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Neurodiversity and Disability: An Analysis of Social Movement Framing in Dialog Between Parents and Autistic Self-Advocates

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Neurodiversity and disability: An analysis of social movement framing in dialog

between parents and autistic self-advocates

BY

Thomas B. Linehan

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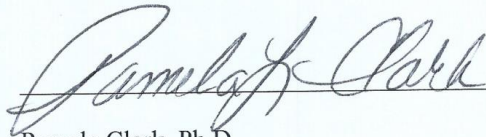
AN ABSTRACT OF THE DISSERTATION OF Thomas B. Linehan for the degree of

Doctor of Education in Learning, Leadership, and Community presented on August

19, 2014.

Title: Neurodiversity and disability: An analysis of social movement framing in dialog

between parents and autistic self-advocates

Abstract approved:

Pamela K. Clark

Pamela Clark, Ph.D.

Dissertation Committee Chair

Neurodiversity, the idea that people experience the world differently based on their

neurological attributes, is emerging as an understanding of autism and other

disabilities as well as the basis of a social movement. This is an idea not without

controversy. Using disability studies as the conceptual anchor, this dissertation looks

closely at an online dialog between two key stakeholders in the neurodiversity debate;

parents of children with autism and autistic adult self-advocates. Using frame analysis

as analytic tool, it explores social movement frames and framing practices utilized in

the dialog. Both the particular dimensions of autism/disability representations that

emerged and the practices used by dialog participants to construct them have

implications for educators, which are discussed.

Dissertation of <u>Thomas B. Linehan</u>

Presented on <u>August 22, 2014</u>

APPROVED:

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Dissertation Committee Chair

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Dissertation Committee

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Dissertation Committee

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Associate Vice President for the College of Graduate Studies

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Thomas B. Linehan, Author

ACKNOWLEDGEMENTS

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Abstract

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the dialog. Both the particular dimensions of autism/disability representations that

emerged and the practices used by dialog participants to construct them have

implications for educators, which are discussed.

Chapter 1: Introduction

When a young child's developmental progress worries his or her parents, it often creates great uncertainty and stress. Sometimes, depending on the nature of the worry, the right actions are clear for parents. With a broken arm or sore throat, for example, what to do, who should do it, and even how worried to be, seems relatively clear. When a parent's or caregiver's worries involve a child's ability to communicate, his or her ability to interact with others, and the presence of strange repetitive behaviors, then what to do and how worried to be is far less clear. These are the worries parents experience when they first encounter autism.

There are many definitions, explanations, and sources of information concerning autism available to those seeking answers. However, answers to even the basic question, what is autism, will vary greatly depending on who you ask. A health care provider may give one answer. The parent of a child with autism may give another answer. An adult self-advocate, who may prefer to be called autistic (Sinclair, n.d.) will give another. The various answers are tied to beliefs about the nature of disease, disability, and normal variations in human neural functioning.

The ways in which educators create an understanding of autism spectrum and related disorders from these various available perspectives have implications for educational practice. In other words, the way a teacher teaches a child with a disability is tied to how that educator understands the disability (Valle & Connor, 2011).

Recently, there have been discussion and debate on the nature of autism playing out online, in books, and in movies (Langan, 2011). Two groups have been

prominent in the national online discussions: parents of children with autism spectrum

disorders (ASD), who have challenged the health care providers' definition and

understanding of autism, and autistic adult self-advocates, who put forth the concept

of neurodiversity, which defines autism as a normal variation and an integral part of

identity. Educators are in the unique position of interacting with both the parents of

children with autism and students with autism who will grow up to be adults,

influenced by and influencing community and societal level discussions of adult

autistics.

Theoretical Positions of the Study

Many students and emerging scholars are exposed to a basic conceptualization

of research as the exploration of a question through the measurement of a variable.

This measurement takes place through the use of an instrument of some type, such as a

survey. This simplistic view of research, meant merely as an illustration and not a

commentary, is most closely aligned with quantitative research. The process of

qualitative research involves the analysis of raw data in the form of observations,

interviews, and texts. Throughout the research process, and particularly the analysis

and interpretation of the data, it is an accepted stance to understand the researcher as

the research instrument (Xu & Storr, 2012). It is in adopting this perspective that it

becomes imperative for the researcher to understand and make explicit his or her

theoretical, philosophical, and personal positions relative to the research.

This study is grounded in a disability studies (DS) perspective of ASD. DS

moves beyond describing disability primarily as a series of deficits to an

understanding of disability that defines it as the social and cultural reactions to

differences in human functioning (Gabel, 2009). Cultural representations of disability are created and passed on largely through the symbolic resources afforded by language. Discourse can be understood as any spoken or written utterance as well as any system of meanings created through verbal or written language (Gee, 2005). Thus the study of discourse through discourse analysis is a means for a close examination of the processes through which varying understandings of autism are created and promulgated. This study centered on a discourse analysis of representations of autism from a DS perspective. This study looked closely at a particular case, an online dialog between parent advocates and adult self-advocates in the form of a series of alternating blog posts hosted by an online autism web site.

Position of the Researcher

I have experienced disability personally, as an individual diagnosed with Nonverbal Learning Disability (NLD), which some consider related to Asperger's syndrome (Asperger's Society of New England, n.d.), as the parent of a child with a learning disability, and as a professional working with young children with disabilities and their parents. However, as a researcher and practitioner informed by interpretive and social constructionist perspectives, I am making this position explicit as part of the analysis.

In preparation for this research, I undertook a firsthand exploration of my personal identity as a person experiencing disability. This part of my doctoral studies was not formal research and can best be understood as a sensitizing experience. I attended a series of social groups and conferences in different regions of the same state intended for adults with Asperger's syndrome and related disorders. These

groups were sponsored by a nonprofit organization and the groups were facilitated by professionals. I attended some of the groups as a participant, thus making my own disability status clear to the participants and the facilitator, because participation was only open to those diagnosed with Asperger's syndrome and related disorders. I attended other groups as a guest/observer, leaving my personal disability status ambiguous. Contrasting these two experiences gave me the opportunity to reflect on the process of constructing identity and disability status through interacting with others in everyday situations. I have also experienced this process as a teacher, as the parent of a child diagnosed with a neurodevelopmental disability, and as a person with a disability. I have repeated this process of negotiating identity in relation to disability status countless times in many contexts throughout the years. The focus of this study, the co-creation of disability and identity through social interaction, is not merely an abstract idea, but is something of import that I have experienced personally.

Purpose of the Study

The purpose of this study was to look closely at the various discourses of stakeholders in the current public discussion on the nature of autism. The aim of this research was to provide insight and understanding and to inform the practice of educators.

Research Questions

1. What resources and techniques do autistic self-advocates and parents of children with autism use to construct a specific understanding of autism for themselves or their children?

2. How do these constructs impact the relationship of these two groups?

3. How might understanding the views of these two groups inform educators' practice?

List of Terms

Autism spectrum disorders (ASD): refers to a group of neuro-developmental disorders described in diagnostic systems used by health care providers and delineated in the Diagnostic and Statistical Manuals of the American Psychiatric Association (APA) and the International Classification of Diseases issued by the World Health Organization (Frith, 2003). From the 1940s through the end of the 1980s, autism was a relatively uncommon diagnosis. In 1987, the category of autism was expanded by the APA to include the broader category of pervasive developmental delay (PDD). In 1993, the APA expanded the autism category further by including Asperger's syndrome (Chamak & Bonniau, 2013). It is these diagnoses, autism, PDD, and Asperger's syndrome, that comprise the autism spectrum (Frith, 2003).

Disability studies: An interdisciplinary field of study that focuses on multiple dimensions of disability and in which disability is defined as the social and cultural responses to human differences (Gabel, 2009).

Neurodiversity: The concept that neurological differences represent an addition to familiar cultural/political categories such as race, class, and gender (Armstrong, 2010).

Self-advocate: Characterized by the saying "Nothing about us without us," self-advocacy by persons experiencing disability has a long history and articulates the right of people experiencing disabilities to control all aspects of their lives (Scotch, 2009). In this paper, adult self-advocates refers to the more recent self-advocacy sub-

movement of autistic adults advocating for a neurodiversity perspective on autism
(Autistic Self-Advocacy Network, n.d.).

Parent: One who is parenting. For this study, it is recognized that many
people are in the role of parents, whether permanent or temporary, for a variety of
reasons. Grandparents as parents, aunts, uncles, significant adults, etc.…

Parent advocate: A parent or person who is parenting a child who advocates
for appropriate services and protects the rights and wellbeing of the child(ren) in his or
her care. As in adult self-advocacy, parent advocacy has a long history and has
resulted in many positives in the lives of persons experiencing disability, particularly
in the deinstitutionalization and creation of community services for persons with
disabilities and their families.

Autistic: A person diagnosed with autism. This term is used by many adult
self-advocates as an alternative to the phrase "person with autism." Jim Sinclair
(1993) first articulated that the phrase "person with autism" implies that the person's
identity can be separated from autism or that if autism is a part of the person, it is not a
very important part.

Language

Language is the primary medium for representing ASD and referring to those
who have been diagnosed or are experiencing being labeled as autistic. I must use
language to refer to children and adults with autism. There are various means of
referring to someone diagnosed with autism; autistic adult, child with autism, person
experiencing the label of autism. Each of these examples makes a specific distinction
and points to a certain understanding of autism. In this paper, I follow parent

advocates who seek to make the distinction between their child and the disorder. Therefore, when referring to children or the views of parent advocates I use person first language, i.e., child with autism (Snow, 2001). When referring to adults with the disorder, I follow identity first language i.e., autistic adult. This term implies that autism is an integral part of the adult's identity and cannot be separated from the person (Sinclair, n.d.). I only break my own convention as described here when referring to the work of another author who has adopted a different standard. When possible, I make the distinctions that are being drawn explicit.

Chapter 2: Review of the Literature

Current understandings of autism are the result of varied and often conflicting public and institutional representations. These understandings at once reflect and create the possible realities of living with ASD (Lester, 2012). The current ecology of understandings of autism can be understood in terms of the history of several parallel developments. The first is the initial and subsequent representations of autism as put forth by medical, academic, and educational professionals. The second is the rise of parent advocates in response to shortcomings in the dominant medical understandings of autism, which have provided an inadequate understanding to guide the everyday lives of families and children with autism. The third is the rise of adult self-advocates, again in response to the inadequacy of the dominant medical discourses of autism, to facilitate the everyday lives of adult autistics. The final development is the evolution of adult self-advocates as the spokespeople for a social movement focused on community, identity, equity, and civil rights. This view contrasts with an early focus on finding a voice and receiving adequate support and services. Following a similar trajectory, there has been a group of educators drawing on the field of DS attempting to broaden the medical understandings underpinning much of special education with understandings that incorporate the social, cultural, and social justice dimensions of disabilities like autism.

Representations of Autism

Autism is a disorder, condition, set of differences, disability, and/or an identity that is very difficult to describe. The descriptions tend to come from a group of people with an interest in understanding and representing their understandings of autism to

others. These groups can be described as a community of interest. Autism is unique, perhaps because even within these communities of interest, understandings can be highly variable. There has been a recent proliferation of news articles about, and television and movie characters with, autism. Arguably, other communities of interest are emerging with a stake in how autism is represented and a role in shaping those representations, which includes the news, popular books, and entertainment media. Major communities of interest that provide representations of autism include the medical community, the education community, the community of parents or caregivers of children experiencing autism, parent advocates, and adults experiencing autism, adult self-advocates.

Medical Model Descriptions

It is hypothesized that literary representations of autism predate the establishment of autism as a disease or disorder. For example, Lane theorized that an account of the wild boy of Aveyron by Itard in the 1801 book *De l'Education d'un Homme Sauvage*, who was thought to have been brought up from infancy in the wild, was actually the story of a child with autism whose desperate parents, unable to care for him, abandoned him in the woods (Frith, 2003). The descriptions of autism by two physicians who were contemporaries, Kanner and Asperger, published 1943 and 1944 respectively (Frith, 2003), are most often cited as the first formal representation of autism. Most communities of interest discuss their own understanding of autism as bearing some relationship to the understandings put forth by the medical community, commonly referred to as the medical model; they may also offer an explicit dismissal

of the medical model, an addition to the medical model, or an alternative biomedical model.

The medical model focuses on defining autism in terms of the individual patient's functioning, as compared to others who are not affected by the condition. Within the medical model, the goal is treatment, cure, or at least amelioration of the negative impacts of the condition, in this case autism. This represents the traditional role and set of values of the medical world, which to a large extent have been adopted by the educational practitioner community. It is the role of medical practitioners to recognize, diagnose, and respond to any condition or difficulty in their patients. The exact nature of that difficultly or condition can vary considerably. With some conditions, for example a paper cut, there is a satisfying, physical, though perhaps painful, aspect to the experience. It involves the body; the injury is observable. There are mechanisms through which the body will heal itself. It all seems so straightforward. However, even with this somewhat simplistic example, many questions could be asked: Could the injury result in an inability to work or perform household duties? Could the cut have been avoided? Would most people avoid the injury? If it occurred at work, should the employer be held responsible? How will other people treat you if you have a paper cut? What laws should be passed in regards to paper cuts? Even though there is an observable site of injury and an articulable, observable process of healing (perhaps a microscope is required for full observation), there are still lots of questions about the implications of having a paper cut.

With autism, there is no observable site on or in the body that can be pointed to or directly observed. In other words, there are no biological markers for autism (Frith,

2003). It is typically diagnosed by the medical community by identifying a cluster of behaviors described as deficits displayed by those diagnosed and labeled as having autism. Often described as the triad of impairments, autism is diagnosed when there is evidence of qualitative impairment in reciprocal social interaction, qualitative impairment in communication, and restricted repetitive and stereotyped patterns of behavior interest or activities. The medical model hypothesizes that there are corresponding defects in the mental processes that result in the triad of impairments that define autism.

Theory of Mind Hypothesis and Other Theories of Autism

The ability to understand that others have thoughts, motivations, and a mental life of their own has been called having a theory of mind (Barnbaum, 2008; Baron-Cohen, 2008; Frith, 2003). The inability to recognize the existence of a mental life in others has been posited as an explanation for the core deficits of autism.

The weak central coherence thesis suggests that the defining deficits of autism can be understood as a deficit in the mental ability to draw inferences about the whole by observing parts of a phenomenon. This skill is essential in creating mental models. The lack of this skill would mean that every phenomenon would seem new in each encounter and all details would be of equal importance (Snyder, 1998). This skill deficit could explain difficulties in social interactions; communication, particularly restricted interests; and obsession with details.

The weak executive function theory describes deficits in the mental processes known as executive functioning, which is the ability to manage complex tasks through prioritizing, switching between them, and problem solving. It is hypothesized that

deficits in executive functioning can account for the existence of the triad of impairments that define autism (Barnbaum, 2008). Presently, there is no known brain scan technology that can find deficits in the presumed neurological structures and processes implied by the theories above.

Therefore, even within the medical model, the focus on individual deficits this understanding of autism puts forth is in a sense interpretive and tentative by nature. When one adds further questions, as in the paper cut example, about the social and political nature of autism, the complexity of understanding and representing autism becomes apparent. It is important to note that describing the responses of medical practitioners and the medical community as the term medical model is somewhat misleading. The medical model may be more accurately understood as a discourse community, a culture of meaning making, with traditions, beliefs, roles, and values. It is one of the many such discourse communities that has a stake in creating an understanding or representation of autism.

Psychiatric Understandings of Autism and Families

The first public knowledge of autism was the result of the work of psychiatrists Leo Kanner and Hans Asperger, which took place roughly at the same time in the 1930s. Professionals, families of children with autism, and the public became familiar with the condition through the dominant theory of the time, psychoanalysis. Through the psychoanalytic lens, autism was described as a form of early onset psychosis. In the 1950s, Bruno Bettelheim, a child psychoanalyst who had survived the Dachau concentration camp, expanded the then current understanding of autism. He believed that the interior experience of a child with autism was similar to the external

experience of concentration-camp prisoners; they withdrew from the world in order to protect themselves. In the case of children with autism, Bettelheim posited that they were withdrawing in reaction to a cold, hard, and unresponsive mother (Feinstein, 2010). This early understanding of autism comes from the tradition of psychoanalysis and describes autism as a form of psychosis brought on by a type of psychopathology present in the mother. This pathology prevented her from reacting normally, read warmly and responsively, to her infant's needs. The treatments that flowed from this conceptualization included institutionalization of the child to prevent further contact with the cause of the problem, the mother (Feinstein, 2010).

Birth of Parent Advocacy

The explanation of autism targeting supposedly dysfunctional parent-child interactions as the cause proved to be an insufficient understanding of autism. It angered mothers and families who were shut out of the lives of their children in the name of treatment. This gave rise to the first round of parent advocates who questioned the information about the disorder coming from medical professionals (King, 2009; Langan, 2011).

This move toward parent advocacy took place in the context of, and was made possible by, a parallel wave of parent advocacy that was responding to similar discrepancies between professional responses and the everyday experience of families. These early parent advocates were parenting children with physical, sensory (deaf, blind, and deaf/blind), and developmental disabilities. At this time, the 40s and 50s, professional services for disabled children were delivered through residential institutions. Thus, parents could keep their children at home and receive no support or

turn their children over to the institution. Educational and health care professionals

often advocated institutional placement as the best way for young children to receive

services during the early stages of development, when early training was seen as

crucial. Parents were told that keeping children at home would deprive them of

needed therapeutic and educational services available only in institutions (Leiter,

2004). Early parent advocates began organizing locally to close the gap between

families and institutions: advocating for increased access to children while they were

in the institutions; transparency; a say in the operation of the facilities; and eventually

home and community support and services to allow children with a disabilities to

remain at home. Local organizations grew into national organizations. After WWII,

national organizations, each centering on a particular disability, proliferated. Some of

the first to form were groups working to improve the availability of community-based

services for individuals with what was then called mental retardation. This may have

been the first time that famous parents, Pearl Buck and Dale Evans Rogers, spoke as

parent advocates. This trend continues in current autism parent advocacy, with

famous parents of children with autism, such as actress/model Jenny McCarthy,

publicly advocating for children with autism (Leiter, 2004).

Current Parent Advocacy

This type of advocacy contributed to the shifting of the mainstream medical

community's conceptualization of autism from a psychiatric disorder to a

neurodevelopmental disability with a presumed genetic component (Feinstein, 2010).

This conceptualization has led to the creation of medical and educational interventions

flowing from this perspective. One intervention that has had significant impact on

how autism is understood and experienced by parents and caregivers is applied

behavior analysis (ABA) (Broderick, 2011). O. Ivar Lovaas was the first to describe

the use of intensive behavioral treatment, ABA, with young children with autism

(Lovaas, 1987). This treatment approach, a version of which remains in widespread

use, is also significant for being the first to offer the hope of recovery from autism

(Broderick, 2009, 2011). This hope for recovery can be understood as a rhetorical,

language-based construction rather than an operationalized treatment outcome,

particularly when considering the exact meaning of the term recovery. The absence of

a precise definition of this term points to the social construction of autism, perhaps

surprisingly, embedded in representations presented as objective scientific

understandings. As stated by Broderick:

> However, given the epistemological (positivist), methodological (quantitative,
> experimental, treatment effect design), and theoretical (operant behaviorism)
> grounding of Lovaas's research, it seems unlikely that a behavioral researcher
> would fail to provide an operational definition for such a provocative
> description of an outcome. This omission suggests that perhaps the power of
> the term recovery lies in its rhetorical, rather than its operational, use. Thus,
> the term did not neutrally describe an observed outcome; rather, it constructed
> the framework through which we understand and constitute our own
> perceptions of outcome for young children labeled with autism within the
> discursive practices associated with ABA. (Broderick, 2009, p. 274)

The promise of recovery that began with the introduction of ABA therapies

continues through to the present. There are current autism controversies that are

centered around challenges to the current medical understanding of autism as a neurodevelopmental disability, countering these understandings with a biomedical conceptualization of autism as being caused by environmental toxins. This challenge again holds the promise of recovery from autism and again, as in the early days of the parent advocacy movement, features at least one prominent celebrity spokesperson, Jenny McCarthy (King, 2009). McCarthy, a famous model and actress, voices her position through books, media appearances, and support of Generation Rescue, an autism organization that promotes the viewpoint that autism is caused by environmental toxins. Specifically, its position is that autism is the result of poisoning caused by mercury contained in vaccines and that the health care and vaccine industries are complicit in covering up this fact (King, 2009). Though there are many studies that fail to support a causal connection between the onset of autism and mercury in vaccines, many parent advocates and advocacy groups challenge the evidence against the vaccine theory, not by questioning the facts of the research, but rather by questioning the motives of the health care and pharmaceutical industries which produce vaccines (King, 2009).

Several studies have looked at the parent's initial reaction to the diagnoses (Brogan & Knussen, 2003; Mansell & Morris, 2004; Nissenbaum, Tollefson, & Reese, 2002). These studies found the initial process of diagnosis stressful for parents. The pragmatic concerns of managing behavior, finding services and supports, and finding the resources to sustain them were of major concern for parents (Leiter, 2004). Several studies have described parents as being burdened and buried by autism (Hines, Balandin, & Togher, 2012; Leiter 2004; Stuart & McGrew, 2009). Parents then seek

relief from these burdens in the form of cures and treatments. By contrast, in an ethnographic study of support groups for parents of children with autism, Cascio (2012) found that despite the heavy investment in the search for treatments, support for the idea of autism as a difference, which she describes a neurodiversity sentiment, was also present. In an online survey of 657 autistic people, parents of people with autism, and friends and relatives of people with autism, Kapp, Gillespie-Lynch, Sherman, and Hutman, (2012) found a possible convergence between a deficit model and a social/difference model of autism.

The social/difference understanding of autism is held by parent advocates countering the medical model. It involves understanding autism as a natural variation in neurological functioning that occurs in some children and adults (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2012).

Birth of Adult Self-Advocates

The emergence of the adult autistic self-advocacy movement can be seen as arising from the larger disability rights movement, which can be seen as arising from the even larger civil rights efforts of the 60s and 70s. The focus of this movement has echoed the civil rights movement's focus on the group member's experiences of marginalization, disenfranchisement, discrimination, stigmatizing, and stereotyping as a result of his or her minority status (Gabel, 2009). As with the rise of parent advocates, the rise of autistic self-advocates occurred, at least in part, in reaction to the inadequacy of biologically based medical understandings of autism. The efficacy of interventions and supports for employment are of concern to autistic adults, as are the challenges inherent in trying to change oneself in order to accommodate the non-

autistic world. In response to these tensions, and in keeping with the social model of disability, the notion of autism as deficits residing in individuals that need to be corrected is being challenged. The counter-narrative being offered by adult self-advocates views autism as a difference and disability arising from the interaction of the individual with the social environment (Broderick & Ne'eman, 2008; Brownlow, 2010; King, 2009). As stated by Bagatelle (2010), "Although most interpretations of autism remain firmly grounded in the biomedical paradigm, individuals with autism, through narrative self-representation and organized activities, are themselves attempting to transform how autism is considered" (p. 33). The evolution of these ideas over time and the increasingly widespread use of online platforms have led to a community of self-advocates organized around the central idea of neurodiversity.

Autism as Identity and Community

As the dominant model of autism defined by deficits, specifically the triad of impairments, has been challenged and has evolved, alternative representations have emerged. These alternatives, as put forth by adult self-advocates, have led to a community that has defined autism as a set of neurological differences that lead to an identity and way of life. Bagatelle (2010) identified three historical trends leading to the emergence of a community of adults identifying as autistic. The first trend is the broadening of the definition of autism and the phenomenon of people receiving their first diagnosis as adults. The second is the self-determination and self-advocacy movement pioneered by individuals with developmental disabilities. The third is the use of Internet technology and online writing to facilitate collective meaning making. For many autistics, the asynchronous nature of writing on the Internet allows for a

very different, less isolated form of expression that some have described as akin to American Sign Language or Braille (Bagatelle, 2010; Jordan, 2010).

Though an autism community is emerging, claiming and negotiating an autism identity on a day-to-day basis is by no means straightforward or inevitable. Davidson and Henderson (2010) analyzed 45 autism biographies. They found that autistic authors described managing identity, deciding whether to come out on the autism spectrum, as parallel to the experience members of other marginalized groups. As a consequence, autistic autobiographers also spent time in their narratives defining and promoting a community to which to come out. A common theme in online communities of autistic individuals is the legitimacy of the experience of living with autism as a knowledge base that can challenge biomedical authority, as well as the related theme of autism as difference and identity versus a collection of deficits. This is not to say that living with autism is portrayed as being without challenges; rather, the challenges are understood as being rooted in a reaction to their differences from those who do not have an autism diagnosis (Brownlow & O'Dell, 2006).

As public and scientific representations of autism have evolved and changed, so has the everyday experience of autistic adults. The seemingly abstract activity of talking about and representing autism through the symbolic medium that is language at once reflects and creates the reality of autism. Themes, tropes, and metaphors are the building blocks of this reality (Broderick & Ne'eman, 2008; Duffy & Dorner, 2011). As stated by Duffy & Dorner (2011):

Perhaps one explanation of the seemingly endless fascination with autism in popular culture and in scientific literature is its status as an essentially narrative

condition. That is, despite numerous and ongoing efforts to identify and locate

a "biological marker" for autism spectrum disorders, autism yet remains

symptomatic, diagnosed through the subjective observations of behavior and

affect. This means that diagnoses of autism are essentially storytelling in

character, narratives that seek to explain contrasts between the normal and the

abnormal, sameness and difference, thesis and antithesis. (p. 201)

A current understanding of autism emerging from adult self-advocates present

clear counter constructions to biomedical deficit-based representations. These counter

constructions, which are often facilitated by Internet technology and take place online,

include the themes of consequences and opportunity inherent in coming out and

accepting an autistic identity, debates over who has the power to define autism, fitting

in to non-autistic society or insisting that society adapt to autism, and understanding

autism as a different alternative way of being rather than a deficit or disorder. These

constructions are leading to tension between adult self-advocates and parent

advocates. Self-advocates are advocating for acceptance of autistic culture, a

neurodiversity perspective, while parents are advocating for relief from the challenges

and struggles inherent in autism, a cure or at least effective treatments for autism.

Studies of online blogs support the idea that parents and self-advocates are split along

these lines (Clarke & van Amerom, 2008), whereas other studies show that the actual

beliefs of parents and self-advocates may be more compatible than first thought

(Cascio, 2012; Kapp et al., 2012).

Davidson and Henderson (2010) conducted a close reading of 45 autism

spectrum autobiographies. Using discourse analysis to anchor their methodology, they

identified several ways language is used to position the experience of autism and articulate aspects of identity in relation to other possible identities. From the text, they derived four meta-narratives or what they termed discourse repertoires related to managing identity. These were a *keeping safe* repertoire, which addresses managing the impact of assertive and autistic identity; a *qualified deception* repertoire, which describes decisions not to disclose and to pass as not disabled; a *like/as resistance* repertoire, which describes the tendency for autistic authors to describe the process of disclosing autistic disability status as akin to coming out in other marginalized groups, such as the gay and deaf communities, and a meta-narrative they named the *educational* repertoire, which is concerned with building a community that supports people who have asserted an autistic identity.

In an ethnographic study of 10 adults diagnosed with Asperger's syndrome conducted in a Swedish educational setting, Bertilsdotter Rosqvist (2012) found expressions of identity that struggled with the tension between fitting in and adapting to larger culture or demanding the culture accept and adapt to their differences. These tensions are consistent with Brownlow and O'Dell's (2006) observations of online communities. Themes from this study included the assertion that the experiential knowledge of adults with autism constitutes an expert knowledge that can and should challenge bio-medical or scientific knowledge.

Another clear theme involved the use of behavioral training of persons with autism as a means to make them more normal. In online forums, adult self-advocates express opposition to a goal of becoming more normal (Brownlow, 2010). These objections to forced normalcy and adaptation to normal or neurotypical (NT) culture

lead to other tensions, noticeably between adult self-advocates, who are looking for acceptance and validation of their own unique way of being in the world, and parents of children with autism, who are looking for the alleviation of pain and suffering through a cure (Bagatelle, 2010). These tensions were supported in the studies of Clarke and van Amerom (2007, 2008). They looked at online blogs of adult self-advocates identifying as Aspies (adult self-advocates with Asperger syndrome) and parents of children with ASD. Blogs of parents and organizations supporting autism define ASD as a disorder defined by deficits in functioning and call for treatments and cures for the disorder. In contrast, writing in blogs, adult self-advocates described themselves as happy with their differences and they further asserted that any suffering they may have undergone is a result of how society has responded to their differences.

Neurodiversity Controversy

Sociologist Judy Singer used the term neurodiversity to describe autism and other neurological conditions as normal variations in cognitive functioning. Further, she argued that neurodiversity represents a new addition to socio-political categories such as race, class, and gender (Jaarsma & Welin, 2012). The concept of neurodiversity counters prevailing deficit models of autism by defining neurological differences as normal variations in the human population. In addition the second feature of the neurodiversity understanding holds that normal variation in neurological functioning is akin to other types of differences, such as race and gender, which have implications for rights, non-discrimination, and other political concerns. This has become the conceptual basis of an autism rights movement that arose largely in response to the perceived marginalization of autistic adults (Kapp et al, 2012).

Advocates of neurodiversity view different though harmless behaviors, such as lack of eye contact, as part of human variation akin to cultural variation and promote dignity and meaningful inclusion in society over normalcy (Kapp et al., 2012). Though some self-advocates have acknowledged the necessity of interventions and supports to manage their personal challenges with behavior and communication, the goal is inclusion with respect for autistic differences versus intervention with the goal of allowing an autistic individual to pass as normal (Ne'eman, 2010; Kapp et al., 2012). The neurodiversity viewpoint of self-advocates is represented as a celebration of difference that opposes diagnoses and intervention to ameliorate deficits (Jaarsma & Welin, 2012). The celebration of difference that implicitly counters medical model-based practices has led to tension between parents of children with autism and adult self-advocates. Parent advocates seeking support and amelioration of difficulties such as self-injurious behaviors see treatments and cures as necessary and view the neurodiversity perspective as in opposition to these needs (Langan, 2011). Contributing to this tension is the question of for whom does neurodiversity apply. Many see the framework as applying only to adult autistics, who communicate directly through spoken language, are described as high-functioning autistic, and are seen as most able to benefit from neurodiversity. Those unable to communicate through spoken language, described as low-functioning autistic, are seen as unable to benefit from neurodiversity as a social movement (Jaarsma & Welin, 2012). This distinction implies that those who are high-functioning are closer to what is perceived as normal on a continuum from low functioning to high functioning. In fact, some individuals described as high-functioning can experience considerable difficulty with

such common activities in the general population as holding down gainful employment and maintaining meaningful relationships. Some low-functioning autistics are able to develop alternative communication methods and participate in many activities associated with the everyday life of the general population, illustrating the counter example (Biklen et al., 2005; Osteen 2008). However, parents of children with low-functioning autism experience the neurodiversity movement as a movement by and for high-functioning adult autistics and in opposition to their own advocacy goals of obtaining more effective treatment options and resources for their children with autism (Langan, 2011). The tension between parent advocates and adult self-advocates can be understood as differences in meaning making.

Theoretical Perspectives: Disability Studies

Attending to the meaning surrounding a disability, such as autism, has a considerable history. The field of DS is acknowledged to have begun with a proclamation by the Union of Physically Impaired Against Segregation in the UK in 1972 and the emergence of the social model of disability put forth in the UK by the disabled peoples' movement in 1975. The social model of disability drew a distinction between impairments and disability, with impairment understood as variations in human behavior, sensory acuity, and functioning (Reid & Valle, 2004) and disability as society's reaction to these variations. This emphasizes a primary tenet of the social model of disability which is that the social and cultural reaction to impairments is disabling rather than the physical impairments themselves. Social constructionism provides a lens through which to interpret how a social model of disability is accomplished as a practical matter. Though there are many variations of

social constructivist theories, generally social construction sees the terms by which the world is understood as social artifacts arising from human interaction (Gergen, 1985). As stated by Gergen (1985), "The degree to which a given form of understanding prevails is not fundamentally dependent on the empirical validity of the perspectives in question, but on the vicissitudes of social process (e.g. Communication, negotiation, conflict, rhetoric)" (p. 268). Different organizations, communities, institutions, and cultures evolve and maintain traditions for the social construction of disability. In the United States, public schools draw on the traditions of the biomedical model to identify and support students considered to have a disability (Reid & Valle, 2004).

Disability Studies in Education

There is currently a public discussion on the nature of autism and how society can and should respond to people and families experiencing this disorder. Educators are in the unique position of interacting with many of the stakeholders in this discussion, including the medical community, parents and families, and students with autism who may well need to develop self-advocacy skills in order to thrive as adult autistics. Some educators may be interacting directly with adult self-advocates. Given the plurality of views in the current public discussions and the wide range of stakeholders, developing an understanding of autism upon which to base practice is a complex undertaking for educators. DS is an emerging field of study that counters the deficit understanding of disability that is the basis for most special education theories and practices. According to Valle and Connor (2011), from the DS perspective, "Disability is viewed primarily through a social lens, as a series of historical, cultural, and social responses to human difference" (p. xi). The implication of this is that "how

we choose to respond to disability shifts significantly depending upon whether we perceive 'that something is "wrong" with disabled people' or 'something is "wrong with a social system that disables people".' Thus, how we educate students with disabilities has everything to do with how we *understand* disability" (Valle & Connor 2011, p. xi).

Operationalizing the Social/Cultural Model of Disability through Discourse

The field of DS moves the definition of disability away from a focus on deficits in the functioning of biological, neurological, or psychological processes located in the individual person to the social and cultural aspects of disability. The field presents an understanding of disability grounded in the social and cultural response to human difference (Valle & Connor, 2011). There is general acceptance that the first model of disability to account for the social and cultural responses to difference was the social model of disability put forth by the disabled peoples' movement in the UK. The second model, which emerged in the United States, is the minority group model, which was inspired by the civil rights movement. Adherents saw those with disabilities as akin to other minority groups experiencing oppression and marginalization (Gabel, 2009). Both these models originated in the late 1970s; since that time, a variety of conceptualizations of disability have been put forward by scholars in the field of DS. Gabel (2009) used the term *social interpretation model* as an umbrella term to refer to the various models of disability that account for the social/cultural responses to human difference. In order to propose a social interpretation model of disability as the basis of research, it is necessary to offer a

precise definition of culture and a framework for accounting for how disability is constructed through social interactions.

There are many definitions of culture. Each definition comes from a certain branch of social science and flows from a particular body of knowledge. Each definition carries implications for the nature of reality, what is knowable and of significance, particularly in terms of social and cultural reality. Definitions of culture range from the attitudes, beliefs, and practices of a community group as a whole to the theory that anthropologists create to understand a community group (Geertz, 1973). These examples can be considered as representative of definitions of culture, with many more definitions possible. The first definition assumes that a particular community group's attitudes and beliefs are held and propagated by all members of the group and can be learned through careful observation by an outside observer. This definition is problematic when considering the various understandings of autism brought forth by various groups of stakeholders, such as parent organizations and self-advocate groups. Each group advocating a particular understanding of autism has its own attitudes, beliefs, and practices. In fact, due to the number of different autism understandings in U.S. popular culture, a neutral outside observer may be a theoretical idea at best. Each observer will hold some view of autism or disability that will bear on how he or she understands what is observed. The second type of definition makes clear the bias of the observer. In the second example, using a definition of culture that is more or less an exaggeration to illustrate a point, the observer is completely outside and apart from the culture being observed. This idea is not reflective of the current reality of autism representations. These types of definitions of culture are incongruent

with the culture/subcultures under consideration, namely parents of children with autism, adult self-advocates, and educators. A definition of culture can only incorporate such varied understandings by attending to patterns and processes of meaning making. As stated by Geertz (1973):

> In any case, the culture concept to which I adhere has neither multiple referents nor, so far as I can see, any unusual ambiguity: it denotes an historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and attitudes toward life. (p. 88)

Culture is the current and historical patterns of understandings that describe and shape the worldview of cultural group members and therefore cultural analysis is not an experimental science; rather, it is an interpretive endeavor to explicate these interconnected meanings (Geertz, 1973).

How, then, can a researcher conceptualize this ecology of meanings and the practices that create and sustain it? Discourse can be understood as any written or verbal communication. It is also a system of meanings created through written and/or spoken language, which simultaneously describes and constructs a coherent worldview of attitudes, assumptions, and beliefs. A discourse also encompasses the practices involved in creating and sustaining the systems through social interactions (Parker, 2012). There is a range of specific formulations; some emphasize how language is used to accomplish meaning making and others focus on the actions accomplished through language in social interaction, such as identity formation and

power relationships (Gee, 2005). A discursive formulation is more than just an account of how written or oral language is used to describe reality; it also encompasses the practices that are used to create meaning through social interaction. "A discourse is, then, both the system of rules that defines what *can be said* (i.e., what counts as natural and true within a particular discursive practice) and the instrument through which people become *positioned,* but not determined, within that discourse" (Reid &Valle, 2004, p. 466).

Discourses are variable; people may choose to present different versions of not only events, but also their thoughts, beliefs, and moral judgments based on what they are trying to accomplish as they present themselves through their interactions with others (Potter & Wetherall, 1987). Language and discourse accomplish actions and humans are active agents, choosing discursive resources to construct the worlds of meaning in which they participate. The rules and traditions associated with particular discursive resources shape and constrain possible actions, thoughts, and beliefs, but do not cause outcomes directly; there is variability and human agency at play.

Discourses of disability are shaped through social interaction. Parents interacting with their children with autism shape the specific meanings that are created around autism in a particular household (Sirota, 2010). Children thus are apprenticed into a specific discourse of autism that has implications for their present circumstance, how they spend their time, with whom they will interact and how they manage difficulties, and also relative to their future, what type of adulthood is possible with autism. All of these things are discursively co-constructed through interaction. Similarly, teachers shape how children with disabilities construct and perform their

understanding of their own and others' disabilities (Valle & Connor, 2011).

Institutions such as schools, human service agencies, and municipal, state, and

national government agencies also promote a version of disability reality through

discourse (Reid & Valle, 2004). Finally, most recently adult self-advocates have been

shaping the discourse of autism (Broderick & Ne'eman, 2008).

In order to research the tension between parents of children with autism and

autistic adult self-advocates, it is necessary to attend to how those individuals

understand autism. To do that, one must attend to social and cultural responses to

autism that shape and constrain parent advocates' and self-advocates' meaning

making. Discourse analysis provides a framework for understanding the traditions and

practices of making sense of autism and the world. Simply put, discourse analysis

allows for the close study of how language is used in the world to accomplish things:

not merely to communicate, but to do things such as co-operating, creating personal

advantage, and building things such as institutions and identities (Gee, 2011).

Through attending to the discourse and discursive practices of parents, self-advocates,

and educators, a greater understanding of how and why certain understandings are

privileged over others and how those understandings promote or constrain actions

relative to the other groups can be obtained.

Summary

Online discourse tends to emphasize the differences and tensions between the

two advocacy communities, parent advocates and adult self-advocates. Neurodiversity

stands as a counter narrative to the disease model. Autistics maintain that they are not

disordered or broken, merely differently wired; not in need of a cure, rather in need of

understanding (Bagatelle, 2010; Broderick & Ne'eman, 2008; King, 2009). This would appear to outline a dichotomy between parents who are seeking cures for their children's autism and adults who view autism as an integral part of their identity. However, in a study of 657 autistic people, parents of children with autism, and friends, Kapp et al. (2012) found that the predicated contrasts between medical model treatment perspectives and neurodiversity identity-based approaches was not as marked as expected. Rather, participants drew from both sets of ideas to make sense of autism. However, examples of online discourse falling within the dichotomy of cure vs. neurodiversity remain common (King, 2009).

Autism representations in a variety of formats and media have become part of the public consciousness. There have been studies that observe online behavior and meaning making through face-to-face interactions. However, there has not been a direct attempt to present a rigorous interpretation of parents' and self-advocates' discursive practices in direct dialog.

Chapter 3: Methods

The social and cultural construction of disability in general, and of autism in particular, through social interaction, is the focus of this study. The theoretical perspective offered by a disability study in education combined with a social constructionist framework informs the research design. Potter and Wetherall's (1987) formulation of discourse analysis can be understood as a set of concepts and tools for applying a social constructivist understanding of disability to research. Central to their formulation are foundational understandings of language and discourse that include the following: Language is used to accomplish something in the social world. Language can perform a variety of functions. Any event or entity may be depicted in innumerable ways. People who are involved in social interactions select a particular version or account of actions, an event, or a phenomenon. A particular selection is made for a particular reason in order to accomplish something. The constructive and selective use of language becomes the central focus of study (Potter & Wetherall, 1987; Wertz et al., 2011). This research focuses on the construction of understanding of autism through language.

Research Questions

1. What resources and techniques do autistic self-advocates and parents of children with autism use to construct a specific understanding of autism for themselves or their children?

2. How do these constructs impact the relationship of these two groups?

3. How might understanding the views of these two groups inform educators' practice?

Research Approach

This study examined the ways parent advocates and adult self-advocates construct a particular understanding of autism and what functions or tasks they accomplish through discourse. This examination was accomplished through the use a discourse analysis approach. Discourse analysis as a research method takes a variety of forms and these forms flow from a particular conceptualization of discourse. As stated by Gee (2011):

> There are many different approaches to discourse analysis. Many of these are part of the discipline of linguistics and tied closely to the study of grammar, though there are also a number of different approaches to grammar. Some approaches to discourse analysis are not as closely tied to the details of language, but concentrate on ideas, issues, and themes as they are expressed in talk and writing. (p. x)

Discourse analysis is concerned with the linguistic features of a given text or conversation; an analysis of how language is used to create such entities associated with social psychology as self, attitudes, and accountability; and an analysis of conversations or text with a particular emphasis on the use of power (Reid & Valle, 2004).

Frames and Framing

Frames can be understood as templates for making sense of lived experience. Some frames present a very defined system of "entities, postulates and rules;" others are more of an "approach" or "perspective" for meaning making (Goffman 1974, p. 21). Frames that are presented and created through language and discourse have a

history in several disciplines. Gregory Bateson postulated the existence of an interpretative framework in communicative interactions that established what is going on and how others' actions and communications could be understood (Noakes & Johnston, 2005 p. 6). Conceptualizations of frames vary along a continuum, ranging from a relatively rigid cognitive schema held by an individual to a toolkit of interpretations that becomes coherent through social interactions (Oliver & Johnston, 2005). A distinction is also drawn between the frame as a product and framing describing the process of constructing a frame (Benford & Snow, 2000).

The analysis of framing and frames as maps of meaning making is particularly applicable in settings where the participants are being moved to take action as advocates of change. Social movement researchers use frames as a basis for analyzing and understanding social movements (Benford & Snow, 2000; Noakes & Johnston, 2005). Through framing analysis, actors are understood as active meaning makers who put forth or counter ideas to further a social movement. Benford and Snow (2000) suggested that core framing tasks that are negotiated by actors in a social movement.

> Collective action frames are constructed in part as movement adherents
> negotiate a shared understanding of some problematic condition or situation
> they define as in need of change, make attributions regarding who or what is to
> blame, articulate an alternative set of arrangements, and urge others to act in
> concert to affect change. (p. 615)

Benford and Snow (2000) explained that in a previous work they had named and described core framing tasks. *Diagnostic framing* involves articulating the

circumstances, problem, or condition that needs changing. This includes defining the specific attributes of the problem that allow for a distinction between what is included in the frame and what is not. *Prognostic framing* involves presenting a solution to the problem or condition outlined in the diagnostic frame. Two activists or social movement organizations will often differ in their framing. They may share roughly the same problem frame while presenting different solutions, a practice known as *counter framing*, in which frames rival one another. The final core framing task is *motivational framing*, in which a case for action is presented. These three tasks allow social movement activists, working through social movement organizations, to build a consensual understanding of the problem and a consensus for action (Benford & Snow, 2000). These core tasks describe social movement framing from the perspective of the movement or social movement organizations. Gamson (as cited in Noakes & Johnston, 2005) presented framing components from the perspective of the social movement actor. The *identity component* describes the shared interests and values that identifies who is in and who is out of the aggrieved group. The *agency component* builds recognition of the activist role as a change agent. The *injustice component* makes explicit that there is a party that has been wronged and a party that is responsible. Given this study's emphasis on social movement frames as emerging between social movement actors in dialog, social movement formed the basis for gathering and analyzing data in this study.

Data Sources

Because of the social constructionist-informed discourse focus of this study, a purposive sampling of a critical case that is strongly illustrative of the unit of analysis

was utilized (Boudah, 2011). In this study, the meaningful unit of analysis was the discourse between parents of children with autism and adult autistic self-advocates.

Blog Analysis

The Internet is the site of social interaction and community for a significant portion of the general population (Kozinets, 2010). Netnography is a term that defines an emerging set of research methods and strategies that are akin to ethnography and other qualitative methods, but are also distinct, because of the unique qualities of online communities. One set of differences between face-to-face and Internet communication which has bearing on the unit analysis of this study involves the slowed down rate of message response and the absence of the need to interpret body language and/or facial expressions, characteristics that make online communication friendly to those on the autism spectrum (Boundy, 2008). These types of differences point to online research as an approach that is congruent with the aims of the study. Given this study's emphasis on language and meaning making, a qualitative research approached was used. Many of the qualitative research approaches that are used for in-person studies have been adapted for use online. These include surveys, focus groups, one-to-one interviews, and social network analysis.

Ethnography has also been adapted for online research. Though an in-person ethnography may be supplemented with the qualitative research methods mentioned above, it is typically characterized by observations of behaviors and activities in the natural environment in which they typically occur. Surveys, focus groups, and the like, even the online versions, are intrusive in the sense that the questions asked are preconceived and created by the researcher.

Netnography shares with ethnography the observation of participant's activities and behaviors in an environment that the researcher is not manipulating. Netnography has the potential to be conducted in a manner that is relatively unobtrusive, using publicly available data (Kozinets, 2010). Blog analysis is a subset of netnographic methods and a method in which the data is unaltered by the researcher. The use of weblogs (blogs) as a data source provides researchers access to authors' self-generated accounts of their own experiences, which highlight precisely that which was important to the author. This study focused on the primary words of the authors, in this case parent advocates and adult self-advocates, as posted on weblogs (Hookway, 2008).

Following the social constructionist formulation of discourse analysis adopted for this study, the emphasis was on meaning making through the analysis of the written discourse within the blog. The blog discourse was seen as valuable and important in its own right (Potter & Wetherall, 1987); there were no interviews of the authors regarding their posts and intended meaning. Interviews might present an alternate version of events rather than access to the truth or an accurate version of the weblog events.

The blog posts selected for this study come from an invited dialog that took place on an autism-themed website. The dialog, in the form of a series of alternating blog posts, included parent advocates, self-advocates, and parents who also identified as autistic. The dialog was organized after conflict emerged between a blogger, a parent advocate, and a commentator (an adult self-advocate) on another website. This conflict became the subject of many posts and comments throughout this online

community. The subject of the initial exchange centered around establishing the authority to speak about the experience of autism. Parent advocates and adult self-advocates presented differing claims and counterclaims to authority. This led to tension between the two groups and the dialog generated around this issue was analyzed in this study. The texts of the dialog can be considered simultaneously the record of an event and the event itself, which is one of the characteristics of online communities/communication.

Data Analysis

In analyzing the data, a particular method of frame analysis, recursive frame analysis (RFA) was utilized. It was developed by Keeney and Chenail (Chenail, 1995) as a system for understanding the precise process of meaning making during family therapy sessions. The system has been expanded from a method of *getting closer to talk* into a qualitative research methodology that allows the schematic re-presentation of meaning making in discourse. This is accomplished by the creation of a series of categories and the relationships between these categories. The basic unit in RFA is the *frame*, which in this method is taken to mean a distinction in the text through which other parts of the text become understood. The analogy is to a picture frame through which the contents of the picture become understood. Continuing this analogy, the next level of categorization is labeled a *gallery*, which is made of up of several frames, as in a museum gallery in which several (picture) frames are displayed. The next level of category is the *wing*, made up of several galleries, as in an art museum which contains several wings. The final level is the *museum* (Chenail, 1995). Taken together these levels of categories, frame, gallery, wing, and museum, represent

a framework of meaning that accomplishes functions that parallel those of the social movement frame described previously. The development of RFA frameworks comprised the first cycle of data analysis.

The second cycle of data analysis for this study involved using the social movement framing practices and components as a coding scheme to analyze the categories generated by the RFA process further. Each RFA framework was coded for classification according to social movement, framing practices, and the social framing components of identity, agency, and injustice (Noakes & Johnston, 2005).

Credibility and Trustworthiness

Validity and reliability are terms congruent with a positivist quantitative paradigm that refer to the accuracy and reliability of research measures (Saldana, 2011). Given the qualitative social constructionist orientation of this study, Lincoln and Guba's constructs of credibility and trustworthiness were used to guide this study's rigor and quality (Saldana, 2011). Credibility was addressed by making the specific analytic procedures used in this study, in this case RFA, explicit. In order to contribute to the study's transparency, the decisions of the researcher were made explicit: examples (exemplars) from the text are listed, supporting decisions to create and include textual passages in a category. Exemplars that characterize key units of meaning from the text were chosen and were presented using words from the text to characterize a unit of meaning comprised of several utterances (Saldana, 2013). Readers will thus be able to judge the researcher's decisions directly. Following the methods outlined by Chenail and Duffy (2011), an electronic auditing trail was created in order to organize and document the decisions throughout the analysis process. The

trail consists of an electronically noted copy of the web log posts using the add comments feature of Microsoft Word, which includes memos, phrases, and comments. Microsoft PowerPoint was used to make graphical representations of exemplars, frames, galleries, and wings.

Ethical Considerations

The unique nature of online research, the various venues such as chat rooms, e-mail, web pages, and web logs, and the fact that most texts, pictures, and other media posted online endure long beyond the initial time of posting raise questions as to how and/or whether ethical concepts from traditional social science can or should be applied to Internet research. The Association of Internet Researchers' (AoIR) working committee on ethics suggested a series of questions to guide ethical decision making for Internet research studies. The procedures for this study regarding informed consent, privacy, benefit versus risk, and confidentiality described below were developed using these questions.

Informed consent. A major consideration for ethical decision making in online research is the venue or online environment under study and particularly the degree to which the site and the material contained within it is considered to be public or private by the proprietors and users of the site. As a general proposition, the greater the acknowledged public nature of a web venue, the less there is an obligation to protect individual privacy or right to informed consent (Ess & AoIR Ethics Committee, 2002). This seems analogous to the principle of observable public behavior versus private behavior long used as an ethical touchstone in offline social science research. The weblog from which the primary data for this study was

retrieved is owned by a nonprofit with the explicit mission of providing public

information for a wide community of those interested in topics related to ASD. Those

whose essays are accepted for posting are informed of and must acknowledge this

mission prior to posting.

     Authors' rights. Another important consideration is whether or not the

researcher should protect participants' privacy or recognize their rights as authors

(Snee, 2010). With a view to protecting participants' rights, a researcher utilizing blog

analysis as a research method would seek informed consent from participants who

participate in the study and disguise identifying details to maintain anonymity, which

is difficult with the Internet. Using the recognition of author's rights standard as a

guideline, the researcher would consider that blog authors may wish and deserve credit

for their creative work. With this as the standard, participants would be treated as

those who had published newspaper articles. In standard offline research, publications

such as this do not require informed consent. In addition, the ethical standard is to

recognize the author and supply a link to his or her blog in published accounts of the

research (Snee, 2010). In the current study, there is a strong case for considering the

blog posts as public data with minimal risk to participants. As stated by Hookway

(2008):

     There is a strong case for blog researchers to adopt the "fair game–public

     domain" position. Blogs are firmly located in the public domain and for this

     reason it can be argued that the necessity of consent should be waived.

     Further, blogs are public not only in the sense of being publicly accessible –

     and heeding Waskul and Douglas' (1996) warning – but also in how they are

defined by users. Blogging is a public act of writing for an implicit audience. The exception proves the rule: blogs that are interpreted by bloggers as "private" are made "friends only." Thus, accessible blogs may be personal but they are not private. (p. 105)

Risks versus benefits. A final consideration for this study is potential risks versus benefits. One could argue that the potential stigma of being labeled as autistic or the parent of a child with autism and the considerable tension between parent advocates and adult self-advocates in various on- and offline forums (King, 2009) might represent risks to participants in this study. However, the bloggers whose essays comprise the data of this study are already experienced autism advocates whose identities and connections to the autism community are clear. Thus, if there is a risk from portions of their work being quoted and interpreted in this study, it is not new and is arguably small. The tension between parent advocates and adult self-advocates is addressed in the submission guidelines of the blog, which call for civility, a standard to which the researcher has also adhered. The potential benefits of this study include a broader understanding of personal, social, and cultural dimensions of living as a parent advocate or adult self-advocate involved in the autism and/or neurodiversity communities. These understandings could act as translations between meaning making communities. A knowledge of how and why parent advocates and self-advocates create different frameworks of understanding for autism could inform the practice of educators as they navigate between these groups.

In conclusion, based upon the application of the AoIR guiding questions for ethical decision-making with respect to research studies, informed consent was not

sought, the recognizing author's rights perspective was adopted for this study, and links to the authors' websites were provided. Additionally, the potential for the results of this study to contribute to improved knowledge for educators and improved practice with parents of children with autism and self-advocates or emerging self-advocates strengthen the justification for this study. This dissertation's research design was reviewed and approved by my university's Institutional Review Board for human subject research.

Chapter 4: Findings

The purpose of this study is to look closely at how meaning is made, how discourses on the nature of disability emerge during a dialog taking place in an online community. The meanings and meaning-making practices of two groups are compared. These comparisons allow for interpretive explanations of why and how particular understandings of autism and disability are constructed and put forth in dialog. Gaining a knowledge and awareness of the what, how, and why of parent advocates' and autistic adult self-advocates' meaning making can inform the practice of educators and support professionals. Focusing on blog posts affords the opportunity to analyze written dialog preserved as it occurred. The words and phrases represent meanings that are intended by the bloggers. Unlike other forms of research methods such as interviews, the texts being analyzed were not created in response to an interviewer's questions. The words are the exact words that the blog author wished the reader to consider. In addition, the blog dialog is at once a record of an event and the event itself. The research questions follow.

Research Questions

1. What resources and techniques do autistic self-advocates and parents of children with autism use to construct a specific understanding of autism for themselves or their children?

2. How do these constructs impact the relationship of these two groups?

3. How might understanding the views of these two groups inform educators' practice?

Data Set

This study, a bounded case study of an online community, looked at an invited dialog that took place on the Thinking Person's Guide to Autism weblog (http://www.thinkingautismguide.com). Entitled The Self-Advocate/Parent Dialogues, the event consisted of eleven blog posts published between Monday, September 19, 2011 and Friday September 30, 2011. This debate was convened by the editors in response to a "spectacular disconnect" that occurred between two popular bloggers, a parent advocate and an adult self-advocate, earlier in 2011. (http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-one.html). Appendix A shows the list of authors and their publication information. As discussed previously, this study takes the author's rights position as a guiding ethical perspective. The blog posts that are interpreted in this study are considered analogous to a newspaper or magazine article (Snee, 2010). Therefore the authors of the post are given credit for their work in Appendix A. However, in order to focus on how the language of the text is used to construct meaning, the blog posts are treated as if they are an interview transcription. Consequently, each of the ten blog posts studied were prepared for analysis by creating a line-by-line number table for each post. The authors are not identified each time a line of the text is quoted in the analysis. The author credit is maintained through identifying the text by dialog day posted (Day 1, Day 2, etc.) and position in the dialog. Explicit positions in this dialog include parent advocate, self-advocate, and autistic parent advocate. Authors can be matched with the dialog day by referring to Appendix A. This is not a strategy to create an objective data set that represents some kind of true meaning of the event. Rather, it is a

technique intended to bring into focus the texts created during the event and the possible meanings and functions of those texts in the dialog. This approach is analogous to happening upon such a dialog in progress on the village square, making it necessary to make sense of events as they unfold. This may more closely follow the experience of educators as they encounter and seek to make sense of these types of dialogs.

Analysis

Analysis was begun using line-by-line coding and noting key phrases from the data to label larger units of meaning according to the tenets of RFA (Chenail, 1995). In RFA, the initial unit of analysis is the frame, which is considered to be a distinction in the text through which other parts of the text become understood. Following the museum metaphor of RFA, frames are then organized into galleries, which are then organized into wings. Wings are then grouped into museums. The RFA is a tool for creating graphic representations of the process of meaning making in dialog. Taken together, the RFA levels, museum, wings, galleries, and frames, perform the functions of a social movement frame as described by Noakes and Johnston (2005).

The parent/self-advocate dialogues (http://www.thinkingautismguide.com) blog posts alternated between self-advocates, parent advocates, and autistic parent advocates contributing, with individual participants deciding how much to respond directly to previous posts. Following the dialog structure, the meaning frameworks created through the analysis process are organized by participant stakeholder groups.

Key Frames and Exemplars

Early in the first day of the dialog, the author, an autistic self-advocate,

introduced the saying "Some parents just want disabled children to speak and disabled

adults to shut up" (http://www.thinkingautismguide.com). What this means, following

semantic framing (Fillmore, 1982), can only be understood by recognizing the

interconnection amongst an ecology of concepts that form a whole. Parts of this

ecology of understanding are evoked throughout the dialog by various authors, either

as an accepted part of an argument or by being refuted directly to present a counter

understanding. In the RFA model, these basic units of understanding are titled frames.

Figure 1 shows a frame and the exemplars, lines from the dialog, which justify and

define a particular frame as a unit of meaning.

F: Society favors the voices of parents

Ex: " I'm trying to point out that you have real privilege , that this culture wants to hear your voice but does not want to hear mine. "

Ex: "It's not because you're a bad person – it's because you live in a society that teaches you that the voices of neurotypical folks are more important than the voices of disabled people."

Ex: "The people who are considered 'experts' on developmental disability right now are all non-disabled . "

Ex: "Just open a newspaper to any story about issues of disability, and see who the reporter sought out for a quote. Overwhelmingly, journalists ask non-disabled parents or doctors to contribute their expertise to such stories."

F: = Frame
Ex: = Exemplar

Figure 1. Society favors the voices of parents frame and exemplars from dialog: Day 1.

The *society favors voices of parents* frame emerges in later posts of self-advocates. The frame is also used by parent advocates. Figure 2 shows the *society favors the voices of parents* frame from the same self-advocate that used the frame during her Day 1 post and then used the frame again during her Day 4 post.

F: Society favors the voices of parents

Ex: "In the public eye you take up the whole picture."

Ex: "I'm not saying you should get out of the picture, but I am asking you to move over a bit and let us in."

F: = Frame
Ex: = Exemplar

Figure 2. Society favors voices of parents frame and exemplars from dialog: Day 4.

This instance of the frame shows some evolution of the self-advocate's stance with some room for sharing voice being implied. During dialog Day 6, the author, who is both a self-advocate and a parent, used the *society favors voices of parents* frame. See Figure 3.

F: Society favors the voices of parents

Ex: "Parents voices undeniably are being heard the loudest."
Ex: "As an Autistic parent, I'm aware of this in a way most people aren't."
Ex: "There are a host of us who have to be in both boats. "
Ex: "When I put my 'parent hat' on, as long as I say nothing about my own Autism, I am heard."

F: = Frame
Ex: = Exemplar

Figure 3. Society favors the voices of parents frame and exemplars from dialog: Day 6.

The author conveys the direct experience of having a voice when identified as a parent and losing that credibility when identified as an autistic self-advocate. During the initial post by a parent advocate on dialog Day 2, the *society favors the voices of parents* frame does not emerge. However, the same parent advocate's second and final posting during dialog Day 5 shows use of the frame. The parent advocate acknowledges that parental voices are being favored in situations where a self-advocate's voice may better serve, albeit with some hedging. See Figure 4.

F: Society favors the voices of parents

Ex: "I don't think it's always inappropriate, to be honest, but the fact remains that our voices are being heard in a great number of places where a self-advocate's voice would better serve the cause."

F: = Frame
Ex: = Exemplar

Figure 4. Society favors the voices of parents frame and exemplars from dialog: Day 5.

The parent advocate is confirming the interpretation of the self-advocate, while also offering the possibility of more inclusive interactions with parent advocates. These examples illustrate some key properties of frames. They are part of an ecology of meanings. Frames can be used and then picked up and used by others with some variations in the meanings associated with the frame.

Frames and Counter-Frames

During dialog Day 2, the parent advocate used a frame that counters the *society favors the voices of the parents* frame by voicing what he has heard from self-advocates, "If you are not disabled you are not part of the disability rights community." See Figure 5. This is an example of counter-framing, which occurs throughout the dialog.

F: If you are not disabled you are not part of the disability rights community

Ex: "So we're in this place now where parent advocates of kids with any disability, not just autism, are told 'You're not one of us, you can't understand our lives.'"

Ex: "And that exclusion might be appropriate sometimes, but not all the time, and I don't think all that often."

Ex: "Just because I don't have a disability doesn't mean what I have to say isn't relevant."

F: = Frame
Ex: = Exemplar

Figure 5. If you are not disabled, you are not part of the disability rights movement frame and exemplars from dialog: Day 2.

By examining key frames and counter-frames, present throughout all ten days of the dialog, three key dimensions of meaning making emerge through which it is possible to make sense of much of the dialog. These foci of meaning making include the following dimensions: who can speak for people with disabilities, are self-advocates able to advocate for all children, and who can make a difference in the lives of people with autism.

Central to each discourse community's position are stances related to who can speak for people with autism, who can define actions, and who is qualified to advocate and influence policy in relation to autism. Figure 6 shows galleries and frames comparing parent advocates' and self-advocates' understandings.

Who can speak for people with disabilities

Parent Advocates

Gallery: *Parents struggle to be heard on disability issues*
• F: If you are not disabled you are not part of the disability rights community • F: Parents have a voice, yet services for disabled children are still not funded adequately • F: If viewed as in conflict society will marginalize both parent advocates and self-advocates

Adult Self-Advocates

Gallery: *Parents and professionals are seen as experts on disability vs. self-advocates*
• F: Society favors the voices of parents • F: Disabled adults are not supported by society • F: Adult self-advocates are seen as too different to speak for themselves • F: It is problematic for parents to speak for children with a disability

Figure 6. Significant frames and counter-frames 1.

The ability to give voice to the experience of living with autism is a central concern to both parent advocates and self-advocates. Both groups describe a struggle for voice. However, self-advocates communicate clearly their understanding that parent advocates are granted authority and opportunity to represent the autism community. There is an exception to this that is illustrated by this statement from a self-advocate during dialog Day 3: "People want to hear from us, but only if what we have to say is limited to our 'true life story of overcoming adversity'," and from the same self-advocate, "The kind of self-advocates who are considered popular in the parent community, like Temple Grandin, are the ones who talk first and foremost about their personal stories, and mainly in the context of how they can be useful to parents raising children" (http://www.thinkingautismguide.com). These statements

imply that the information that is valued by parents speaks to the experience of autism related to overcoming the challenges of everyday living. It can be reasonably assumed that such stories provide practical information, inspiration, and hope for parents whose children are facing challenges. Some kinds of self-advocacy are less welcomed, as a further statement from the same dialog day and self-advocate make clear. "While I recognize and respect the role of disabled speakers who choose to talk about their personal lives, most of us didn't get involved in the disability rights movement to be a resource for parents, however laudable a goal that may be" (http://www.thinkingautismguide.com). Self-advocates understand advocacy as related to seeking disability rights.

Parent advocates also expressed a struggle to be heard to communicate their experience of parenting children with disabilities. During dialog Day 2, the parent advocate expressed concern that self-advocates were excluding the voice of non-disabled parents in the disability community: "So we're in this place now where parent advocates of kids with any disability, not just autism, are told 'You're not one of us, you can't understand our lives'" (http://www.thinkingautismguide.com). Other dimensions of parent advocates' struggle to be heard do not involve self-advocates directly. Parent advocates struggle to be heard by society at large or more specifically the "machinery" of funding for services and supports for children with disabilities. "We as a community have to face a society that all too often rewards our 'privilege' with reductions in early intervention programs for children as well as services for adults with disabilities, a society that looks to special education as a place to cut budgets so the football team can still afford nice buses to away games"

(http://www.thinkingautismguide.com). The parent advocate is describing the challenge to have a voice in a place-based educational community in which educational funding priorities are determined at the municipal, state, and national levels. This is a very different type of community than the community of interest described in the first quote, namely the disability community, where a struggle for voice may have very different connotations than a struggle for funding. Certainly a community of interest may at times advocate for changes in laws or governmental policy; however, this may not always be the goal of a community of interest.

Related to the question of who has voice is the question of self-advocates' ability to advocate for children whose disability or challenges does not resemble their own. Figure 7 shows the significant frames and counter-frames.

Are Self-Advocates able to advocate for all children

Parent Advocates	Adult Self-advocates
Gallery: Autism can be disabling	**Gallery:** Self-advocates see themselves as capable of advocating for all children with disabilities
• F: "High functioning" autistic self-advocates cannot speak for all disabled children • F: The ability to speak and live independently is a privilege • F: The continuum of struggles matters	• F: You do not have to be able to talk or live independently to advocate for yourself • F: Adult self-advocates seek a better future for disabled people

Figure 7. Significant frames and counter-frames 2.

The framing of level of functioning or being too high-functioning to speak on issues related to autism occurs throughout the dialog. First introduced during dialog Day 2, the parent advocate is apparently aware of the controversial nature of his statement. "Self-advocacy has to extend beyond (and again, forgive the phrase, which I know is problematic) high-functioning persons with autism" (http://www.thinkingautismguide.com). In this case, high functioning is equated with the ability to talk and live independently. This use of the term high functioning is countered directly throughout the dialog as in these statements from dialog Day 3: "I'll be open about the fact that I have the ability to live independently, albeit with some struggle, but not all self-advocates – or even all the self-advocates you've spoken to in these arguments – do" and "Nor does it mean having no cognitive impairment – the term self-advocacy actually originated from people with intellectual disabilities, not Autistic people" (http://www.thinkingautismguide.com), as well as this statement from Day 4: "You say that I don't understand the scope of the disability community because I live independently which you seem to have extrapolated – incorrectly – from the fact that I write a blog." This appears to be an attempt to counter the parent advocate's original frame that high-functioning self-advocates cannot speak for all children. The idea that self-advocates cannot speak for children who have different needs than their own is also countered, as in this statement from dialog Day 6 by a parent and self-advocate who prefers to be called a disability rights advocate. "I'm advocating, whether to other families, to an audience or in a one-on-one conversation, for the entire population. I don't make a divide between those who bang their heads, smear their poop, and can't talk. What helps one, helps all"

(http://www.thinkingautismguide.com). Self-advocates state that they also receive the opposite message that they are too low functioning to advocate for the wider disability community, as in this statement of a self-advocate from dialog Day 1 reporting an encounter with a parent advocate: "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" (http://www.thinkingautismguide.com).

These statements and counter-statements could be understood as a conflict over facts, known and unknown. The parent advocate is unaware that some autistic self-advocates use assistive technology to communicate and are dependent on caregivers. Perhaps this difference of understandings can be best understood in the context of the third major dimension of meaning making, which describes the goals and actions that are priorities for the participants in the dialog. Figure 8 shows the third dimension of meanings derived from surfacing frames and counter-frames.

Who can make a difference

Parent Advocates

Adult Self-Advocates

Gallery: The parent as provider role is unique and essential

- F: Parents provide for disabled children, lifelong
- F: Parent as ally
- F: Struggling to envision the future for children with autism
- F: Adjusting parental expectations for a child's life

Gallery: Self-advocates as civil rights advocates

- F: Disability awareness vs. disability rights advocacy
- F: Disability rights (political) advocacy is fundamentally different than parental advocacy for an individual child
- F: Disability rights as civil rights

Figure 8. Significant frames and counter-frames 3.

The *parent as provider* framework is a meaning framework for understanding parent advocacy that sheds light on the tension of who has voice, as well as the tension concerning the validity of self-advocates advocating on behalf of children with disabilities. As stated by a parent advocate in dialog Day 2, parents have a vital role in promoting language and communication development in children. "Parents work to give children the tools for self-expression they lack" (http://www.thinkingautismguide.com). Parents must also plan simultaneously to contend with at least two major contingencies and the myriad variations in the details of those contingencies. The first is the necessity to prepare their children to live independent lives as adults. The second is preparing for the possibility that their children will stay in their care and household for the whole of their lives (dialog Day 2, http://www.thinkingautismguide.com). Balancing this dichotomy between independence, which is expected of most children, and some degree of lifelong dependence on caregivers, is clearly difficult and emotional for parent advocates, as evidenced by this statement of a parent advocate from dialog Day 9. "When I wrote some years ago about college not being likely for Charlie, some felt that I was being too limited in my hopes for him, too presumptive of what an autistic child can achieve; that I was somehow 'writing off' possibilities for Charlie" (http://www.thinkingautismguide.com).

Given the parents' application of a particular *parent as provider* framework and associated meanings, the tensions arising over self-advocates' ability to communicate and seemingly to live independently can be seen as emerging from

parents interpreting the dialog through this framework. The self-advocates' responses and assertions are shaped by a different frame.

The phrase "disability rights advocacy" is used by self-advocates throughout the dialog. The role of self-advocates as disability rights advocates vs. the role of parent advocates is described clearly in these statements by a self-advocate from dialog Day 7. "Your individual advocacy on behalf of your children is your job, and to my knowledge no one is saying it isn't. But in terms of general disability rights work? That is the domain of disabled people, and it needs to be recognized as such" (http://www.thinkingautismguide.com).

The framework of *disability rights advocate* is very different than that of *parent as a provider.* These two frameworks represent distinct repertoires of interpretations and these repertoires make possible the different positions along the dimensions of voice, credibility, and role that emerge from attending to frames and counter-frames. These different frameworks can be understood as a distinct toolkit for making sense of the world. The different frameworks of meaning making used by parent advocates and self-advocates lead to the process of framing and counter-framing evident in the dialog.

Frame Amplifiers

Social movement frames are passed from one social movement actor to another through *frame amplifiers*, which are catchphrases that deftly summarize key movement components (Noakes & Johnston, 2005). These catchphrases may include such statements as "I'm Pro-Choice and I Vote" and "It's a Child Not a Choice" (Noakes & Johnston, 2005, p. 15). Recognizable from the pro-choice and pro-life

movements, these phrases capture essential frame elements in an easily transmittable package. Often provocative, these phrases present a social movement's major conceptual building blocks.

"Some parents just want disabled children to speak and disabled adults to shut up" (http://www.thinkingautismguide.com) is one such catchphrase from Day 1 of the dialog. The author acknowledged the provocative nature of the phrase and repeated the phrase several times throughout her initial Day 1 post. What does it mean to the self-advocate and why is repeated throughout her statement? The second half of the question has already been answered: it is repeated because it captures the major ideas that the advocate is putting forward. But what is the significance of these ideas? This can be understood by making explicit the ecology of meaning that surrounds the catchphrase/frame amplifier. Figure 9 shows the catchphrase and associated meanings.
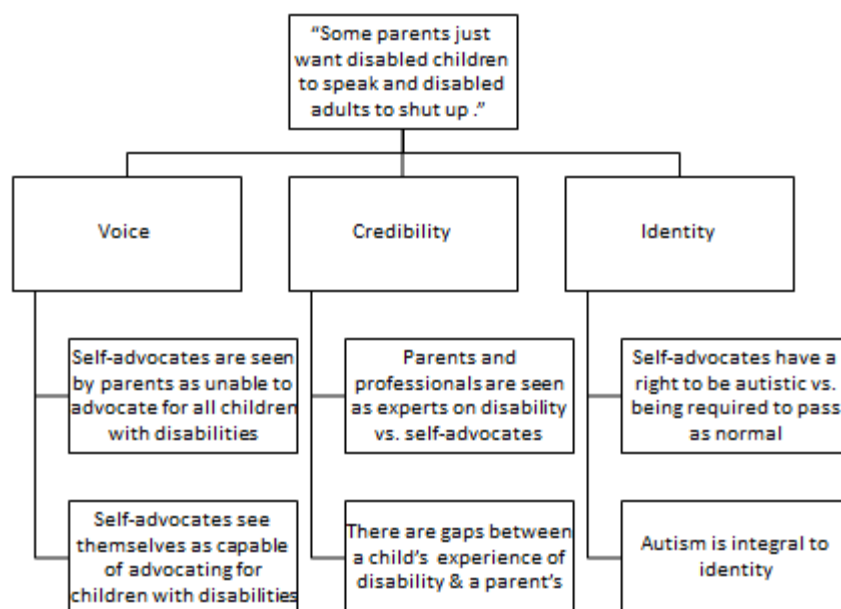
Figure 9. Frame amplifier/RFA wings and galleries: Self-advocates.

The wings and galleries from the RFA process, which were derived from the frames, make possible an understanding or interpretation of the catchphrase. Each time the frame amplifier/catchphrase is used, parts of a meaning framework are referenced; some parts are referenced explicitly and the remaining meanings are implied. Since the catchphrase is used by a self-advocate, the RFA framework of the self-advocates is used as an interpretive framework. The first half of the phrase: "Some parents just want children to speak …" makes sense in terms of the RFA wing of credibility. This dimension of the meaning framework involves self-advocates understanding that parent advocates are seen as having the most credible position from which to influence the disability agenda and priorities in society. Therefore, "parents … want children to speak …" (http://www.thinkingautismguide.com) refers to the

goals of many parents to promote the use of oral language by children with autism. This can also be understood through the dimension of identity, where some self-advocates would understand the push to speak as an attempt by parents to help their child to act or pass as normal or neurotypical. This contrasts with the self-advocate view that autistic identity is valid on its own merits. This identity may include the use of alternative or augmentative communication techniques and technology instead of using spoken language. The second half of the catchphrase: "… and disabled adults to shut up …" makes sense when considered in terms of the dimension of voice in the meaning framework. When self-advocates offer a counter understanding to the parent's understanding of children learning to speak or using alternative communication strategies, they experience their attempt to be heard on the subject as being discounted by parent advocates. In particular, they dislike being discounted for being able to speak and, consequently, unable to appreciate the struggles of children who are unable to speak and thus lacking the credibility to advocate for children. The dimension of identity also comes into play because, of course, some of the self-advocates in the dialog use alternatives to speaking to communicate. With just one catchphrase, the entire repertoire of interpretation derived from the RFA analysis comes into play. The provocative nature of the frame amplifier/catchphrase, that of grabbing attention and evoking a complicated meaning framework with a simple phrase, illustrates a property of frame amplifiers ideal for promoting the frame.

Of course, a similar analysis using a frame amplifier can be made of the parent-advocacy RFA meaning framework. Figure 10 shows a frame amplifier and the parent-advocacy framework.
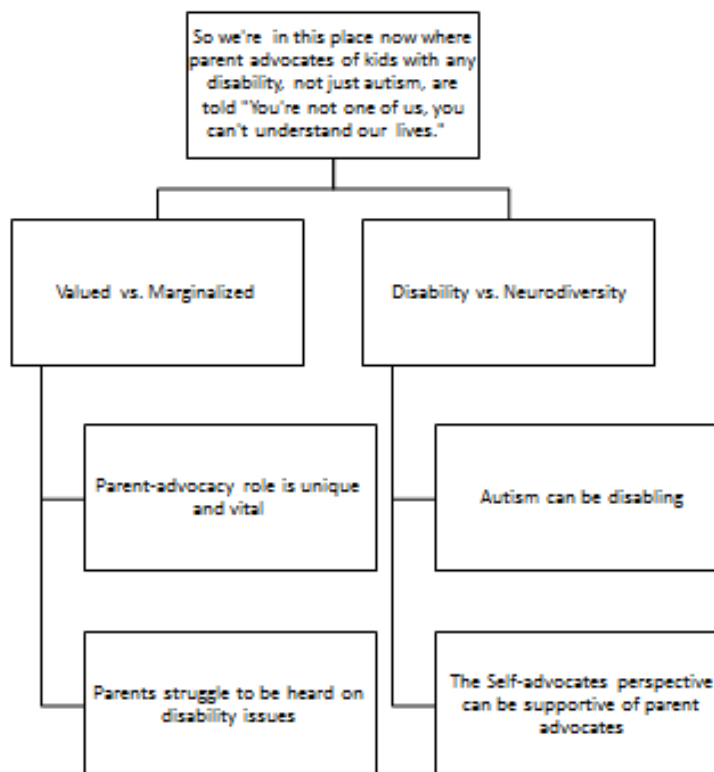
Figure 10. Frame amplifier/RFA wings and galleries: Self-advocates.

This catchphrase, minus the explanatory preamble, boils down to: "You're not one of us, you can't understand our lives" (http://www.thinkingautismguide.com). The first half of the phrase, "You're not one of us …" can be understood in terms of the RFA wing dimension valued vs. marginalized, with a unique role that is valued and recognized. Parent advocates understand that their role is not being recognized. Their experience is that their efforts to be heard on behalf of their children are not enough to earn acceptance and inclusion of self-advocates into a broader disability community. The second RFA wing *dimension of disability vs. neurodiversity* comes into play in order understand the second half of the phrase. "… you can't understand our lives" (http://www.thinkingautismguide.com). The gallery *autism can be*

disabling describes the very real challenges and pain parents and children with autism can experience as they help their children move toward effective communication skills, sensory and emotional awareness, and meaningful social interactions. These challenges can be disabling in the sense that the lives of the entire family can be disrupted. These everyday challenges can seem at odds with the idea of neurodiversity. Are the challenges and pain something to be accepted as a difference? Is it not the role of a parent to provide care and relieve pain when possible? The *parent as provider* frame appears in contrast to the *autism as difference* understanding. However, frames can be extended and modified. Parent advocates, particularly at the end of the dialog, described how meeting adult advocates and hearing of neurodiversity, the philosophy that autism constitutes a difference to be accepted in contrast to a disabling condition, has informed their parenting of their young child with autism. This gives rise to an extension of the *parent as provider* frame, which becomes *parents have a unique and vital role with adult self-advocates as consultants and allies*. This hints at the potential for parents to be included in the disability community.

Frames, Galleries, Wings, and Museums

The RFA analysis began by determining the RFA level of frames. First, exemplars or key statements from the text through which other statements have meaning were identified. This can be considered a type of in vivo coding where the participants' words are used in order to stay with what is significant to the participant (Saldana, 2013). Frames were condensed from the exemplars, galleries from frames, and wings were condensed from the galleries. Together, frames, galleries, and wings

comprise an interpretive explanatory framework that delineates not just themes, but rather dimensions or ranges of a property (Saldana, 2013). In this dialog, crucial dimensions included being valued vs. marginalized and disability vs. neurodiversity for parent advocates. Dimensions for self-advocates included having a voice versus no say, being seen as credible versus not credible, and autistic identity being recognized versus not recognized. The negotiating of meanings along these dimensions throughout the dialog accounts for much of the variation of understandings of autism presented and is the source of tensions, contention, and agreement.

Properties of Social Movement: Framing

The techniques and strategies for meaning making can be understood through the meaning-making practices associated with social movement framing. Framing and counter-framing is used extensively throughout the dialog. After compiling the significant frames and counter-frames from throughout the dialog, three areas of meaning making emerged, including who can speak for people with disabilities, are self-advocates able to advocate for all children, and who can make a difference in the lives of people with autism. These can be understood as positions along the dimensions from the RFA analysis. Frame resonance or the adoption of parts of a frame from one participant by another participant is a practice used by social movement framers that was evident throughout the dialog. So was frame extension, a technique that can be understood as akin to counter-framing, where a participant picks up on part another participant's frame and extends the meaning. The dialog can also be understood in terms of the social meaning components, identity, agency, and

injustice. These components emerge through the related practice of frame articulation, in which highly contrasting, or extreme, examples are used to present the frame clearly.

These practices are used to create a social movement framework that includes components that accomplish the necessary meaning-making work considered crucial to establishing a social movement. Gamson (as cited in Noakes & Johnston, 2005) described creating a social movement frame from the perspective of the movement actor. His description includes three components. The first component or building block of a social movement frame involves identity, defining the shared interests and values of those who are part of the aggrieved group at the center of the movement and defining who is and who is not part of that group. The second component, agency, involves the social movement actor as agent of change, presenting the opportunities for change. The final component from Gamson involves articulating the injustice faced by the movement actors and can be seen as the factors that served as motivations for change. This necessitates clearly defining the parties responsible for committing the wrongs which lead to the injustice.

The frames identified in the RFA process were categorized according to social movement components of identity, agency, and injustice. Two frameworks were created: one for self-advocates and the other for parent advocates. Figure 11 shows the social movement components for self-advocates.
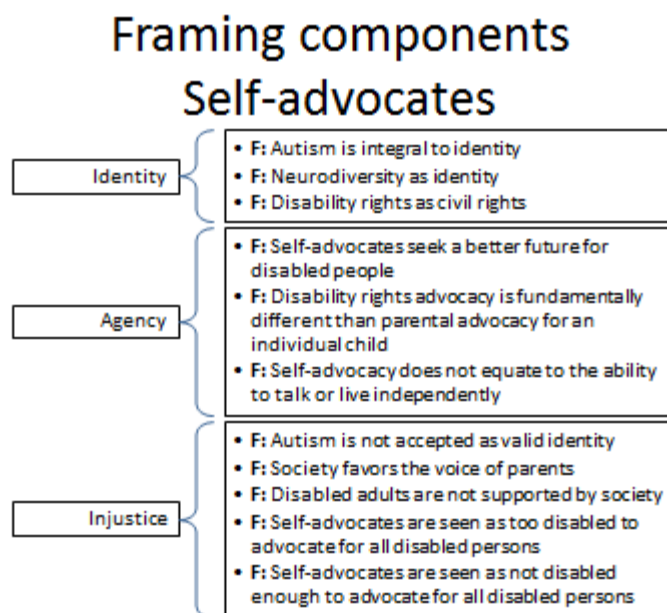
Figure 11. Self-advocate social movement framing components.

The social movement components as categories overlap to a significant extent with the gallery and wing level categories emerging from the RFA process. The frames fit easily within the social movement categories. Using the language and meanings of the frames as a basis, the following social movement framing component statements are possible. Identity: Self-advocates view autism as integral to identity and the differences associated with autism as a natural variation in human existence, neurodiversity. Agency: Self-advocates possess much-needed expertise and seek a better future for all disabled people, including children. Injustice: Self-advocates challenge the view that they are too disabled or not disabled enough to advocate for their rights. Further, they challenge the position that true acceptance and inclusion in

society requires passing as normal. In other words, they challenge the idea that autism is not a valid identity.

Figure 12 shows the social movement components as categories for parent advocates.

Framing components
Parent advocates

Identity	• F: Parents provide for disabled children lifelong • F: Struggling to envision a future for children with disabilities
Agency	• F: Focus on children and the adults we want them to grow into • F: Self-advocates as allies • F: Neurodiversity emerges through interactions with others
Injustice	• F: Parents can be excluded from the disability rights movement • F: Parents have a voice, yet services for disabled children are still not funded • F: "High functioning" self-advocates cannot speak for all children with disabilities • F: The continuum of struggles matters

Figure 12. Framing components for parent advocates.

Using the language and meanings of the frames as a basis, the following social movement framing component statements are possible for parent advocates. Identity: Parent advocates have a unique and essential role providing for and helping to envision a future for their children with disabilities. Agency: Parents advocate for services and supports to meet their needs now while simultaneously considering the adults they will grow into. Injustice: Parent advocates resist the view that their

contribution to the disability community is marginal at best. Parents realize that autism can represent real challenges for many children and can impact their life negatively. They are dedicated to supporting their children.

Taken together, the RFA meaning dimensions and the social movement, framing practices and components point to an explanation for tension and contention between parent advocates and self-advocates referenced in this dialog and the literature.

Summary

This analysis focused on both the meanings created in the dialog and the strategies used to create these meanings. A version of the RFA process was used to create a framework of meaning that forms the basis of the interpretation of this online dialog. Elements of social framing theory were used to understand the process and techniques of meaning making and to make explicit a way of understanding meaning frameworks as embodying a repertoire of interpretations and actions that are used at certain times in the dialog to accomplish certain tasks.

Chapter 5: Conclusions and Suggestions for Further Research

Autism, once the concern of relatively few, has become the part of popular culture (Lester, 2012). Various communities of meaning have offered differing understandings of autism and disability. These differing ways of understanding autism are not merely differences in the words and phrases used to describe a disability whose essential characteristics are considered self-evident. Rather, these differing meanings represent a set of choices, the use of a toolset, a repertoire of understandings created by a particular community of meaning making. This meaning-making activity at once describes and creates a particular understanding of autism and disability. This meaning making also evokes a world in which a particular understanding of autism and disability makes sense. This study looked at the resources and techniques that autistic self-advocates and parents of children with autism used to construct a specific understanding of autism and how these constructs impacted the relationship of these two groups. It also examined how understanding the meanings and meaning-making practices of these two groups might inform the practice of educators.

The concept of neurodiversity, though mentioned by name relatively few times, permeates the dialog. Neurodiversity is the idea that autism and other disabilities represent differences in neurological functioning that should be as respected as any other human variation (Armstrong, 2010). Asserting, modifying, or countering the neurodiversity viewpoint drives a lot of this dialog. The themes of voice, inclusion, and the right to exist as who you are and be appreciated for your uniqueness can be seen as an operationalization of neurodiversity. These issues are

articulated by self-advocates, parent advocates, and autistic parents throughout the dialog. Each blogger had his or her own understanding or version of these issues. The bloggers are united, however, in their articulation of an injustice and a call to action. This is, of course, the essential meaning making required to launch or sustain a social movement.

These dialogs have moments where participants make provocative, controversial, or even harsh comments. It has been suggested in this dialog that these types of statements can be attributed to the black-and-white thinking and lack of empathy sometimes associated with autism, in the case of self-advocates, or with a callous reluctance to share power and influence, as some allege in the case of parent advocates (http://www.thinkingautismguide.com). An alternative explanation supported by this study suggests that the contentious statements follow the function of the discourse, namely to state a case for social change. The meaning-making practices of social movement framing, framing and counter framing, frame articulation, frame resonance, and the use of frame amplifiers, provide an alternative interpretation of the context, structure, and function of self-advocates' and parent advocates' most contentious discourse.

The debate between parent advocates and self-advocates has been painful and contentious because there is a lot at stake. Both parties are seeking equality, equity, and social justice. For adult self-advocates, no less than the assertion of the right to exist is the central goal of the movement. In other words, the differences in such things as communication, sensory style, and emotional awareness/style associated

with autism are representative of a valid identity, as well as an emerging social movement and culture.

For parent advocates, what is at stake is nothing less than a renewal of the social contract in which the value of every child is recognized, as well as the recognition of the vital role of parents/caregivers and the unique role of communities in the care of children with disabilities.

Recommendations for Educators and Family Support Professionals.

This study was designed to present an interpretation of the understandings of autism and disability put forth by various participants in a dialog in an online community. Attention was paid to both describing an ecology of understandings and explaining the techniques used to create those understandings Recommendations for practitioners address both the meanings and the techniques. In a traditional study, the concept of generalizability would be in the foreground. A central requirement of this is having a large and diverse sample, so that the results of the study can be extended to the population at large. In contrast, given the social constructionist underpinnings of this study, the focus is on the utility and transferability of ideas emerging from the interpretation presented here. Care was taken to make explicit the techniques and intentions of the analysis; it is left to the judgment of the practitioner to assess the utility of the recommendations outlined below.

For educators, understanding others begins with understanding their own frames and framing. How teachers understand or frame autism will affect how they interact with students with disabilities. It is important for teachers to make explicit

their personal definitions and understanding of disability, including the role of culture, society, policy, and politics in shaping their ways of viewing disability.

Awareness of parents and caregivers' understandings of autism and disability is a valuable tool for educators. As illustrated in the dialogs studied, parents may hold many different understandings of autism and disability. These understandings comprise different lenses or frameworks for understanding disability. These frames/frameworks constitute a repertoire of interpretations for making sense of a situation. Each framework has a different function and is useful for certain tasks in particular situations. For example, a family may use one meaning framework when first receiving a diagnosis for its child from a medical professional. Later, when advocating for the child at a special education team meeting, the same family may use a very different framework. Awareness of these different frameworks for understanding can assist educators in connecting with and listening to the families with whom they work.

An understanding of the neurodiversity movement as a civil rights movement is important. The political dynamics occurring outside the school affect the dynamics inside of school. The neurodiversity movement seeks to place neurological difference alongside such political categories as class, gender, and race, (Singer, as cited in Armstrong, 2010). If parents, educators, or others use this type of framework for understanding a student's situation, it will clash with traditional special education and health professionals' frames for understanding disability. Working in this type of situation for an educator becomes a matter of intercultural communication, one of negotiating between two cultures, two profoundly different ways of

understanding the world. Collaboration with adult self-advocates as cultural consultants could be very useful. Educators could use consultation not only in understanding the emergent civil rights implication of neurodiversity, but also in examining the implications of school culture and policy related to differences of all kinds.

Social movement framing practices are useful as heuristic tools. Social framing practices are useful as heuristic tools. One such useful tool is semantic framing, the idea that concepts make sense only when they are considered in relation to other ideas. Not all of the concepts of a particular semantic framework necessarily need be made explicit. Using parts of a meaning framework can evoke meanings from the entire network. This may have profound implications in an educational setting. If a parent or other person is using an explanatory framework that at first hearing does not seem to make sense, it is possible that some of the concepts in the framework have not been made explicit. That much may be obvious. There is, however, the more subtle implication of semantic framing in current times, due to the fact that many meaning-making communities exist solely online. It is possible that the educational staff interacting with a parent or caregiver may never have been exposed to the elaborate set of understandings a parent or other advocate is expressing, because this meaning making takes place in an online community of which the teacher is unaware. Educators can respond by listening, asking questions about how different concepts connect, and resisting the urge to fill in the gaps of understanding with their own frameworks of meaning (assumptions).

Various strategies are possible for educators seeking to gain an understanding of emerging social movement activities, beginning with understanding the student and family members as persons with creditable expertise in their everyday life experiencing the label of autism. This inquiry could be expanded to include adult self-advocates and parent advocates in the community as well as local advocacy organizations. Administrators also have a role providing the resources and promoting a culture that supports good faith exploration of differing understandings of disability.

Frame articulation is the practice of articulating a social movement frame in a condensed version in stark black-and-white terms, often using extreme examples. This is done in order to communicate clearly the meanings necessary to accomplish the functions typical of a social movement frame, which includes establishing to whom the frame pertains, what type of actions are required, and the injustice or wrong that needs righting. Educators may respond by asking questions that help to make explicit all of the elements of a particular frame. It is also an opportunity to discuss how much of a particular social movement framing is relevant to a student at this moment in time. Educators may use an understanding of the particulars of a social movement frame being used by educators in order first to appreciate the social justice and ethical dimensions always inherent in a particular interaction with a student and his or her family and second to promote the co-construction of understanding that bridges the educator's frames and the student's and family's frame.

Frame amplifiers or catchphrases such as "you're not one of us; you can't understand our lives" (http://www.thinkingautismguide.com) may be encountered by educators when uttered by a parent or caregiver in an individualized educational

program (IEP) meeting. A statement of this nature can be understood as a deliberately provocative, perhaps rude statement. This type of statement may also be interpreted by educators as an opportunity to discuss a social movement position by asking questions of a statement that embodies a complete way of making sense of the world. The statement could then be seen not as a provocation, but rather as a significant gift of a conversation starter and an opportunity to understand a parent advocate's, self-advocate's, or autistic parent's point of view. The goal is increased mutual understanding, the possibility for meaningful inclusion of the student, and collaboration with the family.

Dimensions of Meaning Making

The dimensions of meaning making that emerged in this study represent a starting point, a rough map of meaning making that can be used to guide educators' interactions with parents and families as well as in the co-construction of new meanings. These dimensions included:

1. Being valued versus being marginalized.
2. Voice: Having a say versus being ignored.
3. Credibility: Being seen as having legitimate disability expertise.
4. Identity: Autism as valid identity versus only being included when able to pass as normal.
5. Neurodiversity versus disability.

A particular family, student, or advocate may hold beliefs that vary greatly along these continuums. These various positions may be a point of contention or common ground. Some of these stances may be made explicit in a meeting, while others remain implicit

and still influence the discussion. These dimensions can be used by educators to craft questions and guide the discussion. Again, this is done with the goal of increased collaboration and meaningful inclusion.

Recommendations for Further Research.

This study used blog analysis to interpret the meaning-making practices of participants in an invited online dialog. Arguably, blogs function often as the contemporary equivalent of standing on a soapbox in the village square and loudly stating your views. This dialog had the explicit goal of providing a forum for differing views of autism advocacy. As these differing views were put forth, social movement frames emerged in dialog. These frames could be contrasted with the formal crafted frameworks of social movement organizations. Comparing the social movement frames of organizations such as the Autism Self Advocacy Network and Autism Speaks with the frames created by parents of children with autism and adult self-advocates could provide a broader, more complete understanding of the entirety of the neurodiversity and autism rights movements, particularly as these movements become increasingly widespread and formalized.

Educators will encounter families who embrace a neurodiversity approach to autism, families who do not, and families whose understandings fall anywhere between those positions. Increasing awareness of social movement frames and the practices of framing among educators could be an important step towards meaningful inclusion of all students/families. Research that facilitates educators' awareness of their own disability/neurodiversity frames and leads them to trace how these ways of seeing the world influence practice could be a useful next step.

Conclusion.

This study did not attempt to examine positions to provide a determination of who was right, who won the debate. Did parents present the best arguments? Were self advocates more convincing? Rather, this study attempted to understand the perspectives of the participants without resorting to explanations that pathologized or assumed the worst of the advocates. This study did not describe the style and substance of self-advocates' statements, as stemming from deficits related to an autism diagnosis. Nor were psychological theories from the parenting children with disabilities literature, such as grieving the loss of the ideal child, introduced to explain the parent advocates' ideas. In contrast, ideas from social movement framing were used, producing a straightforward interpretation. The tension and frustration, as well as the acceptance and evolution of viewpoints, however incremental, occurs in dialogs where there is a lot a stake and where there is a need to bring the dialog to society at large.

A question implicit in this discussion of the educator's role is this: Do we value students for who they are now or who they will become? This dichotomy is present for every child and the dilemma of teaching today with an eye toward the future parallels every parent's reality. The neurodiversity movement brings this to the fore. The future, self-advocates have taught us, may involve very real struggles for civil rights and meaningful inclusion. So what is an educator to do? Adopt a spirit of not knowing, using the metaphors of teaching as inquiry and collaborating with families as intercultural communication? If it is true that the opposite of love is not hate but rather indifference, then spending time carefully attending to one's own

framing of neurodiversity and the frames of others with whom one interacts is a

profound act of empathy and caring.

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APPENDICES

Appendix A: List of Dialog Authors by Dialog Day

Dialog Conveners and Host: A Thinking Person's Guide to Autism http://www.thinkingautismguide.com **Editors:** Shannon Des Roches Rosa, Jennifer Byde Myers, Emily Willingham, & Carol Greenburg
Day 1: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-one.html **Author:** Zoe **Blogger at:** Illusion of Competence
Day 2: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-two.html **Author:** Robert Rummel-Hudson **Blogger at:** Fighting Monsters With Rubber Swords
Day 3: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-three.html **Author:** Ari Ne'eman **Website:** The Autistic Self-Advocacy Network
Day 4: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-four.html **Author:** Zoe **Blogger at:** Illusion of Competence
Day 5: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-five.html **Author:** Robert Rummel-Hudson **Blogger at:** Fighting Monsters With Rubber Swords
Day 6: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-six.html **Author:** Melody Latimer **Blogger at:** ASParenting

Day 7: http://www.thinkingautismguide.com/2011/09/advocateparent-dialogues-day-seven.html
Author: Kassiane
Blogger at: Radical Neurodivergence Speaking

Day 8: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-eight.html
Author: Amanda Forest Vivian
Blogger at: I'm Somewhere Else

Day 9: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-nine.html
Author: Kristina Chew
Blogger at: We Go With Him and Care2.com.

Day 10: http://www.thinkingautismguide.com/2011/09/self-advocateparent-dialogues-day-ten.html
Author: Paula C. Durbin-Westby
Blogger at: Paula C. Durbin-Westby Autistic Advocacy Blog

Appendix B: Recursive Frame Analysis Framework
Museum: Self-advocacy

I. **Wing: Voice**

    a. *Gallery: Self-advocates are seen as unable to advocate for children with disabilities different than their own*

        1. **Frame:** Self-advocates are too disabled to be credible (disability itself precludes the ability to advocate)
        2. **Frame:** "High-functioning" Self-advocates are not disabled enough to be credible
        3. **Frame:** Adult self-advocates cannot advocate for all children with disabilities

    b. *Gallery: Self-advocates see themselves as capable of advocating for children with disabilities*

        1. **Frame:** Adult Self-advocates seek a better future for disabled people
        2. **Frame:** Parents as allies
        3. **Frame:** You do not have to be able to talk or live independently, to advocate for yourself

II. **Wing: Credibility**

    a. *Gallery: Parents and professionals are seen as experts on disability vs. self-advocates*

        1. **Frame:** Society favors voice of parents
        2. **Frame:** Disabled adults are not supported by society
        3. **Frame:** Adult self-advocates are too different to speak for themselves
        4. **Frame:** It is problematic for parents to speak for children with a disability

    b. *Gallery: There are gaps between a child's experience of disability and a parent's*

        1. **Frame:** Not all parents provide for disabled children
        2. **Frame:** Gap between child's experience of disability and parents

III. **Wing: Identity**

    a. *Gallery: Self-advocates have a right to be autistic vs. being required to pass as normal*

        1. **Frame:** Disability awareness vs. Disability rights advocacy
        2. **Frame:** Disability rights (political) advocacy is fundamentally different than parental advocacy for an individual child
        3. **Frame:** Disability rights as civil rights

    b. *Gallery: Autism is integral to identity*

        1. **Frame:** Autism integral to identity
        2. **Frame:** Autism not accepted as valid identity
        3. **Frame:** Challenge integrating child's disability into family identity
        4. **Frame:** Neurodiversity as Identity

Appendix C: Recursive Frame Analysis Framework
Museum: Parent Advocacy

I. **Wing: Valued versus Marginalized**
   a. ***Gallery:*** *Parent advocates struggle to be heard on disability issues*
      1. **Frame:** If you are not disabled, you are not part of the disability rights community
      2. **Frame:** Parents have a voice, yet services for disabled children are still not funded adequately
      3. **Frame:** If viewed as in conflict society will marginalize both parent advocates and self-advocates

   b. ***Gallery:*** *Parent advocacy role is unique and vital*
      1. **Frame:** Parents provide for disabled children, lifelong
      2. **Frame:** Parents as allies
      3. **Frame:** Struggling to envision the future for children with autism
      4. **Frame:** Adjusting parental expectations for a child's life

II. **Wing:** Disability versus Neurodiversity
   a. ***Gallery:*** *Autism can be disabling*
      1. **Frame:** "High functioning" autistic self-advocates cannot speak for all disabled children
      2. **Frame:** The ability to speak and live independently is a privilege
      3. **Frame:** The continuum of struggles matters

   b. ***Gallery:*** *The Self-advocacy perspective can support parent advocates*
      1. **Frame:** Listening to self-advocates
      2. **Frame:** Awareness of Neurodiversity emerges through interactions
      3. **Frame:** Self-Advocate as ally model