neurodevelopmental disorders. In *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> Ed.). doi: abs/10.1176/appi.books.9780890425596.dsm01.

@AngieGorz [Angie Gorz]. (2015a, Apr. 2). #AcceptanceIs embracing, even celebrating Autism. Not trying to cure, fix, or eradicate Autism. Autistics are not broken! [tweet]. Retrieved from <https://twitter.com/AngieGorz/status/583519891409477632>.

@AngieGorz [Angie Gorz]. (2015b, Apr. 2). #AcceptanceIs understanding that behavior is communication. [tweet]. Retrieved from <https://twitter.com/AngieGorz/status/583528359331758080>.

Anonymous. (2014, Oct. 11). Martyr moms [web log post]. Retrieved from <http://iamnotkellistapletonflashblog.blogspot.com/2014/10/martyr-moms.html>.

AP News. (2014, Oct. 8). Mom who tried to kill daughter gets 10-22 years. *Townhall.com*. Retrieved from <http://townhall.com/news/us/2014/10/08/sentencing-for-mom-who-tried-to-kill-autistic-girl-n1902212>.

@AsanWashington [ASAN Washington]. (2015, Apr. 2). #AcceptanceIs "Autistic persons should be recognized as the main experts on autism and on their own needs." <http://buff.ly/1NCMIzv> [tweet]. Retrieved from <https://twitter.com/AsanWashington/status/583649850811617280>.

Autism Acceptance Month. (n.d.). About [web page]. Retrieved from <http://www.autismacceptancemonth.com/about/>.

Autism Genetic Resource Exchange [AGRE]. (2013). [Researcher login page]. Retrieved from <http://agre.autismspeaks.org/site/c.lwLZKnN1LtH/b.5332889/k.B473/AGRE.htm>.

Autism Media Channel. (2013). Who killed Alex Spourdalakis? [video].

<http://www.indiegogo.com/projects/who-killed-alex-spourdalakis--2>.

Autism Memorial. (2013, July 23). Index [LiveJournal]. Retrieved from <http://autism-memorial.livejournal.com/8807.html>.

Autism Speaks. (n.d.a). Autism Speaks celebrates first anniversary: Highlights of year include media exposure, mergers, unprecedented fundraising and first scientific grants program [web page]. <http://www.autismspeaks.org/news/news-item/autism-speaks-celebrates-first-anniversary>.

Autism Speaks. (n.d.b). Light It Up Blue. [campaign flyer].

<http://www.lightitupblue.org/Markslist/userfiles/file/LIUB-OneSheet.pdf>.

Autism Speaks. (n.d.c). "New Decade" fundraiser brings in over \$2M. [archived press release]. Retrieved from <http://archive.today/ngRWK>.

Autism Speaks. (2005-2012). Corporate partners/friends. Retrieved from

<http://lightitupblue.org/Markslist/charityAffiliate/displayPage.do?siteIdCode=LSE0Q1A0&pageId=365>.

Autism Speaks. (2006a). Autism every day [video]. Retrieved from

<https://www.youtube.com/watch?v=O0vCz2KWMM0>.

Autism Speaks. (2006b, January 17). Autism Speaks makes first major funding commitment, supporting development of unprecedented National Autism Database [press release].

<http://www.autismspeaks.org/about-us/press-releases/autism-speaks-makes-first-major-funding-commitment-supporting-development-un>.

Autism Speaks. (2006c, Dec. 6). Cure Autism Now and Autism Speaks applaud approval of the Combating Autism Act by United States House of Representatives [press release].

Retrieved from <http://www.autismspeaks.org/about-us/press-releases/cure-autism-now-and-autism-speaks-applaud-approval-combating-autism-act-unit>.

Autism Speaks. (2007, Apr. 23). Autism Every Day premieres at Sundance [press release].

Retrieved from <http://www.autismspeaks.org/news/news-item/autism-every-day-premieres-sundance>.

Autism Speaks. (2009a). Do you want to be in a world autism video? *Autism Speaks* [web page].

<http://www.autismspeaks.org/news/news-item/do-you-want-be-world-autism-video>.

Autism Speaks. (2009b). I am autism [video]. Retrieved from <http://vimeo.com/20692567>.

Autism Speaks. (2012a, March 29). Autism Speaks to congress: Why do federal dollars for

autism go down when prevalence is on the rise? [web page]. Retrieved from

<http://www.autismspeaks.org/advocacy/advocacy-news/autism-speaks-congress-why-do-federal-dollars-autism-go-down-when-prevalence->

Autism Speaks. (2012b). Hacking autism [video]. Retrieved from

<https://www.youtube.com/watch?v=UKzIRTCQU2A>.

Autism Speaks (2012c). I want to say [video]. Retrieved from

<https://www.youtube.com/watch?v=Iu3c8fqBQcA>.

Autism Speaks. (2013a). Autism Speaks Global Autism Public Health initiative [web page].

Retrieved from <http://www.autismspeaks.org/science/research-initiatives/global-autism-public-health>.

Autism Speaks. (2013b, Jan. 6). Autism Speaks and Mass. General Hospital's Lurie Center for

Autism host documentary film premiere [press release]. Retrieved from

<http://www.autismspeaks.org/about-us/press-releases/autism-speaks-massachusetts-general-hospital-lurie-center-sounding-the-alarm-premiere>.

Autism Speaks. (2013c). Autism Speaks to Washington [web page]. Retrieved from <http://www.autismspeaks.org/news/news-item/autism-speaks-washington>.

Autism Speaks. (2013d). Autism Treatment Network [web page]. Retrieved from <http://www.autismspeaks.org/science/resources-programs/autism-treatment-network>.

Autism Speaks. (2013e). "I'm here for you." *Autism Speaks* [blog post]. <http://www.autismspeaks.org/blog/2013/12/04/im-here-you>.

Autism Speaks. (2013f). Sixth annual world focus on autism emphasizes global efforts [news post]. Retrieved from <http://www.autismspeaks.org/news/news-item/sixth-annual-world-focus-autism-emphasizes-global-efforts>.

Autism Speaks. (2013g, Oct. 9). What is Autism Speaks? [video]. Retrieved from <https://www.youtube.com/watch?v=qSTFDUmXMOI>.

Autism Speaks. (2014a). Adult services [Web page]. Retrieved from <http://www.autismspeaks.org/family-services/adults>.

Autism Speaks. (2014b). About us [webpage]. Retrieved from <http://www.autismspeaks.org/about-us>.

Autism Speaks. (2014c). I want to say [press release]. Retrieved from <http://www.autismspeaks.org/hacking-autism/i-want-to-say>.

Autism Speaks. (2014d). In our own words: Understand me [web log post]. Retrieved from <http://www.autismspeaks.org/blog/2014/10/08/our-own-words-understand-me>.

Autism Speaks. (2014e, July 10). MSNBC highlights autism documentary "Sounding the alarm" [press release]. Retrieved from <http://www.autismspeaks.org/news/news-item/msnbc->

[highlights-autism-documentary-quot-sounding-alarmquot.](#)

Autism Speaks. (2014f). Mission [web page]. Retrieved from

<http://www.autismspeaks.org/about-us/mission>.

Autism Speaks. (2014g). Sounding the alarm: Battling the autism epidemic [video trailer].

Retrieved from <https://www.youtube.com/watch?v=oSpA-pU2dsk>.

Autism Speaks. (2014h). Walk now for Autism Speaks [web page]. Retrieved from

[http://www.walknowforautismspeaks.org/site/c.igIRL6PIrH/b.7683511/k.2EFB/Walk\\_Now\\_for\\_Autism\\_Speaks\\_Home.htm](http://www.walknowforautismspeaks.org/site/c.igIRL6PIrH/b.7683511/k.2EFB/Walk_Now_for_Autism_Speaks_Home.htm).

Autism Speaks. (2014i). What is autism? [web page]. Retrieved from

<http://www.autismspeaks.org/what-autism>.

Autism Speaks. (2015b). Board members [web page]. <http://www.autismspeaks.org/about-us/board-directors>.

Autism Speaks, Inc. (2013). Consolidated financial statements years ended December 31, 2012 and 2011. Retrieved from

[https://www.autismspeaks.org/sites/default/files/documents/2012\\_audit\\_autism\\_speaks\\_and\\_subs\\_financials.pdf](https://www.autismspeaks.org/sites/default/files/documents/2012_audit_autism_speaks_and_subs_financials.pdf).

Autism Tissue Program [ATP]. (n.d.) Autism Tissue Program in transition [web page].

Retrieved from

<http://www.autismtissueprogram.org/site/c.nlKUL7MQIsG/b.5183271/k.BD86/Home.htm>.

Autism Women's Network. (2013). AWN calls for zealous prosecution in the attempted murder of Issy Stapleton. Retrieved from [http://us5.campaign-](http://us5.campaign-archive2.com/?u=d0b61c166ab330f756ab407d0&id=4cf634f58a)

[archive2.com/?u=d0b61c166ab330f756ab407d0&id=4cf634f58a](http://us5.campaign-archive2.com/?u=d0b61c166ab330f756ab407d0&id=4cf634f58a).



@AutismDogGirl [AutismDogGirl]. (2015, Apr. 2). #AcceptanceIs having the right to communicate in whatever method I prefer and feel most comfortable using! [tweet].

Retrieved from <https://twitter.com/AutismDogGirl/status/583500914872492033>.

Autistic Self Advocacy Network. (n.d.a) Before you donate to Autism Speaks, consider the facts [flyer]. [http://autisticadvocacy.org/wp-content/uploads/2012/05/Autism\\_Speaks\\_Flyer.pdf](http://autisticadvocacy.org/wp-content/uploads/2012/05/Autism_Speaks_Flyer.pdf).

Autistic Self Advocacy Network [ASAN]. (n.d.b). Neurodiversity and autistic people. In National Autism Research and Information Center & Autistic Self Advocacy Network, *A curriculum for self advocates*, p. 6. Retrieved from [http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates\\_r4.pdf](http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates_r4.pdf).

Autistic Self Advocacy Network. (n.d.c). To the sponsors, donors, and supporters of Autism Speaks [petition]. <http://www.ipetitions.com/petition/autismspeaks/>.

Autistic Self Advocacy Network [ASAN]. (2009, Sept. 23). Autistic community condemns Autism Speaks [press release]. Retrieved from <http://asansouthwestohio.blogspot.com/2009/09/autistic-community-condemns-autism.html>.

Autistic Self Advocacy Network [ASAN]. (2012, Nov. 1). Autistics Speaking Day 2012: Reclaiming voice. Retrieved from <http://autisticadvocacy.org/2012/11/autistics-speaking-day-2012-reclaiming-voice/>.

Autistic Self Advocacy Network. (2013a). 2013 joint letter to the sponsors of Autism Speaks. Retrieved from <http://autisticadvocacy.org/2013/11/2013-joint-letter-to-the-sponsors-of-autism-speaks/>.

Autistic Self Advocacy Network [ASAN]. (2013b, Oct. 14). ASAN condemns media coverage of

the attempted murder of Issy Stapleton. Retrieved from

<http://autisticadvocacy.org/2013/10/asan-condemns-media-coverage-of-the-attempted-murder-of-issy-stapleton/>.

Autistic Self Advocacy Network. (2013c). Category archives: Disability rights and

neurodiversity. [web page] <http://autisticadvocacy.org/category/topic/disability-rights-and-neurodiversity/>.

Autistic Self Advocacy Network [ASAN]. (2014a). *Anti-filicide toolkit*. Retrieved from

<http://autisticadvocacy.org/anti-filicide/>.

Autistic Self Advocacy Network. (2014b, Oct. 6). ASAN, disability community statement on the sentencing of Kelli Stapleton [sentencing statement]. Retrieved from

<http://autisticadvocacy.org/2014/10/asan-disability-community-statement-on-sentencing-of-kelli-stapleton/>.

Autistic Self Advocacy Network. (2014c, Jan. 6). 2014 joint letter to the sponsors of Autism

Speaks. Retrieved from <http://autisticadvocacy.org/2014/01/2013-joint-letter-to-the-sponsors-of-autism-speaks/>.

Autistic Self Advocacy Network [ASAN]. (2015a). About [web page]. Retrieved from

<http://autisticadvocacy.org/about-asan/>.

Autistic Self Advocacy Network [ASAN]. (2015b). About autism [web page]. Retrieved from

<http://autisticadvocacy.org/about-autism/>.

Autistic Self Advocacy Network [ASAN]. (2015c). Anti-filicide toolkit [web page]. Retrieved

from <http://autisticadvocacy.org/2015/01/2015-day-of-mourning-vigils/>.

Autistic Self Advocacy Network [ASAN]. (2015d). Autism acceptance month [web page].

Retrieved from <http://autisticadvocacy.org/projects/autism-acceptance-month/>.

Autistic Self Advocacy Network [ASAN]. (2015e). Category archives: Autistic community and allies [web page archive]. Retrieved from

<http://autisticadvocacy.org/category/topic/autistic-community-and-allies/>.

Autistic Wiki. (2015, Mar. 24). You are not your child's voice [Wiki]. Retrieved from

<http://autisticwiki.blogspot.com/2015/03/you-are-not-your-childs-voice.html>.

@autistichoya [Lydia Brown]. (2015, Apr. 2). #AutismIs suffering through the month April as the world fills with traumatizing fear and pity based rhetoric about your existence.

[tweet]. Retrieved from <https://twitter.com/autistichoya/status/583605792332500992>.

Autisticcook. (2013, Dec. 28). Meltdown [web log post]. Retrieved from

<http://wearelikeyourchild.blogspot.com/2013/12/meltdown.html>.

@AutisticWiki [AutisticWiki]. (2015a, Apr. 2). #AcceptanceIs being patient enough for me to finish a sentence without cutting me off. What's the rush, anyway? #autismawareness

[tweet]. Retrieved from <https://twitter.com/AutisticWiki/status/583771297525538816>.

@AutisticWiki [AutisticWiki]. (2015b, Apr. 2). #LIUB is an advertisement by non-autistics.

#WalkinRed is a movement by #ActuallyAutistic's. Real #autismawareness from the inside. [tweet]. Retrieved from

<https://twitter.com/AutisticWiki/status/583770928414199808>

AWARES.org. (n.d.). About Autism [web page]. Retrieved from

[http://www.awares.org/static\\_docs/about\\_autism.asp?docSection=3](http://www.awares.org/static_docs/about_autism.asp?docSection=3)

@BabyBloodheart [Bloodheart]. (2015, Mar. 13). My childhood was meltdowns, self-harm,

unable to talk, eat, acknowledge others, etc...but #HighFunctioningMeans apparently it didn't happen [tweet]. Retrieved from

<https://twitter.com/BabyBloodheart/status/576475599797116928>.

- Baggs, A. (2007). In my language [video]. Retrieved from <https://www.youtube.com/watch?v=JnylM1hI2jc>.
- Baggs, A. (2010). Cultural commentary: Up in the clouds and down in the valley: My richness and yours. *Disability Studies Quarterly*, 30(1). <http://dsq-sds.org/article/view/1052/1238>.
- Bakhtin, M. M. (1999[1986]). The problem of speech genres. In A. Jaworski & N. Coupland (Eds.), *The discourse reader*, pp. 121-132. London: Routledge.
- Bale, R. (2015, Apr. 7). 13 deaths blamed on abuse and neglect at California state-run homes. *Reveal*. Retrieved from <http://www.revealnews.org/article/13-deaths-blamed-on-abuse-and-neglect-at-california-state-run-homes/>.
- Bamberg, M. & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk* 28(3), 377-396. doi 10.1515/TEXT.2008.018
- Bambury, B. (2015, Feb. 27). What do people with autism need most: Acceptance or a cure? In CBC Radio (producer), *Day 6 with Brent Bambury*. Toronto, ON: CBC Radio-Canada. Retrieved from: <http://www.cbc.ca/radio/day6/episode-222-the-religious-roots-of-isis-redefining-autism-a-black-hole-mystery-more-1.2975305/what-do-people-with-autism-need-most-acceptance-or-a-cure-1.2976088>.
- Barnartt, S., Schriener, K., & Scotch, R. (2001). Advocacy and political action. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies*, pp. 430-449. Thousand Oaks: Sage.
- Barnartt, S. N. & Scotch, R. K. (2001). *Disability protests: Contentious politics 1970-1999*. Washington, D.C.: Gallaudet University Press.

- Bascom, J. (2011a, Apr. 5). About [web page]. Retrieved from <https://juststimming.wordpress.com/about/>.
- Bascom, J. (2011b, July 14). Metaphors are important: 1/4 [weblog post]. Retrieved from <https://juststimming.wordpress.com/2011/07/14/metaphors-are-important-14/>.
- Bascom, J. (Ed.). (2012a). *Loud hands: Autistic people, speaking*. Washington, D.C.: The Autistic Press.
- Bascom, J. (2012b, Feb. 16). Metaphors are important: An ethnography of robotics [web log post]. Retrieved from <https://juststimming.wordpress.com/2012/02/16/an-ethnography-of-robotics/>.
- Bascom, J. (2014a, Dec. 21). Dangerous assumptions [web log post]. Retrieved from <https://juststimming.wordpress.com/2014/12/21/dangerous-assumptions/>.
- Bascom, J. (2014b). Webinar: Same old story – Strategies to combat media misrepresentations [video]. Retrieved from <https://www.youtube.com/watch?v=gQaH0iGvC28&feature=youtu.be>.
- Bayetti Flores, V. (2014, Dec. 20). On cynicism, calling out, and creating movements that don't leave our people behind. *Feministing*. Retrieved from <http://feministing.com/2013/12/20/on-cynicism-calling-out-and-creating-movements-that-dont-leave-our-people-behind/>.
- Becker, C. (n.d.). Self-advocate or activist? [web log post]. Retrieved from <http://nostereotypeshere.blogspot.com/p/self-advocate-or-activist.html>.
- Benham, J. L. (2014). Proud to be autistic: Reclaiming a slur as the basis for self-advocacy. *Society for Disability Studies* [unpublished conference presentation].

- Benwell, B. & Stokoe, E. (2006). *Discourse and identity*. Edinburgh University Press: Edinburgh.
- Berns, P. (2013, Nov. 16). An open letter to Suzanne Wright, co-founder, Autism Speaks [web log post]. Retrieved from <http://blog.thearc.org/2013/11/16/open-letter-suzanne-wright-co-founder-autism-speaks/>.
- Biklen, D. (2005). *Autism and the myth of the person alone*. New York: New York University Press.
- Biklen, D. & Burke, J. (2006). Presuming competence. *Equity & Excellence in Education*, 39(2), 166-175. DOI: 10.1080/10665680500540376
- Biklen, D. & Wurzburg, G. (Producers). (2010). *Wretches and jabberers* (Motion picture). USA: State of the Art, Inc.
- Billawalla, A. and Wolbring, G. (2014). Analyzing the discourse surrounding autism in New York Times using an ableism lens. *Disability Studies Quarterly*, 34(1). Retrieved from <http://dsq-sds.org/article/view/3348/3524>.
- Bingham, J. (2013, Mar. 19). Doctors put lower value on lives of the disabled, study finds. *The Telegraph*. Retrieved from <http://www.telegraph.co.uk/news/health/news/9940870/Doctors-put-lower-value-on-lives-of-the-disabled-study-finds.html>.
- Bjornstad-Kelly, K. (2012, Apr. 2). Awareness is not enough [web log post]. Retrieved from <http://autisticadvocacy.org/2012/04/awareness-is-not-enough/>.
- Blaylock, A. & Washburne, X. (2014, Oct. 29). Autism Speaks and Penn's neurodiversity problem. *The Daily Pennsylvanian*. Retrieved from <http://www.thedp.com/article/2014/10/autism-speaks-penn-neurodiversity-problem>.

- Blommaert, J. (2005). *Discourse: A critical introduction*. New York: Cambridge University Press.
- Blume, H. (1998, Sept. 30). Neurodiversity: On the neurological underpinnings of geekdom. *The Atlantic*. <http://www.theatlantic.com/magazine/archive/1998/09/neurodiversity/305909/>.
- Bourdieu, P. (1998[1994]). *Practical reason*. Stanford: Stanford University Press.
- Boycott Autism Speaks (n.d.). Autism Speaks does NOT speak for us! [web page]. Retrieved from <http://www.boycottautismspeaks.com/>.
- Boycott Autism Speaks. (2013, Nov. 19). [open letter]. <http://boycottautismspeaks.com/why-boycott-1.html>.
- Boycott Autism Speaks. (2015). Powerful words M. Kelter! [Facebook status update]. Retrieved from <https://www.facebook.com/boycottautismspeaksnow/photos/a.617487991630971.1073741827.617475298298907/811178622261906/>.
- Boyles, S. (2008, Sept. 18). Chelation study for autism called off. *WebMD*. Retrieved from <http://www.webmd.com/brain/autism/news/20080918/chelation-study-autism-called-off>.
- Bridget. (2012, Oct. 7). Self injurious behaviors [web log post]. Retrieved from <http://itsbridgetsword.com/2012/10/07/self-injurious-behaviors/>.
- Brown, L. (n.d.). Autism FAQ [web log post]. Retrieved from <http://www.autistichoya.com/p/introduction-to-autism-faqs-of-autism.html>.
- Brown, L. (2011a, Nov. 1). Disability is a social construct: A sociological perspective on autism and disability [web log post]. Retrieved from <http://www.autistichoya.com/2011/11/disability-is-social-construct.html>.

- Brown, L. (2011b, Aug. 4). The significance of semantics: Person-first language: Why it matters [web log post]. Retrieved from <http://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html>.
- Brown, L. (2012a, Mar. 8). Letter to the parents of autistic children [web log post]. Retrieved from <http://www.autistichoya.com/2012/03/letter-to-parents-of-autistic-children.html>.
- Brown, L. (2012b, Jan. 31). Self-advocacy isn't all about legislation [web log post]. Retrieved from [http://www.autistichoya.com/2012\\_01\\_01\\_archive.html](http://www.autistichoya.com/2012_01_01_archive.html).
- Brown, L. (2012c, June 9). The dangers of misrepresentation [web log post]. Retrieved from <http://www.autistichoya.com/2012/06/dangers-of-misrepresentation.html>.
- Brown, L. (2012d, Jan. 13). Tired. *Shift*. Retrieved from <http://www.shiftjournal.com/2012/01/13/tired/>.
- Brown, L. (2013a, Feb. 1). Ableism, tone police, and hypocrisy [web log post]. Retrieved from <http://www.autistichoya.com/2013/02/ableism-tone-police-and-hypocrisy.html>.
- Brown, L. (2013b, Nov. 14). Autism Speaks and representation [web log post]. Retrieved from <http://www.autistichoya.com/2013/11/autism-speaks-and-representation.html>.
- Brown, L. (2013c, Mar. 26). Constructing disability: Deviant bodies, deviant minds, disabling society [web log post]. Retrieved from <http://www.autistichoya.com/2013/03/constructing-disability-deviant-bodies.html>.
- Brown, L. (2013d, Nov. 8). Co-opting the movement: Autism Speaks, John Elder Robison, and complicity in oppression [web log post]. Retrieved from <http://www.autistichoya.com/2013/11/coopting-the-movement.html>.
- Brown, L. (2013e, Mar. 23). This is why I am angry [web log post]. Retrieved from <http://www.autistichoya.com/2013/03/this-is-why-i-am-angry.html>.



Brown, L. (2015a, Mar. 24). 5 ableist reasons autistic bloggers lag behind [web log post].

Retrieved from <http://www.autistichoya.com/2015/03/5-ableist-reasons-autistic-bloggers-lag.html>.

Brown, L. (2015b, Jan. 1). Black lives still matter [web log]. Retrieved from

<http://www.autistichoya.com/2015/01/black-lives-still-matter.html>.

Calabrese, A. (2004). Virtual nonviolence? Civil disobedience and political violence in the information age. *Info*, 6(5), 326-338. doi:10.1108/14636690410564834

Camley, V. (2005). Celebrate neurodiversity [poster].

<http://unicornchildrensfoundation.blogspot.com/2013/05/celebrate-neurodiversity.html>.

Campbell, F. K. (2009). *Contours of ableism*. London: Palgrave Macmillan.

CAN Radio. (2014, Dec. 8). Healing autism parents. *blogtalkradio* [talk radio show]. Retrieved from <http://www.blogtalkradio.com/neurodiversitynews/2014/12/08/healing-autism-parents>.

Caracasson, M. & Sprain, L. (2010). Key aspects of the deliberative democracy movement. *Public Sector Digest*.

Carey, M. (2014, Sept. 3). When a child is killed by a parent the word ‘but’ does not apply [web log post]. Retrieved from <http://leftbrainrightbrain.co.uk/2014/09/13/when-a-child-is-killed-by-a-parent-the-word-but-does-not-apply/>.

Carlson, L. (2001). Cognitive ableism and disability studies: Feminist reflections on the history of mental retardation. *Hypatia*, 16(4), 124.

Castrodale, J. (2014, Sept. 12). Kelli Stapleton: County jail has been better than this “jail of autism.” *People Magazine*. Retrieved from <http://www.people.com/article/kelli-stapleton-daughter-dr-phil-jail>.

- CBC News. (2010, Dec. 6). "Compassionate homicide:" The law and Robert Latimer. *CBC News*. Retrieved from <http://www.cbc.ca/news/canada/compassionate-homicide-the-law-and-robert-latimer-1.972561>.
- CBS News. (2013, Aug. 30). Film provides glimpse into life of autistic teen killed by his mother. *CBS This Morning*. <http://www.cbsnews.com/news/film-provides-glimpse-into-life-of-autistic-teen-killed-by-his-mother/>.
- CDC. (2006, Mar. 3). Deaths associated with hypocalcemia from chelation therapy—Texas, Pennsylvania, and Oregon, 2003-2005. *CDC.gov*. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5508a3.htm>.
- Centers for Disease Control and Prevention. (2015a, Feb. 26). Autism spectrum disorder (ASD). Retrieved from <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>.
- Centers for Disease Control and Prevention. (2015b, Feb. 26). Data and statistics. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>.
- Çevik, K. (2015a, Apr. 14). Justice for Kayleb Moon Robinson #AliveWhileBlack and autistic [web log]. Retrieved from <http://intersecteddisability.blogspot.com/2015/04/justice-for-kayleb-moon-robinson.html>.
- Çevik, K. (2015b, Mar. 8). On digital exhibitionism by autism parents: Why parents live-tweeting their disabled children's worst moments is red flag that should concern everyone [web log post]. Retrieved from <http://theautismwars.blogspot.com/2015/03/on-digital-exhibitionism-by-autism.html>.
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press.

Chavisory. (2014a, May 11). A checklist for identifying sources of aggression [web log post].

Retrieved from <http://wearelikeyourchild.blogspot.com/2014/05/a-checklist-for-identifying-sources-of.html>.

Chavisory. (2014b, Aug. 10). The unrecovered (response to the New York Time's "The kids who beat autism") [web log post]. Retrieved from

<http://wearelikeyourchild.blogspot.com/2014/08/the-unrecovered-response-to-new-york.html>.

Chesebro, J. W. (1972). Rhetorical strategies of the radical revolutionary. *Today's Speech*, 20(1), 37-48.

Chew, K. (2010). The disabled speech of Asian Americans: Silence and autism in Lois-Ann

Yamanaka's *Father of the Four Passages*. *Disability Studies Quarterly*, 30(1). <http://dsq-sds.org/article/view/1068/1233>.

Chilton, P. A. & Schäffner, C. (2002). Introduction: Themes and principles in the analysis of political discourse. In P. A. Chilton & C. Schäffner (Eds.). *Politics as text and talk: Analytic approaches to political discourse*, pp. 1-41. Philadelphia: John Benjamins Publishing Company.

@chromesthesia [shondolyn Gibson]. (2015, Mar. 18). #HighFunctioningMeans you're expected to tolerate a world that makes no sense to you but the world doesn't have to tolerate you [tweet]. Retrieved from <https://twitter.com/chromesthesia/status/578288882288054273>.

Clark, H. (2015a, Mar. 8). Humiliation is abuse [web log post]. Retrieved from

[http://raisingrebelsouls.blogspot.com/2015/03/humiliation-is-abuse\\_8.html](http://raisingrebelsouls.blogspot.com/2015/03/humiliation-is-abuse_8.html).

- Clark, H. (2015b, Feb. 21). Mother of autistic children, not autism mom [web log post]. Retrieved from <http://raisingrebel souls.blogspot.com/2015/02/mother-of-autistic-children-not-autism.html>.
- Clarke, C. E. (2008). A Question of Balance: The Autism-Vaccine Controversy in the British and American Elite Press. *Science Communication*, 30(1), 77-107.
- Clarke, J. N. (2012). Representations of Autism in US Magazines for Women in Comparison to the General Audience. *Journal of Children & Media*, 6(2), 182-197.  
doi:10.1080/17482798.2011.587143
- Cohen-Rottenberg, R. (2014, Feb. 15). The problem with person-first language: What's wrong with this picture? [web log post]. Retrieved from <http://thebodyisnotanapology.com/magazine/the-problem-with-person-first-language/>.
- Cook, A. (2013, Oct. 21). Stapleton wants to write book for parents of children with autism. *UpNorthLive*. Retrieved from <http://www.upnorthlive.com/news/story.aspx?id=961316#.UrauPyg5R8N>.
- Craig, R. T. (2006). Communication as a practice. In G. J. Shepherd, J. St. John & T. Striphas (Eds.), *Communication as ...: Perspectives on theory* (pp. 38-47). Thousand Oaks, CA: Sage.
- Craig, R. T. (2007[1999]). Communication theory as a field. In R. T. Craig & H. L. Muller (Eds.). *Theorizing communication: Readings across traditions*, pp. 63-98. Thousand Oaks: Sage.
- Craig, R. T., & Tracy, K. (1995). Grounded practical theory: The case of intellectual discussion. *Communication Theory*, 5, 248-272.

- Cramer Walsh, K. (2007). *Talking about race: Community dialogues and the politics of difference*. Chicago: The University of Chicago Press.
- Crimesider Staff/AP. (2014, Oct. 8). Blogger who tried to kill autistic daughter gets prison. *CBS News*. Retrieved from <http://www.cbsnews.com/news/blogger-who-tried-to-kill-autistic-daughter-gets-prison/>.
- daVanport, S. (2014). Autism and race anthology. *Indiegogo* [crowdfunding page]. Retrieved from <https://www.indiegogo.com/projects/autism-and-race-anthology>.
- Davis, L. J. (1997). Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century. In L. J. Davis (Ed.), *The disability studies reader*. New York: Routledge.
- de Villiers, J. (2011). "I saw the yellowish going south": Narrative discourse in autism spectrum disorder. *Belgian Journal of Linguistics*, 253-29.
- Dean, M., Adams, G. F., & Kasari, C. (2013). How narrative difficulties build peer rejection: A discourse analysis of a girl with autism and her female peers. *Discourse Studies*, 15(2), 147-166. doi:10.1177/1461445612471472
- @deray [deray mckesson]. (2015, Mar. 25). The burden of marginalized people is not, can never be, the moral conversion or salvation of allies. Our burdens are freedom and justice. [tweet]. Retrieved from <https://twitter.com/deray/status/580879850354794496>.
- Des Roches Rosa, S. (2011a, Sept. 13). On parents listening to self-advocates [web log post]. Retrieved from <http://www.squidalicious.com/2011/09/on-parents-listening-to-self-advocates.html>.

Des Roches Rosa, S. (2011b, Sept. 24). The self-advocate/parent dialogues: Intermission [web log post]. Retrieved from <http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues.html>.

Des Roches Rosa, S. (2011c, Aug. 5). I want to tell you a secret about autism awareness [web log post]. Retrieved from <http://www.thinkingautismguide.com/2011/08/i-want-to-tell-you-secret-about-autism.html>.

Des Roches Rosa, S. (2013, Jan. 21). Why did Amy S.F. Lutz attack the neurodiversity movement? [web log post]. Retrieved from <http://www.thinkingautismguide.com/2013/01/why-did-amy-sf-lutz-attack.html>.

Des Roches Rosa, S. (2014a, Sept. 22). An open letter to Radiolab: Stop your dangerous autism reporting [web log post]. Retrieved from <http://www.thinkingautismguide.com/2014/09/an-open-letter-to-radiolab-stop-your.html>.

Des Roches Rosa, S. (2014b, Nov. 30). Autism parents, self-advocates, and shared concerns [web log post]. Retrieved from <http://www.thinkingautismguide.com/2014/11/autism-parents-self-advocates-and.html>.

Des Roches Rosa, S. (2014c, Sept. 11). Changing conversations: When parents murder disabled children [web log post]. Retrieved from <http://www.blogger.com/changing-conversations-when-parents-murder-disabled-children>.

Diament, M. (2009, Sept. 25). Groups outraged over video released by Autism Speaks. *Disability Scoop*. Retrieved from <http://www.disabilityscoop.com/2009/09/25/autism-speaks-video/5541/>.

Disability History Project. (n.d.). Disability militancy—The 1930s. Retrieved from <http://www.disabilityhistory.org/militanc.html>.

- Dixon, G. N., & Clarke, C. E. (2013). Heightening Uncertainty Around Certain Science: Media Coverage, False Balance, and the Autism-Vaccine Controversy. *Science Communication*, 35(3), 358-382. doi:10.1177/1075547012458290
- Doctorow, C. (2013). Christmassy science fiction ebook to benefit Autism Speaks, in memory of teacher killed at Newton [web log post]. Retrieved from <http://bbs.boingboing.net/t/christmassy-science-fiction-ebook-to-benefit-autism-speaks-in-memory-of-teacher-killed-at-newton/15767/5>.
- Donaldson James, S. & Vinograd, C. (2014, Nov. 5). Jillian McCabe was “overwhelmed” before autistic son’s fatal plunge. *NBC News*. Retrieved from <http://www.nbcnews.com/health/mental-health/jillian-mccabe-was-overwhelmed-autistic-sons-fatal-plunge-n241176>.
- Donnellan, A. M., Hill, D. A., & Leary, M. R. (2010). Rethinking autism: Implications for sensory movement differences. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1060/1225>.
- Driedger, D. (1989). *The last civil rights movement: Disabled Peoples’ International*. New York: St. Martin’s Press.
- Durbin-Westby, P. C. (n.d.). Autism Speaks does not speak for me [web log post]. Retrieved from <http://paulacdurbinwestbyautisticblog.blogspot.com/p/autism-speaks-does-not-speak-for-me.html>.
- Durbin-Westby, P. C. (2011, Sept. 30). The self-advocate/parent dialogues, day ten: Paula C. Durbin-Westby [web log post]. Retrieved from <http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-ten.html>.

- Durbin-Westby, P. C. (2012a, Nov. 5). I am \*not\* a “self-advocate” [web log post]. Retrieved from <http://paulacdurbinwestbyautisticblog.blogspot.com/2012/11/i-am-not-self-advocate.html>.
- Durbin-Westby, P. C. (2012b, Dec. 25). Nonspeaking (at times) autistic makes video, version II [video]. Retrieved from <https://www.youtube.com/watch?v=dGeL8WoToCI>.
- Durbin-Westby, P. C. (2014, Sept. 13). K. Stapleton murder update—Justice for Issy [web log post]. Retrieved from <http://paulacdurbinwestbyautisticblog.blogspot.com/2014/09/kelli-stapleton-murder-update-issy.html>.
- Ellerman, M. (n.d.). Interview with Jim Sinclair. Retrieved from [http://www.autism.se/RFA/uploads/nedladningsbara%20filer/Interview\\_with\\_Jim\\_Sinclair.pdf](http://www.autism.se/RFA/uploads/nedladningsbara%20filer/Interview_with_Jim_Sinclair.pdf).
- Endow, J. (2013, Sept. 5). It is wrong to murder an autistic child [web log post] Retrieved from <http://ollibean.com/2013/09/05/wrong-murder-autistic-child/>.
- Endow, J. (2014, June 20). Is autism a disability or a difference? [web log post] Retrieved from <http://ollibean.com/2014/06/20/autism-disability-difference/>.
- Endow, J. (2015, Feb. 1). High-functioning or low-functioning? [web log post]. Retrieved from <http://ollibean.com/2015/02/01/high-functioning-or-low-functioning/>.
- Equal Rights Center. (n.d.). Two decades of protecting disability rights: The ADA turns 20. Retrieved from [www.equalrightscenter.org/site/DocServer/The\\_ADA\\_Turns\\_20.docx](http://www.equalrightscenter.org/site/DocServer/The_ADA_Turns_20.docx).
- Eyal, G., Hart, B., Onculer, E., Oren, N., & Rossi, N. (2010). *The autism matrix: The social origins of the autism epidemic*. Malden, MA: Polity Press.
- Fairclough, N. (1992). *Critical language awareness*. New York: Longman.



Fairclough, N. (2010). *Critical discourse analysis: The critical study of language* (2<sup>nd</sup> ed.). New York: Longman.

Fairclough, N. (2012). Critical discourse analysis. In J. P. Gee & M. Handford (Eds.), *The Routledge handbook of discourse analysis*, pp. 9-20. New York: Routledge.

Fairclough, N. & Wodak, R. (1997). Critical discourse analysis. In T. A. van Dijk (Ed.), *Discourse as interaction: Discourse studies: A multidisciplinary introduction, vol. 2*, pp. 258-268. Thousand Oaks: Sage.

Feld, L. (2014[2013]). Notes from the Hill [web log post]. Retrieved from

<http://www.autismspeaks.org/blog/2013/11/15/notes-hill>.

Feminist Aspie. (2015, Apr. 2). Autism acceptance 101: What's the big deal? [web log post].

Retrieved from <https://feministaspie.wordpress.com/2015/04/02/autism-acceptance-101-whats-the-big-deal/>.

@FeministAspie [Feminist Aspie]. (2015, Apr. 2). #AcceptanceIs respecting accommodations - yes, even the ones you've never heard of before and currently think are just silly and ridiculous [tweet] Retrieved from

<https://twitter.com/FeministAspie/status/583553598581297152>.

@Fifi\_flea [Felicia Styles]. (2014a, Aug. 19). Raising a child with special needs is a daily challenge. Unless you're facing this, you can't begin to understand. #KelliStapleton #DrPhil [tweet]. Retrieved from

[https://twitter.com/Fifi\\_Flea/status/501790832358207488](https://twitter.com/Fifi_Flea/status/501790832358207488).

@Fifi\_flea [Felicia Styles]. (2014b, Aug. 19). Unless you've walked a mile in another person's shoes, it's hard to understand the challenges. Have compassion! #KelliStapleton #DrPhil [tweet]. Retrieved from [https://twitter.com/Fifi\\_Flea/status/501780588844429312](https://twitter.com/Fifi_Flea/status/501780588844429312).

- @FilmSpectrum [Film Spectrum]. (2015a, Mar. 13). #FunctioningLabelsMean a harmful binary measure of how autistic someone is in a neurotypical society. [tweet] Retrieved from <https://twitter.com/FilmSpectrum/status/576466509460967424>.
- @FilmSpectrum [Film Spectrum]. (2015b, Mar. 13). #FunctioningLabelsMean we need to uselessly debate “which severity of autism is more valid?” [tweet]. Retrieved from <https://twitter.com/FilmSpectrum/status/576494729774247936>.
- @FilmSpectrum [Film Spectrum]. (2015c, Mar. 13). #LowFunctioningMeans “Pity the poor precious soul. It’s a tragedy that he turned out like that. It’s a fate worse than death.” [tweet]. Retrieved from <https://twitter.com/FilmSpectrum/status/576427851160817664>.
- Finkelstein, V. (2001). *The social model of disability repossessed*. The Disability Studies Archive U.K., Centre for Disability Studies, University of Leeds. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/finkelstein-soc-mod-repossessed.pdf>.
- Fleischer, D. Z. & Zames, F. (2001). *The disability rights movement: From charity to confrontation*. Philadelphia: Temple University Press.
- Food and Drug Administration [FDA]. (2010, July 30). FDA warns consumers of serious harm from drinking miracle mineral solution (MMS) [news release]. Retrieved from <http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm220747.htm>.
- French, S. & Swain, J. (2004). Whose tragedy? Towards a personal non-tragedy view of disability. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers—Enabling environments*, pp. 34-40. Los Angeles: Sage Publications.
- Gardiner, F. (2012, Dec. 10). Autism Speaks does not speak for autistic people. *The Tufts Daily*. Retrieved from <http://www.tuftsdaily.com/op-ed-autism-speaks-does-not-speak-for-autistic-people-1.2802262#.UrXEqiq5R8P>.

- Gardner, F. (2015, Feb. 5). Autism community's leaders make it crystal-clear: Vaccines do not cause autism. *Daily Kos*. Retrieved from <http://www.dailykos.com/story/2015/02/05/1362474/-Autism-community-s-leaders-make-it-crystal-clear-Vaccinations-do-not-cause-autism>.
- Garland-Thomson, R. (1997). *Extraordinary Bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Gee, J. P. (2011). *An introduction to discourse analysis: Theory and method* (3<sup>rd</sup> ed.). New York: Routledge.
- Gee, J. P. & Handford, M. (2012). Introduction In J. P. Gee & M. Handford (Eds.), *The Routledge handbook of discourse analysis*, pp. 1-6. New York: Routledge.
- Goffman, E. (1990[1968]). *Stigma: Notes on the management of spoiled identity*. New York: Penguin Books.
- Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability and Society*, 12(3), 367-379. DOI: 10.1080/09687599727227
- Goodley, D. (2003). Against a politics of victimization: Disability culture and self-advocates with learning difficulties. In S. Riddell & N. Watson (Eds.), *Disability, culture and identity*, pp. 105-130. New York: Routledge.
- Goodley, D. (2011). *Disability studies: An interdisciplinary introduction*. Washington D.C.: Sage.
- Goodley, D. (2014, Jul 15). How self-advocacy inspires ideas in academia [video]. Retrieved from <https://www.youtube.com/watch?v=kqgTRxBx9m0>.

- Gorski, D. (2013, June 16). The murder of autistic teen Alex Spourdalakis by his mother and caregiver: What happened? *Science-Based Medicine*. Retrieved from <http://www.sciencebasedmedicine.org/the-murder-of-autistic-teen-alex-spourdalakis-by-his-mother-and-caregiver-what-happened/>.
- Gross, Z. (2012). Metaphor stole my autism. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking*, pp. 258-276. Washington, D.C.: The Autistic Press.
- Grue, J. (2011). Discourse analysis and disability: Some topics and issues. *Discourse & Society*, 22(5), 532-546. doi:10.1177/0957926511405572
- Halliday, M. A. K. (1994). *An introduction to functional grammar* (2<sup>nd</sup> ed.). London: Edward Arnold.
- Harmon, A. (2004, May 9). Neurodiversity forever: The disability movement turns to brains. *The New York Times*. Retrieved from <http://www.nytimes.com/2004/05/09/weekinreview/neurodiversity-forever-the-disability-movement-turns-to-brains.html>.
- Harp, B. (2012). Connecting the dots. In Autistic Self Advocacy Network (Eds.), *Loud hands: Autistic people, speaking*, pp. 256-257. Washington, D.C.: The Autistic Press.
- Harris, P. & Lewan, L. (1998). *Information package on disability studies*. Syracuse, NY: Center on Human Policy.
- Hayasaki, E. (2015, Feb. 18). The debate over an autism cure turns hostile. *Newsweek*. Retrieved from <http://www.newsweek.com/2015/02/27/one-activists-search-cure-his-autism-drawing-violent-backlash-306998.html>.
- Heim, J. (2015, Mar. 13). Just asking: Ari Ne'eman, co-founder of the Autism Self Advocacy Network. *The Washington Post*. Retrieved from

[http://www.washingtonpost.com/lifestyle/magazine/just-asking-ari-neeman-co-founder-of-the-autistic-self-advocacy-network/2015/03/05/ccb87f44-b2e1-11e4-854b-a38d13486ba1\\_story.html](http://www.washingtonpost.com/lifestyle/magazine/just-asking-ari-neeman-co-founder-of-the-autistic-self-advocacy-network/2015/03/05/ccb87f44-b2e1-11e4-854b-a38d13486ba1_story.html).

Hendrickx, S. (2010). *The adolescent and adult neuro-diversity handbook: Asperger syndrome, ADHD, dyslexia, dyspraxia, and related conditions*. Philadelphia: Jessica Kingsley Publishers.

Hillary, A. (2012a, Sept. 25). The “high functioning blogger” [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2012/09/the-high-functioning-blogger.html>.

Hillary, A. (2012b, Aug. 29). Yes, self-diagnosis can be valid [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2012/08/yes-self-diagnosis-can-be-valid.html>.

Hillary, A. (2013a, Sept. 7). Dear Issy [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2013/09/dear-issy.html>.

Hillary, A. (2013b, March 5). Erased, silenced, derailed [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2013/03/erased-silenced-derailed.html>.

Hillary, A. (2013c, Mar. 16). True, but incomplete [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2013/03/true-but-incomplete.html>.

Hillary, A. (2014, Sept. 18). Acceptance vs. recovery [web log post]. Retrieved from <http://yesthattoo.blogspot.com/2014/09/acceptance-vs-recovery.html>.

Holton, A. E. (2013). What’s Wrong With Max? Parenthood and the Portrayal of Autism Spectrum Disorders. *Journal of Communication Inquiry*, 37(1), 45-63.

doi:10.1177/0196859912472507

Holton, A., Weberling, B., Clarke, C. E., & Smith, M. J. (2012). The Blame Frame: Media Attribution of Culpability About the MMR–Autism Vaccination Scare. *Health*

- Communication*, 27(7), 690-701. doi:10.1080/10410236.2011.633158
- Huckin, T. (2002). Textual silence and the discourse of homelessness. *Discourse & Society*, 13(3), 347. DOI: 10.1177/0957926502013003054
- Hughes, B. (2007). Being disabled: Towards a critical social ontology for disability studies. *Disability & Society*, 22(7), 673-684.
- Hughes, B. (2012). Civilising modernity and the ontological invalidation of disabled people. In D. Goodley, B. Hughes, & L. Davis (Eds.), *Disability and social theory: New developments and directions*, pp. 17-32. New York: Palgrave Macmillan.
- Hughes, B. & Paterson, K. (2010). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society*, 12(3), 325-340.  
<http://dx.doi.org/10.1080/09687599727209>
- Hughes, V. (2015, Feb. 23). Autistic people spark Twitter fight against Autism Speaks. *BuzzFeed News*. Retrieved from <http://www.buzzfeed.com/virginiahughes/autistic-people-spark-twitter-fight-against-autism-speaks>.
- Ianthe [Belisle Dempsey, I.] (2014). Autism acceptance month (and why Autism Speaks should stop talking) [web log post]. Retrieved from <http://ianthe.tumblr.com/post/46872544525/autism-acceptance-month-and-why-autism-peaks>.
- IMDb. (2014). Autism every day. Retrieved from <http://www.imdb.com/title/tt0923597/>.
- Independent Living USA. (n.d.). Ed Roberts: "Father of independent living." Retrieved from [http://www.ilusa.com/links/022301ed\\_roberts.htm](http://www.ilusa.com/links/022301ed_roberts.htm).
- Interacting with Autism. (n.d.). DIR/Floortime [web page]. Retrieved from <http://www.interactingwithautism.com/section/treating/floort>.

Interactive Autism Network [IAN]. (n.d.). Interactive Autism Network [web page]. Retrieved from <http://www.ianproject.org/>.

ischemgeek. (2014, Apr. 22). On functioning labels [web log post]. Retrieved from <https://ischemgeek.wordpress.com/2014/04/22/on-functioning-labels/>.

ischemgeek. (2015, Mar. 17). #HighFunctioningMeans [web log post]. Retrieved from <https://ischemgeek.wordpress.com/2015/03/17/highfunctioningmeans/>.

Jager, E. (2010, Nov. 3). Autism self-advocates: Please speak for yourselves [web log post]. Retrieved from <https://autismparents.wordpress.com/2010/11/03/autism-self-advocates-please-speak-for-yourselves/>.

Jeff. (2014, Apr. 8). Autism acceptance vs awareness [web log post]. Retrieved from <http://www.abpathfinder.com/autism-acceptance-vs-awareness/>.

Jones, A. (2013a, Oct. 2). Issy and Kelli Stapleton: Murder, suicide, and family [web log post]. Retrieved from <http://www.nopointsforstyle.com/2013/10/issy-and-kelli-stapleton-murder-suicide-and-family.html>.

Jones, S. R. (2013b). *No you don't: Essays from an unstrange mind*. Unstrange Publications.

Jones, S. R. (2014a, Oct. 7). ABA [web log post]. Retrieved from <https://unstrangemind.wordpress.com/2014/10/07/aba/>.

Jones, S. R. (2014b, June 26). Your children are listening [web log post]. Retrieved from <http://unstrangemind.wordpress.com/2014/06/26/your-children-are-listening/>.

Jones, S. R. (2015, Apr. 1). A is for acceptance [web log post]. Retrieved from <https://unstrangemind.wordpress.com/2015/04/01/a-is-for-acceptance/>.

Jorgensen, C. (2005). The least dangerous assumption. *Disability Solutions*, 6(3).

- @K1mmyR0cks [Kimberly Faith]. (2015, Mar. 9). .@RobotPete You don't disrespect your child bcuz you have feels why is that so hard to get? @Mom2Rebels @WileyAutLibrary @aintlifeswells [tweet]. Retrieved from <https://twitter.com/K1mmyR0cks/status/575126961535713281>.
- @k8lynncutie [Kate]. (2014, Sept. 16). It's sad that #KelliStapleton ha to attempt murder-suicide in order to get the help she needed. Michigan has failed her. God bless #DrPhil [tweet]. Retrieved from <https://twitter.com/k8lynncutie/status/511992500429807616>.
- Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology, 49*(1), 59-71. DOI: 10.1037/a002835
- @KatiexFowler [Katie Fowler]. (2014, Oct. 12). @tradmum Kell's BFF's still don't get that. Scary as many have ASD kids of their own! #justiceforIssy [tweet including picture of screenshot calling for "compassion and leniency for Kelli Stapleton"]. Retrieved from <https://twitter.com/KatiexFowler/status/521293032134828032>.
- Kim. (2014, Oct. 12). You don't get to speak for me, #IAmNOTKelliStapleton! [web log post]. Retrieved from <http://eccentrickimmy1.blogspot.com/2014/10/you-dont-get-to-speak-for-me.html>.
- Kim. (2015, Jan. 7). A letter from the heart of one autistic adult to an autistic child. [web log post]. Retrieved from <http://eccentrickimmy1.blogspot.com/2015/01/a-letter-from-heart-of-one-autistic.html>.
- Kim, C. (2012, Oct. 24). The angry aspie explains it all [web log]. Retrieved from <http://musingsofanaspie.com/2012/10/24/the-angry-aspie-explains-it-all/>.



- Kim, C. (2013a, June 26). Decoding the high functioning label. [web log post]. Retrieved from <http://musingsofanaspie.com/2013/06/26/decoding-the-high-functioning-label/>.
- Kim, C. (2013b, Oct. 24) The myth of passing [web log post]. Retrieved from <http://musingsofanaspie.com/2013/10/24/the-myth-of-passing/>.
- Kim, C. (2014, Apr. 30). Behavior is communication: Are you listening? [web log post]. Retrieved from <http://musingsofanaspie.com/2014/04/30/why-behavior-is-communication-is-no-longer-good-enough/>.
- Kim, C. (2015, Jan. 14). Acceptance as a well being practice [web log post]. Retrieved from <http://musingsofanaspie.com/2015/01/14/acceptance-as-a-well-being-practice/>.
- Kremer-Sadlik, T. (2004). How children with autism and Asperger Syndrome respond to questions: a 'naturalistic' theory of mind task. *Discourse Studies*, 6(2), 185-206.  
doi:10.1177/1461445604041767
- Kuppers, P. (2008). Dancing Autism: The Curious Incident of the Dog in the Nighttime and Bedlam. *Text & Performance Quarterly*, 28(1/2), 192-205.  
doi:10.1080/10462930701754465
- Langan, M. (2011). Parental voices and controversies in autism. *Disability & Society*, 26(2), 193-205. DOI: [10.1080/09687599.2011.544059](https://doi.org/10.1080/09687599.2011.544059)
- Leah Jane. (2012, Dec. 7). Masterpiece societies and puzzle pieces: An open letter to Patrick Stewart [web log post]. Retrieved from <http://quixoticautistic.wordpress.com/tag/autism-peaks/>.
- Lei. (2015, Mar. 12). What is acceptance? [web log post]. Retrieved from <https://autloveaccept.wordpress.com/2015/03/12/what-is-acceptance/>.

- Lemke, J. L. (2012). Multimedia and discourse analysis. In J. P. Gee & M. Handford (Eds.). *The Routledge handbook of discourse analysis*, pp. 79-103. New York: Routledge.
- Lester, J. N., & Paulus, T. M. (2012). Performative acts of autism. *Discourse & Society*, 23(3), 259-273. doi:10.1177/0957926511433457
- Levinas, E. (1989[1984]). Ethics as first philosophy. In S., Hand (Ed.), *The Levinas reader*. Cambridge, MA: Basil Blackwell.
- Liss, J. (2006, July 10). Autism: The art of compassionate living. *Alternet*. Retrieved from [http://www.alternet.org/story/38631/autism%3A\\_the\\_art\\_of\\_compassionate\\_living](http://www.alternet.org/story/38631/autism%3A_the_art_of_compassionate_living).
- Little, D. L. (2010). Identity, efficacy, and disability rights movement recruitment. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1013/1226>.
- Loan Trần, N. (2013a, Dec. 14). Calling in [web log post]. Retrieved from <http://www.nloantran.com/select-writings/2013/12/14/calling-in>.
- Loan Trần, N. (2013b, Dec. 13). Calling IN: A less disposable way of holding each other accountable [web log post]. Retrieved from <http://www.blackgirldangerous.org/2013/12/calling-less-disposable-way-holding-accountable/>.
- Logsdon-Breakstone, S. (2015, Feb. 27). Parents [web log post]. Retrieved from <https://crackedmirrorinshalott.wordpress.com/2015/02/27/parents/>.
- @lopear11 [PearL]. (2014, Sept. 16). #drphil #kellistapleton As usual holier than thou types judging. Murder is wrong but this woman was pushed to the brink. Compassion first [tweet]. Retrieved from <https://twitter.com/lopear11/status/511972436804665344>.
- Lutz, A. S. F. (2013, June 16). Is the neurodiversity movement misrepresenting autism? *Slate*. Retrieved from

[http://www.slate.com/articles/health\\_and\\_science/medical\\_examiner/2013/01/autism\\_neurodiversity\\_does\\_facilitated\\_communication\\_work\\_and\\_who\\_speaks.html](http://www.slate.com/articles/health_and_science/medical_examiner/2013/01/autism_neurodiversity_does_facilitated_communication_work_and_who_speaks.html)

Lutz, A. S. F. (2014, Oct. 10). Why has Kelli Stapleton polarized the autism community?

*Psychology Today*. Retrieved from

<http://www.psychologytoday.com/blog/inspectrum/201410/why-has-kelli-stapleton-polarized-the-autism-community/comments>.

Magnusson, L. (2014, Oct. 7). I am Kelli Stapleton [web log post]. Retrieved from

<http://www.lexistential.com/2014/10/i-am-kelli-stapleton/>.

Magro, K. (n.d.) About Kerry [web page]. Retrieved from <http://kerrymagro.com/about/>.

Magro, K. (2013). *Defining autism from the heart: From nonverbal to national speaker*. Self-published manuscript.

Mailick Seltzer, M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C. & Stawski,

R. S. (2011). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, 40(4), 457-469. doi:

10.1007/s10803-009-0887-0

Malhotra, R. (2001). The politics of the disability rights movement. *New Politics*, 8(3). Retrieved

from <http://nova.wpunj.edu/newpolitics/issue31/malhot31.htm>.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S. . . .

Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99(3), 493-498. doi:

10.2105/AJPH.2007.131243

Martin, J. N., & Nakayama, T. K. (1999). Thinking Dialectically About Culture and

Communication. *Communication Theory* (10503293), 9(1), 1.

- Martinez, J. M. (2008). Semiotic phenomenology and the 'dialectical approach' to intercultural communication: Paradigm crisis and the actualities of research practice. *Semiotica*, 2008(169), 135-153.
- @MattJDever [Matthew Jason Dever]. (2015, Apr. 2). #AcceptanceIs Strengths and challenges. #AutismAcceptance <http://fb.me/1Ea4qTSi3> [tweet]. Retrieved from <https://twitter.com/MattJDever/status/583668562696478721>.
- McKinley, J. C. (2014, Sept. 9). Trial to begin for a millionaire who calls her son's death "altruistic filicide." *The New York Times*. Retrieved from <http://www.nytimes.com/2014/09/10/nyregion/woman-accused-of-killing-autistic-son-to-go-on-trial.html>.
- Melissa Harris-Perry. (2014, Apr. 27). "Sounding the alarm" on autism. *MSNBC* [news segment]. Retrieved from <http://www.msnbc.com/melissa-harris-perry/watch/sounding-the-alarm-on-autism-238925379728>.
- Melody. (2014, Feb. 4). The false dichotomy—"High" and "mid-to-low" functioning [web log post]. Retrieved from <http://www.asparenting.com/the-false-dichotomy-high-and-mid-to-low-functioning/>.
- Mills, S. (2003). *Michel Foucault*. New York: Routledge.
- Mitchell, D. T. (2014) "Non-Normative Positivism: Towards a Methodology of Critical Embodiment." *Society for Disability Studies* [conference panel]. Retrieved from <http://nonnormativepositivisms.wordpress.com/>.
- Mitchell, J. (2007). Neurodiversity: Just say no [web log post]. Retrieved from <http://www.jonathans-stories.com/non-fiction/neurodiv.html>.

- Mitchell, J. (2015). Autism's gadfly [web log]. Retrieved from <http://autismgadfly.blogspot.com/>.
- Mitchell, P. (1997). The impact of self-advocacy on families. *Disability & Society*, 12(1), 43-56.  
doi: 10.1080/09687599727452
- @Mom2Rebels [Heather Clark]. (2015, Mar. 8). Hey @JasonWells72 @aintlifewells  
Humiliation is Abuse. Stop violating your child's privacy.  
[http://raisingrebelsouls.blogspot.com/2015/03/humiliation-is-abuse\\_8.html?spreftw ...](http://raisingrebelsouls.blogspot.com/2015/03/humiliation-is-abuse_8.html?spreftw...)  
[tweet]. Retrieved from <https://twitter.com/Mom2Rebels/status/574669218307817472>.
- Monje, Jr., M. S. (2013, Sept. 5). Bodies and behavior [web log post]. Retrieved from <http://www.mmonjejr.com/2013/09/bodies-and-behaviors.html>.
- Montgomery, C. (2012[2001]). Critic of the dawn. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking*, pp. 71-87. Washington, D.C.: The Autistic Press.
- Moran, R. (2014, Sept. 14). My rift with some autistic self-advocates. [web log post]. Retrieved from <http://blog.robertmoran.org/2014/09/14/my-rift-with-some-autistic-self-advocates/>.
- Murray, S. (2010). Autism functions/the function of autism. *Disability Studies Quarterly*, 30(1).  
Retrieved from <http://dsq-sds.org/article/view/1048/1229>.
- Muskie. (2002). Institute for the Study of the Neurologically Typical [web site]. Retrieved from <http://isnt.autistics.org/>.
- Myung-Ok Lee, M. (2014). Jerry Seinfeld's not helping: Celebrity autism claims distract from reality and research. *Salon*. Retrieved from [http://www.salon.com/2014/11/10/jerry\\_seinfelds\\_not\\_helping\\_celebrities\\_with\\_autism\\_distract\\_from\\_reality\\_and\\_research/](http://www.salon.com/2014/11/10/jerry_seinfelds_not_helping_celebrities_with_autism_distract_from_reality_and_research/).

Nadesan, M. H. (2005). *Constructing autism: Unraveling the “truth” and understanding the social*. New York: Routledge.

Narby, C. (2012, Feb. 24). Double rainbow: Autism and race. *Bitch Media*. Retrieved from <http://bitchmagazine.org/post/double-rainbow-autism-and-race>.

Nat. (2013, Sept. 13). Understanding the ‘spectrum’ in autistic spectrum [web log post]. Retrieved from <http://graphicexplanations.info/2013/09/13/understanding-the-spectrum-in-autistic-spectrum/>.

National Autism Research and Information Center & Autistic Self Advocacy Network. (n.d.). A curriculum for self advocates. Retrieved from [http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates\\_r4.pdf](http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates_r4.pdf).

National Council on Independent Living. (2013). About NCIL [web page]. <http://www.ncil.org/about/>.

National Symposium on Neurodiversity at Syracuse University [NSNSU]. (n.d.). What is neurodiversity? [web page]. Retrieved from <http://neurodiversitysymposium.wordpress.com/what-is-neurodiversity/>.

Ne’eman, A. (n.d.). Neurodiversity and the autistic community. Retrieved from <http://nyln.org/Clearinghouse/Documents/Neurodiversity%20and%20the%20Autistic%20Community.doc>.

Ne’eman, A. (2009, Sept. 24). Help us fight back against Autism Speaks’ attempts to speak for us! Retrieved from <http://autisticadvocacy.org/2009/09/help-us-fight-back-against-autism-speaks-attempts-to-speak-for-us/>.

- Ne'eman, A. (2010). The future (and the past) of autism advocacy, or why the ASA's magazine, *The Advocate*, wouldn't publish this piece. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1059/1244>.
- Ne'eman, A. (2011a, Sept. 21). The self-advocate/parent dialogues, day three: Ari Ne'eman [web log post]. Retrieved from <http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-three.html>
- Ne'eman, A. (2011b). Where we've been and where we're going: The evolution of the autistic self-advocacy community [speech transcript]. Retrieved from <http://www.thinkingautismguide.com/2011/08/ari-neeman-at-syracuse-university.html>, [http://www.thinkingautismguide.com/2011/08/ari-neeman-at-syracuse-university\\_26.html](http://www.thinkingautismguide.com/2011/08/ari-neeman-at-syracuse-university_26.html), <http://www.thinkingautismguide.com/2011/09/ari-neeman-at-syracuse-university.html>.
- Nelander, J. (2013, Dec. 5). Autism Speaks post rattles some readers. *Palm Beach Daily News*. Retrieved from <http://www.palmbeachdailynews.com/news/news/local/autism-speaks-post-rattles-some-readers/ncBrW/>.
- Neurodivergent K [Sibley, K.]. (2011a, Sept. 23). "Dialogue," disillusionment, disheartening [web log post]. Retrieved from <http://timetolisten.blogspot.com/2011/09/dialogue-disillusionment-disheartening.html>.
- Neurodivergent K [Sibley, K.]. (2011b, Apr. 11) "What would meeting you halfway be?" [web log post]. Retrieved from <http://timetolisten.blogspot.com/2011/04/what-would-meeting-you-halfway-be.html>.

Neurodivergent K [Sibley, K.]. (2012, Aug. 9). There is blood on your hands [web log post].

Retrieved from <http://timetolisten.blogspot.com/2012/08/there-is-blood-on-your-hands.html>.

Neurodivergent K [Sibley, K.]. (2013a, Sept. 6). I could have been Issy Stapleton [web log post].

Retrieved from <http://timetolisten.blogspot.com.au/2013/09/i-could-have-been-issy-stapleton.html>.

Neurodivergent K [Sibley, K.]. (2013b, June 25). So what is this? [web log post]. Retrieved from

<http://wearelikeyourchild.blogspot.com/2013/06/so-what-is-this.html>.

Neurodivergent K [Sibley, K.]. (2014, May 28). You, yes you, need Autistic friends [web log post]. Retrieved from [http://timetolisten.blogspot.com/2014/05/you-yes-you-need-](http://timetolisten.blogspot.com/2014/05/you-yes-you-need-autistic-friends.html)

[autistic-friends.html](http://timetolisten.blogspot.com/2014/05/you-yes-you-need-autistic-friends.html).

@nicocoer [Savannah LBreakstone]. (2015, Feb. 21). You've pitted our parents against us- I want parents supporting us not taking our fight against ableism personally!

#autismspeaks10 [tweet]. Retrieved from

<https://twitter.com/nicocoer/status/569319664574210048>.

Not Dead Yet. (2013). Who we are [web page]. Retrieved from

<http://www.notdeadyet.org/about>.

@NuttyNaturalist [The Nutty Naturalist]. (2015, Apr. 2). #AcceptanceIs realising that reading body language is of supreme importance in communicating with us. Use your eyes, not

just your mouth! [tweet]. Retrieved from

<https://twitter.com/NuttyNaturalist/status/583531461774540800>.

Oliver, M. (1996). *Understanding disability: From theory to practice*. New York: St. Martin's Press.



- Onaiwu, M. (2014a, Sept. 8). Guest Post: Morénike Onaiwu on why the autistic PoC anthology is important [web log]. Retrieved from <https://crackedmirrorinshalott.wordpress.com/2014/09/08/guest-post-morenike-onaiwu-on-why-the-autistic-poc-anthology-is-important/>.
- Onaiwu, M. (2014b, Oct. 16). “Who really cares about all this?” I do [web log post]. Retrieved from <http://iamnotkellistapletonflashblog.blogspot.com/2014/10/who-really-cares-about-all-this-i-do.html?spref=tw>.
- Osteen, M. (Ed.). (2008a). *Autism and representation*. New York: Routledge.
- Osteen, M. (2008b). Conclusion: Toward an empathetic scholarship. In M. Osteen (Ed.), *Autism and representation*, pp. 297-302. New York: Routledge.
- Padawer, R. (2014, July 31). The kids who beat autism. *The New York Times*. Retrieved from <http://nyti.ms/1zypbdQ>.
- Parenting Autistic Children with Love & Acceptance [PACLA]. (2015a). About PACLA [web page]. Retrieved from <https://autloveaccept.wordpress.com/about/>.
- Parenting Autistic Children with Love & Acceptance [PACLA]. (2015b, Mar. 9). There is a huge double standard when it comes to how we talk about Autistic people. When we refuse to judge parents who harm their children emotionally, yet harshly judge Autistic people who speak out against this type of treatment, what exactly are we telling [Facebook status update]. Retrieved from <https://www.facebook.com/ParentingAutisticChildrenWithLoveAcceptance/photos/a.558548997516317.1073741831.540203919350825/798621663509048/?type=1>.
- Parenting Autistic Children with Love & Acceptance [PACLA]. (2015c). For our community members: old and new. A reminder that we do not allow the use of functioning labels in

this space. Posts using them to describe people will be deleted. If you still have questions after reading these links, please feel free to ask them [Facebook status update]. Retrieved from

<https://www.facebook.com/ParentingAutisticChildrenWithLoveAcceptance/posts/812252765479271>.

Park, M. M. (2010). Beyond calculus: Apple-apple-apple-ide and other embodied pleasures for a child diagnosed with autism in a sensory integration based clinic. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1066/1232>.

Parker, S. (2015, Mar. 21). Amy Sequenzia: Non-speaking autistic speaking [web log post]. Retrieved from <http://sydscarnivalofsouls.com/2015/03/21/amy-sequenzia-non-speaking-autistic-speaking/>.

@PatTrudeau [Pat Trudeau]. (2015, Mar. 11). I've been pretty out of the Twitter loop lately but if you have anything other than support for @aintlifewells & @JasonWells72, fuck off. [tweet]. Retrieved from <https://twitter.com/PatTrudeau/status/575790736135819264>.

Pennington, C. (Executive Producer). (2014a). Exclusive: Kelli Stapleton: A mother's worst nightmare. *Dr. Phil* [talk show promo]. Los Angeles: CBS.

Pennington, C. (Executive Producer). (2014b). Exclusive: The mother who attempted to kill her autistic daughter. *Dr. Phil* [talk show promo]. Los Angeles: CBS.

People First Spokane Valley. (2005). "People First History." *People First of Spokane Washington*. Retrieved from [http://www.peoplefirstsv.com/people\\_first\\_history.htm](http://www.peoplefirstsv.com/people_first_history.htm).

People First West Virginia. (2015). History of People First [web page]. Retrieved from <http://www.thearcofwv.org/people-first/about/history.html>.

Peteski Productions, Inc. (2014). About Dr. Phil. *Dr. Phil* [web page]. Retrieved from <http://www.drphil.com/shows/page/bio/>.

@pgzwicker [Patricia]. (2015, Apr. 2). #AcceptanceIs understanding #No, #Icant, #leavemealone, #DontTouchMe, are complete sentences. #RespectThem #ActuallyAutistic [tweet]. Retrieved from <https://twitter.com/pgzwicker/status/583500286632787968>.

Picciuto, E. (2014). The mommy blogger who tried to kill her autistic daughter talks to Dr. Phil. *The Daily Beast*. Retrieved from <http://www.thedailybeast.com/articles/2014/10/01/the-mommy-blogger-who-tried-to-kill-her-autistic-daughter-talks-to-dr-phil.html>.

Pinchevski, A. (2005). *By way of interruption: Levinas and the ethics of communication*. Pittsburgh: Duquesne University Press.

@PixelPusher83 [Pixel Pusher]. (2015, Mar. 20). #HighFunctioningMeans that if I've been given this label to elevate me there is someone who has had the opposite and has been devalued. [tweet]. Retrieved from <https://twitter.com/PixelPusher83/status/579122333446713344>.

Pollak, D. (Ed.). (2009). *Neurodiversity in higher education: Positive responses to specific learning differences*. Malden, MA: Wiley-Blackwell.

Prince, D. (2010). Cultural commentary: The silence between: An autoethnographic examination of the language prejudice and its impact on the assessment of autistic and animal intelligence. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1055/1242>.

@Privetine [Sarah Akin]. (2015a, Apr. 2). #AutismIs sensory joy & intellectual vibrancy. But without respect/acceptance, it's near constant shame, secrecy, & fear. #WalkInRed

#WAAD [tweet]. Retrieved from

<https://twitter.com/Privetine/status/583622730349727745>.

@Privetine [Sarah Akin]. (2015b, Mar. 15). #HighFunctioningMeans “No, I didn’t say YOU were a soulless burden.” #LowFunctioningMeans \*taps mic\* “You’re a soulless burden. Yes, you.” [tweet]. Retrieved from

<https://twitter.com/Privetine/status/577182170147659776>.

PTBOCanada. (2015, Mar. 7). Peterborough couple live tweet a severe meltdown from their autistic child. *PTBO Canada*. Retrieved from

<http://www.ptbocanada.com/journal/2015/3/7/peterborough-couple-live-tweet-a-severe-meltdown-from-their-autistic-child>.

Quinn, R. (2014, Nov. 5). Accused killer mom wrote son was stolen from her. *Newser*. Retrieved from <http://www.newser.com/story/198208/accused-killer-mom-autism-is-a-thief.html>.

Real Social Skills. (2014, Aug. 29). You don’t have to like being disabled [web log post].

Retrieved from <http://realsocialskills.org/post/96093019502/you-dont-have-to-like-being-disabled>.

Respectfully Connected. (2015). What is ‘respectfully connected’ about? [web page]. Retrieved from <http://respectfullyconnected.blogspot.com/p/what-is-respectfully-connected.html>.

@retiredwaif [Hala]. (2015, Mar. 17). #functioninglabelsmean harmful divisions in our community. Participating in our own oppression. #HighFunctioningMeans #LowFunctioningMeans [tweet]. Retrieved from

<https://twitter.com/retiredwaif/status/577792028232294400>.

Roberts, E. (n.d.). Highlights from speeches by Ed Roberts. *World Institute on Disability*.

Retrieved from <http://www.wid.org/about-wid/highlights-from-speeches-by-ed-roberts>.

Roberts, J. (2011, Oct. 12). The silo effect with parents and self advocates [web log post].

Retrieved from <http://supportforspecialneeds.com/2011/10/12/the-silo-effect-with-parents-and-self-advocates/>.

Robinson, D. (2014, Jan. 10). Aspies and race [video]. Retrieved from

[https://www.youtube.com/watch?v=Aga8Yem\\_21w&feature=youtu.be](https://www.youtube.com/watch?v=Aga8Yem_21w&feature=youtu.be).

Robison, J. E. (2007). *Look me in the eye: My life with Asperger's*. New York: Three Rivers Press.

Robison, J. E. (2009, Feb. 28). The myth of the black Aspergian [web log post] Retrieved from

<http://jrobison.blogspot.com/2009/02/myth-of-black-aspergian.html>.

Robison, J. E. (2013a). About John Elder Robison. *JohnRobison.com* [web page]. Retrieved

from <http://www.johnrobison.com/about-john.php>.

Robison, J. E. (2013b). I resign my role at Autism Speaks. [blog post]. Retrieved from

<http://jrobison.blogspot.com/2013/11/i-resign-my-roles-at-autism-speaks.html>.

Robison, J. E. (2013c, Oct. 8). What is neurodiversity? [web log post]. Retrieved from

<http://www.autismspeaks.org/blog/2013/10/08/what-neurodiversity>.

Rosin, H. (2014, Oct. 19). Kelli Stapleton can't forgive herself for trying to kill her violent, autistic daughter. Can you? *New York Magazine*. Retrieved from

<http://nymag.com/daily/intelligencer/2014/10/kelli-stapleton-issy-stapleton.html>.

@rsocialskills [Real Social Skills]. (2015a, Apr. 2). #AcceptanceIs seeing autism as part of who someone is, not all of who someone is [tweet]. Retrieved from

<https://twitter.com/rsocialskills/status/583497131786379264>.

@rsocialskills [Real Social Skills]. (2015b, Apr. 2). #AcceptanceIs seeking out ways to listen to autistic people who live in group homes and aren't allowed to use the internet [tweet].

Retrieved from <https://twitter.com/rsocialskills/status/583519706813960192>.

@rsocialskills [Real Social Skills]. (2015c, Apr. 2). #AcceptanceIs speaking openly about the aspects of autism that can suck, and still being seen as a full human being with a worthwhile life [tweet]. Retrieved from

<https://twitter.com/rsocialskills/status/583495335055601664>.

@rsocialskills [Real Social Skills]. (2015d, Apr. 2). #AutismIs having intense interests. Taking joy in them. Having your interests carry you when others treat you like you're not a person. [tweet]. Retrieved from

<https://twitter.com/rsocialskills/status/583608455199592448>.

Rubin, S. M. (2014). About me [web page]. Retrieved from <http://sue-rubin.org/about-me/>.

Rummel-Hudson, R. (2011a, Aug. 9). Just a word: The Change-Up edition [web log post].

Retrieved from <http://www.schuylersmonsterblog.com/2011/08/just-word-change-up-edition.html>.

Rummel-Hudson, R. (2011b, Sept. 20). The self-advocate/parent dialogues, day two: Robert Rummel-Hudson [web log post]. Retrieved from

<http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-two.html>.

Russo, J. (2014, Oct. 12). Hysterical Paroxysms: I am NOT Kelli Stapleton [web log post].

Retrieved from <http://iamnotkellistapletonflashblog.blogspot.com/2014/10/hysterical-paroxysms-i-am-not-kelli.html>.

- Ryan, B. (2013a, Jan. 30). The cost of compliance is unreasonable [web log post]. Retrieved from <http://loveexplosions.net/2013/01/30/the-cost-of-compliance-is-unreasonable/>.
- Ryan, B. (2013b, Dec. 4). Why? Why? Why? [web log post]. Retrieved from <http://loveexplosions.net/2013/12/04/why-why-why/>.
- Ryan, B. (2014a, Oct. 31). Oops they did it again: Autism Speaks' 2013 financials just released [web log post]. Retrieved from <http://loveexplosions.net/2014/10/31/oops-they-did-it-again-autism-speaks-2013-financials-just-released/>.
- Ryan, B. (2014b, Nov. 10). Owning it [web log post]. Retrieved from <http://loveexplosions.net/2014/11/10/owning-it/>.
- S., K. [Sibley, K.]. (2012, Apr. 4). Acceptance vs. awareness [web log post]. Retrieved from <http://autisticadvocacy.org/2012/04/acceptance-vs-awareness/>.
- Sacks, H. (1992). *Lectures on conversation: Vol. 1*. Cambridge, MA: Blackwell Publishers.
- Salas, R. (2012). Awareness to acceptance: It's a process [web log post]. Retrieved from <http://www.goldenhatfoundation.org/about-us/blog/162-awareness-to-acceptance-its-a-process>.
- Salas, S. R. (2015a, Jan. 31). On being a mom|2015 Day of Mourning #DDOM2015 [web log post]. Retrieved from <http://srsalas.com/on-being-a-mom-2015-day-of-mourning-ddom2015/>.
- Salas, S. R. (2015b, Mar. 1). Why acceptance is so damned hard [web log post]. Retrieved from
- Savarese, D. J. (2010). Cultural commentary: Communicate with me. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1051/1237>.

- Savarese, E. T. & Savarese, R. J. (2010). "The superior half of speaking:" An introduction. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1062/1230>.
- Schaber, A. (2013, Nov. 8). Active acceptance: Why does it matter? [web log post]. Retrieved from <http://neurowonderful.tumblr.com/post/66386003279/whydoesitmatter>.
- Schaber, A. (2014a, Apr. 3). What about functioning labels? [video]. Retrieved from <https://www.youtube.com/watch?v=RLJXqlOPZ5U>.
- Schaber, A. (2014b, July 3). What are autistic meltdowns? [video]. Retrieved from <https://www.youtube.com/watch?v=FhUDyarczqXE>.
- Schaber, A. (2014c, Aug. 28). What is neurodiversity? [video]. Retrieved from [https://www.youtube.com/watch?v=H6xl\\_yJKWVU](https://www.youtube.com/watch?v=H6xl_yJKWVU).
- Schaber, A. (2014d, Jan. 30). What is passing? Or, should I stop my child from stimming? [video]. Retrieved from <https://www.youtube.com/watch?v=EsH1fX4MM60>.
- Scollon, S. W. & de Saint-Georges, I. (2012). Mediated discourse analysis. In J. P. Gee & M. Handford (Eds.). *The Routledge handbook of discourse analysis*, pp. 66-78. New York: Routledge.
- Self Advocates Becoming Empowered [SABE]. (n.d.a). Forward. In National Autism Research and Information Center & Autistic Self Advocacy Network, A curriculum for self advocates, pp. 3-4. Retrieved from [http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates\\_r4.pdf](http://www.nyln.org/wp-content/uploads/2010/10/CurriculumForSelfAdvocates_r4.pdf).
- Self Advocates Becoming Empowered [SABE]. (n.d.b). [YouTube channel]. Retrieved from <https://www.youtube.com/channel/UCBxZhc5AWPUNA3ufQy5JzpQ>.



- Senator, S. (2012, Jan. 2). The parents vs. the autistics [web log post]. Retrieved from <http://susansenator.com/blog/2012/01/the-parents-vs-the-autistics/>.
- Sequenzia, A. (2012a, Sept. 3). It's not hate [web log post]. Retrieved from <http://autismwomensnetwork.org/its-not-hate/>.
- Sequenzia, A. (2012a, Jan. 11). Non-speaking, "low-functioning" [web log post]. *Shift: Journal of Alternatives: Neurodiversity and social change*. Retrieved from <http://lynesoraya.sharedby.co/share/EgJ1XD>.
- Sequenzia, A. (2013a, Sept. 9). Dear Issy [web log post]. Retrieved from <http://ollibean.com/2013/09/09/dear-issy/>.
- Sequenzia, A. (2013b, Sept. 13). More problems with functioning labels [web log post]. Retrieved from <http://ollibean.com/2013/09/26/problems-functioning-labels/>.
- Sequenzia, A. (2013c, Dec. 6). To the corporate sponsors of Autism Speaks [web log post]. Retrieved from <https://boycottautismspeaks.wordpress.com/2013/12/06/to-the-corporate-supporters-of-autism-speaks-by-amy-sequenzia/>.
- Sequenzia, A. (2013d, Aug. 17). What is independence anyway? [web log post]. Retrieved from <http://wearelikeyourchild.blogspot.com/2013/08/what-is-independence-anyway.html>.
- Sequenzia, A. (2014a, Sept. 14). Attitudes—Grading people [web log post]. Retrieved from <http://ollibean.com/2014/09/14/attitudes-grading-people/>.
- Sequenzia, A. (2014b, Aug. 19). Is Autism Speaks a hate group? [web log post]. Retrieved from <http://autismwomensnetwork.org/is-autism-speaks-a-hate-group/>.
- Sequenzia, A. (2014c, Nov. 11). "Please don't murder us" shouldn't be controversial [web log post]. Retrieved from <http://autismwomensnetwork.org/please-dont-murder-us-shouldnt-be-controversial/>.

Sequenzia, A. (2014d, Nov. 4). Why I don't like "awareness" [web log post]. Retrieved from <http://ollibean.com/2014/11/05/why-i-dont-like-awareness/>.

Sequenzia, A. (2015, Apr. 2). I don't want your awareness [web log post]. Retrieved from <http://ollibean.com/2015/04/02/i-dont-want-your-awareness/>.

Sevarese, E. T., Baggs, A., Burke, J., Kochmeister, S., Rubin, S., Schwarz, P., Shore, S., Sibley, K., & Thresher, T. (2010). Self-advocate roundtable with members of AutCom. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1073/1239>.

Shakespeare, T. (2006). *Disability rights and wrongs*. New York: Routledge.

Shakespeare, T. & Watson, N. (2001). Making the difference: Disability, politics, and recognition. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies*, pp. 546-564. Thousand Oaks: Sage.

Shaw, A. (n.d.). 5 years after my son's autism diagnosis, I realized something [web log post].

Retrieved from <http://themighty.com/2014/10/5-years-after-my-sons-autism-diagnosis-i-realized-something/>.

Shildrick, M. (2009). *Dangerous discourses of disability, subjectivity and sexuality*. New York: Palgrave Macmillan.

Shi-xu. (2007). Discourse studies and cultural politics: An introduction. In Shi-xu (Ed.), *Discourse as cultural struggle*, pp. 3-16. Hong Kong: Hong Kong University Press.

Siebers, T. (2011). *Disability theory*. Ann Arbor: University of Michigan Press.

Silberman, S. (2010). Exclusive: First autistic presidential appointee speaks out. *Wired*.

Retrieved from <http://www.wired.com/2010/10/exclusive-ari-neeman-qa/>.

- Silberman, S. (2012). Autism awareness is not enough: Here's how to change the world. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking*, pp. 358-386. Washington, D.C.: The Autistic Press.
- Silberman, S. (2013, Apr. 16). Neurodiversity rewires conventional thinking about brains. *Wired Magazine*. Retrieved from <http://www.wired.com/2013/04/neurodiversity/>.
- Sinclair, J. (1993). Don't mourn for us. *Our Voice*, 1(3).
- Sinclair, J. (2005). Autism Network International: The development of a community and its culture. Retrieved from [http://www.autreat.com/History\\_of\\_ANI.html](http://www.autreat.com/History_of_ANI.html).
- Singer, A. (2009, Sept. 9). Speaking out about "Autism every day" [web log post]. Retrieved from <https://autismsciencefoundation.wordpress.com/2009/09/09/speaking-out-about-autism-every-day/>.
- Singer, J. (2002[1999]). 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference. In M. Corker & S. French (Eds.), *Disability discourse*, pp. 59-67. Philadelphia: Open University Press.
- Sirota, K. G. (2004). Positive politeness as discourse process: politeness practices of high-functioning children with autism and Asperger Syndrome. *Discourse Studies*, 6(2), 229-251. doi:10.1177/1461445604041769
- smith, s. e. (2014, Jan. 8). Can't communicate, or won't communicate the way you want to? [web log post]. Retrieved from [http://meloukhia.net/2014/01/cant\\_communicate\\_or\\_wont\\_communicate\\_the\\_way\\_you\\_want\\_to/](http://meloukhia.net/2014/01/cant_communicate_or_wont_communicate_the_way_you_want_to/).
- Snow, K. (2007). Presume competence: Challenging conventional wisdom about people with disabilities. Retrieved from <http://a2zedad.com/People-with-Disabilities.html>.

- Snyder, S. L. & Mitchell, D. T. (2006). *Cultural locations of disability*. Chicago: The University of Chicago Press.
- Solomon, O. (2004). Narrative introductions: discourse competence of children with autistic spectrum disorders. *Discourse Studies*, 6(2), 253-276. doi:10.1177/1461445604041770
- Sontag, S. (1989[1977, 1988]). *Illness as metaphor and AIDS and its metaphors*. New York: Picador.
- Sophie's Trains. (2015, Feb. 19). Don't say rainbows [web log post]. Retrieved from <http://respectfullyconnected.blogspot.com/2015/02/don-say-rainbows.html>.
- Soraya, L. (2013, Mar. 17). New research on autism and suicide. *Psychology Today*. Retrieved from <https://www.psychologytoday.com/blog/aspergers-diary/201303/new-research-autism-and-suicide>.
- Soraya, L. (2015, Mar. 23). Shopping while autistic: The sensory experience of a shopping trip. *Psychology Today*. Retrieved from <https://www.psychologytoday.com/blog/aspergers-diary/201503/shopping-while-autistic>.
- SpacerobotStudio. (n.d.). Communication necklace – Autism – Interaction and overload – Silver rolo chain. Retrieved from <https://www.etsy.com/listing/214307442/communication-necklace-autism?ref=related-3>.
- Stapleton, K. (2013a, Apr. 5). Autism's hard to love club [web log post]. Retrieved from <http://thestatuswoe.wordpress.com/2013/04/05/hardtloveclub/>.
- Stapleton, K. (2013b, Feb. 5). Dancing on the edge [web log post]. Retrieved from <http://thestatuswoe.wordpress.com/2013/02/05/315/>.
- Stapleton, M. (2013, Sept. 8). Family, friends, and anyone who has sent prayers, I wanted to share this update on the progress of my daughter Isabelle. So many of you have followed

- her progress and have sent positive thoughts and prayers to her with the [Facebook status update]. Retrieved from [https://www.facebook.com/TeamIssy/timeline?ref=page\\_internal](https://www.facebook.com/TeamIssy/timeline?ref=page_internal) (Facebook account deleted; link no longer functional).
- Stephan, L. (2013, Feb. 7). Benzie County mom goes public with her struggle to help a violent daughter. *Interlochen Public Radio*. Retrieved from <http://interlochenpublicradio.org/post/benzie-county-mom-goes-public-her-struggle-help-violent-daughter>.
- Sterponi, L. (2004). Construction of rules, accountability and moral identity by high-functioning children with autism. *Discourse Studies*, 6(2), 207-228. doi:10.1177/1461445604041768
- Stevenson, S. (2008). (M)Othering and autism: Maternal rhetorics of self-revision. In M. Osteen (Ed.), *Autism and representation*, pp. 197-211. New York: Routledge.
- Sullivan, F. (2013, Dec. 30). Boycott the Thinking Person's Guide to Autism [web log post]. Retrieved from <https://theconnorchronicles.wordpress.com/2013/12/30/boycott-the-thinking-persons-guide-to-autism/>.
- Suszynski, M. (2010, Jan. 12). Autism: Accepting the diagnosis. *Everyday Health*. Retrieved from <http://www.everydayhealth.com/autism/accepting-diagnosis.aspx>.
- Sutton, M. (2014, June 9). Sesame Street partners with Autism Speaks: Why are autistic people upset? *Huffington Post* [web log post]. Retrieved from [http://www.huffingtonpost.com/michelle-sutton/sesame-street-partners-wi b\\_5466917.html](http://www.huffingtonpost.com/michelle-sutton/sesame-street-partners-wi b_5466917.html).
- Sutton, M. (2015, Mar. 18). The autism community and the Autistic community [web log post]. Retrieved from <http://amazingadventuresautism.blogspot.com.au/2015/03/the-autism-community-and-autistic.html>.

Swain, J. & Cameron, C. (2002). Unless otherwise stated: Discourses of labeling and identity in coming out. In B. Corker & S. French (Eds.), *Disability discourse*, pp. 68-78.

Philadelphia: Open University Press.

Synapse. (n.d.). My child's been diagnosed as having autism—What do I do now? [web page].

Retrieved from <http://www.autism-help.org/child-diagnosed-autism.htm>.

Syracuse University School of Education. (2015). Institute on communication and inclusion.

*Syracuse University School of Education* [web page]. Retrieved from

[http://soe.syr.edu/centers\\_institutes/institute\\_communication\\_inclusion/default.aspx/schoolsofpromise/](http://soe.syr.edu/centers_institutes/institute_communication_inclusion/default.aspx/schoolsofpromise/).

Tardistic. (2015, Mar. 19). Balancing acts [web log post]. Retrieved from

<https://tardistic.wordpress.com/2015/03/19/balancing-acts/>.

Tate, R. (2014, Oct. 19). What's the difference between high-functioning and low-functioning autism? [web log post]. Retrieved from <http://autismwomensnetwork.org/whats-the-difference-between-high-functioning-and-low-functioning-autism/>.

<http://autismwomensnetwork.org/whats-the-difference-between-high-functioning-and-low-functioning-autism/>.

@TealBassoon [Megan]. (2015, Apr. 2). #AcceptanceIs hubby signing with me on really difficult/nonverbal days. [tweet]. Retrieved from

<https://twitter.com/TealBassoon/status/583467714846425088>.

@Teresa\_Fraylick [Tere]. (2014, Aug. 19). I am unqualified to judge this woman's decision

when she was at her wit's end. I have never walked in her shoes. #KelliStapleton #DrPhil

[tweet]. Retrieved from [https://twitter.com/Teresa\\_Fraylick/status/501775939249111040](https://twitter.com/Teresa_Fraylick/status/501775939249111040).

thatfeministdyke. (2012). TW: Murder, ableism, Autism \$peaks [web log post]. Retrieved from

<http://thatfeministdyke.tumblr.com/post/20423632676/tw-murder-ableism-autism-peaks-i-don't>.

@thestatuswoe [Kelli Stapleton] (2013, June 9). 6 moms meeting for the first time on 2/28. Autism has become a deadly condition for all of us. Extreme behaviors.

@peoplemag Share our story? [tweet]. Retrieved from

<https://twitter.com/thestatuswoe/status/343765704950022146>.

The Caffeinated Aspie. (2013, Mar. 2). Autistic people are . . . [web log post]. Retrieved from

<http://autisticpeopleare.blogspot.com/2013/03/the-caffeinated-aspie-autistic-people.html>.

The Unpuzzled Project. (2014, Jan. 16). F\*%\$ your functioning labels [web log post]. Retrieved

from <https://theunpuzzledproject.wordpress.com/2014/01/16/f-your-functioning-labels/>.

@thinkingautism [TP Guide to Autism]. (2015, Apr. 2). #AcceptanceIs understanding that my

#ActuallyAutistic son repeats phrases to comfort and reassure himself. Not to annoy

anyone. [tweet]. Retrieved from

<https://twitter.com/thinkingautism/status/583756415409397761>.

Thinking Person's Guide to Autism [TPGA]. (n.d.). Mission [web page]. Retrieved from

<http://www.thinkingautismguide.com/p/mission-statement.html>.

Thinking Person's Guide to Autism [TPGA]. (2011, Sept. 19). Introduction to the self-

advocate/parent dialogues [web log post]. Retrieved from

<http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day->

[one.html](http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-one.html).

Thinking Person's Guide to Autism [TPGA]. (2013). CBS News: Take down the video Behind

the tragedy: Mother murders autistic son [petition]. Retrieved from

<https://www.change.org/petitions/cbs-news-take-down-the-video-behind-the-tragedy->

[mother-murders-autistic-son-2](https://www.change.org/petitions/cbs-news-take-down-the-video-behind-the-tragedy-mother-murders-autistic-son-2).

Thinking Person's Guide to Autism [TPGA]. (2014, Nov. 4). How ASAN helped Issy Stapleton get justice [web log post]. Retrieved from

<http://www.thinkingautismguide.com/2014/11/how-asan-helped-issy-stapleton-get.html>.

Thomas, C. (2004). Disability and impairment. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers—Enabling environments*, pp. 21-27. Los Angeles: Sage Publications.

Tracy, K. (2005). Reconstructing communicate practices: Action-implicative discourse analysis. In K. L. Fitch & R. E. Sanders (Eds.). *Handbook of language and social interaction*. Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.

Tracy, K., Martínez- Guillem, S., Robles, J. S., & Casteline, K. E. (2011). Critical Discourse Analysis and (U.S.) Communication Scholarship. *Communication Yearbook*, 35, 241-286.

@TrishTorz [Trish Torz]. (2015, Mar. 25). Pay more attention and be mindful!

#autismawareness [tweet]. Retrieved from

<https://twitter.com/TrishTorz/status/580801066234736640>.

Tsouderos, T. (2010, Oct. 14). FDA cracks down on autism treatment. *Chicago Tribune*.

Retrieved from [http://articles.chicagotribune.com/2010-10-14/health/ct-met-fda-autism-chelation-20101014\\_1\\_chelators-autism-treatment-metal-poisoning](http://articles.chicagotribune.com/2010-10-14/health/ct-met-fda-autism-chelation-20101014_1_chelators-autism-treatment-metal-poisoning).

tuttleturtle42. (2014, Feb. 27). I am not a burden (Day of mourning 2014) [web log post].

Retrieved from <http://turtlesaverb.blogspot.com/2014/02/i-am-not-burden-day-of-mourning-2014.html>.



@tykat22 [Ty McSandry]. (2015, Mar. 17). #HighFunctioningMeans no one believes me when I tell them I have autism. They think I can just get over mental & social issues. [tweet].

Retrieved from <https://twitter.com/tykat22/status/578005156639342592>.

United Nations. (2012). Conventions on the rights of persons with disabilities. Retrieved from <http://www.un.org/disabilities/default.asp?id=150>.

United Nations Educational, Scientific, and Cultural Organization [UNESCO]. (2012, Feb. 24).

Douglas Biklen: "Begin by presuming competence." *Media services*. Retrieved from

[http://www.unesco.org/new/en/media-services/single-view/news/douglas\\_biklen\\_winner\\_of\\_unesco\\_kuwait\\_prize\\_begin\\_by\\_presuming\\_competence/#.VTAvTJTF--o](http://www.unesco.org/new/en/media-services/single-view/news/douglas_biklen_winner_of_unesco_kuwait_prize_begin_by_presuming_competence/#.VTAvTJTF--o).

Unumb, L. (2014). On the road to autism insurance reform—NC stories—The Robinsons [web log

post]. Retrieved from <http://www.autismspeaks.org/blog/2014/06/30/road-autism-insurance-reform---nc-stories---robinsons>.

U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth, and Families, & Children's Bureau. (2013). *Child maltreatment 2012*. Retrieved from

<http://www.acf.hhs.gov/sites/default/files/cb/cm2012.pdf#page=56>.

U.S. Food and Drug Administration. (2010, July 30). FDA warns consumers of serious harm from drinking Miracle Mineral Solution (MMS). *FDA.gov*. Retrieved from

<http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm220747.htm>.

@UVGKassi [Kassiane]. (2015, Mar. 7). @WileyAutLibrary @Berdena @AutismHWY

@aintlifewells Judgement is the ONLY appropriate way to respond to parents who

- humiliate their kids. [tweet]. Retrieved from <https://twitter.com/UVGKassi/status/574422725810253824>.
- van Dijk, T. A. (n.d.). Discourse in society. Retrieved from <http://www.discourses.org/>.
- van Dijk, T. A. (2008). *Discourse and context: A sociocognitive approach*. Cambridge: Cambridge University Press.
- van Dijk, T. A. (2009a). Critical discourse studies: A sociocognitive approach. In R. Wodak & M. Meyer (Eds.), *Methods of critical discourse analysis*, pp. 62-86. Thousand Oaks: Sage.
- van Dijk, T. A. (2009b, May 1). Project on critical discourse studies [web page]. Retrieved from <http://www.discourses.org/projects/cda/>.
- Vinograd, C. & Connor, T. (2014, Nov. 4). Jillian McCabe accused of throwing autistic son off Oregon bridge. *NBC News*. Retrieved from <http://www.nbcnews.com/news/us-news/jillian-mccabe-accused-throwing-autistic-son-oregon-bridge-n240606>.
- Walker, N. (2014a, Apr. 22). Autism acceptance month 2014: Nick Walker [web log post]. Retrieved from <http://www.thinkingautismguide.com/2014/04/autism-acceptance-month-2014-nick-walker.html>.
- Walker, N. (2014b, Sept. 27). Neurodiversity: Some basic terms and definitions [web log post]. Retrieved from <http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/>.
- Wallis, C. (2009, Nov. 6). "I am autism." An advocacy video sparks protest. *Time Magazine*. Retrieved from <http://content.time.com/time/health/article/0,8599,1935959,00.html>.

- Walsh, M. (2013, Sept. 7). Michigan mom tries to kill self, autistic teen in murder-suicide try: Cops. *Daily News*. Retrieved from <http://www.nydailynews.com/news/crime/michigan-mom-kill-autistic-teen-daughter-cops-article-1.1448694>.
- Waltz, M. (2008). Autism = death: The social and medical impact of a catastrophic model of autism spectrum disorders. *Popular Narrative Media* 1(1), 13-24.
- Wells, K. & Wells, J. (2015). #autismparents live tweet meltdown. Storify by J. M. F. Hughes. Retrieved from <https://storify.com/garlictoastbrot/couple-live-tweets-meltdown>.
- Wendell, S. (1997). Toward a feminist theory of disability. In L. J. Davis, *The disability studies reader*, pp. 260-278. New York: Routledge.
- White, B. (2014, June 30). Intellectual disability and self-regulation: Jason's list [web log post]. Retrieved from <http://alacosta-acat.org/2014/06/30/intellectual-disability-and-self-regulation-jasons-list/>.
- @WileyAutLibrary [Lei Wiley-Mydske]. (2014, Oct. 20). /@HannaRosin Even now, she is using her daughter for cheap martyr mom points and her murder apologist supporters are eating it up. #Ableism [tweet]. Retrieved from <https://twitter.com/WileyAutLibrary/status/524253204272648192>.
- @WileyAutLibrary [Lei Wiley-Mydske ]. (2015, Mar. 9). @RobotPete @Mom2Rebels @Boycott\_AS @aintlifewells <https://www.facebook.com/notes/parenting-autistic-children-with-love-acceptance/on-publicly-shaming-autistic-children/798199990217882> ... No, you don't put your kid's private struggles on blast. [tweet]. Retrieved from <https://twitter.com/WileyAutLibrary/status/575124954489950208>.

- Willingham, E. (2013, September 5). If a parent murders an autistic child, who is to blame? *Forbes*. Retrieved from <http://www.forbes.com/sites/emilywillingham/2013/09/05/if-a-parent-murders-an-autistic-child-who-is-to-blame/>.
- Willingham, E. (2014, Dec. 21). On Autism Speaks' Suzanne Wright, the frustrated savior [web log post]. Retrieved from <http://www.emilywillinghamphd.com/2014/12/on-autism-speaks-suzanne-wright.html>.
- Winegardner, J. (2011, Sept. 30). On the dialogues and being an ally [web log post]. Retrieved from <http://www.stimeyland.com/2011/09/on-dialogues-and-being-ally/>.
- Winter, P. (2012). Loud hands and loud voices. In J. Bascom (Ed.), *Loud hands: Autistic people, speaking*, pp. 115-128. Washington, D.C.: The Autistic Press.
- Wodak, R. & Meyer, M. (2009). Critical discourse analysis: History, agenda, theory and methodology. In R. Wodak & M. Meyer (Eds.), *Methods of critical discourse analysis (2<sup>nd</sup> Ed.)*, pp. 1-33. Thousand Oaks: Sage.
- Wright, S. (2013, Nov. 11). Autism Speaks to Washington - A call for action. Retrieved from <http://www.autismspeaks.org/news/news-item/autism-speaks-washington-call-action>.
- Wrightslaw. (2012). Self-advocacy. Retrieved from <http://www.wrightslaw.com/info/self.advocacy.htm>.
- WrongPlanet. (2015, Jan. 30). What do you think of the autism mom blog controversy here? [forum]. Retrieved from <http://dev.wrongplanet.net/forums/viewtopic.php?f=19&t=275571&sid=4bbc0a15761a815ec95169e972f461a2> on Mar. 21, 2015.
- Yergeau, M. (2010). Circle wars: Reshaping the typical autism essay. *Disability Studies Quarterly*, 30(1). Retrieved from <http://dsq-sds.org/article/view/1063/1222>.

- Young, I. M. (2000). *Inclusion and democracy*. New York: Oxford University Press.
- Young, L. (2012, Mar. 27). Disability advocates alarmed by parents who kill. *Disability Scoop*. Retrieved from <http://www.disabilityscoop.com/2012/03/27/disability-advocates-parents-kill/15248/>.
- Zifendorf. (2002, Dec. 20). Self-narrating zoo exhibit. *Everything 2*. Retrieved from <http://everything2.com/title/self-narrating+zoo+exhibit>.
- Zoe. (2011a, Sept. 19). The self-advocate/parent dialogues, day one: Zoe [web log post]. Retrieved from <http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-one.html>.
- Zoe. (2011b, Aug. 16). The R-word and perspective-taking: Whose perspective are we taking? [web log post]. Retrieved from <http://illusionofcompetence.blogspot.com/2011/08/r-word-and-perspective-taking-whose.html>.
- Zurcher, A. (2012a, Oct. 26). Non-speaking (at times) autistic provides insight into communication differences, Part II. *Huffington Post*. Retrieved from [http://www.huffingtonpost.com/ariane-zurcher/life-with-autism\\_b\\_2005489.html](http://www.huffingtonpost.com/ariane-zurcher/life-with-autism_b_2005489.html).
- Zurcher, A. (2012b, Oct. 24). Non-speaking (at times) autistic provides insight into communication differences, Part I. *Huffington Post*. Retrieved from [http://www.huffingtonpost.com/ariane-zurcher/life-with-autism\\_b\\_1996962.html](http://www.huffingtonpost.com/ariane-zurcher/life-with-autism_b_1996962.html).
- Zurcher, A. (2013a, June 20). An interview with Tracy Thresher of Wretches and Jabberers [web log post]. Retrieved from <http://emmashopebook.com/2013/06/20/an-interview-with-tracy-thresher-of-wretches-and-jabberers/>.
- Zurcher, A. (2013b, Dec. 6). Autism Speaks and signal boosting [web log post]. Retrieved from <http://emmashopebook.com/2013/12/06/autism-speaks-and-signal-boosting/>.

Zurcher, A. (2013c, Aug. 28). Presuming competence & expectations [web log post]. Retrieved from <http://emmashopebook.com/2013/08/28/presuming-competence-expectations/>.

Zurcher, A. (2013d, Mar. 7). “Presuming competence”-What does that mean exactly? [web log post]. Retrieved from <http://emmashopebook.com/2013/03/07/presume-competence-what-does-that-mean-exactly/>.

Zurcher,A. (2013e, Mar. 20). “Splinter skills” and other words we use [web log post]. Retrieved from <http://emmashopebook.com/2013/03/20/splinter-skills-and-other-words-we-use/>.

Zurcher, A. (2013f, May 22). Taking action~Presuming competence [web log post]. Retrieved from <http://emmashopebook.com/2013/05/22/taking-action-presuming-competence/>.

Zurcher, A. (2014a, May 1). Dare to hope [web log post]. Retrieved from <http://emmashopebook.com/2014/05/01/dare-to-hope/>.

Zurcher, A. (2014b, July 21). Presuming competence – Revised [web log post]. Retrieved from <http://emmashopebook.com/2014/07/21/presuming-competence-revised/>.

@zymish [Pixel Smith]. (2015, Apr. 1). #AcceptanceIs my housemates checking my communication necklace before talking to me, without impatience regardless of what state it declares [tweet]. Retrieved from <https://twitter.com/zymish/status/583455202944032769>.