Can Autistics Redefine Autism? The Cultural Politics of Autistic Activism

Ronnie Thibault*

The author acknowledges many professional and institutional agents prefer the use of people first language when referencing autistics; however, this project focuses on the narrative of autistic individuals including many who write extensively on the politics of identity first/people first language¹. I take great care to honor each individual's declared naming convention when referencing their words, cultural productions and political efforts whether the stated preference is for identity first signifiers such as 'autistic person,' 'autistic activist' etc., or people first 'person with autism,' individual with autism,' or 'those diagnosed with autism.'

This study was made possible with support from The Mary Gates Undergraduate Research Endowment Committee and The University of Washington Disability Studies Harlan Hahn Award.

¹ In Why I dislike People First Language (1999), ANI co-founder Jim Sinclair argues, "I am not a 'person with autism' I am an autistic person" (223) and believes "saying a 'person with autism suggests that the autism can be separated from the person. But this is not the case." Sinclair also argues, "saying 'person with autism' suggests that autism is something bad so bad it isn't even consistent with being a person... I am autistic because I accept and value myself the way I am" (224). Activist Lydia Brown writes extensively on identity first language: "many self-advocates and their allies prefer terminology such as 'Autistic,' 'Autistic person,' or 'Autistic individual' because we understand autism as an inherent part of an individual's identity -- the same way one refers to 'Muslims,' 'African-Americans,' 'Lesbian/Gay/Bisexual/Transgender/Queer,' 'Chinese,' 'gifted,' 'athletic,' or 'Jewish'' (The Significance of Semantics). ASAN founder Ari Ne'eman explains, "Many of us refer to ourselves as autistic people rather than people with autism... the reason for that is we're very adamant that the autism spectrum is not something that is external to us... It is something that is very much a part of us and always has been" (CBC News). There are also many discussions regarding the use of people first language as a way of signifying respect for the person before a diagnosed condition. It is beyond the scope of this study to provide an exhaustive comparative analysis of these conflicting views; it is the intent of this research to rely on individual preferred naming conventions.

^{*} Ronnie Thibault is a M.A. student in Cultural Studies at the University of Washington Bothell.

"The Neurodiversity Movement stands for the idea that we should view neurology through the same civil rights lens as we currently view race, religion, sexual orientation and other forms of what's termed 'legitimate human difference."

- Ari Ne'eman, (CBC News)

Introduction

Common frameworks throughout the clinical and professional fields of autism contextualize autistic experience through diagnostic categories of difference constructed by physicians, psychologists, neurologists, educators, and service providers. These characterizations are determined through standard observational criteria such as delayed communication and language, repetitive physical behaviors, and marked deficits in social skills (Centers for Disease Control). While this deficit mindset influences how television programs, movies, websites, awareness campaigns, journalists, print media and other cultural industries represent autism and sway public assumptions about autistics, there is a lack of attention to and research on how the social consumption of these perspectives from the outside influence the lived experience of autistic adults.

The following article explores recent highly publicized and contentious debates over how non-autistic produced fundraising organizations, government apparatuses and mainstream media industries to represent autism and whether Autistic acts of resistance are shifting the debate about what it means to be Autistic. This critical discourse analysis explores how the global efforts of a politically active and increasingly visible Autistic culture known as the Neurodiversity (ND) Movement challenges commonly held assumptions about autism and whether their efforts are successfully broadening our social imagination beyond the practitioner, caregiver, and service provider experience.

The dominance of these governing ideologies regarding autism set the political stage for new stories and alternative interpretations to emerge from autistic individuals and the ND Movement. In his critical work regarding race, class and the media, Cultural Theorist Stuart Hall locates ideologies as "those images, concepts, and premises which provide the frameworks through which we represent, interpret, understand and 'make sense' of some aspect of social existence" (81). Autistic activists labor to make sense of their social existence and to counter normative ideologies that paint autism as "the latest global epidemic" (Johansen), "a huge national health burden" (Kristoff) "a national emergency" (D. Brown), "the worst possible thing that can happen to a family" (Autism Speaks, In the News), or as 'new

parents' No. 1 fear" (McCarthy and Carey).² The ND Movement further contests editorial claims that they are "living in a state of lonely despair" (Wright) and that their families are "beleaguered" (Scelfo and Kantrowitz), "devastated," and "in crisis" (Cain). Economically powerful and politically influential non-autistic apparatuses govern the socio-political discourse of autism and the rising tensions between these externally prescribed representations and autistic descriptions about their own lives construct what this article contextualizes as the cultural landscape of autism.

Analyzing the political terrain of the ND Movement demonstrates how psychological, medical, educational and political apparatuses exclude autistic perspectives, privilege the caregiver/child view, influence therapeutic care, regulate political conversations and persuade media representations that ultimately provoke social misunderstandings about Autistic identity. This project asks how the ND Movement's struggle for social justice and individual, collective, political, and embodied space within the cultural landscape influences the definition of autism and whether autistic perspectives can expand shared social understandings about what it means to be Autistic.

The lens of critical cultural studies helps situate the lived experience of Autistic adults in a historical, political and social struggle over meaning, value and autonomy in society.³ This endeavor draws on experiential methods of analysis as "an intermediary category coming between ways of being and ways of knowing" (Pickering 18) to form a better accounting of Autistic frames of representation, what society makes of their interpretations and the cultural meanings situated within this complex and circulatory process. Cultural Analyst Stuart Murray believes "the presence of the person with autism, rather than an abstracted idea of the condition itself... needs to be [the] starting point of any inquiry" (28). Interrogating lived experience is one evidentiary component of this work; Autistic activists question the dominant discourse through astonishingly candid narratives, published works, acts of

² There are numerous historical and contemporary examples of epidemic framing in mediated discourses of autism. The NBC.com article Children in the Grip of Autism (2005) claims "many experts point out, autism is not simply 'quirkiness' or an unusual personality trait, but a serious disorder capable of destroying families and children's futures" (Masland). Larry King Live: Mystery of Autism (2007) named autism a "global epidemic," and Oprah Winfrey's The Faces of Autism (2007) declared autism "a national health threat," "financial burden," and "difficult and devastating disorder" (Oprah.com) and The New York Times Nicolas Kristof's Do Toxins Cause Autism? Situates autism as "a frighteningly common affliction."

³ As a researcher, I embrace my positionality as framed, in part, through my experience as a mother and wife of Autistic individuals

political resistance and media counter-campaigns. As a cultural studies approach "experience is always to be interrogated" (19) and while it is crucial to engage the narrative experiences of autistic adults as a frame of reference, this work does so with the clear understanding they are situated within larger discursive formations that must also be explored. This project interrogates institutional, economic and political factors that significantly impact Autistic experience, while acknowledging that how the public chooses to consume, interpret and respond to these particular 'ways of knowing' is where the meaning and value really lies (Pickering 18, 19).

Cultural Geographer Don Mitchell situates cultural politics as "contestations over meanings, over borders and boundaries, over the ways we make sense of our worlds, and the ways we live our lives" (159). As an ideology, autism is socially constructed and culturally produced and "ideas about autism derive from many sources, always reflect power relationships between the defined and those who do the defining" (Biklen 46-47). The preliminary phases of this exploration into the powerful apparatuses that drive public opinions about autism exposed a population fiercely determined to locate their lived experience within the discourse on their own terms. However, critical cultural methods need to "move back and forth between what informants say and do, and what can be made of all of that, for otherwise you stand in danger of becoming either awash in immediacies... or stranded in abstractions and smothered in jargon" (20). Few contemporary discussions are at greater risk of becoming awash in immediacies and smothered in jargon than the discourses that construct autism.

Diagnostic interpretations, socially accepted idioms and media assumptions saturate representations that at times disregard the heterogeneous nature of Autistic individuals and exclude their lives from the cultural landscape. This article situates the cultural politics of Autistic activism between what Autistics say and do as they negotiate for identity and space within the cultural landscape and how society chooses to value their definition of what it means to embrace Autistic identity. To engage this culture war, this inquiry considers who has the right to speak for the Autistic community and whose values the public characterizes as authentic. Finally, this project asks whether Autistics are redefining autism and considers how their struggle for social justice reframes their position in political discussions about them.

Discursive Frames

Autism is an intensely scrutinized and well-documented topic of scientific, medical and social inquiry that occupies a significant space in the contemporary imagination. Clinical interpretations rely on psychiatric codes of impairment to classify this complex diagnosis currently studied by neurologists, psychologists, behaviorists, and

geneticists alike. Scholars such as American educator Douglas Biklen, sociologist Majia Holmer Nadesan and Stuart Murray move beyond scientific and medical categories to situate autism as an idea that is both socially constructed and culturally produced. Fixing autism into specific disciplines or categories of analysis is highly problematic, largely because "even at the dawn of the twenty first century we do not know what autism is" (Nadesan 9). Autism is among many things a heterogeneous and ambiguous notion that refuses definitive representation, embodies multiple forms and, as Biklen argues, "is list of symptoms or behaviors or representations that can be studied and discussed, but it is not knowable as truth. It must always be interpreted" (3). The following analysis of the prevailing and guiding ideologies that construct autism shows how dominant systems of representation authorize media and awareness campaigns to reproduce stigmatizing assumptions that characterize autistics as isolated lone "objects" of pity and despair.

Murray frames the persistent storyline of tragedy as an "overcoming narrative... in which autism is seen as a potential destroyer of the family unit... an affliction that can be fought" (15). These marginalizing narratives essentialize autistic subjectivities within a child-centered frame that represents their experience as a "condition to be therapied, remedied, assaulted, in an effort to 'save' afflicted children locked inside an autistic cage" (Nadesan 2). Some awareness campaigns center their message on autistic children and their families as victims of an abstract and foreboding metaphorical entity known as "autism." While this is a common fundraising strategy to garner public sympathies and increase donor interest, it ultimately serves to erase Autistic adults from the cultural landscape. Activists contend humanitarian discourses that rely on these kinds of pejorative misinterpretations objectify their existence and limit their access to desperately needed support services, medical care and equal education opportunities.

The literature on the social and cultural construction of autism highlights widespread descriptions pointing to autism as an epidemic disease of developmental deficiency that situate autistics as isolated in worlds of their own and unreachable to so-called normal members of society. The medical deficiency model approaches autism "as a triad of deficits... involving social interaction, communication, and imagination" (11) with little or no input from those they diagnose. These are the very conventions that drive media interpretations and ultimately shape how society comes to imagine autism, treat Autistic people and construct crucial education, medical, service and social support policies.

In the narratives that follow, Autistics tell compelling stories about how representations of abnormality become embedded in critical interactions regarding their right to a fair and appropriate education, equal employment opportunities,

access to health care and full participation in public conversations about their lives. They vehemently argue that the prevalence of the tragedy cure and deficit mindset fixes their existence into a child-centered frame that generalizes "autism as a biologically based psychiatric condition to be therapied, remedied, assaulted, in an effort to 'save' afflicted children locked inside an autistic cage" (Nadesan 2).

Consideration for the personal accounts of autism illustrates precisely why representation matters, why society is implicit its reproduction across time and place, and how envisioning autism through strict diagnostic codes limits the ability to embrace its diverse nature, imagine what it means to live as an autistic or appreciate the right of autistics to move throughout the world with dignity and self-determination. There is a profound absence of autistic perspective in the discourse and this invisibility leaves much open for misinterpretation and mistranslation in the spaces of the cultural landscape. This article calls for a new paradigm that reflects Murray's "focus upon the accounts produced by those with autism themselves... in the form of fiction, artwork, memoir, blog, internet chat room discussion," (14), draws from Biklen's lens of presumed competence and critically attends to the transformative ways autistics interact with and influence social and political conversations about their lives.

Methods

The framework for this study encompasses three evolutionary sites of engagement that inform and influence each other. The preliminary media analysis considers how awareness organizations, government apparatuses, "radio, television, film, and the other products of media culture" (Kellner 7) frame and represent autism. This primary representational analysis uncovered the emerging efforts of the ND Movement and shifted the project towards imaging the many discourses of autism as produced within a cultural landscape.

Alternative ways of seeing autism appear in news reports, blogs and chat rooms regarding the ND Movement and its public protest of what activists consider dehumanizing representations put forth by *Autism Speaks* and *The New York University Child Study Center*, *PBS*, multiple journalists and the mainstream media. The political and cultural activities of the Autistic-run advocacy groups *Autism Network International* (ANI) and *The Autistic Self Advocacy Network* (ASAN) appear frequently in the course of this critical analysis. Zukin describes a cultural landscape as "a contentious, compromising, 'product of society' formed through 'power, coercion and collective resistance" (cited in Mitchell 113) and examining how representational tactics of power influence and inform the cultural politics of the ND Movement became central to this work.

While analyzing the political formations of the ND Movement it became apparent, the concept of neurodiversity itself grew from multiple modes of individual autistic expression and any comprehensive study requires an inquiry into how autistic autobiographical accounts inform the landscape. This third exploratory site provides an exhaustive study of Autistic experience and the narrative accounts of autism. Individual Autistic expressions produced by ANI founder Jim Sinclair, ASAN President Ari Ne'eman, Global and Regional Asperger Syndrome Partnership (GRASP) founder Michael John Carley, activists Amanda Baggs and Cal Montgomery, and reflections from autistics Sue Rubin, Lydia Brown and others tell a different story about autism that significantly informs this work. Pickering's analytical methods take into account "experience as an intermediary category coming between ways of being and ways of knowing" (18) and discursive cultural methods allow for a critical view of Autistic narratives, while bringing both "agency and ideology into continual view of each other" (20). The Autistic works in this article highlight experiences of selfidentified members of a population. However, I do not suggest that these individual accounts transfer to autistic culture as a whole as this is a misconception they suggest would confirm essentializing stereotypes they adamantly work to erase.

Mitchell believes cultural politics are embedded in the manner in which "complex circuits of meaning and value" are constructed and "representations themselves take on a circulatory life of their own" (147). The circulatory life of the representational politics of autism come into view through these three interacting sites of inquiry that encompass institution, caregiver, practitioner, media and autistic interpretations as discursive *forces* that explicitly shape and depend on each other, take on a circulatory life of their own and form new ways of seeing and understanding autistic lives.

Narrative Frames

Autistic activists Robertson and Ne'eman believe some non-autistic produced representations rely on pejorative misinterpretations about their lives and "accounts of autistic people's experience sometimes shaped distorting metaphors that patronized, dehumanized, and demeaned autistic people" (4). Activist and self-advocacy websites, blogs, published works, television and print news interviews, auto-ethnographic materials and video productions illustrate "self-legitimizing narratives" (Pickering 20) that strongly evidence a movement towards the collective formation of autistic culture. Sinclair determines, "autism is not an appendage... autism is a way of being" (*Don't Mourn For Us*), Ne'eman emphasizes autistic "lives are not tragedies" (*No Myths*) and *Autistic Hoya* stresses, "It is impossible to affirm the value and worth of an Autistic person without recognizing his or her identity as an

Autistic person" (Brown). These claims of empowerment highlight the transformative potential for Autistics to create new cultural meanings and social interpretations of their lives while countering non-autistic produced representations that they believe "Question the very value of lives with autism" (CBC News).

Amanda Baggs narrates her involvement as an activist, published author, and autistic adult through journal articles, blogs, media and news interviews and YouTube productions. Her WordPress website *Ballastexistenz* illustrates a battle for autonomy against tragedy discourses and non-autistic frames:

Autistic people are frequently described... as empty shells without souls, burdens on our families and society, contributing nothing, ballast that merely weighs everyone down...I am and have been exactly the sort of person who is meant when these awful concepts are used (ballastexistenz).

GRASP leader Michael John Carley offers his poignant reflection on the painful emotional ramifications resulting from highly publicized epidemic frames and discourses of affliction, assumptions that he argues privilege caregiver and family perspectives:

It is terrifying for someone on the spectrum who is desperately seeking positive self-images to be lectured by the world that his life will be, or is, awful, not to mention a burden on their loved ones; for when added to the already-existing obstacles, such negative imagery doesn't help. (GRASP.org)

In sharing their experiences and contesting ideologies that suggest they are somehow living separate of their diagnosis, Carley, Ne'eman, Baggs, Sinclair and the others are asking society to re-imagine autism as an acceptable form of difference. By openly sharing their lived interpretations and illustrating how they experience the collective culture that is forming around autistic identity, autistics are provoking society to engage in new ways of understanding, treating and embracing autism.

Over the past decade, in addition to medicalized and psychiatric categories of deficiency, Murray locates a "seeming division between 'low-functioning' and 'high functioning' autism has found its way into popular vocabulary used to describe autistic identity" (1). Binary representations classify autistics as either high functioning or low functioning and permeate parent support sites, special education planning guides, practitioner materials and conversations regarding behavior intervention methodologies. Autistic reflections on how they experience and live with particular function designations appear repeatedly in narratives regarding the social inclusion and civil rights of autistic people. Activists argue function labels

construct misunderstandings about their physical and behavioral features that in turn influence the ways they are treated within the public sphere. Biklen finds that "the term *high-functioning* is not a technical term; it has been used in both professional and lay discussions to refer to individuals who evidence the ability to converse in oral dialogue using speech... it implies that those people who can carry on spoken conversations are intelligent and those cannot, are not" (26). Murray critically interprets diagnostic conventions of function as clinically detached from autistic life and believes "those with autism perform their condition for the (impersonal) expert whose expertise, in turn, allows for the grading of the condition through an idea of 'functioning' behavior'" (5). In *A Conversation with Leo Kanner*, Autistic writer Sue Rubin describes how objectifying gazes conflate her functional performance and intellectual abilities:

Sometimes I feel as if I am the eighth wonder of the world as people stare and marvel at my irregular behaviors which led to poor assumptions that I am simply mentally disabled with little or no intellectual functioning. (95)

Rubin offers a concrete example of precisely how pejorative ways of connecting her physical features to assumptions about her intellectual capabilities set the stage for the public to dehumanize and demean her embodied existence as she moves throughout the social sphere.

The functions discourse is particularly burdensome for those who communicate in non-traditional ways, and autistics frequently articulate the painful consequences they experience living under these classifications. Sinclair reflects on how the low-functioning label projected judgments of limited intelligence based wholly on Xe verbal abilities as a youth:

Assumptions that I know things which in fact I don't understand often lead directly to conclusions that I can't learn things which in fact I already know. Such assumptions nearly led to my being placed in an institution. Because I didn't use speech to communicate until I was twelve, there was considerable doubt about whether I would ever be able to function. (Bridging the Gaps: An Inside-Out View of Autism 26)

Xe continues with an evocative explanation of *why* throughout childhood Xe did not communicate verbally:

No one guessed how much I understood, because I couldn't say what I knew. And no one guessed the critical thing I *didn't* know, the one missing connection that so much else depends on: I didn't communicate by talking,

not because I was incapable of learning to use language, but because I simply didn't know what talking was for. Learning *how* to talk follows from knowing *why* to talk—and until I learned that words have meanings, there was no reason to go to the trouble of learning to pronounce them as sounds. (Bridging the Gaps: An Inside-Out View of Autism)

Sinclair's translation is a profound reminder of Biklen's presumption of competence paradigm, which understands "people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives and their relationship to the world" (1).

Autistic author Cal Montgomery also writes about life within the dual spaces of the high/low boundaries. She frames the functions discourse as an ideology "often... reducible to a rights/cure distinction: it's about our political positions. I don't believe you can meaningfully separate autistic people into 'high' and 'low' functioning in the first place, but if you can it's not by comparing their political positions" (3). Similarly, Murray offers the critical reminder that "autism, because of its seeming 'invisibility' and its manifestations in terms of behavior, has had more than its fair share of examples of... abuse, often emanating from sources of medical or social power" (17). Montgomery graphically connects her experiences of institutionally imposed abuse to assumptions about her behaviors and how powerful forces in her life perceive her functioning:

I've watched people—professionals and institutionalized persons, and people I once counted as family members and friends—react as I rapidly slid across the lines they were using to mark the boundary between "high-functioning" and "low-functioning" (or acute and chronic). It wasn't pretty. They condoned my being gang-raped, my being beaten, my being denied food and water and access to a toilet and even a heated room in the Yankee winter nights, and then when they had allowed my life to be well and truly wrecked they left me alone to deal with the wreckage. ("Defining Autistic Lives")

These narratives are intense, and while they may invoke visceral imageries of autistic life, it is crucial the consumption of their reflections avoid the dehumanizing practice of the gawker's gaze. It is important not to objectify their candid offerings as "self-narrating zoo exhibits" (Sinclair 28), "voyeuristic freak show[s]" (Baggs), or as "the same old 'hear our silence' stuff' (Montgomery 1). While the above segment offered by Montgomery details evidence of degrading institutional and social practices, her narrative moves on to profoundly *re-humanize* her embodied presence:

I... see myself as an autistic person. The behaviors and experiences that get me labeled "autistic" are, I think, part of me. I want to change some of them, sure. I want to not hurt myself, (or at least manage to only do it when I am alone), and it frustrates me that I am getting worse at that. I want to always manage to get my helmet on before I hit my head on something. I want enough motor control to type on my communication device and navigate my power chair whenever I'm out. I also want to understand the writings of Michel Foucault, to stop cursing so much, and to make friends where I live. And I want a dog. ("Defining Autistic Lives")

Montgomery deeply contextualizes autistic behavior within socially relatable dreams and desires, and effectively counters the dominant spaces of institutionally sanctioned violence by making those otherwise unaware of these practices understand how deeply the abuses influenced her life.

Mitchell theorizes that individual expressions of self-determination produce broader social justice movements and "struggle for rights—for inclusion—[that are] more and more fought not at the level of the liberal individual... but at the level of the social (or cultural) group" (290). Sinclair is widely considered a "pioneer of the autistic self-advocacy community" (Robertson and Ne'eman), predominant figure in the ND Movement and co-founder of *Autism Network International* (ANI), an organization Sinclair describes as "the first autistic community to be created naturalistically by autistic people" ("Being Autistic Together"). In 1992, Sinclair and "a handful of verbal autistic people who had made contact with each other via a pen pal list maintained by a parent-run organization" (Sinclair, "Autism Network International"), created ANI as a support network and newsletter written by and for autistic adults. In 1994, ANI launched the internet ANI-L forum, which quickly morphed into an international online presence. According to Sinclair, ANI remains one of the few autistic forums determined to maintain a safe virtual space for autistic expression.

Sinclair's now infamous 1993 conference presentation, *Don't Mourn for Us*, touched a nerve in autistic adults who began to realize new possibilities of seeing autism as a shared experience beyond the socially constructed lens of abnormality. Sinclair originally presented *Don't Mourn* to a parent audience and the following segment illustrates how overcoming tragedy storylines and cure ideologies provoked Sinclair's call for socially recognized autistic self-determination:

This is important so take a moment to consider: Autism is a way of being. It is not possible to separate the person from the autism. Therefore, when parents say, I wish my child did not have autism what they are really saying is,

I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.... This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces. (1)

Don't Mourn for Us "drew a lot of interest to ANI" (Sinclair 18) and provided a significant moment in the cultural production of autism, the construction of the ND Movement and a collective sense of belonging for autistic adults. Struggles over rights and justice, or "culture wars," are produced as "groups of people bound together by some commonality seek to reconstruct the world in such a way that they may live on their own terms, not on the terms of those who seek to control them" (Mitchell 290). Don't Mourn for Us bound autistics together in collective protest against the iterative flow of non-autistic interpretations dominating the popular discourse about them.

ANI's online community invites individual expressions of autistic being. Here, "the most central shared value... is that it's okay to be autistic—it's not 'wrong' for us to be the way we are, and it's not our goal to become... NTs [neurotypical or non-autistic]" (Sinclair 16). In 1996, ANIs resolve to generate protective virtual territories online progressed into the physical project known as Autreat, an annual "retreat-style conference run by and for autistic people, designated to accommodate autistic people as much as possible, with presentations geared to the interests of autistic people" (26). Cultural theorist Fred Inglis clarifies culture as a "system of humanly expressive practices by which values are renewed, created, and contested... 'value' is the name given to those fierce little concentrations of meaning in an action or state of affairs which fix them as good or important" (cited in Mitchell 71). Autreat and ANI provide spaces for autistics to perform and renew shared values and interests "without NT interference" (26), to construct their lives together and on their own terms and to reframe the meaning autism and collectively validate autistic life as a good, important and perfectly acceptable way of being.

Political Sites of Engagement

While ANI and Autreat construct *internal* cultural spaces for autistics to interact openly and to express their lived experiences together, the ND movement inhabits a more public stage for autistic political performances. The cultural politics of autistic activism surface on the landscape as Ne'eman describes the ND Movement, its shared motives and definition of neurodiversity:

The neurodiversity movement stands for the idea that we should view neurology through the same civil rights lens as we currently view race, religion, sexual orientation and other forms of what's termed "legitimate human difference." And basically from that perspective instead of trying to find a way of making autistic people normal or making people with other forms of neurological difference normal, what we should be doing is addressing the true problems and barriers that exist in our lives. (CBC News)

Ne'eman serves on The U.S. National Council on Disability and is President and founder of The Autistic Self Advocacy Network (ASAN), an international advocacy group "run entirely for and by autistic adults" (ASAN). As an autistic navigating the political and public domain and a leader in the ND Movement, Ne'eman reflects on the marginalization of autistic input in crucial decisions regarding autism: "Sadly, the traditional autism community has been driven by a set of priorities different from our own. Led almost exclusively by those not on the autism spectrum, it has made harmful decisions without our input" (4). These and similar observations coming from the ND Movement shift well-established mainstream territories of deficiency structured, produced, and reproduced through the practitioner, parent, caregiver, and service provider perspective, reified by cultural industries and ultimately consumed by the public.

Recent tensions between the ND Movement and PBS New Hour host Robert MacNeil illustrate how popular media productions structured around assumptions of deficiency and values of performative function publically shift the embodied presence of autistics into deeper and increasingly fractured spaces of difference, while simultaneously carving new territories for meaningful autistic produced definitions. In 2011, PBS aired the six-part production *Autism Now*, a documentary series promoted as "designed to provide viewers with an authoritative, balanced look at the latest scientific research and medical thinking about the disorder. Equally important, it chronicles the growing impact of autism as seen through *the eyes of families, children, educators and physicians* [emphasis added]" (PBS).

PBS implicitly emphasizes the medicalized child/caregiver perspective by situating its production as authoritative and balanced while excluding the "eyes" of autistic adults and rendering them invisible throughout the cultural broadcast terrain it mediates. Furthermore, PBS sanctioned their documentary as "the most comprehensive look at the disorder and its impact that's aired on American television in at least five years" (PBS) and announced the return of legendary news anchor Robert MacNeil as its co-producer and host. MacNeil explained his remergence onto the public scene after fifteen years retirement "grew out of the fact that I have a six-year-old grandson... who's on the autism spectrum" (PBS).

In a promotional interview MacNeil offers ideologies the ND Movement protests as "erroneous and offensive tropes" (ASAN) and as a dehumanizing representation of their lives. In the promotional interview, MacNeil's non-autistic definition of autism invokes the medical deficit mindset and reiterates the dominant child/caregiver tragedy focus:

There are wires crossed in the brain as it develops or something analogous to that, which delays speech. It delays the most—delays or impairs for life—the most human thing we have, which is our ability to look into each other's eyes and feel that other person's existence and what might being going on in their mind, and to empathize with them. That is denied—largely denied—to children with autism. (PBS)

In response to MacNeil and PBS' tone, ASAN issued a press release expressing concern "over the failure of... Robert MacNeil to interview representatives of any organization run by Autistic adults, and the presence of concerning stereotypes about Autistic Americans in the promotional material" (ASAN, Autistic Self Advocacy Network).

In a politicized effort to reform what activists found to be dangerous and objectifying perspectives that called on, including "unsupported statements suggesting that Autistic adults are disproportionately and randomly violent" (ASAN 3), the ND Movement invited MacNeil to engage in a dialogue about their lived experience prior to the *Autism Now* scheduled air date. The battle between the ND Movement, PBS, and MacNeil demonstrates conflicting performances between autistics vying for recognition, identity, and representation and the powerful non-autistic interests that govern vital cultural industries and mediated territories of the landscape of autism. MacNeil responded indirectly to the ND Movements invitation and concerns in a PBS interview *after* the documentary aired without seeking autistic input or participation:

We tried to concentrate of what we thought were urgent issues, urgent problems. And a lot of adults with autism, particularly those who describe themselves as a *kind of neurodiversity community* [my emphasis], are high functioning people with autism, who have busy and productive lives in the world, who serve a wonderful purpose of helping the community at large to understand and witness autism and be tolerant of it. But they speak for themselves. And *we didn't see them as an urgent issue* [my emphasis], as urgent as the impending arrival into adulthood of hundreds of thousands of teenagers. (PBS NewsHour Health)

MacNeil's presumption about the functions of autism constructs restrictive boundaries around the ND Movement and privileges social assumptions about one particular form of autistic embodiment over another.

Mitchell suggests "geography... is structured in fights—in culture wars—over inclusion and exclusion, over the making or shaping of boundaries around race, gender, ethnicity, and sexuality [and neurological difference *my insertion*], and over defining who constitutes part of the group" (289). Through his conjecture about urgency and need, MacNeil practices deeper categorization and removes what he assumes are higher-functioning adults from the public discourses that shape the cultural frames of autism. ASAN's response to MacNeil engenders autistic civil rights and justice while re-establishing territory for autistic adults:

To ignore the widespread discrimination, lack of services, un—and under—employment, stigma and countless other issues facing hundreds of thousands of Autistic adults today is unconscionable. Furthermore, to pretend that any comprehensive account of autism is meaningful without substantively engaging with Autistic people ourselves is disgraceful and offensive. (ASAN)

The interactions between PBS, MacNeil and the ND Movement over who is qualified to speak for the autistic community, and more precisely, who exactly society presumes capable of making such determinations, is a common theme in autistic autobiographical accounts.

Montgomery argues that debates over the embodied features of autism force autistics to struggle against externally prescribed notions about who has the right to define what it means to be, live and identify as autistic:

The "high-functioning"/ "low functioning" issue, which is also about who has the right to define what autistic lives are like and what people with autism and autistic people want...If you are capable of making your opinions known, then you're obviously not autistic, because autistic people can't communicate. And if you're not autistic, obviously you aren't qualified to pontificate on what autistic people believe. (4)

Public assumptions about autistic embodiment and stereotypical projections about autistic behaviors produce a performative, cultural, and human rights struggle that Autistic Author Lydia Brown situates as a collective battle for inclusion, civil rights, justice and *access* to society:

Respect us. We are people, fellow human beings. We deserve to be treated with the same respect afforded to our non-Autistic peers. Respect starts by understanding that we are full and complete human beings, with individual personalities, life experiences, goals, and preferences. We deserve an education, access to communication, and a place in society as we become adults. We deserve to live without fear of being abused, manipulated, or hurt. We are not less than. (364)

Collectively these narrative statements of self-determination and autonomy demonstrate how a portion of autistic culture perceives the discourses that surround their lives and by what means their endeavor for recognized agency, inclusion and equality facilitate the "making and shaping of boundaries" within the cultural landscape of autism.

The Public Formations of the Neurodiversity Movement

The Neurodiversity Movement attracted mainstream attention in 2007 when Ari Ne'eman and ASAN spearheaded an energized effort to halt a New York University Child Study Center "Ransom Notes" billboard and print campaign designed to attract public awareness to childhood disorders (see Appendix 1). Analysis of the New York University Child Study Center campaign, its interaction with the ND Movement and the widespread media attention it attracted illustrates how support organizations and practitioners can unknowingly construct spaces in the landscape for the ND Movement and the cultural politics of autistic activism.

The "Ransom Notes" representations produced by New York University depict autism as the kidnapper of stolen children that demands public and parent attention through a series of ominous notes appearing across New York billboards and public spaces with the following text:

We have your son. We are driving him into a life of complete isolation. - Asperger Syndrome.

We have your son, We will make sure he will not be able to care for himself or interact socially as long as he lives, this is only the beginning - Autism. (New York University Child Study Center)

The NYU Child Study Center claims they are "the nation's premier organization for advancing the prevention, identification, and treatment of child and adolescent psychiatric and learning disorders through scientific practice, research, and education," and the following edited "Ransom Notes" press release states the intended purpose of the campaign:

MILLIONS OF CHILDREN HELD HOSTAGE BY PSYCHIATRIC DISORDERS

Provocative New PSA Campaign Highlighting Autism, Asperger's ADHD, OCD, Depression and Bulimia, Debuts in December in NYC.

New York City, December 1, 2007— Alerting Americans to the silent public health epidemic of children's mental illness, the NYU Child Study Center has launched a public awareness campaign called "Ransom Notes...we hope the campaign will act as a wake-up call to families, educators and healthcare professionals, and spark dialogue so children can get the help they need. (Press Room Ransom Notes)

In the press release, marketers highlight families, educators, professionals and children's needs while excluding the adult perspective from public concern.

The mock "Ransom Notes" campaign images ran in "New York magazine and Newsweek as well as on kiosks, billboards and construction sites around New York City"" (Kaufman) and were originally intended to reach 700 million national public consumers over a four-month run (New York University Child Study Center). Five days after "Ransom Notes" launched into public view, Ne'eman and ASAN instigated an online "Urgent Call to Action" and petitioned activists to demand that NYU reconsider its use of what the ND Movement signaled as dehumanizing language and metaphorical imagery. Ne'eman's petition vehemently argued against fundraising tactics that he believed reproduced dehumanizing stereotypes and potentially dangerous metaphors for social consumption and public interpretation:

The ads suggest that our true selves have been "kidnapped" by terrible "diseases" and that we need urgent treatment to become normal again. This "stolen child" stereotype has been associated with horrible abuses against individuals with disabilities, ranging from social cruelty to beating, electric shock and even murder. (An Urgent Call to Action)

The New York Daily News, Washington Post, New York Times, Washington Post, York Dispatch, and Wall Street Journal immediately addressed the ND Movement's political actions and word spread quickly through activist blogs and online forums. New York Times columnist Joanna Kaufman spoke with NYU Child Study Center founder director Dr. Harold Koplewicz who indicated he expected intense reactions from the provocative imagery but the activist counter-campaign caught him off guard:

While we knew the campaign was edgy and we knew it would be harsh and upsetting, the facts of mental illness are even more upsetting. I am disappointed. I thought the people we'd be arguing with are the people who believe mental illness doesn't exist... I thought we would be fighting ignorance, I didn't think we'd be fighting adult patients or the parents of patients whose feelings have been hurt. (Campaign on Childhood Mental Illness Succeeds at Being Provocative)

ASAN argued aggressively that NYU's marketers failed to consider the lived experiences represented in the ads or to value adult autistic perspectives and in doing so they "inadvertently reinforced many of the worst stereotypes that have prevented children and adults with disabilities from gaining inclusion, equality and full access to the services and supports they require" (www.autisticadvocacy.org).

Ne'eman's petition attracted over "1,300 signatures and comments from individuals, as well as representatives from more than 20 advocacy and disability rights groups" (Kras 2), a collective reaction against the campaign that Koplewicz initially acknowledged yet remained resolute that NYU "should stick with it and ride out the storm" (Kaufman). After 19 days of its intended three month run NYU did pull the "Ransom Notes" images and cancel the project. "Ransom Notes" is a political site based on a public service message produced by non-autistic forces, focused on the overcoming narrative and parent caregiver discourses, contested by the forces of autistic activism and reframed by cultural industries in full view of New York and national cultural consumers.

This complex cultural production illustrates a political shift when the public begins to imagine autism as defined by autistics on their own terms. ASAN's efforts, the media attention and NYU's decision to pull the advertisements are pivotal events Kras contextualizes as "an opportune moment for cultural development... a shift from parent's rights and concerns to self-advocate rights and concerns" (4). The New York Daily News, Washington Post, New York Times, Washington Post, York Dispatch, and Wall Street Journal coverage centered on the narrative of the movement to the exclusion of NYU's representational practices and the ND Movement successfully established new spaces within the cultural landscape of autism.

In 2008, public attention turned to the global stage as the General Assembly of the United Nations adopted resolution 62/139 and "unanimously declared 2 April as World Autism Awareness Day" (The United Nations). According to the United States based non-profit organization Autism Speaks, "the inaugural WAAD [World Autism Awareness Day] was celebrated in over 40 countries on six continents and received extensive media coverage, bringing the message of autism awareness to

hundreds of millions of people around the world" (Autism Speaks). Autism Speaks maintains a powerful and dominant space in the landscape of autism, its discourses and in UN mediations concerning autistic lives. Autism Speaks describes their foundation as 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 History").

Autism Speaks' interpretation of autism and how the public should attend to the needs of autistic people appears frequently in journal articles, media reports, television accounts and online discussions regarding autism. In the 2009 MSNBC indepth interview feature article "Philanthropist wages fight to cure autism," Autism Speaks co-founder Suzanne Wright discusses her organization's *Annual World Focus on Autism Day Breakfast Seminar* and talks about how her and husband/co-founder Bob Wright's early global involvement played a central role in the construction of The United Nations' World Autism Awareness Day:

On Dec. 18, 2007, Bob and I went to the General Assembly of the United Nations. I worked very hard with the state of Qatar and the Arab League. They co-sponsored a World Autism Awareness Day resolution that I asked them to do for us, because in the history of the United Nations, they've only done this for World AIDS Day and World Diabetes Day. I said, well we've got a world epidemic, why can't we do it? (2)

As a global foundation, Autism Speaks' interpretations, definitions and representations of autism hold the attention of national and international audiences and the organization raises millions in funding through national walks, global events, concerts, galas and government grants. The Wrights publically define autism as "a growing health burden" (Wright), "global health crisis" (Autism Speaks) and "a world epidemic" (Pace) while framing the autistic subject as a "terribly isolated... stranger to the social skills we take for granted, of how to relate to other people or read their emotions" (Wright).

In 2007, Autism Speaks was "officially designated a non-governmental organization associated with the United Nations Department of Public Information" and in 2008 hosted the first *Annual United Nations World Focus on Autism Forum* to "discuss the global epidemic of autism" (Autism Speaks). During the *Second Annual World Focus on Autism*, the non-profit awareness and research organization issued the "\$100 Million Challenge... Global Decade for Autism Initiative" (Autism Speaks), followed the next year with the annual *Light it Up Blue* marketing project and a 2011 announcement that "more than 1000 structures in over 180 U.S. cities and 30

countries will join Autism Speaks to shine a bright light on autism" (Autism Speaks: About Us). According to Autism Speaks, since the inception of *Light It Up Blue* "iconic landmarks around the world—including the Empire State Building and the Intrepid Sea, Air & Space Museum in New York City, the Willis Tower in Chicago, Universal Studio in Hollywood and Orlando… the Official Residence of the Prime Minister… Bangladesh, Christ the Redeemer Statue in Brazil" (Autism Speaks), The Space Needle in Seattle and thousands of businesses and individuals around the world illuminate their structures blue on April 2 to raise awareness.

Along with international awareness events and fundraising strategies, Autism Speaks 2011 summary of accomplishments additionally describes how the "Autism Speaks' Autism Response Team provided support to individuals with autism and their families through: 7,200 emails; 5,160 phone calls; 5,000 readers during Live Chats...; and 3,100 readers during Office Hours" (Autism Speaks, "About Us"). Celebrities also embrace Autism Speaks' version of autism and popular icons Bruce Springsteen, Bill Cosby, Toni Braxton, Toni Bennett and Jerry Seinfeld have headlined fundraisers and performed at "unprecedented events" (Autism Speaks, "About Us") in support of the organization's efforts. BBDO advertising and the AD Council donate millions in marketing and advertising expertise annually. Autism Speaks is a powerful economic and political force and by their own accounting international governments, dignitaries, cultural industries, societies and families around the globe consider their representational practices as the dominant authority on autism.

In 2009, Suzanne Wright recorded a personal message in the organization's "Do You Want to be in a World Autism Video" for posting on their website and Autism Speaks Video Channel on *YouTube*. In her video request, Wright explains organizational plans to produce an awareness video for debut at the *Autism Speaks'* Second Annual United Nations World Focus on Autism:

At this meeting, Academy Award-nominated director Alfonso Cuarón and Grammy-nominated songwriter/producer Billy Mann will unveil their video "I am Autism." Alfonso and Billy need your help to create this unique film—send us video footage of people from around the world who are on the autism spectrum. The footage will underscore the gravity of this global health crisis, and inform those in a position to effect a change. ("Do you want to be in a world autism video?")

Families responded and Autism Speaks screened *I am Autism* for "nearly 150 international dignitaries" (Autism Speaks) and posted the video on their website and YouTube Channel shortly after the event.

I am Autism is a visually stunning production intended to increase international awareness for the organizations goals; however, activists offended by the tenor of the short film protested what they characterized as a demoralizing and objectifying illustration of autistic experience. The narrator speaks in a deep foreboding tone, scripted in linguistic patterns reminiscent of "Ransom Notes", as images of lone children hover in the frame and filmed in shadow. The following segment illustrates the production's tragedy mindset:

I am autism. I am visible in your children but if I can help it am invisible to you until it's too late... I am Autism. If you are happily married, I will make sure that your marriage fails... I will bankrupt you for my own self-gain... I am autism. I will fight to take away your hope, I will rob you of your children and your dreams... you are scared, and you should be... I am autism. You ignored me and that was a mistake (Pace).

By embracing and reproducing the discourse of deficiency for an international audience, this agency run by non-autistics broadened the landscape for activists to tell a different story about their lives.

The ND Movement forged a powerful collaboration against Autism Speaks reminiscent of the "Ransom Notes" controversy. In "The Autism Speaks Conundrum—A response from GRASP," Carley bemoans Autism Speaks' decision to release *I Am Autism* as "a sad setback... that most folks on the spectrum, as well as many families, rightfully found very offensive" (The Autism Speaks Conundrum). Ne'eman spoke with *TIMES Health & Family* reporter Claudia Willis after the video release and argued the use of stereotypes and myths about autism are exclusionary practices that do nothing to improve the lived experience of autistic adults. Ne'eman argues, "Groups like Autism Speaks choose to use fear and stigma to raise money, but very little is going towards services, research into improved educational methodologies and things that have a practical impact on our lives" ("*I Am Autism*: An Advocacy Video Sparks Protest)"). Autistic writer Zoe Gross pushes against the metaphorical representations of autism that drive awareness campaigns like "Ransom Notes" and *I Am Autism*:

The idea of autism as separable from autistic people has lead professionals and parent-advocates to disregard the priorities and perspectives of autistic people themselves... many of the metaphors which surround autism foster the exclusion of autistic people by portraying us as non-entities-corpses, empty shells—or as being without agency awaiting rescue. (268-269)

Citing the metaphorical tone of *I am Autism*, the movement organized a complex and multi-layered collaboration in solidarity with over 60 disability rights groups around the globe. The international strategy targeted Autism Speaks national corporate sponsors with an intensive show of force in a letter that included a transcribed segment of *I Am Autism*, a detailed historical construction of activist frustrations with Autism Speaks and a call for funding re-allocation:

By choosing to portray Autistic people as husks of real people, stolen out of our own bodies, Autism Speaks reinforces stereotypes and prejudice against people with disabilities that have existed for centuries and have been the source of pain, segregation and violence. We are calling on you to end your support for Autism Speaks and to find new ways to show your support for Autistic people and others with disabilities... We are Autism's true voice—Autistic people and those with other disabilities ourselves, and our allies, family members, friends and supporters. Autism Speaks does not speak for us. We are not stolen—we are right here. Our lives may be difficult—but they are worth living. (ASAN, Letter to the Sponsors, Donors and Supporters of Autism Speaks)

Through the organized protest of *I Am* Autism, the cultural politics of the ND Movement moved beyond letter writing into an engaged and visible national protest throughout the public sphere.

Columbus ASAN members marched in protest of the Annual Autism Speaks Walk Event, offered signs of self-determination and carved their own definitions onto the landscape with messages such as, "Listen to Me, I have Autism," "Diverse not Diseased," "First-Class Autistic, Second-Class Citizen," "Autism Speaks Doesn't Speak for Me," and "Nothing About us Without Us" (ASAN Central Ohio). The Hilltop Online article Autistics Plea Less Pity, and TIME, The Huffington Post, Education Week, New Scientist, and Disability Scoop coverage of the increasingly contentious debate between the ND Movement and Autism Speaks indicates a significant shift in the way cultural industries are framing autism for public viewing.

In addition to the letter campaign targeting Autism Speaks' fiscal donors, autistic participation in media interviews and public protest of Autism Speaks Walk events, ASAN collaborated with the Dan Marino Foundation and Kent Creative to produce No Myths, an autistic written public service video that creates an alternative illustration for cultural consumers. No Myths features autistic testimonials narrated by Dena Gassner, Ben Liske, Jacob Pratt and Ne'eman and "offers a refreshingly positive and optimistic view about life with autism....written and performed by people who should know—individuals who are on the autism spectrum themselves"

(Ne'eman, No Myths). No Myths provides the stage for autistics to meaningfully claim authority over the definition of autism:

Autism steals. Autism leaves an empty shell. Autism is no hope, no future. These are not facts; these are myths... I am an autistic person and a national conversation about autism is happening without us. This has to change. Our futures have not been stolen; our lives are not tragedies. You must hear our voices. Leave the old stereotypes behind. (Dan Marino Foundation)

No Myths and the many additional modes of resistance and counter-campaigns constructed by the ND Movement succeeded in capturing media attention, public interest and the concern of executives at Autism Speaks, whose Chief Community Officer expressed I Am Autism "was received well at the event... controversy came later when it was posted on the web. The video has been pulled from Autism Speaks Web site, but remains on YouTube... it's an artifact... it exists" (Fine). An Autism Speaks representative also indicated, "Staff... made every effort to reach out to those who have expressed their disapproval" (Diament) and GRASP board members report they did receive a private apology.

In his exhaustive historical analysis of the ongoing contentions between Autism Speaks and the ND Movement, Carley recognizes, "some people within Autism Speaks were deeply offended by [the] video" and stresses the ND Movement should continue to "press Autism Speaks for preventative steps, not damage control, so that this never happens again" (The Autism Speaks Conundrum). Due to the insistent well-ordered, multi-layered and highly visible cultural political interventions of the ND Movement, Autism Speaks removed *I am Autism* from their website and publicly announced through multiple media platforms its exclusion from future awareness efforts.

Conclusion

The Neurodiversity Movement and Autistics are reframing debates about their lives, shifting mediated representations and commanding wider spaces in the cultural landscape. For Pickering, "the production of culture is inseparable from the culture of production" (59), and this work finds the production of autistic culture is an evolutionary process shifting between and within autistic narratives, the politics of the ND Movement and how mediated spaces and non-autistic agencies respond and react to their mounting influence. The cultural politics of autistic activism signify a resistance to those assumptions about autism driven by the deficit and cure ideologies. However, cultural politics are also "contestations over meanings... over the ways we make sense of our worlds and the ways we live our lives" (Mitchell 159)

and non-autistic governed productions such as *Autism Now*, "Ransom Notes" and *I* Am Autism provide the means for autistics to make sense of their own lives while transforming social assumptions about autism.

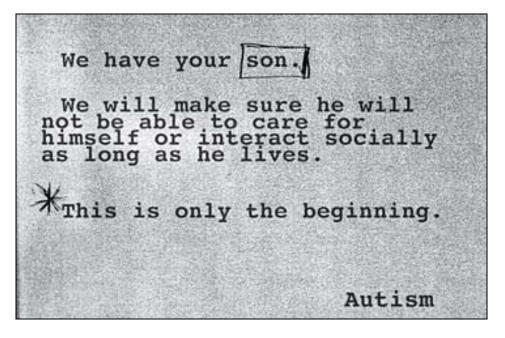
Autistics believe representational practices that actively seek to privilege their experiences can and will translate into dignified medical and psychiatric diagnostic conventions, therapeutic behavioral approaches that address individual embodied features, well-informed educators, policy decisions that reflect and respond to autistic needs and social norms that value autistic ways of being. Rubin envisions a different kind of social practice that embraces and finds value in multiple modes of autistic expression and communication:

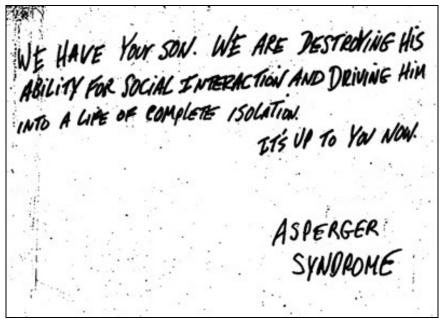
Not all communication is best served through speech. Art and music are great examples of languages that do not have to be spoken to be conveyed... look beyond the obvious, stop being lazy and look at things and others from a new perspective, it may not be comfortable, but at least it will broaden one's horizons. (105)

The ANI website argues, "supports for autistic people... should be aimed at helping them to compensate, navigate, and function in the world, not at changing them into non-autistic people" ("Introducing ANI"). Early in 2006, 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" (Autistic Self Advocacy Network), and GRASP aims "to improve the lives of adult and teens on the autism spectrum through community outreach, peer supports, education, and advocacy" ("The Origins of GRASP"). These valuable autistic-driven resources are readily available for practitioners, cultural industries, caregivers, educators, foundations, governments, societies and autistics to access and embrace.

In November 2012, the *United States House Committee on Oversight and Government Reform* held a hearing on autism policies, and for the first time, invited autistics and self-advocates into the discussions. The ND Movement and autistic individuals are now a powerful, visible and present culture influencing policy debates about their lives and the lived experience of those not yet diagnosed. Ne'eman affirms, "The rise of the autistic community has been the result of increased awareness and diagnosis, leading to more and more autistic adults who are ready to come together and to ask 'Where do we go from here?" (Ne'eman). Autistics are redefining autism and the cultural politics of autistic activism are creating new spaces in the cultural landscape, shifting boundaries, changing old paradigms and altering abnormality discourses. Autistic experience saturates the internet and appears more frequently in scholarly works. Autistic stories are readily obtainable through social media, self-advocacy

platforms, books and media productions. Further research into how this growing presence influences future legislation decisions, improves education policies, shifts discussions concerning autistic rights and inspires how society imagines future autistic experiences will demonstrate the effectiveness and value of this emerging civil rights movement.





Appendix 1 (Cripchick)

Works Cited

ASAN. "Autistic Adult Community Condems PBS NewsHour for Ignorant Remarks." 27 April 2011. *The Autistic Self Advocacy Network Public Policy*. 28 May 2011. http://www.autisticadvocacy.org.

—. "Autistic Self Advocacy Network." 11 April 2013. *Autistic Community Concerned about Robert MacNeil's Upcoming PBS Special "Autism Today"*. 5 May 2011. http://www.autisticadvocacy.org/modules/smartsection.

ASAN Central Ohio. *Protest Against Autism Speaks in Columbus*. 12 October 2010. 20 November 2010. http://asancentralohio.blogspot.com/>.

ASAN. "Letter to the Sponsors, Donors and Supporters of Autism Speaks." 7 October 2009. *ASAN smart section public policy*. 25 Febuary 2011. http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=63>.

Autism Speaks. *About Us.* 06 November 2009. 15 October 2010. http://www.time.com/time/health/article/0,8599,1935959,00.html>.

- —. "About Us Autism Speaks." 2011. 12 May 2013. http://www.autismspeaks.org/sites/default/files/docs/2011_accomplishments.pdf.
- —. *Autism Speaks History*. 2013. 15 June 2013. http://www.autismspeaks.org/about_us.php.
- —. "Autism Speaks: About Us." 2013. *Autism Speaks*. 8 December 2010. http://www.autismspeaks.org/about-us/annual-reports.
- —. Do you want to be in a world autism video? 2009. 12 November 2010. http://www.autismspeaks.org/news/news-item/do-you-want-be-world-autism-video>.
- —. In the News. Wrights Discuss Autism Research with Nobel Laureate. 2006. 19 November 2010. http://www.autismspeaks.org/news/news-item/wrights-discuss-autism-research-nobel-laureate.

Baggs, Amanda. *ballastexistenz*. 2008. 15 august 2010. http://ballastexistenz.autistics.org/?page_id=2.

Biever, Celeste. "Poetic' autism film divides campaigners." *New Scientist* 29 September 2009. 20 November 2011.

.">http://www.newscientist.com/article/dn17878-poetic-autism-film-divides-campaigners.html#.UccXsM7n_IU>.

Biklen, Douglas. *Autism and the Myth of the Person Alone*. New York: New York University Press, 2005.

Bilken, Douglas. "Representing Autism: Culture, Narrative, Fascination." *Journal of Literary & Cultural Disability Studies* 3.1 (2009): 107-109.

Brown, David. "Autism rate rises nearly 80 percent in a decade." *The Washington Post* 30 March 2012: A01. 17 May 2013. http://articles.washingtonpost.com/2012-03-29/national/35447546_1_prevalence-of-autism-spectrum-asperger-syndrome-autistic-children.

Brown, Lydia. "Moving Forward." *Loud Hands: autistic people speaking.* Washington, DC: The Autistic Press, 2012. 364-365.

—. The Significance of Semantics: Person-First Language: Why It Matters. 4 August 2011. 25 May 2013. http://www.autistichoya.com/2011/08/significance-of-semantics-person-first.html.

Cain, Barbara. *Autism's Invisible Victims: The Siblings.* 30 November 2012. http://ideas.time.com/2012/11/30/autisms-invisible-victims-the-siblings/>.

Carley, Michael John. "The Autism Speaks Conundrum." 2009. *GRASP* . 12 December 2010. http://grasp.org.

CBC News. "The National." 10 December 2009. October 2010. http://www.cbc.ca/thenational/indepthanalysis/transcripts/story/2009/10/08/national-arineeman.html.

—. "The National ." *Positively Autistic*. Toronto: CBC News, 10 December 2009. October 2010.

http://www.cbc.ca/thenational/indepthanalysis/transcripts/story/2009/10/08/national-arineeman.html.

Centers for Disease Control. *Autism Spectrum Disorders (ASD's)*. 12 June 2012. 2012 12 2012. http://www.cdc.gov/ncbddd/autism/index.html.

CNN Larry King Live. "Larry King Live: The Mystery of Autism." 22 March 2007. 14 April 2011. http://poac-nova.org/newsmanager/news_article.cgi?news_id=1263.

Cripchick. *Scary Ransom Notes Campaign*. 2007. 12 October 2010. http://misscripchick.wordpress.com/2007/12/14/scary-ransom-notes-campaign/.

Dan Marino Foundation. *No Myths.* 2009. Video . 2010. http://vimeo.com/34466821.

Diament, Michael. *Autism Speaks Pulls Video As Critics Turn Up Heat*. 2 October 2009. 22 March 2013. http://www.disabilityscoop.com/2009/10/02/autism-speaks-apology/5624/.

Fine, Lisa. Video for Autism Advocacy Group Sparks Controversy. 29 September 2009. 24 March 2011.

http://blogs.edweek.org/edweek/speced/2009/09/autism_video_campaign_sparks_c.html.

GRASP.org. The Origins of GRASP. 2004. 20 January 2011. http://grasp.org/.

Gross, Zoe. "Metaphor Stole My Autism: The Social Construction of Autism as Separable from Personhood, and its Effect on Policy, Funding and Perception." *Loud Hands, autistic people, speaking.* Washington, DC: The Autistic Press, 2012. 258-269.

Hall, Stuart. "The Whites of Their Eyes." *Gender, Race and Class in Media: a critical reader.* Ed. Gail Dines and Jean M. Humez. 3rd. London: SAGE Publications, 2011. 81-94.

Huffington Post. I Am Autism Video Draws Controversy. 18 March 2010. 17 April 2012. http://www.huffingtonpost.com/2009/11/09/i-am-autism-advocacy-vide_n_351296.html.

In My Language. By Amanda Baggs. Dir. Amanda Baggs. Perf. Amanda Baggs. 2007. You Tube. http://www.youtube.com/watch?v=JnylM1hI2jc.

Johansen, Jan. *Autism The Latest Global Epidemic*. 2013. 13 June 2013. http://www.newswire.net/newsroom/financial/74620-autism-the-latest-global-epidemic.html.

Kaufman, Joanne. "Campaign on Childhood Mental Illness Succeeds at Being Provocative ." *New York Times* 14 December 2007. 16 October 2010. .">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://www.nytimes.com/2007/12/14/business/media/14adco.html?_r=1&>.">http://

Kellner, Douglas. "Cultural Studies, Multiculturalism, and Media Culture." *Gender,* Race, and Class in Media: a critical reader. Ed. Gail Dines and Jean M. Humez. Thousand Oaks: Sage Publications, Inc, 2011. 7-24.

Kras, Joeseph F. "The "Ransom Notes" Affair: When the Neurodiversity Movement Came of Age." *Disability Studies Quarterly* 30.1 (2010).

Kristoff, Nicolas. "Do Toxins Cause Autism?" *The New York Times* 24 February 2010. 3 July 2010.

http://www.nytimes.com/2010/02/25/opinion/25kristof.html?_r=0.

Lakew, Genet. "Autistic Plea Less Pity." 2 November 2009. *The Hilltop Online*. 20 October 2010. http://thehilltoponline.com/autistic-ples-less-pity-1.2046862>.

MacNeil, Robert. *PBS NewsHour Health*. 11 April 2011. 23 October 2011. http://www.pbs.org/newshour/bb/health/jan-june11/autismquestion_04-26.html.

Masland, Molly. *Children in the grip of autism.* 23 2 2005. 12 November 2010. http://www.nbcnews.com/id/6901860/ns/health-mental.

McCarthy, Jenny and Jim Carey. "Jenny McCarthy My son's recovery from autism." 2 April 2008. *CNN.com/US*. 13 March 2013.

http://www.cnn.com/2008/US/04/02/mccarthy.autsimtreatment/index.html?_s = PM:US>.

Mitchell, Don. Cultural Geography A Critical Introduction. Malden: blackwell Publishing, 2000.

Montgomery, Cal. "Defining Autistic Lives." 30 June 2005. Ragged Edge Online. 12 January 2011.

http://www.raggededgemagazine.com/reviews/ckmontrubin0605.html.

Murray, Stuart. "Autism Functions/The Functions of Autism." *Disability Studies Quarterly* 30.1 (2010): 1-20. http://www.dsq-sds.org/article/view/1048/1229>.

—. Representing Autism Culture, Narrative, Fascination. Liverpool: Liverpool University Press, 2008.

—. Representing Autism, Culture, Narrative, Fascination. Liverpool: Liverpool University Press, 2008.

Nadesan, Majia Holmer. Constructin Autism Unraveling the truth and understanding the social. New York: Routledge, 2005.

Ne'eman, Ari. 2007. http://autisticadvocacy.org.

—. An Urgent Call to Action. 7 December 2007. 12 October 2010. http://www.autisticadvocacy.org/modules/smartsection/item.php?itemid=21.

—. No Myths . 2009. 6 October 2010.

http://asansouthwestohio.blogspot.com/2009/04/no-myths-autism-psa-different-kind-of.html.

Neeman, Ari. *Scary Ransom Notes Campaign*. 14 December 2007. 8 October 2010. http://www.misscripchick.wordpress.com/2007/12/14/scary-ransom-notes-campaign/.

Ne'eman, Ari. "The Future and The Past of Autism Advocacy, Or, Why the ASA's Magazine, The Advocate, Wouldn't Publish this Piece." *Disability Sturdies Quarterly* 30.1 (2010).

New York University Child Study Center. "Press Room Ransom Notes." 1 December 2007. *About Our Kids.* 2009.

<www.aboutourkids.org/files/news/press_room/assets/ransom_notes_release.pdf
>.

Oprah.com. *Living with Autism.* 5 April 2007. 9 December 2010. http://www.oprah.com/world/Living-with-Autism>.

Pace, Giacinta. *Philanthropist wages fight to cure autism.* 12 November 2009. 11 December 2010. http://www.nbcnews.com/id/33868343/ns/us_news-giving/t/philanthropist-wages-fight-cure-autism/.

PBS. Robert MacNeil Returns to NewsHour for Autism Now Series. 1 April 2011. 11 April 2011. http://www.pbs.org/newshour/video/archive/2012/04/24/index.html.

Pickering, Michael. Research Methods for Cultural Studies. Edinburgh: Edinburgh University Press, 2008.

Robertson, Scott and Ari Neeman. "Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia." *Disability Studies Quarterly* 28.4 (2008).

Robertson, Scott and Ari Ne'eman. "Autistic Acceptance, the College Campus, and Technology: Growth of Neurodiversity in Society and Academia." *Disability Studies Quarterly* 28.4 (2008).

Rubin, Sue. "A Conversation with Leo Kanner." Biklen, Douglas. *Autism and the Myth of the Person Alone*. New York: New York University Press, 2005. 82-109.

Scelfo, Julie and Barbara Kantrowitz. "Families Cheer as Autism Bill." *Newsweek/Daily Beast* 6 December 2006. http://www.thedailybeast.com/newsweek/2006/12/06/families.

Shulman, Robin. "Child Study Center Cancels Autism Ads--Many People Found Campaing Offensive." *The Washington Post* 20 December 2007: 27.

Sinclair, Jim. "Autism Network International: The Development of A Community and its Culture." January 2005. *Autism Network International.* 28 October 2010. http://autreat.com/History_of_ANI.html.

- —. "Being Autistic Together." Disability Studies Quarterly (2010).
- —. "Bridging the Gaps: An Inside-Out View of Autism." Schopler, Eric and Gary Mesibov. *High-Functioning Individuals with Autism.* New York: Plenum Press, 1992.
- —. *Don't Mourn For Us.* June 1992. 20 October 2010. http://www.autreat.com/dont_mourn.html>.
- —. "Introducing ANI." 6 June 2002. *Autistic Network International.* 10 October 2010. http://autreat.com/History_of_ANI.html.

The United Nations. "World Autism Awareness Day." 21 January 2008. *United Nations*. 9 December 2010. http://www.un.org/en/events/autismday/>.

Wallis, Claudia. "'I Am Autism': An Advocacy Video Sparks Protest." *TIME* 06 November 2009.

http://www.time.com/time/health/article/0,8599,1935959,00.html.

Wright, Bob. "Autism Speaks. It's time for the world to listen." *The Times London* 28 October 2008: 32.