Vulnerable Voices: Various Perceptions of Well-being in Autism Advocacy.

Qualitative Analysis of Themes and Narratives in Disability Studies

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Author's Note

When my brother was diagnosed with autism, my family changed forever. Suddenly the future was approaching quickly, there were not enough resources available, and we had so much to learn. Over the past three and a half years, I can confidently say that despite the challenges that come with an autism diagnosis, my family dynamic has never been better. My mom serves as my brother's advocate while my step-dad works. She put him into therapies before researching them, used formulas in his bottle she googled, and still is resisting signing up for disability benefits. After some time watching my mom learn to be an autistic advocate, I began to wonder about the different ways parents care for their autistic children. This curiously led me to search for definitions of well-being in the autistic community. Seeing as there is no one designation of well-being for autistic people, I started to wonder "how do people differently perceive and pursue well-being for autistic people?" This work is an attempt to answer this question and explore political implications from the findings.

This project includes an investigation into debated conversations among autism stakeholders. Recent literature published in disability studies, op-eds written by self-advocates, and from experiences being in a neurodiverse family, helped me determine rhetoric is recent in terms of reflecting autistic people's interests. It is important to note that rhetoric usage in this study is meant with the best intentions, but it is possible that the societally dominant and preferred version of language use in autism advocacy changes in the next twenty years. I use language that attempts to reflect the interests and wishes of autistic people. The controversial nature regarding language use then speaks to the variation in how people understand autism, and it will be portrayed more extensively in the following study. Also, there may be instances where authors use the term “ASD” rather than autism, referring to autism spectrum disorder. Descriptions of contentious types of language in autism advocacy are detailed in Chapter 2, section B.

Abstract

The growing rate of autism diagnoses contributed to an increase in the number and type of advocates for people with autism. Advocates’ perceptions of well-being are important to study in order to compare different methods used to seek out the interests of autistic people. This thesis explores different perceptions of well-being in the autism advocacy community. I analyze blogs of various types of advocates to determine the political implications of understanding well-being. I extract themes from autism advocates’ narratives using the Labov Method and a theoretically-motivated coding scheme. When looking at advocates’ online blogs, I find that autistic people and their parents have the most similarity in thematic characterization out of all three advocacy subgroups. Both autistic people (self-advocates) and parents of autistic people (individual-advocates) feel alone and anxious about the future. Thematic crossover among types of advocates presents questions about how interactions between autistic and non-autistic people can improve advocacy efforts. While well-being is not defined in one way, this study encourages further investigation into how autistic people’s interests can inform perceptions of well-being.

Chapter 1: Introduction

Many conceptualizations of autism are controversial. The majority of the research on autism is carried out by non-autistic people, so the bulk of the literature on autism advocacy is authored by researchers with no firsthand experience (Collins and Evans 2007). Both autistic and non-autistic perspectives contribute to stereotypes about what “typical autism” looks like, which impacts how autistic people are treated by society (Collin et al. 2010). Qualitative research shows that parents and autistic people hold a variety of opinions about autistic people’s well-being. These stakeholders present contrasting or competing dialogues about this issue (Milton 2012).

One recent example of the impact that competing perceptions can have on autism advocacy is the nonprofit organization Autism Speaks’ misallocation of funds raised for autism research. The organization’s deceit affects other advocates and their positions in advocacy by undermining trust among potential donors. Analyzing articles about advocacy organizations and other entities in advocacy helps to identify the key players and themes. Advocates differ in their ideologies, experiences, and perceptions, so the autism advocacy community will be divided into three subgroups to better explore their personal narratives and varying ideas about how autistic people can achieve well-being. Thus, this study focuses on well-being while acknowledging that doing so necessitates a deep examination of the narratives of stakeholders in autism advocacy.

This study focuses on well-being in order to explain the way that many autistic people, academics, practitioners, and family members understand autism. Polarized understandings, contrasting fields of autism research, and stakeholders' competing opinions expose areas neglected or oversimplified areas of autism advocacy (Baron-Cohen 2008).

The aim of this study is to examine how different autism advocates define well-being and what, if anything, this means for political action. The autism advocacy community comprises a variety of stakeholders, i.e., people who play active roles in advancing the efforts of the community. Advocacy stakeholders employ various methods to achieve their goals, including grassroots advocacy, lobbying, volunteering, and petitioning within a community (Brain Injury Resource Center 1998). The discourses between the advocates often take place in comparisons of online blogs, as the number of disability forums and community blogs around autism continues to increase (Yergeau 2018; American Psychiatric Association 2013). Examples of advocacy in the autism community include lobbying for policy change, organizing autism awareness weeks in schools and workplaces, creating Facebook communities, and publishing online blogs dedicated to documenting the author's advocacy.

A. The Autism Advocacy Community

Advocacy is defined as "a service aimed at helping people understand their rights and express their views" (Hodgkinson 2020; Dawson 2010). The autism advocacy community can be split into subgroups that encompass sectors of stakeholders holding a similar outlook on autism: individual-advocates, self-advocates, and group-advocates. I use the term "individual-advocates" to include parents of autistic children, "self-advocates" for autistic people who advocate for themselves, and “group-advocates” to describe people who advocate for more than one person within the autism community, e.g., special education teachers, researchers, or treatment specialists. The definitions were derived from author Van Reusen’s research on self-advocacy strategies. While he and I use the same terminology for naming self-advocates and individual-advocates, he refers to what I call the subgroup group-advocates as “system advocates.” I use the term group-advocates rather than system advocates because part of advocacy concerns enhancing the lives of multiple people or an organization. System advocacy, on the other hand, is referenced as grassroots efforts to change policies, rules, or some other aspect impacting the way someone lives their life (Van Reusen et al. 1994).

Concerning this paper’s use of the phrase “autism advocacy community,” the term “community” is preferred over “movement” because the former includes a larger range of human subjects in the research. It is vital to emphasize that the three advocacy subgroups (individual, self, and group-advocates) do not officially form an organization and are not tied together. Indeed, the only tie between the three subgroups is having personal ties to autism and expressing their beliefs around the diagnosis. In efforts to examine various well-being definitions and its effects on political action, exploring advocates’ experiences represents a key first step. Accordingly, this study focuses on the themes emerging from the patterns that arise in the personal narratives of the different subgroups (Cummings, Newbert, and Rawhouser 2017).

B. Conceptualizing Well-Being

Well-being is a concept many people struggle to define. Although seeking to attain a sense of well-being is a standard human need, understanding well-being has high stakes for members in the autism advocacy community. I select well-being as the concept to explore among autism advocates due to the implications of understanding the word. Well-being is vaguely individualistic as there is no one definition or strategy that applies to what one must do to fully achieve well-being. Instead, people act in accordance with their own perceptions of well-being. If the concept of well-being is not explored to ascertain the interests of vulnerable populations, advocates will be less able to construct a common narrative; although opportunities for autistic self-advocates have increased in recent decades, there are still large gaps in advocates' knowledge of autism and how to progress autistic people's interests.

Such a narrative is necessary to create collective efforts for advocacy; in other words, there have to be at least some specific positions moderated by advocates. Recent literature includes a collection a broad range of scholastic journals, article reviews, and the books from local libraries. However, nowhere in autism studies literature is there a sole, trustworthy definition that describes well-being specifically in pursuit of the interests of autistic people. Among the sources that do refer narrative analyses in autism, many refer to people without an intellectual disability as neurotypical, and people with an intellectual disability are called neurodivergent (Saunders 2018).

It is politically important to explore the debates that center around how to conceptualize, and eventually seek out, well-being in the autism advocacy community. These stakeholders are the people who ensure that disability rights are maintained, the interests of autistic people are reflected in various institutions, and social progress is sustainable over time. Debates concerning well-being are significant and politically important because these conversations reveal who holds a stake in the outcomes in policy developments in the disability sphere. For the sake of this paper, the term “conversations” within autism advocacy refers to the differing and interchanging perspectives around similar issues, different focus areas of advocacy, and different ideologies. These differences play into how an author constructs his or her narrative via an online blog as well as the elements it includes (Ryan et al. 2003).

People have different ideas on how to construct the identities of certain types of people. The puzzle I examine is how to negotiate over-conceptualizing well-being when seeking out well-being is a highly individualistic process. A qualitative method is used to study the phenomenon of well-being in the autism advocacy community as opposed to traditional methods of exploration in political science, such as empirical studies.

Real-world data is collected while the analysis is conducted, so hypothetical ideas for themes arise while creating analytic codes and categories from the data (Berterö 2012). The unit of analysis in this study, or the units the data is gathered around, are online blogs created by autism advocates. Advocates’ narratives are examined on a macro level, with the assumption that they reflect trends prevalent in larger parts of disability society and the general public. This research centers around analyzing stakeholders in autism advocacy and the varying perspectives on well-being by focusing on each advocacy subgroup individually. Instead of settling on a single definition of well-being for autistic people, the stakeholders' narratives are carefully examined and their ideas about well-being are extrapolated from such elements as the frequency with which words are used, comparisons to other authors' findings, and comparisons to advocates in the same subgroup. Recent literature is selected by searching for studies analyzing narratives of advocates in the autism advocacy community.

Specifically, narratives are analyzed through a comparison of blogs among advocates within the same subgroup, which I refer to as "within subgroup comparison analysis." This is followed by a comparison of the conversations and different perceptions that arise from different subgroups. This is "between subgroup comparison analysis." The labels used to name the modes of subgroup analyses are personally coined.

Patterns are scrutinized to isolate stakeholders' various perceptions of well-being so it can be seen whether mediation occurs among the advocates. If so, there will be evaluations of the patterns in 1) singular subgroups and 2) contrasting positions between members in the same subgroups (Waitzkin 1989).

This study makes no attempt to settle the debate on which definition of well-being is most beneficial and realistic for members of the autism advocacy community. Rather, this study builds on the research of autism scholars who have established a framework for studying competing discourses around autism and well-being.

Chapter 2: Literature Review

Many strands of academic scholarship from several fields are included in this review: political, autism-specific studies, disability studies, and works on grassroots activism (Tilly and Wood 2020).

Understandings of autism have changed since the autism rights movement first gained traction in the late 20th century (Pitney Jr. 2015). The disability studies and political science literature from 1970 until the present presents a wide variety of perspectives on autism. Any studies that discuss well-being and autism (among other concepts) are considered here, as they contribute to the diversity of outlooks in narrative analysis. Advocates' varying perspectives on how to understand, define, and seek well-being for autistic people create a wide range of narratives within the autism advocacy community. However, determining how to approach the topic well-being with the interests of autistic people in mind is challenging because doing so typically entails viewing well-being in a single way. The lack of unity, communication, and understanding among advocates seeking well-being for individuals with autism highlights how perceptions of certain concepts have serious implications that shape the experiences of autistic people. Thus, this literature review is arranged by concept, with authors discussing a concept grouped with those who share similar sentiments. The differing perspectives on autism are explored before moving on to a discussion about well-being and narratives. This section presents authors' approaches to exploring aspects of narratives in the autistic community.

Reflecting on the well-being of autistic people, various stakeholders voice their opinions from a range of places: academics and researchers, the parents of children with autism, and autistic people. Authors who study autism stakeholders set precedents for this study and are discussed in the following sections.

A. Well-being Depictions in Autism

The most accessible depictions of autism come from mass media and politics (Yergeau 2018). Examples of autism-related media that propagandized the disorder include the movie Rain Man, singer Sia's canceled movie Music, and even subtle depictions such as the character of Buster in the television show *Arrested Development*. There are even resources that rank pop culture characters from "least to most autistic," such as the character Patrick Star from the animated television show SpongeBob, who is listed as number four. All of these cultural references are authored by members of the neurotypical community. In this way, non-autistic stakeholders frame the autistic community's narratives (Hurwitz 2009; Hillenburg 1999; Open-Source Psychometrics Project n.d.).

Most researchers focus on one subgroup per study: self-advocates, individual-advocates, or group-advocates. The authors do not present a multi-population analysis for all the three subgroups used in this study. One author, Kelly, includes both individual-advocates and self-advocates in her examination.

Authors vary in how they approach well-being in terms of disability rights, with the chief differences centered around advocates' concerns. Well-being is not directly associated with a specific list of concerns. In this study, it was the person or thing that was the subject of concern that was noted, thus distinguishing the author's narrative from that of someone in a different subgroup.

Some authors saw well-being as a personal responsibility regardless of disability status (Berkman et al. 2000). Other authors claim that defining well-being in disability communities is similar to asking who defines autism at all (Yergeau 2018). Researchers Orsini and Smith (2010) assert that the lack of clarity in describing concepts in autism, confusing treatment protocols, and varying social perceptions of autism all influence the ways that autistic people's autonomy is diminished. Therefore, the concern of this study is connecting concepts without defined points to the different areas of advocacy.

Completing this task depends on figuring out how to frame well-being around the interests of autistic people (Barnes). Building on Broderick and Ne'eman's 2011 article, my research attempts to explain the difficulty in understanding such a vague concept as well-being. Barnes' 2014 article outlines the characteristics of distinct conceptions of well-being. However, despite trying to categorize multiple concepts of well-being, the author concluded that there is no clear way to distinguish which type of member in the autism advocacy community adopts which concept as the most "accurate" depiction of well-being.

1. Advocates and Literature: General Overview

The individual-advocates include parents of children, teenagers, and adults with autism. I particularly focus on mothers in this subgroup because there is a large gap in the number of blogs created by mothers of children with autism and those created by fathers. There is not an inclusion of the implications this may have for the relationship between fathers and a child with autism or the motivation to father a neurodivergent child, but there is room for additional research in this area. The self-advocates are those advocates who have received an autism diagnosis themselves. Last, the group-advocate subgroup is the broadest of the three, as this group is represented by thousands of special education teachers, autism researchers, speech therapists, behavioral specialists, and others who have no personal ties to autism but still have an interest in autism advocacy. To mark the difference, group-advocates are defined by their desire to effect positive change for an entire group or population rather than just one person. A sufficient number of previously published studies have focused on the narratives of parents within the autism advocacy community. However, it was somewhat difficult to find eighteen blogs that fit the study's inclusion criteria. When performing research, the greatest difference between the subgroups was the number of blogs that could be located for each online. While six blogs per subgroup were found over a matter of weeks for the individual-advocates and the self-advocates, this was not the case for the group-advocates.

This may be due to such factors as the various personal investments in autism activism and the limited number of autism professionals, many of whom likely have no interest in publishing a blog. Self-advocates and individual-advocates are far more likely to share their personal experiences with autism, as displayed through their narratives. The samples of data include the list of eighteen advocacy blogs (six per subgroup). I found it more difficult to locate independent examples of blogs that fulfilled my criteria of being included in my study. In this sense, there was no one source that helped point to a definition of well-being when the narratives of people in the autism advocacy community are examined.

B. Autism and Rhetoric

While a variety of authors from disability studies, autism research, political science, and advocacy community analytics are included in the research for this study, the initial collection of literature began with Taylor and Francis' Routledge *Handbook of Disability Studies* (Hanes et al. 2012) to gain a background in how disability studies and advocacy have changed over time, how advocacy communities are defined depending on the goals of advocates, and how the study uses the language that is currently preferred among people with autism.

For autism advocates, understanding the diagnosis itself does not equate to an understanding of how autism affects an individual. The way an author perceives the impact of autism plays into their personal narrative, and thus, their ideas about well-being and autistic people. What authors decide to focus on in their studies highlights where their interests lie in autism advocacy. For instance, many of the authors who examine autism diagnoses and their prevalence express concern about the rising rate of diagnoses.

When authors explore problems, they are concerned about in the advocacy community, such as trends in autism diagnoses, it helps to observe how certain themes fit their data and the author's treatment of topics such as advocacy motivations, perceptions around autism, personal narratives, and themes (Baron-Cohen 2012).

For example, if an author is focusing on language and its affects, then the author is emphasizing through their narrative that they believe language is important to the state of autistic peoples interests and well-being. One of the studies discussing autism rhetoric discussed identity-first and person-first language to determine which type is preferred among autistic people. Identity-first language (IFL) stresses that the person's disability plays a role in defining who that person is, e.g., "an autistic person" or "a person with autism," as this change in wording is said to have an impact on the personal autonomy of autistic people. Person-first language (PFL) is exemplified as using the latter phrase "a person with autism" rather than the former, thus emphasizing the person over the disability. Identity-first language is the preferred option among autistic people and the author contributes to his own narrative by sharing this with his audience (Whelton 2020; Brown 2012). The aforementioned authors' themes will inevitably be determined from their descriptions of their motivations for conducting the studies while considering the needs of autistic people.

Authors can be concerned about autism while viewing the issue in different ways. Autism researchers whose purpose is not to study the preferences of autistic people tend to focus on the causes of autism and trends within the autism community.

Examining the factors impacting the rates of autism diagnoses or looking for reasons autism has become more prevalent is indicative of authors' environmental concerns in autism advocacy. Identifying such authors' motivations is helpful for the thematic comparisons that are conducted later in this study. Environmental examinations from this study include authors' perception that autism is a symptom of environmental factors and that having autism inherently makes life more difficult. Issues surrounding autism advocacy, such as the causation of trends or the nature versus nurture debate, are addressed less often than other topics in the research included in this study (Kanner 1943; Asch, Blustein, Putnam, and Wasserman 2016).

C. Narratives and Themes

It would be easier for the autism advocacy community to conduct reforms if all advocates had similar ideas about the well-being of autistic people. Greater communication among advocates, including the sharing of narratives and personal experiences, would contribute to a community-wide understanding that could help progress advocacy efforts (Davis 2002). Advocates in different subgroups have unique characteristics according to identity, age, personal narrative, and experiences, so there is an identification of self-selection among advocacy groups and external factors that cause social categorization. In this paper, narratives are "the symbolic presentation of a sequence of events" (Mackenzie 1987; Davis 2002).

There is a limited amount of research to review on group-advocates when looking at narrative analyses because of the broad range of stakeholders who fall within the subgroup. Unlike how individual-advocates could be identified, for example, as parents, I cannot make a generalized word that encompasses all of the identities and experiences of the members of a group or organization. One example of diverging interests in an organization can be found in the notorious non-profits for online advertisements and misleading scams. Autism Speaks, in particular, is a known offender in terms of misappropriation of funds. In her 2013 "A Call for

Action," the late Autism Speaks co-founder Suzanne Wright reiterates this sentiment, exhorting parents with the following: "These families are not living. They exist. Breathing—yes. Eating—yes. Sleeping—maybe. Working—most definitely—24/7. This is autism" (Yergeau 2018).

Narrative research is helpful to comprehend how larger chunks of texts can be broken down into elements with meaning. Narrative storytelling is described as the main takeaway from the collection of rhetorical elements encapsulating the concept of well-being. Stories show how the elements of the Labov Method are portrayed in certain aspects of online blogs. I decided to use this method for analysis in conjunction with a coding method called grounded theory coding after reading Fleischmann's 2004 study comparing the narratives of parents [individual-advocates] of autistic children online. Building on this idea of narrative comparison, I used this framework to perform my thematic analysis and comparisons. The framework helped serve as a starting point for within subgroup comparison analysis as it drew on elements in the Labov Method before using those conclusions to compare my thematic findings with themes discovered by a other scholars in fields for different types of autism advocates (Labov 1972; Fleischmann 2004).

Online blogs are used in other studies to look for similar or contrasting narratives about well-being in the disability community. Fleischmann's study, whose approach to modifying the Labov Method serves as a framework in this study, analyzes only the parents of autistic people, i.e., individual-advocates. However, this study widens the subject population pool in the narrative analysis and perform a modified narrative analysis using the Labov Method; the details of which are presented in Table 1. The authors whose themes I pull from the literature review for my comparison are listed in Appendix 2.

Some authors have established credibility in connecting themes with perceptions of well-being. In previous literature, members of the Office of Behavioral and Social Science Research (OBSSR) have had success performing thematic studies on emotional well-being. The office reported on a roundtable meeting where emotional well-being is discussed. The roundtable participants were asked to identify common themes across “models of success” (as provided by the research team). “Its focus was on issues in developing, testing, and implementing intervention strategies to promote emotional well-being” (Shurtleff et al. 2017). The usage of participant-identified themes directly impacted the proceedings of the roundtable meeting and the organization’s plan for the upcoming year.

In another narrative study, the Labov Method was used by another author to examine the competition between the dominant narrative of disabilities and the counternarratives presented by people with disabilities. The author ultimately describes three types of failures among counternarratives: 1) narratives of the frustration of everyday parenting, 2) narratives of giving up, and 3) narratives of failed parent advocacy (Barton 2007). The intent of the study differs from mine, as hers looks at the forms that narratives do not take among advocates, particularly no mention of the struggles for disability and narrative rights and the lack of communication. Ultimately, the counternarratives in disability rights highlight where people struggle to incorporate the counter arguments over the dominant ones.

The steps comprising the Labov Method are as follows:

1. The “Abstract” is in the introduction of the blog. Welcoming comments, personal introductions, or summaries to introduce the contents of the narrative can be included in the abstract of the narrative.
2. “Orientations” include the table of contents or drop-down menu as well as any hyperlinks or social media references that are attention-grabbing directly after the abstract. The set-up of the blog provides insights into the author’s motivations for its backbone or essential theme.
3. The “Complicating Action” of the narratives includes the central conflict in the specific story, along with an explanation of what events are moving it forward. The actions may be thoughts (stream-of-consciousness writing while events take place) or physical actions. Action in the author’s plot is what the authors present as data and later discuss. The part of the entry that includes complicating actions is often surrounded by a stream-of-consciousness style form of writing.
4. The “Evaluation” includes the identifiable reasons the author is writing the story and consists of both internal and external evaluations. This step engages the problem within the complicating action and explains why the author has chosen that topic, issue, or concern. The findings from examining an evaluation are centered around the author’s intent, personal motivations, and larger-scale motivations for advocacy. There is no specific point in a text to see “why” a story is being told and it is often not directly stated.
5. The “Resolution” is the part of the narrative following the story’s climax or where the author addresses the problems referenced earlier. The resolution is helpful to look at moments in advocacy, the different types of advocates, and how they manage the issues differently. The last of the narrative’s actions conclude here and this place in the text signals the reader is approaching the conclusion.

6. The “Coda” notes any patterns or repetitive plot points within the whole website. Comparing the patterns emerging in one advocate to another in the same subgroup makes it easier to determine what helps point to a theme or themes.

D. Online Blogs

In addition to reviewing narratives, researchers use online blogs for different purposes. This study specifically focuses on blogs that discuss any of the following: autism, well-being, personal narratives, and advocacy. For example, one author describes her strategy for finding articles about online blogs: specifically looking for information about “mommy bloggers,” or mothers who blog after becoming new moms (Hermanson 2013). Although most of the research focuses on individual-advocates (parents), studying online blogs can reveal the impact that online blogs and the personal narratives within them have. “Among other findings, the study shows that mom bloggers are much more politically involved and socially minded than their non-blogging counterparts.” (Keenan et al. 2015).

While many agree that the influx of online blogs created by autism advocates is a positive development that improves autism awareness, not all advocates feel that these websites help to promote autistic peoples’ interests. With the expansion of online network, more able to debate issues like autism and well-being. However, when their contributions or questions are ignored, individual-advocates can feel like failures as parents.

Self-advocates also present mixed opinions on the benefits of autism blogs, particularly those written by neurotypical people. Yergeau’s book details her frustration as a self-advocate while watching other advocates take on the responsibility of changing the autism narrative. A significantly smaller proportion of voices are present online to contribute to defining the concept of well-being among self-advocates. The lack of scholarship on the idea of well-being may be partly due to the social stigma of disability agency in the literature, the discomfort many people have with the autonomy of the “disabled,” or simply an overabundance of content by members occupying concrete advocacy roles in the advocacy community. Through diagnosis, Yergeau points out that “non-autistic stakeholders become authorized as autism somethings—as autism parents, as autism researchers, as autism therapists and specialists and mentors and advocates” (2018).

The rest of the thesis focuses on gaps in perceptions of well-being among stakeholders and their representation in online narratives. Published authors’ findings are also analyzed to determine whether they are consistent with my data. Additionally, different perceptions of well-being are compared and are linked to different advocate subgroups. Finally, the analysis concludes with thematic findings, and the themes found in the published studies are analyzed to determine whether they fit this study’s subject populations.

Examining the current conversations about autism has provided me with a framework for what themes may arise for the subgroups. For example, a study revealing self-advocates’ increased political polarization over time on websites gave me an idea of what themes I may find in the online blogs that I code. Having a faint set of expectations for the advocates will allow me to conduct my comparisons within a single subgroup and between two or more subgroups. It will then be possible to fully assess the various understandings of well-being,

Chapter 3: Methodology

A qualitative explorative methodology is necessary to examine different autism advocacy groups' perceptions of well-being and the consequences for political action. In this study, two qualitative methods are used to analyze the advocates. First, the Labov Method of narrative analysis is helpful to understand the role that the elements play in the advocate's narrative. Second, grounded theory coding is a coding method that "starts from a set of empirical observations or data, and [. . .] develop(s) a well-grounded theory from the data" (Lazar, Feng, and Hochheister 2017).

The study sample includes the authors of autism advocacy blogs, eighteen of which were analyzed in my data set. The number of advocates was determined by referencing other thematic analyses studies on the blogosphere. In the literature providing thematic examples for narrative analysis, the sample ranged from five to ten participants (Fleischman 2004; Kelly 2018; Boshoff et al. 2016). This implies that the authors completed a narrative analysis on five to ten separate blog websites.

This study does not propose new methods of performing effective advocacy under a new lens of well-being. The motivation for this study is understanding how people perceive, seek out, and negotiate the concept of well-being. The sources of these motivations are determined by analyzing online blogs and the authors' narratives. To conduct this analysis on the various perceptions of well-being among advocates in different subgroups in the autism advocacy community, I use a qualitative method, versed with the theoretical, focused grounded theory coding to analyze my data collection of the narratives of the three different subgroups (Strauss and Glaser 1967).

A. The Labov Methodology of Narrative Analysis

The Labov Method is used to deconstruct and organize the texts into discrete components, which is treated data. This qualitative data is then evaluated in order to extract common themes and meanings. Below are explanations for certain parts of the methodology.

I examine the data and used the six narrative components of the Labov Method to determine themes by looking at my completed list of discovered patterns, common topics in the entries, or similarities in the plot points (Labov 1972; Labov 1982). Then I evaluated whether themes in the recent literature applied to my data and which subgroup the theme(s) applied to in order to obtain a clear picture of well-being perceptions among my study subjects and those in other studies. An important part of research is that the idea is reliable or that it is repeatedly consistent in measure. Consistently looking at themes pulled from various sets of text is a way to lay out analytical findings.

I look at the different components of the online blogs: the abstract, the orientation, the complicating action, the evaluation, the resolution, and coda. These elements help me determine the important narrative details that distinguish a particular advocate or their subgroup, which are subsequently coded according to the Labov Method. This method is beneficial for qualitative studies because it allows the researcher to record, collapse, merge, and rename the concepts into the parent, child, and other relational nodes (Strauss and Corbin 1998). A Labov Method narrative analysis was completed for all three subgroup's collection of participants. Unlike other methods of study included in the recent literature, using grounded-theory coding to code my data allows me to determine possible patterns as I continue to analyze the qualitative data. Extracting themes drawn from various texts helps show a clear picture of well-being perceptions among the present study's subjects and those in other studies.

The six narrative components of the Labov Method help to determine themes by looking at the completed list of discovered patterns, common topics in the entries, or similarities in the plot points (Labov 1972; Labov 1982). Themes in the recent literature are then evaluated to determine whether they apply to the data, and if so, which subgroup they apply to. Looking at multiple sources of themes, pulled from various sets of texts, supports analytical findings that are consistent across different bodies of text.

B. Grounded Theory Coding

In describing grounded theory coding, Berterö highlights the method's dominant characteristics. These include "simultaneous data collection and analysis, construction of analytic codes and categories from data (not from preconceived logical hypotheses), use of the constant comparative method/analysis, making comparisons during all steps of the analysis" (2012). In the social sciences, researchers use grounded theory coding for the conceptual analysis of meticulous qualitative data.

Building on Kelly's definition of the coding method, grounded theory coding can be described as a way for transparent concept development to break through "theoretical muddles"

(Tucker 2016; Kelly 2018). Grounded theory coding is said to “allow for the generation of new theories based on close engagement with qualitative data, be they field notes, interview transcripts, or other texts” (Glaser and Strauss 1967; Bryant and Charmez 2007). To code the six elements utilizing the Labov Method of narrative analysis, the grounded theory approach of coding was applied. This includes, “…continuous questioning of what the codes (or elements of texts) imply, thus preventing preconceived ideas from being imposed and focusing the researchers’ attention on possible areas to explore in the subsequent data collection. Open coding [. . .] was carried out in the first stage of the coding process” (Danker, Strnadova, & Cumming 2016; Glaser and Strauss 1967). In other words, grounded theory coding permits a continuous examination of data while adapting descriptions of the subgroups’ narratives. As multiple rounds of data collection and analysis is required from the method, the method creates room for authors to come up with findings that he or she would otherwise have missed.

Grounded theory coding is useful for this project because it makes systematic comparisons across units of data. The units of data are the six elements of the Labov Method. The term “grounded theory” is appropriate; it is defined as the “continuous questioning of what the codes (or elements of texts) implied, prevented preconceived ideas to be imposed, and focuses the researchers’ attention on possible areas to explore in the subsequent data collection” (Danker, Strnadová, & Cumming 2016; Glaser and Strauss 1967). Grounded theory coding does not have a particular list of steps, but it prevents the author from developing themes before all the content is analyzed.

C. Population Sample

The advocates included in this study are broken into three subgroups: individual-advocates, self-advocates, and group-advocates. The criteria that apply to a specific subgroup will be described. Among individual-advocates, for instance, additional criteria includes being a mother, and indeed mothers are the main focus in the individual-advocate subgroup. First, there is a surprisingly large gap in the number of blogs created by mothers of children with autism and those created by furthers. Second, there is a societal assumption that a mother's duty is to take care of a child. Among parents of children with disabilities, mothers feel more judged for their parenting styles than fathers. The pressure of mothering a child with autism adds to the concerns and patterned topics that make up mothers' narratives. The process of selecting online blogs as sources took two months, but the bulk of the time was spent deciding how to conceptualize the group-advocate subgroup. There are significant variations among group-advocates in autism, so only those in non-profits or special needs teachers are included. The inclusion criteria for self-advocates, in contrast, is simple, only requiring that the individuals have been diagnosed with autism.

A list of inclusion criteria was created to determine which advocates would be selected for review. The guidelines include a range of requirements, such as being either a self-advocate, a parent of someone with autism, or working in the field of autism research or treatment. Blogs must have been active for at least eighteen months, publish a minimum of one blog post a month, and receive comments on posts every other day at minimum. Isolating the different subgroups is also necessary. Subgroups are separated by categorizing advocates according to experiences, information in "About Me" sections of their blogs, and the person for whom the author advocates.

This study's data analysis methodology in this study requires separating the autism advocates; this is accomplished by categorizing advocates by their experiences and personal information. Ten blog entries were adequate for painting a picture for the Labov Method, such as identifying personal motivations for advocacy or repetition of phrases in different blog entries. Evaluating authors' blog posts while using grounded theory coding gave me room to consider patterns emerging within and between subgroups. The Labov Method sets up a step-by-step guide to perceiving well-being among the three advocate subgroups.

D. Themes and Division

The narrative analysis of three subgroups, rather than only one or two subgroups, is this study's primary contribution this field. However, the dataset's subjects may yield different themes than what might be expected from studying the themes of only one subgroup. Depending on the applicability of a subgroup's theme, inferences can be drawn about the relationship between the two advocate subgroups. The applicability of a theme is also indicative of a subgroup's involvement with the concerns expressed by other subgroup advocates. After themes are compared, general patterns can help deduce the concerns that are expressed in the subgroups' narratives, as depicted in their blogs. The comparisons are presented alongside possible reasons for differences and similarities among the three subgroups.

Within-subgroup comparison analysis involves comparing the pattens that arise in narratives expounded by members of the same subgroup. It is the first of two subgroup comparisons intended to categorize advocates to extract themes. The purpose of dividing advocates within subgroups is to determine prominent points in the subgroups' narrative data within their respective subgroups and to identify points of overlap with the Labov Method that can provide further insight into the groups' perceptions of well-being. This step requires descriptions of the general narrative characteristics of each subgroup, specifically, the recurrent plot points and main concerns expressed by the subgroup as displayed by a count of blogs showing that pattern within that particular subgroup. The same process is followed for the other two subgroups.

Next, the between subgroup comparison analysis follows as the advancement of within subgroup comparison analysis. It includes analyses of trends, wide-reaching patterns affecting more than one subgroup, and repetition arising in the Labov Method. Grounded theory coding comes in handy in this step because data can continuously be examined while descriptions of the subgroups' narratives are altered accordingly. The freedom granted by grounded theory coding and the concision of the Labov Method permits me to start painting a picture that illuminates the differences and similarities in the online narratives. This step precedes the thematic categorization of different advocates, as the between subgroup comparison analysis inspects how patterns from within subgroup comparison fit together.

If similar sentiments/reflections from the Labov Method elements, or patterns, are prominent in a majority [four of six] members of the advocacy subgroup, then a theme is considered regarding that pattern. The processes of highlighting similarities in the same subgroups' Labov Method elements, applying themes to these patterns, and comparing the themes to different bodies of texts determines how I view a subgroup's perception of well-being. Once a theme is considered as possible to characterize the advocate subgroup, the themes are sorted for organization purposes.

To help sort and separate potential themes for the different subgroups while using grounded theory coding, a Google Sheets page is created and the potential themes for different subgroups were color-coded and sorted into informal groups. This helps compartmentalize the themes. The sheet is color coded to identify similar patterns or references as overarching concepts or trends. For example, blue might be used to represent loneliness and red to indicate an interest in the future.

Before comparing themes from this and other research, the terms most commonly used by advocates are identified, with keystroke shortcuts employed to discover the terms and phrases that appear most often. The website used to measure the frequency of words provides the most common terms in list form, and these lists are later used to compare the subgroups' main focuses. Keyword frequency is compared in a few ways. First, the comparison only includes the elements of the Labov Method without referencing any subgroup. Second, a comparison of the members within a subgroup that does not focus on any specific element does not provide greater insight. Needing more specific points of comparison, the six elements of advocates in a subgroup were compared, and the advocates' coded data will be compared. This is the most productive form of comparison to find the most frequently used terms (listed in Appendix D), and is the last comparison made before themes for the subgroups are determined.

The lists of frequently used words are used to check the validity of the themes chosen for the subgroups; if the word representing the theme is not present in the author's blog, the theme likely does not apply. Themes established from between-subgroup comparison analysis are used to extract patterns from the elements of each subgroup. Furthermore, information about the most frequently used terms contributes to the validity and reliability of the themes identified, thus permitting comparisons with the recent literature.

A list of themes in the recent literature, separated into subgroups and detailed, can be found in Tables 4-6.

E. Conclusion of Methodology

This section reflects the motivations for exploring the broad variations of conceptions of well-being in the autism advocacy community. It establishes the groundwork for the remainder of the study to explore and analyze these variations.

Grounded theory coding compliments the Labov Method because the latter lacks a means of extracting thematic findings from narrative elements. The Labov Method compliments the grounded theory coding method because grounded theory coding does not require data to emerge from pre-existing hypotheses. Rather, this study employs a deductive analysis that sorts data into organizational categories (Kafer 2013).

Political and social scientists have attempted to study the factors that stimulate change in the inner workings of the autism advocacy community through case studies, interviews, regression models, and ethnographic forms of methodology. However, the bulk of the literature regarding changes in the autism advocacy community focuses on moments in disability history in which tangible changes were made to laws or policies. In this research a broader view is assumed, as the catalysts for change in the autism advocacy community clearly are not limited to policies from the 20th century. Multiple sources are utilized to portray themes in real-life contexts, such as Ari Ne'eman. Themes are better explained through the perspective of political science when applying them to concrete, tangible examples. To establish credibility in this field, narrative comparisons are useful, particularly for studies that focus on the implications of data collection.

This study does not propose new methods for more effective advocacy. Instead, there is a focus on the ways that people perceive, seek out, and negotiate the concept of well-being in the autism advocacy community, as demonstrated in online blogs and the authors' narratives. To conduct this analysis, a qualitative method is used in addition to grounded theory coding to analyze the data collected about the narratives of the three different subgroups.

Below is a table of the modifications made to the Labov Method to suit this study. The modifications are necessary for multiple reasons. Labov intended for his method to be used with physical texts, so standard webpage conventions are used to correspond with each element. For instance, where Labov would have referred to the introduction a book, this study substitutes the homepage of a website.

Table 1: Modifications Made to the Labov Method

Method Steps	**Modification**
Abstract	I look at the information on the homepage of the blogs, looking for any eye-catching information and captions on the first page.
Orientation	look for the drop-down menu, subtitles in the narratives, hyperlinks, and captions on homepages in the blogs. The orientation can serve as an unspoken explanation for why things are the way they are, in terms of character, setting, timing, or the blog's central idea.
Complicating Action	In the blog posts, I look to the middle of the narrative, right after the author introduces a problem, to find the most prominent issue. I try to predict how the complicated action will resolve itself, feeding into the next three steps.
Evaluation	I include internal thought actions, which is the inner voice monologue present in the text. In sum, the author usually describes their thoughts as they review the complicated action. In this step, the story's plot separates the author's reasoning from the intent behind the story. Evaluations are helpful so the readers can get a sense of the motivation for writing.
Resolution	The resolutions can be found the end of the blogs' entries or where the authors seemed to be "wrapping up" their narrative. To find resolutions, key moments plot points unfold are noted. I analyze the ending of the story's complicating action and analysis of the evaluation.
Coda	Coda is the last step of the method, and I find this by looking for patterns in the main messages, plots, and common concerns in the narratives.

Chapter 4: Results of the Labov Method

"People overlook me because I am odd or because I don't speak, but I still watch, wishing one day to be liberated from my cage that traps me inside my own body" (Kedar 2012).

This chapter details the first part of my data collection and analysis, the within subgroup group comparison analysis. By looking at the narrative elements of authors' blogs in the same subgroup, themes are retracted from the patterns in texts, any notable arguments arising within the group, or the authors' tones. It should be noted that the identities of the advocates included in the forthcoming analysis are omitted to maintain the study's focus on the narrative content.

A. Abstract

All hyperlinks on the homepages are noted. Over a third (seven) of the homepages among the eighteen blogs promote the author's books and include hyperlinks to Amazon pages where these books are sold. Other blogs have links on their homepage, although they are not solely for purchasing books. The eight blogs with links to books on their homepages also included links to advertising donation pages, social media, webinars on Zoom, and therapy blogs. Here we can see that the blogs' homepages help frame the rest of the content. Author A1 writes:

> "I've written many articles on parenting, special needs, autism, politics, and life in general that convey moments of struggle and resolution, of self-doubt and understanding. My work has appeared in a variety of publications, from educational journals to the New

> York Times. I have covered topics such as my autistic son’s bar mitzvah, his transition to adulthood…”

Out of the eighteen blogs, thirteen included “autism” in their name. The use of the word autism in the blog name signals the narrative’s focus to readers; these rhetorical references throughout the blog stories emphasize the positive and negative effects of an autism diagnosis. Depending on the use of language and framing of autism in a negative or positive light, the author can shape how the reader views disabilities. As an example, I present the words of one mother describing her experience of living with her 17-year-old autistic son (M1):

> “He keeps himself busy. It clearly soothes him [. . .] But in other ways, it’s hard because he now refuses to leave the house on a Sunday and like it or not, sometimes we have stuff to do. Plus, I cannot leave him home alone to do these things like a parent could of a typical seventeen year old. We try our best to accommodate and it’s clear he very much NEEDS this routine right now. Like all things with autism, I have learned to just go with it. It will pass but it’s sometimes very hard to watch your child struggle.”

In five of the blogs, autism is not implicitly named as the main focus on the blog on the homepage. However, the majority of the narratives share the goal of describing the ups and downs of living with autism. Depending on the blog’s goal and the author’s narrative, the author may want to show the challenges of being on the spectrum, the advantages of being considered neurotypical, or the benefits of advocacy. In a motivational-style abstract that suggests the content of the rest of the blog, self-advocate A3 observes:

> “Many people, again lay and professional alike, believe that all people with autism are by definition incapable of communicating, that they do not experience emotions, and that they cannot care about other people or the world around them. My experience, both personally and with others like me, is that in many cases quite the opposite is true.”

B. Orientation

Hyperlinks are noted on other pages in addition to the homepage. Most links are located within the first two elements of the drop-down menus—either in the “About Me” section or the mission statement before the beginning of the blog. Ten of the eighteen blogs have hyperlinks to an external blog. The different links raise questions about the commercial motivations behind creating a blog and presenting one’s advocacy efforts to the world. After examining this external resource promotion, other “extra” elements on the homepage of these blogs are examined as well. Author A2 writes:

> “I am an autistic guy with a message. I spent the first half of my life completely trapped in silence, the second on becoming a free soul. I had to fight to get an education. Now I am a regular education student. I communicate by typing on an iPad or a letter board. My book is now available on Amazon. It is an autism diary, telling the story of my

> symptoms, education, and journey into communication. I hope to help other autistic people find a way out of their silence too."

Characteristics are assigned to orientations based on the blog's intended purpose or table of contents. A large archive of prior blog entries indicates that the author has used the website for a prolonged period of time and likely discusses a more comprehensive range of concerns (Tannen 1982). The orientation shows how blogs of the same subgroup vary in behavior and identity. On the websites with archives, the sharing of perspectives about autism is easily identifiable. Nine out of the eighteen blogs have archives of their blog entries, and this provides more relevant and helpful information to understand and characterize the blog and its author. The following is an example of a description of one of the blogs that includes a blog archive. The mother of A2 shares:

> "I've been doing this for almost nine years and one trend I have noticed is by the time you have read this blog post; ten new autism blogs will have been born. I have a hard time finding other blogs dealing with teenagers on the spectrum. As a friend pointed out to me, '"Well, it looks like it's gonna be you doing it."'

C. The Complicating Action

Regardless of which of the three subgroups the blog represents, every blog in the data analysis includes entries in which the narrative centers around having autism. When the narrative is written varies. Only one blog has entries written predominately pre-diagnosis, while eight blogs have entries written after the autism diagnosis and two that describe receiving the diagnosis. The remaining seven blogs used flashbacks and flashforwards to describe events both pre- and post-diagnosis. It is difficult to say whether post-diagnosis narratives are becoming more beneficial for the autism advocacy community, mainly because of the rapid changes that have occurred due to COVID-19. I find that nine blogs use COVID-19 as a plot point in their narratives. Six of the authors specifically write about challenges of living with autism during the COVID-19 pandemic. One parent of a child whose school shut down for quarantines writes,

> “We always had made him calendars when he was home on the weekend, but what could we do now? Monday: Wake up, Eat breakfast. Sit around. Get bored. Snack. Laundry. Dishwasher. Sit around. Lunch. Sit around. ‘No calendar,’ he said when he looked at the week that yawned before him.”

Many of the narratives describe the process of receiving and eventually accepting an autism diagnosis. This reaction varies for members of different subgroups as the experience of receiving an autism diagnosis differs depending on whether it is oneself, one’s child, or a group of people with no direct familial connection who is receiving the diagnosis. Whether the caregiver receives the diagnosis with confusion, denial, motivation, or anger depends largely on their temperament. One self-advocate writes about his diagnosis,

> "In some ways I'm getting used to autism, but I can't get too used to it or I won't get better. I have to strike a balance between the need to accept myself the way I am and the need to not accept myself the way I am, so I can keep fighting to improve."

Self-advocates and individual-advocates worry about being misunderstood, but this sentiment is only vaguely detected among the group-advocates' narratives. This concern may be partly due to the personal attachment that individual-advocates and self-advocates feel to autism diagnoses. Writing about this concern, advocate Z1 observes,

> "When the knowledge that is missing from a perspective is the insight of the group that is subject of the narrative being created, there is a very strong case for the deliberate exclusion of that group in order to perpetuate control or dominance, to keep that group oppressed, or simply the reinforcement of stigmatized assumptions based on the previous perpetuation of that narrative: namely that autistic people are incompetent."

In the complicating actions, there is also a recurrent sentiment of feeling judged. The blogs describe numerous hurtful interactions resulting from either malice or a lack of knowledge. At least one author describes an interaction in which someone is sensitive about another person's perception of them in each subgroup. As the authors express in many entries, feeling judged is a common experience among stakeholders. Of the three subgroups, the individual-advocates' narratives show the most concern about being judged. Five out of the six individual-advocates write about the fear of being judged, mainly by fellow parents and medical professionals, for how they are taking care of their child. The parent of Z2 writes,

> "At several points during our appointments, she would tell me that I was failing him as a parent when I would question her or her recommendations. That immediately instilled a [sense of] distrust in developmental disability professionals from that point forward… He fights an inner battle with the autism diagnosis. It makes him feel less than others."

These frustrating moments of being looked down on by other children in a classroom, being called a name by another mother, or being unable to share information that could help others ignite anger and exhaustion in advocates. It is easy for members of the autism advocacy community to grow frustrated in their attempts to effect change and share their experiences while simultaneously fighting against the social stigma of intellectual disabilities. Advocate Z1 continues,

> "Nearly everyone who has been diagnosed as autistic as an adult has felt the exhaustion of the aftermath: having so many questions answered only to have so many more raised, the mental gears grinding trying to process what it means and facing up to the potential of being dismissed by the people you trust and love."

Meanwhile, group-advocates deviate from these experiences of judgment and frustration. The concerns expressed in their narratives reflect clinical worries that are more objective than someone advocating for a close family member with autism. Authors in this group describe fears centered around their ability to provide sufficient support for the advocacy community. Thus, they encourage donations to charities for autism research, advocate for better treatment practices, or promote their nonprofit group as a resource for more people needing assistance in navigating the diagnosis. According to a group-advocate in nonprofit X1,

> “Increased workforce training, including clinical training around ID for professionals (e.g., pediatricians, psychologists, and psychiatrists), research staff, advocacy community liaisons, and others who may work directly on improving research methods for this population.”

Feelings that arise during the complicating action in all three subgroups are isolation, anger, exhaustion, motivation, and loss. The idea of spending life alone, leaving one’s child alone, or leaving a group of needy people to manage their problems by themselves are common fears among advocates in the autism advocacy community. Advocates also suffer from exhaustion after prolonged periods of worry, although the degree of exhaustion varies among the subgroup members. Parents of children with autism mention their fatigue far more often than members of the other two subgroups. More generally, the idea of wanting to give up is introduced in most entries that describe any long-lasting challenge, no matter the subgroup.

D. Evaluation

Evaluations in online blogs are easily extractable from a little over half of the blogs. Self-made blogs include clear distinctions as to the aim of the evaluation in each blog entry. However, there is usually only one evaluation per blog. I identify three possible evaluations: *revealing the truth, sharing a sense of pride, and joining or creating an advocacy community.*

Of the eighteen different blogs, only three lack an evaluation. Six blogs are included per subgroup and four evaluations are established according to the subgroups. The four evaluations cover all the subgroups' narratives in the sense that all three subgroups have at least one of these evaluations. Consequently, there are at least four evaluations per subgroup.

Different stakeholders in the autism advocacy community use their positions as advocates to construct particular narratives to communicate with their readers and share their experiences with autism. The first evaluation identified in this study is revealing the truth. Depending on the subgroup the advocate falls into, they may feel a sense of responsibility to correct common misconceptions about autism or to share with the public the "realities" of living with autism or advocating for someone on the autism spectrum. The second is sharing a sense of pride, which is seen in bloggers who desire to share stories with an online audience regarding children and adults with autism who make strides in their treatment and personal progress. The third and last evaluation detected in this study is the desire to join or create an advocacy community. Once an online blog has received engagement from an audience, a sense of community is created. The author is motivated to share stories of loneliness and isolation with the autism advocacy community, and in doing so is relieved of their loneliness and sense of seclusion.

The four evaluations are as follows:

1. Revealing the Truth

Among the blog included in this study, four have authors who are dedicated to educating readers on the underlying truths about autism. A desire to reveal the truth encompasses a wide range of motivations for sharing an authentic experience with autism, be it about daily physical difficulties, educational challenges, familial struggles, or social stigmas. These various elements are often discussed using a stream-of-consciousness style to effectively convey the author's perspective. The authors typically use a persuasive writing tone, especially in blog entries where the goal is to convince the reader of a reality or opinion that diverges from the mainstream perspective.

Some advocates want to be open and honest about their personal challenges, and they do not hold back when doing so. Among the authors in the individual-advocate subgroup, parents seem to be particularly desperate to share the hardships they have experienced, which are often undertaken alone. For instance, one mother, M2, writes about the moments that test her patience the most: "Some people will take your last breath if you're willing to give it to them. My adult children will probably stand over my grave and yell, "but Mom I need…'"

A similar evaluation is expressed by another advocate, at least in the sense that she uses her online blog to speak about misconceptions and issues in the autism advocacy community. A2 writes,

> "Your misrepresentation has consequences for the cognitively and neurodevelopmentally disabled people who are going to bear most of the burden, most of the energy costs, of attempting to rebut you and mitigate the impact of the misrepresentation you've once again lent credence to."

The authors write about feeling challenged, learning to fight through these obstacles, and then identifying the problems in the advocacy community that make life more difficult for advocates.

2. Sharing a Sense of Pride

Compared to the first evaluation, the second is more commonly identifiable among advocates' blogs and is present among all three subgroups, not just the individual-advocates and self-advocates. Four blogs' narratives have elements that can be identified with this evaluation. Sharing a sense of pride describes any sort of advancement that brings gratification to the advocate, whether that is visiting a new doctor for speech therapy, having completed a year in school, or using a new skill to overcome a stressful situation, there are endless sources of pride in this advocacy community. Accordingly, it makes sense that there are numerous points in the different blogs where this evaluation can be identified. M1 writes,

> “He just saw his whole nighttime wind down routine get tossed aside and he "mixed it up" and found his own way to cope. In fact, I think it was safe to say he coped better than I did.”

Pride comes from different sources and places in the autism advocacy community and is linked to the advocate’s particular goals. As described previously, members of different advocacy subgroups have focused on various goals depending on their experiences, abilities, ideologies, and resources. Thus, pride as an evaluation is generally a result of moving toward an improvement, taking a step forward, or the achievement of a goal aligned with the author’s subgroup. Further, expressing feelings of pride regarding certain areas of advocacy and progression in autism treatment helps highlight the areas of advocacy that subgroup’s advocates associate with seeking well-being. For individual-advocates or parents, it may be that feelings of pride in a child’s treatment progression is an indication of getting closer to determining the interests and well-being of the child. Group-advocate G1 writes about one of her students, recalling the day she experienced the most gratifying and best day of her life as a teacher:

> “The very next day she took off and was walking all across campus on her own. The entire campus celebrated this milestone as everyone saw the progress she made. The janitor was excited, the secretaries were excited, students were excited, and other teachers were excited. More importantly, her face when she was walking on her own was just elated with excitement.”

Although belonging to a different subgroup, the following advocate experiences a similar sense of pride when a child takes a step forward (as seen in the example above, quite literally) and closer to a goal.

> "All of these skills have taken years and countless hours of school, therapy, and work at home to achieve. I can't even begin to describe the pride I feel when I see her achieve a new skill or I hear a positive report from her teacher or therapist. No skill goes unnoticed. We celebrate everything and take nothing for granted."

3. Joining an Advocacy Community

The majority of the narratives from the online blogs have characteristics of the evaluation category "joining or creating advocacy communities." Seven out of the eighteen blogs share descriptions of either the process of joining the autism advocacy community or the author's attempts to create their own sense of community. The path to gaining acceptance into an advocacy community, whether by joining or creating one, differs for each individual-advocate, and there are significant differences among the subgroups as well. However, part of the motivation for forming the larger autism advocacy community stems from the desire to create an advocacy communities for people on the autism spectrum in particular or to feel as though one is part of a community. Group-advocate X2 writes,

> "We have to start thinking differently about the different thinking of those on the spectrum. Many of the unusual behavior [that] others observe in the autistic are simply

> nothing more than neurotypical normal behaviors amplified, extended, or taken out of context. Most of all, let's just remember that having a different brain modality, a different way of thinking, is not necessarily bad—it's just different."

Whether someone chooses to join or create an advocacy community depends on their personal goals and experiences. Being able to rely on an advocacy community on has made an enormous difference in many people's lives. Self-advocate Z3 explains,

> "I am peacefully making friends now. I learn normally. My school values me and I make my own goals. I feel loved when I am accepted. I feel loved when I am seen not by my momentary deficits but by my attributes that make me a complete person."

Motivations for creating and joining communities differ, with the emotions behind them playing a major role. Desiring a sense of togetherness and family and wanting to share knowledge and help others inspires many advocates to work to improve the autism advocacy community. Group-advocate X1 writes,

> "So, this is what I feel we need to do. We need to calmly, without the anger or rage we are obviously feeling (and which we have a right to feel), say not only are they a bit counterfactual but also give the reasons why. And when we do this, we need to speak only for ourselves, not for others. We need to lead by example."

E. Resolution

Resolutions relate to the different ways the authors describe their advocacy. All the narratives from the online blogs contained some description of the author's focus and long-term goals. The resolutions have three dimensions focusing on either the past, present, or future of autism advocacy. Advocates' focus on moving forward or constantly striving to improve certain aspects of the advocacy community indicates their belief that their work will result in some form of progress. Some of the authors express concern about the (at the time of writing) present state of the autism advocacy community; past improvements have not been sufficient to make further advocacy efforts unnecessary. Others resolve their entries by summarizing the advocacy efforts that have thus far resulted in momentous improvements for the autism advocacy movement. In addition, authors whose work influenced this study mentioned nothing of previous advocacy efforts and only theorized about the future of the advocacy community.

In contrast, some of the advocates gushed about the progress in advocacy they helped achieve in the past. These advocates mention smaller goals that are more easily attainable, such as with individual-advocates encouraging their child to try a new food or listen to music. Advocate X3 proudly writes,

> "She's starting to make comments on our daily activities instead of scripting. I know these skills and achievements will not earn her any awards and most wouldn't post these victories on Facebook. But these are successes for my Anna! I'm so proud of her. Her achievements and those of children like her deserve to be celebrated, posted, awarded,

> and shouted out to the hilltops! Our children can make great progress and achieve the impossible!"

The mother of advocate M3 describes their past in a similar way:

> "Our kids (17 and 20) have grown up fixing their mistakes and apologizing. They think of others, and they don't trash the place anymore. What we've noticed is that people with "perfect kids" have bred children who don't know how to take responsibility or how to apologize."

The advocates do not need to explicitly state their goals for the future or the failures in their pasts. Frequently, they contemplate giving up in the face of the constant challenges of advocacy.

> "You can be an advocate, writer, public speaker and general loudmouth for all things autism, and it can still knock you on your arse when you least expect it. It doesn't make me a bad person. It makes me human. Feelings are fluid. They can ebb and flow around your heart and in your mind."

Attempts to improve language usage and control the societal autism narrative are described by advocates of all kinds. Reflected in ten out of the eighteen narratives, this resolution was the most common. As advocate X1 writes,

> “If we are going to be able to personalize our approach to care and provide benefits to ALL people, we need terminology and language that are specific and meaningful.”

Meanwhile, advocate X4 writes about the advocacy efforts she envisions for the future,

> “We are developing courses, training, and eLearning resources to help all the people that are important to the lives of the autistic in mainstream society; yes, that’s like the old children’s song, “the butcher, the baker, the candlestick maker.” Everyone needs to know about autism, but more importantly, how to respect, and to cherish our autistic friends, neighbors, and colleagues.”

X1 continues,

> “We should be seeking to make it easier for these families to articulate their child’s needs, not harder. Normalizing the term “profound autism” will help families more efficiently access the support and services they need, giving people the best chance to live fulfilling lives with dignity.”

The online blogs express the advocates’ perceptions of advocacy efforts and signal how these perceptions affect the author’s narrative. These perceptions impact not only to the advocates determining what has been accomplished and where the advocacy community has gained ground but also the places in the autism advocacy community where advocacy efforts fall short.

A proud mother writing about her son's progress creates a different narrative than a mother who is exhausted from trying every treatment type to help her son. The construction of narratives is revealed to differ even more greatly when different subgroup members' perceptions are compared. The mother of M1 writes:

> "We will celebrate each milestone in a grand style in this autism house for my kiddo has certainly earned every parade of praise we give him. I will smile and hide the tears at the same time, savor each victory even if it's just that I got him to finally eat meatballs and meatloaf in the same week."

Having two children on the spectrum, M1's mother feels quite differently about her sons' diagnosis. She explains, "I will not speak in detail of my adult children, but their mental health, or lack thereof, impacts my mental health. It has been a shit show of a year. I am holding on to life by my fingernails."

F. Coda

Coda is identified in the blogs by way of narrative analysis reflecting patterns. All the blogs match at least one of the three codas described earlier. They demonstrate how the evaluation and resolution bring the story to its conclusion; a narrative's code reflects the reason for constructing that narrative (Simpson 2005). The first component of the coda is similar to the evaluation about pride: different advocates have varied perspectives related to autism, and they express opinions on the topics they write about on their online blogs. This is especially notable when personal examples come into play—there is a common pattern of advocates believing that they are “heading in the right direction” in their advocacy efforts. The advocates in each subgroup also end their entries in different ways, thus indicating their feelings toward their own advocacy and how the autism advocacy movement has progressed, either pertaining to themselves or a more general application. For instance, self-advocate A2 shares his opinion on how parents should reprimand their children with autism:

> “When we are rude, we need to be told that clearly and not enabled by understanding polite tolerance of something that isn’t acceptable. My mom wouldn’t have let a dog snatch her food, let alone a human, but we tend to be too forgiving if people have autism.”

In contrast, a rather different sentiment is expressed by the mother of M1:

> “Sometimes he just has to scream it out. Lately he is accepting going to his room to do so. This is a big improvement from kicking holes in the walls. (*fist bump* to all the parents who keep sparkle and wall patches on hand. (HOLLA!)”

The second pattern relates to the notion of revealing the truth: identifying and addressing a challenge is presented in the coda of half (nine out of eighteen) of the online blog entries. Moreover, all three subgroups include at least one advocate with this pattern in this part of the analysis’ coda. Toward the end of their narratives, many authors disclose information that seems exclusive to persuade readers to return for more personal content. Thus, this pattern reflects the reality that while many advocates are willing to talk about disability in a positive, open way, discussions about the downsides of having a disability must be approached far more subtly.

There is no shortage of hurdles challenging people in the autism advocacy community and the conclusions, unspoken yet agreed on by many of the authors, seem full of relief to talk about both the good and the bad days. Self-advocate Z3 writes, “I am going to tell you why open communication is hard. Talking takes all the energy I have. Day to day I use language in my inner thoughts. I hear my own voice. It sounds perfect in my own mind. Getting my thoughts out is a lot of hard work.” As can be seen from the above, worries about the future are a consistent and common narrative component of the coda. While Z3 describes the difficulties he has with communication, Author A2 brings up a different stressor. Note that the tone of the writing is different, and the concept is framed differently. A2 states, “I need the right kind of support to succeed in high school, and I will need the same to go to college and to work in a career. If I can’t get this, what then?”

The last pattern in the coda pertains to the evaluation of advocacy communities. Once a person gains experience in advocacy, they often reach out to other similarly minded or similarly experienced people to request they join their online advocacy community. As a pattern in the narrative coda, the desire to create an advocacy community does not only apply to a single subgroup. There are many occasions in which an advocate from one of the three subgroups emphasizes on his or her blog that any person who needs resources or wants to feel like they are part of the advocacy community can join in the advocacy efforts. For instance, advocate X2 calls for the combination of the advocacy efforts of the three subgroups used in the present analysis, although the author refers to the subgroups by different names. X2 writes, “Parents, caregivers, and the individual autistic citizens are the first line of the political fight for acceptance, equality, fairness, and protections.”

Chapter 5: Analysis

This section focuses on thematic similarities, differences, or patterns among the three subgroups in the autism advocacy community. The themes identified in all three advocate subgroups are: *fleeting sense of time*, *what it means to be the “Other,”* and *persistent challenges.* Among the self-advocates and group-advocates, shared themes include *focusing on the future.* Among the individual-advocates and group-advocates, shared themes include *focusing on the future.* The self-advocates and individual-advocates shared the themes *isolation* and *time as an obstacle.*

Utilizing grounded theory coding in the Labov Method of narrative analysis, thematic characterizations are formed. The aim of this study is to identify themes that characterize advocates’ narratives. Themes are helpful as a determinant in qualitative studies because they require explanation and description, and the different perceptions of well-being are well suited to demonstrating the themes as applied to an advocate. They also help to determine which characteristics are applicable between subgroups. The general goal of the study, which was to examine online blogs to understand conceptions of well-being in the autism advocacy community, was successful, and part of this success is due to the fact that it was unnecessary to pose theories or hypothesis at the beginning of the research while using grounded code theory.

The themes in this section include time as an obstacle, fleeting sense of time, knowing what it means to be the "Other," consistent challenges, isolation, focusing on the future, maintaining a positive mindset. The themes are explained in accordance with the subgroups to which they apply.

These blogs reveal themes to either separate, connect, compare, or characterize the members of the advocacy community based on their narrative. Comparing the same elements, uniformly, across different types of advocates in the same advocacy community demonstrates how narrative differences affect authors' thematic developments. A list of the themes presented by authors whose studies were used to collect this data can be found in Appendix C.

A. Findings: Themes

"Well, right from day one the narrative of Autism research has been this: 'Expert' looks at Autistic person (usually a child; usually white child; usually white boy child; usually white boy child that presents in a particular way). 'Expert' takes notes. 'Expert' forms opinion… Whole world believes in 'experts.' Services are developed around 'Expert' knowledge" (The Autistic Advocate).

Thematic analysis is a credible way to address political science issues. Not only does it highlight areas where subgroups have similar concerns but seeing the contrast in themes helps point out disagreed-upon areas of advocacy or ignored areas of advocacy. It also shows which advocates contrast in their goals related to well-being.

The themes in my analysis are related to well-being. They come from my research around disability, autism, rhetoric, and well-being. Concepts and ideas pertaining to satisfaction, autonomy, agency, and other aspects of well-being are presented in books like the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 2002) in various contexts. Through using multiple disability, medical, and social science journals to determine well-being-related terms, I move forward to develop themes with an informed understanding perception of well-being among disability advocates (World Health Organization [WHO] 2013).

Themes that apply to one subgroup in one study and also apply to other subgroups with different methodologies to determine themes can reveal the main focus areas in the larger advocacy community. Themes that apply to one subgroup in one study that apply to other subgroups with different methodologies to determine themes tell the readers specific signals about the main focus areas among the overarching advocacy community.

B: Shared Themes

1. All Advocacy Subgroups

1.1. Fleeting Sense of Time

One theme that dominated many narratives among all three subgroups was identified in Kelly's 2018 study of five focus groups: one study on children with disabilities and their sense of time lead to conclusions about themes among the self-advocates she used in her subject pool. Kelly writes in her analysis of the themes that autistic children express the need for more time and that task are hard, “both of which generate a sense of being out of pace” (2018). Kelly highlights this theme’s applicability to self-advocates, so this study is intended to show how similar sentiments are shared by individual-advocates and group-advocates.

From the perspective of an individual-advocate**,** the author of a blog suited for parents with children on the autism spectrum, Z2 writes**, “**What will happen to him if I’m no longer here? Will the rest of the world have the time and patience to deal with his difficult personality? A question many autism parents ask.” The theme of a fleeting sense of time is played in the group-advocate subgroup as well. One special-education teacher brings up the same dilemma as Z2: that when an autistic child’s parent passes on, the transition to having another support system is daunting. This leads to the group-advocate calling for a change in how the education system teaches basic skills such as financial literacy. X2 writes, “Without proper learning to cope with their own needs, the child will grow up unable to help themselves once the parents are gone. That puts the task of caregiving on siblings or cousins whose dedication will never match that of a parent.

1.2. What it Means to be the “Other” / Loneliness

Brown’s 2004 paper on author Hans Christian Anderson displays an example of a self-advocate using fiction to construct his own narrative through his writing. Though his works are not about himself, he is believed to have written stories to celebrate his difference, because he thought it made him so special (Anderson 1990). Brown writes, “Fairy tales are the perfect genre for the autistic writer who wants to explore themes of isolation, otherness, destiny, and legitimation. In each of Andersen's tales, a character with traits of Autism Spectrum Disorder "learns a lesson" and gains valuable insight." Brown highlights this theme's applicability to self-advocates, so I showed how Similar sentiments are shared in individual-advocates and group-advocates. Individual-advocate and parent of advocate M1 describe, "The older your kid gets with autism, the less 'stuff' will be out there for your rapidly growing kid. Not gonna lie, that kind of freaking sucks. There's just very little that both neurotypical and autistic teens joined together. There's a very distinct line. "A group-advocate, Doctor of Psychology, writes about his experiences working with parents finding out about their child's diagnosis and the advice he would give any future parents who had trouble accepting a disability. G3 writes, "Although their paths may not be traditional and they may take many twists and turns, people with autism can find success and happiness on their own terms. As I am writing this, I just learned that a young adult I have worked with earned an associate degree in film production; all the while, he maintained his own apartment and made tons of friends."

1.3. Persistent Challenges

Group-advocate, Hedges, writes about the themes that are presented from a study about challenges for high school students with autism. "Teachers discussed how many of the behaviors of students with autism "annoy" their peers, are not socially acceptable, and can be offensive, which negatively impacts their ability to build peer relationships." Individual-advocate M3 writes, "We're finding that the more we talk about our issues, the more we discover similarities. Many of these children have sensory issues and every day is torture for them. Reducing these sensory issues using noise reduction headphones, light shielding glasses and touch-friendly clothing can significantly reduce the anti-social behavior of these children. Take away their daily "torture" and suddenly our child is far less explosive." Self-advocates also portray this theme in The subgroups' collective narratives. Advocate Z3 writes about her personal experiences in being assumed as unintelligent in school. "I need the support for my challenging body. Many have made the mistake of thinking that my intelligence is totally challenged too. Daring to believe challenged bodies are still intelligent is hard for most educators. Could teachers do better?"

2. Self-Advocates and Group-Advocates

2.1. Focusing on the Future

Group-advocate X1 writes in their blog about participating in a group of researchers who proposed a comprehensive 64-page report regarding changes for the future of disability policy. It specifically detailed "changes that should be made over the next five years to improve the quality of life of autistic people and their families."

The future is a topic of hope, planning, and excitement for advocates to think about their advocacy efforts. However, among autistic people, thinking about the future brings on fear. Self-advocate A2 says, "My hopes include college and career and a girlfriend one day. The whole thing. Am I frightened that I will never get to achieve the things I want? Very, very, very."

3. Individual-Advocates and Group-Advocates

3.1. Maintaining a Positive Mindset

The theme of maintaining a positive mindset is prominent among the individual and group-advocates, and this may provide insight about hope for the future one has, depending on the advocate subgroup they fit into. One author writes, “The disability and health organizations largely present detached futures. That is, hopeful, positive visions of the future, some veering toward what might be considered ‘crip futurity’ that sharply contrasts the daily reality of survival as organizations” (Kelly 2018).

Writing about her strategies to encourage her students to continue following the classroom rules, the group-advocate G2, a special education teacher, explains, “The ultimate goal of implementing these working cards is to spread the amount of time between reinforcements and to gradually reduce the overall amount of reinforcers in one day. KEY WORD -> GRADUALLY!” When talking about her son getting upset when they went out to eat, advocate M1 writes, “I will try to beam positive vibes to the other parents who are there waiting and have just witnessed this. I will pretend I don't care that they gave each other that ‘look’. Cause I don't have the energy to worry about what they think. I hope maybe next time will be better or maybe his hair won't grow as fast.”

4. Self-Advocates and Individual-Advocates

Among the possible ways of pairing two of the three subgroups for within subgroup analysis comparison, the individual-advocates and self-advocates have the most thematic crossover. I contribute to disability studies by presenting that self-advocates and individual-advocates share more themes than any other pairing of subgroups: isolation and time as an obstacle. Shared themes highlight agreed-upon areas of advocacy. I use this insight to consider the areas of advocacy that are shared. One deduction made from the crossover of themes is that both subgroups recognize that community/social support is a concern for autism stakeholders. Thus, the themes serve as narrative information to point towards what advocates care about, thus showing the differences in how advocates understand well-being.

4.1. Isolation

In her study of how children with autism perceive their well-being in schools, Danker attributed much of the barriers to well-being as social. He writes, “Bullying was also a barrier, and which included being teased, and having their money stolen. To cope with the bullying, six students shared that they ignored it, put up with it, informed their parents, and “minimized” themselves to avoid noticing by their peers” Among self-advocates, “With autism I may as well be on Mars sometimes because the inability to talk is isolating. It creates a barrier from other people because I may think of ideas, but I can’t speak to them. Yes, I type, but it’s slow compared to speech or I may not have access to typing the instant I want” Individual: Mothers either worried about isolation for themselves socially or for their children in making their own social identities. “In his lifetime he has faced so many more challenges than most people. Most of his school experience was an exercise in pain, competition, isolation, and rejection. When your boy is obviously depressed in the fourth grade, so much so, that he says he wants to die.” – confession.

4.2. Time as an Obstacle

In Woodgate et al.’s study on parents’ experiences parenting children with autism, the author notes, “Parents described always having to anticipate the next course of action to ensure that their child received the most appropriate and timely treatment. It was important, as one parent expressed, ‘not to let the window of opportunity pass them by.’” Advocate G3 writes, “In my mind, Philip’s window of recovery was shrinking with every passing year. Every year he fell further and further behind his peers. Every year he would be less tolerable in public as he grew in size but remained at a static developmental level (so I thought). And then there was always the thought lurking in the recesses of my mind: what will happen to Philip when he grows to be an adult?” In an article commemorating the ten-year anniversary of his autism diagnosis, self-advocate G3 describes the perspective he had before he understood why he feels different from others. Detailing how his diagnosis changed his life and how he saw himself as he entered adulthood, G3 observes, “Ten years ago, I believed myself to be a failure of a human, whose weaknesses mattered so much more than his strengths. Ten years ago, I felt like an uninvited guest at the rest of the world’s dinner party as if everyone else just had a natural place at the table, I had to be given a stool and sit by the wall. It felt like I was trespassing in everyone else’s world just by being there.”

C. Uncommon Themes and Unique Conversations

1. Self-Advocates

Self-advocates’ narratives are often centered around the daily challenges of living with autism, either as social problems, physical or communicative hurdles, or personal struggles. The theme “working around barriers and limitations” was uniquely common among the self-advocates’ narratives. The themes that are uniquely applicable to the individual-advocates relate primarily to the more general drawbacks of advocacy. This is unsurprising for the subgroup that has written the most about the stresses they face in their autism advocacy and parenting. Group-advocates had less novelty in their themes, both in the findings of the authors whose studies were used to collect data for this study and the thematic conclusions. The group-advocates’ narratives emphasized a message of encouragement, highlighting many researchers’ and behavior analysts’ wishes for increased communication among the three subgroups in the autism advocacy community and for them to come together on wider-scale policy issues where wide-scale mobilization would be useful.

2. Individual-Advocates

The themes that solely apply to individual-advocates concern general concerns about participating in autism advocacy, such as worries about what other parents might think (Pitney Jr. 2015). This is a not surprise, as some general conclusions are bound to emerge from the subgroup that releases the highest number autism blogs, as portrayed through several searches in different search engines and web browsers.

3. Group-Advocates

The group-advocates’ narratives communicate a more hopeful attitude than the other advocacy subgroups. Many blog entries among group-advocates focus on idealistic situations and theoretical possibilities for the future of advocacy. Some of the bloggers stress the importance of focus on wider-scale policy issues to conduct any lasting-change on the autism community. They refute the idea that thinking up ideals for improvement, treatment, and reform is acting in attempts to “cure” autism; rather, the focus is on highlighting ineffective areas of the advocacy community regarding encouraging reform. Group-advocates have less variation in the patterns and contrasting conversations Labov Method elements than the other two subgroups except for one exception. The only topic that group-advocates have drastically contrasting discussions about is the infamous Applied Behavioral Analytics (ABA) therapy (Broderick 2011; Melvin et al. 2020; Lovaas 1987).

Chapter 6: Discussion

A. Thematic and Political Implications

Well-being is political. The concepts of welfare and well-being are a focal point in modern times, particularly during the COVID-19 pandemic. Social science researchers have been concerned with well-being and citizens’ welfare after World War II (Lindorff 2002). However, the concern about well-being has been dominantly focused on the neurotypical community. Bringing light to the discussions around intellectual disabilities, then, is important to bring autism awareness into the general public’s focus. The assumption that well-being for autistic people is different than neurotypical people is a barrier that open prevents autistic people from opportunities. This is coined as being on the “fringes of citizenship,” which typically describe minority groups. One author explains, “The fringes of citizenship are not merely a location – that is, they are not simply ‘out there’ – but can be understood as a dynamic relationship, almost a power struggle'" (Sardelić 2021). By showing different perceptions around pursuing autistic people's interests, using grounded theory coding, and conducting the variety of comparisons in my analysis, this study presents data about the efficacy of the advocacy around autism. Particularly, there is a need for similar understandings of well-being and more communication between the three subgroups. To conduct reform in providing space for vulnerable voices, autistic people on the outskirts of society, the concept of well-being must be contextualized within the lens of autism. Also, stakeholders wanting to conduct efficient and effective advocacy should encourage agreement in how to seek out the interests of autistic people.

Thematic analyses provide potential to determine what aspects of advocacy are impeded by the competing disciplines or discourses among stakeholders. The importance of a theme depends on how frequently it is mentioned in the text, whether it pervades into cultural ideas or concept, and people's reactions to the themes in different contexts (Opler 1945). For example, repetitive use of the same phrase or question in the blog entries, for example, highlights the idea or concept that advocates have yet to agree on. "This classification is discovered when concepts are compared one against another and appear to pertain to a similar phenomenon. Thus, the concepts are grouped together under a higher order, more abstract concepts" (Strauss and Corbin 1998).

Identifying and assigning themes to subgroups speaks to the noticeable parts of written narratives. Especially with so many elements in this study- the eighteen blogs, the three subgroups, the grounded theory coding tables, and the analysis within each subgroup and between them, determining themes helped generalize many of my findings.

1. General Contributions

This study contributes to existing literature about well-being in disability and political science for various reasons. Important questions about neurological diversity are raised, and the bulk of the research includes the exploration of dominant discourses associated with neurotypical and neurodivergent autism advocates, whether neurodivergent people conceptualize ideas differently than neurotypical people, and what the identities, motivations, and experiences of advocates are among those with different conceptualizations. A specific and important contribution to disability and political studies is the addition of systematicity to the blogosphere genre; the goal of the blogosphere is not to follow systematic models but rather to advocate. In this thesis, however, the blogosphere is opened up for more qualitative, systematic exploration. Political implications from this study highlight how the decisions of neurotypical advocates affect how neurodivergent advocates' interests are served. Once the narratives of advocate subgroups are compared, barriers for autistic people's well-being are isolated

Self-identified barriers to well-being suggests the areas in autism advocacy where autistic voices are not heard. For example, there are more blog entries about rhetoric among self-advocates than the other two subgroups, so this is a point in advocacy that has not been reformed and has negative effects on autistic people's well-being. One author emphasizes that listening to autistic people would help people's acceptance of autism. By spreading awareness about autism, but more so about the silenced voices within the community, gaps in future policy are highlighted.

One author who also examines discussions in autism studies emphasizes more autistic involvement in autism research. He writes, “it is the voices and claims of autistic people regarding their own expertise in knowledge production concerning autism that is most recent in the debate, and traditionally the least attended to” (Milton 2014). Further, the lack of investigation into the well-being of autism advocates exposes the autism knowledge “bubble” and how typically only autism stakeholders take part in advocacy. Despite this, the majority of “critical autism experts,” are neurotypical. The gap in opportunities for autism research implies trends of workplace discrimination, disability based bias, and inequitable hiring practices. In this case, policy can be implemented for reform (Tilly and Wood 2020**).**

B. Aims of the Study

A goal of the project is to highlight the relationship between the subgroups’ narratives and their implications for political participation. While well-being is discussed in a wide range of fields, political science is increasingly addressing it as a priority and facet of quality of life and life satisfaction. However, measurement of well-being has presented difficulties for those looking for public policy implications, so this is one reason for the initial goal of exploring the advocates’ different ways to perceive well-being. Research in well-being interventions increase during times of national or world-wide crises; particularly after the 2008 financial housing crisis, the bulk of the primary well-being research was published. The reason for well-being investigations during times of crisis may be the desire for change during hardship; when displeased with the current state, referencing well-being is a way to advocate for reform in policy (Dennis 2021).

As the previous discussions indicate, there are differences in narrative components (abstract, orientation, complicating action, evaluation, resolution, code) among the three subgroups included in this study, not just in the way that the advocates identify. In fact, the narrative components in this study help distinguish between the narratives of advocates in different subgroups. The use of grounded theory coding allows for simultaneous analysis of data while gradually changing the expectations for the study. The aim of this study is not to arrive at a definition of well-being that is suited to advocates in the autism advocacy community, but rather to determine whether the themes presented by the scholars used as a point comparison apply to the results of the present study.

A full analysis of narrative and thematic similarities and differences is conducted, along with the results of the within-subgroup comparison analysis and between-subgroup comparison analysis. In researching three separate advocacy subgroups, only one piece of research studied more than one population sample (or one subgroup) at a time.

The lack of multi-group studies is brought to light from a research perspective. This is vital to consider when thinking back to Chapters 2 and 3, where advocacy, well-being, and narratives are discussed. Mentioned previously, the components of an online blog can reveal the repeating patterns in the narrative as well as common concerns, points of contention, and other points of comparison within a subgroup. Those findings are then used to identify themes, some repeating among the three types of subgroups, and some only applying to one subgroup. Coming into the research on the three different subgroups, expectations for the results included a variety of themes.

One implication from patterns in the narratives is that “the assumption is that these disability narratives never become dominant narratives, and it is true that they usually do not in the exchanges of the publications of the disability rights movement. But these narratives do become dominant narratives in some contexts, such as the support group described here, and it is when these narratives were functioning as dominant narratives that we can see counter-narratives that question the representativeness and efficacy of those narratives” (Barton 2007). The Labov Method was an extremely helpful tool to understand how the authors constructed different elements of their narratives. It is important for narrative studies to look at small elements of the authors’ narratives, rather than summaries of the whole text or blog.

The conclusions of the methods are satisfactory in that they provided a proper ground for within and between subgroup comparison analyses, to extract themes, and then to compare the themes between subgroups to determine any political implications.

C. Advantages of Methodology

The decision to organize my data using the grounded theory coding method of coding was the best choice made in this project. It allows for description of the moments that are interesting, important, or unique within the data sets. “When the original text does not contain a key term to describe the instance of interest, the researcher needed to find an appropriate term to describe the instance. Those terms are coined as “researcher-denoted concepts.” For example, if you read the following descriptions in the data, you may use the term “frustration” to describe the underlying theme of both responses” (Feng, Hochheiser, Lazar 2017). The conversations that emerge between subgroups, along with the comparison of elements from the Labov Method of narrative analysis, helped me to determine the thematic characteristics of the three subgroups in a few ways. First, looking at authors' published work that analyzed only one of the three subgroups helped me gain a perspective on the different data analysis methods that function with texts and the goal of narrative analysis. I was able to compare the different studies as a baseline idea for the difference in themes of subgroups, even though I compare the findings of different studies, subjects, and with different methods. I only wanted to ensure I saw a study on each of the three subgroups and the narratives within them. Second, the conversations and patterns emergent through the Labov Method are helpful once my data collection and analysis was completed for the within subgroup comparison analysis, as described above. Knowing the patterns within a subgroup helped me to compare them to one another, thus allowing me to assign themes to the subgroup depending on the characteristics they displayed in the elements of the Labov Method.

The Labov Method of narrative analysis was originally used in linguistics, so looking to authors in disability studies who utilize the Labov Method helped give the method credence. Narrative analysis for disability studies and disability activism can be used for more than comparing conceptions of well-being, as is done here. If there are narratives among autism advocates that do not reflect the narratives and interests of those being advocated for, then there is a mismatch in the narrative and counter-narratives emerging. As Barton (2007) observes, “the assumption is that these disability narratives never become dominant narratives, and it is true that they usually do not in the exchanges of the publications of the disability rights movement. But these narratives do become dominant narratives in some contexts, such as the support group described here, and it is when these narratives were functioning as dominant narratives that we can see counter-narratives that question the representativeness and efficacy of those narratives." The Labov Method was an extremely helpful tool to understand how the authors constructed different elements of their narratives. This allows smaller elements of the authors' narratives to be compared, rather than the summaries of entire blog entries or blogs.

In sum, the between subgroup comparison analysis was more helpful in pulling out themes from the online blog, but this was only possible once within subgroup comparison analysis us completed. Many trends were surprising even though they were in the form of trends instead of surprising pieces of data. Using the grounded theory coding method and the Labov Method is helpful to examine the interests of self-advocates under the lens of different narrative comparisons with the subgroups, I perform my analysis to look for crossover in the authors' themes and my own findings. I do this through an exploration of frequently used terms in a singular subgroup, only within one Labov Method element, to be much more helpful in pointing me to themes. One author describes their use of noting the frequency of themes in qualitative data, "we provide quantitative information regarding the frequency of the occurrence of each theme to give relative weights to those who seek this comparison" (Kuo et al. 2018). The list of most repeated words and phrases among each subgroup is found in Appendix D.

D. Disadvantages of Methodology

The Labov Method was useful only to a limited extent; the six components of comparison are described for the reader, but there are few opportunities to use the elements in a normative sense or to make an argument. According to one author, the Labov Method's focus on one author is a disadvantage. They claim that "the personal narrative is a monologue, audience and co-construction is considered irrelevant, and the speech act is considered in isolation" (Hunter et al. 2013). Thus, the method does not take all people into consideration, as it only focuses on the connection between the narrative of the author and the political impact of their words.

Finally, I addressed the question of whether or not I was able to settle on one way to best seek out well-being for autistic people. Ideally, my collection of online blogs and analysis of them according to subgroup would have shown clearly distinguished perceptions of well-being for autistic people; my results instead yielded patterns within the subgroup members' narratives that are somewhat applicable across the division of subgroups. While this made it harder to discern one subgroups' strategy in seeking out well-being from another, instead the blended aims of the overall advocacy community are highlight.

Among recent literature, there is not one set of themes, for one subgroup, that is applicable to the subgroups in my data collection. While I do not single out one well-being definition, way to seek it out, or one author whose study most matched my own, I can still use my study to make room for further investigations into how to best promote the well-being of autistic people. I discuss the gaps in my research and findings in the following section.

Chapter 7: Implications

I reviewed the lists of the most common words in my coda after looking at the different ways to divide my data: by subgroup, by blog, and by elements of the Labov Method. I decided to compare the most common words between each subgroup in order to extract themes and eventually deduce the nature of well-being in the autism advocacy community. Although once I compared the common words in each element, I could have seen more specifically some of the differences in motives that I was searching for when I was coding the different blogs, it seems that I needed a more concise form of comparison as I was doing my grounded-theory comparison as this would have kept me on a path towards a more organized way to collect and keep my data analysis.

The proposed analysis appears to be sufficient to present different perspectives on well-being as shown by the subgroups' narratives. There is no consensus on the concept of well-being in the autism advocacy community. Rather, the themes assigned to subgroups are characteristic of the coordinating, collective understandings of well-being. Different attitudes, experiences, and areas of concern emerged once the Labov Methodology was completed. The narrative elements within the method hold elements of the differences between subgroups. The method helps spread out [or focus on one subgroup at a time] the analysis of differences among the subgroups when coded into the Labov Method and the subgroups' narratives are described with patterns and notes of similarities and differences.

If well-being is assumed to be too vague of a concept to pinpoint ways to seek it in the interests of autistic people, on what can the autism community agree to collectively work towards? Which concepts could be more reasonably interpreted, recorded, and measured than the concept of well-being: 1) ensuring the upkeep and sharing of a general mission statement agreed on by all subgroups or 2) forming a small, specialized plan of action for people to individually act on?

This is a qualitative study that utilizes rhetorical analysis based on textual factors. Due to the scarcity of autism blogs, particularly for group-advocates, there is a lack of a statistical sample to validate the thematic similarities and differences I draw from the groups. There are also a number of possible counter explanations that may have skewed the reasons I find certain themes emerge in each group. The self-advocate subgroup's themes were the most applicable to other subgroups; their themes are recognizable among plot points and events in the other two subgroups, even if the patterns were not strong enough to portray a theme. This is not surprising since the self-advocates in the autism advocacy community encompass so many peoples' motivations to engage in advocacy. I am not surprised by the applicability of self-advocate themes on others as the interests of the self-advocates should be felt and heard in every part of the advocacy community. I initially thought I could determine one sole author whose data could be applied across all the advocates I studied. However, there is no way to determine which author applies the themes most to my data, neither by looking at individual subgroups nor comparing the three. Moreover, determining the applicability of a subgroup's themes to the other two can be evidenced more easily than determining the applicability of a single author's themes to eighteen different advocacy websites.

There are also a number of possible counter explanations that may have skewed the reasons I find certain themes emerge in each group. This leaves room for different narrative constructions to be made after the subgroups are combined, depending on the characteristics and experiences of the individual researcher. Members that fall into this group may play a part in closing the gap in subgroup communication in the autism advocacy community in that the interests of those being advocated for can be discussed in one subgroup and that perspectives can be shared in a different subgroup (i.e., online communities). The lack of research on narrative development of advocacy members, specifically members who fall within multiple subgroups, highlights a need for further academic exploration into the ways that well-being is most productively defined and sought after in the autism advocacy community. This research did not help conclude whether the within-group analysis, between-group analysis, or neither helped me compare the themes to previous literature, along with approaches and concepts of well-being arising from the different subgroups. It also may be the case that both types of division analysis helped me compare the themes accurately from my dataset and themes from previous literature as with a larger number of subgroups more extensive research was necessary. I compare the themes in my data, after completing grounded theory coding and the Labov Method, to the themes that researchers deduced about specific subgroups. Therefore, my comparisons are unlike the conclusions of several different studies based on *one* subgroup of autism advocacy and thematic analysis as mine focus on multiple subgroups. (See Appendix B). This may cause variation in themes. One description includes the characteristic that “parents are often required to make decisions when they do not feel that they have sufficient information to do so and to act as clinical experts rather than experts in their knowledge of their children” (Valentine 2010). Had the data that I gathered not provided insights into well-being in the autism advocacy community, additional research would have needed to be done to pinpoint the themes that emerge in different narratives of actors in the autism advocacy community. The methods and concepts outlined in my work could be used to assess other patterns in future research, which might be useful in testing whether my claims hold true in general or if they are specific to disability activism. There are a few examples of essays using qualitative/rhetorical analysis for methods within the political science scholarship.

Once again, it is important to emphasize that my personal findings are not an expression of faces within an advocacy community. With the Labov Method, it is generally difficult to prove to other academics that literary analysis is an effective and legitimate form of studying variables and important questions that impact and question how the world works. One limitation of this study is the lack of research on the concept of well-being among several types of advocates. I find several sufficient. This is how advocacy movements form, but there are few people who care about what happens to the groups once they form and begin their advocacy work.

With the grounded theory coding method, it is hard to know if what I am doing is working as I am constantly adding to and reanalyzing my data throughout the entire project. I also discovered one limitation of the Labov Method when I was finding the most common phrases and words in order to extract themes from the subgroups. Had I used the entire text from all ten entries of the author's blogs, I would have had a more accurate picture of their narratives. However, since the narratives are contained in so many individual stories, each unique and needing to have one element at a time focused on, I paraphrased/summarized the main points of the element in the coding as the previous researcher, Fleischmann, did in her 2004 study.

My thesis hopefully deepens the reader’s understanding of narratives and their impact on how an advocacy community works. Although not every person has a stake in the autism advocacy community, the more aware the public is about disability rights about autism and language and about what [attempting] to be communicated between neurodiverse advocates and neurotypical people, the better. The similarities within the subgroups’ narratives point out where a consensus exists in terms of facing education, social equality, health care, who gets to define disease, ableism, and reaching a state of well-being.

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Appendix A: List of Online Blogs and Articles for Data Collection

Autism Journey, or Autismjourney.org, by author and parent Priya Kahn, has multiple parts of the blog that I used for data collection. I incorporated the welcome page, “The Boy From My Dreams” (September 15, 2021), “Having ‘The (Autism) Talk’ with My Son” (June 11, 2019), “My Child is Not An Autism Success Story” (October 26, 2021), “A Friendly Reminder” (July 20th, 2021), “Overcoming Obstacles On and Off the Golf Course” (February 9, 2021), “Confessions of An Autism Mom” (May 22, 2019), “10 Tips for New Autism Parents” (April 30, 2019), “The Microbiome and Autism” (April 9, 2019), and “Five Incredible Ways Dogs Help People With Autism” (March 3, 2020).

I collect data from Autism with a Side of Fries’ elements: welcome page, “Sunday Funday” (June 27, 2021), “Hello Fries!” (June 2, 2021), “Chase’s Friend Zone” (February 15, 2020), “Potty Training and Autism” (March 7, 2019), “Autism and the Dentist” (July 18, 2019), “The Waiting” (September 9, 2019), “The Show Must Go On” (December 30, 2018), “Autism Around the Clock” (September 18, 2018), and “You can Miss So Much” (June 26, 2018).

Marguerite Elisofon’s blog has elements that are mainly on the same page, but it still allowed me to collect data from the different blog posts. I analyzed the opening welcome page, “An Autism Family’s Complicated Vacation” (Sep 20, 2021), “A Prodigal Son Comes Home” (Aug 16, 2021), “A New Nest for an Autism Family” (Aug 9, 2021), “What Happens When One Twin Has Autism” (Oct 22, 2020), “An Autism Mom’s Vacation Rules During Covid19” (Aug 26, 2020), “Life Lived Backwards” (Jul 17, 2020), “Not Quite Independence Day 2020” (Jul 5, 2020), “Life in the Middle of the Autism Spectrum” (Dec 29, 2017), and “The Autism Crisis for Adults – Statistics vs. Solutions” (Oct 12, 2017).

Confessions of an Asperger’s Mom has an excellent amount of resources for textual analysis of the individual-advocate in the autism advocacy community. There is no opening page/welcome page. I used for my data collection: “Unhappy Anniversary” (June 11, 2021) “Aspie From Maine” (March 27, 2021), “Sunday's Dance” (October 29, 2020), “Boundaries” (August 25, 2020), “Conversations with Depression” (August 14, 2020), “All Hands on Deck” (July 24, 2020), “Quarantine Stories” (May 22, 2020), “Self-Preservation” (March 22, 2020), “Gentle Pushes” (February 24, 2020), and “Quiet is Everything” (October 29, 2019).

Life with [Autism] Asperger’s components for data are: the welcome page, “Do we become more autistic as we get older?” (June 05, 2021), “When kids on the Spectrum Trash the House” (December 13, 2020), “Article: Autism Stimming, Hand flapping and other self-stimulatory behaviors” (September 05, 2020), “Autism and Lockdown - Part 1 Things you need to do” (April 07, 2020), “Our Partners and Autism Acceptance” (August 18, 2019), “Over-Parenting kids on the Autism Spectrum” (March 24, 2019), “Time Management on the Autism Spectrum” (December 09, 2018), “Autistic Burnout - Causes and Prevention” (June 11, 2018), and “Autism Representation and the Road Ahead” (April 03, 2018).

Susan Senator’s blog had no home or welcome page, so her blog components for my analysis are her posts: “Dancing With My Mom” (August 31, 2021), “Autism and Lockdown as Rebirth” (May 20, 2021), “How to Just Bee” (September 20, 2020), “Connection and Autism: It May Not Be What You Think” (June 16, 2020), “Special Needs Voting Social Story” (February

17, 2020), “Fun is a Superpower” (May 29, 2019), “Someone Called the Police on Nat” (June 30, 2019), “Why Autism Parents Say “’I Can Never Die”’ (April 28, 2019), “Timer heals all things” (December 24, 2018), and “Autumn Chill” (October 25, 2018).

Autistic Not Weird is a blog from a self-advocate, so the context used for data analysis are different from the aforementioned sources, from individual-advocates. Sources for coding are the home page/welcome page, “Five ways to damage autistic children without even knowing” (January 4, 2016), “What to do when your family doesn’t accept autism” (March 9, 2016), “I just found out I’m autistic. What do I do now?” (February 19, 2018), “Five tips for autistic students starting college or university” (August 13, 2018), “Finding employment as an autistic person” (July 22, 2019), “Ten vital reasons to never, ever share an autism meltdown video” (July 17, 2020), “Twenty tips for aspiring writers, from an autistic novelist” (August 9, 2020), “Fifty Autism Facts for World Autism Acceptance Day” (April 2, 2021), and “Top ten acts of cruelty that would cause outrage if they happened to non-autistic children” (August 14, 2021).

The Autistic Advocate’s elements: homepage, “One day they will join us in the sun” (February 5, 2021), “An Autistic Burnout” (May 21, 2018), “Covid, 2020, and Autism: Where is my mind?” (December 28, 2020), “What world are we preparing for?” (November 25, 2020), “Recommended Autism Positive Books” (March 29, 2020), “Regarding the use of dehumanizing rhetoric” (February 29, 2020), “What is Neurodiversity?” (March 14, 2019), “An Autistic Invalidation” (September 5, 2018), “An open letter to employers of Autistic people” (August 1, 2018), “A perspective on diagnosis” (March 27, 2018), Autistic and Unapologetic: Home page, “Autism & Eye Contact: Why Autistic People Find It SO Hard To Look Someone in the Eyes” (April 30, 2021), “Why do Autistic People LOVE Pokémon?” (February 14, 2021), “10 Tips to improve autistic confidence and self-esteem” (January 17, 2021), “Autism Facial Expressions: How Autistic People Express Emotions Differently” (September 19, 2020), “What causes speech delays in autism (speaking and non-verbal)? (August 23, 2000). “Autism and Aggression: Understanding Autistic Anger on the School Playground” (November 10, 2019), “What are the Different Types of Autism? The MANY Autism Types Explained” (October 20, 2019), “Should IQ define Autism and Autistic People?” (June 8, 2019), “5 Tips to Help Manage Anxiety in Autistic People” (April 27, 2019). Faith, Love, and Hope’s blog included: homepage, “Handwriting” (April 24, 2020), “Goals for 2021” (January 1, 2021), “Covid 19 Poem” (October 27, 2020), “Anxiety” (June 30, 2020), “Choosing My Path at School” (February 20, 2020), “Advocacy Outside My Comfort Zone” (December 16, 2019), “Independence through Dependence- Why I need a Communication Partner” (August 29, 2019), “My Own Path” (November 20, 2018), and “Why I Advocate” (August 24, 2018).

Blog posts included in my dataset from Chavisory's Notebook are “Fiction does affect reality. That’s good” (May 28, 2021), “Neurodiversity is not a euphemism” (July 26, 2021), “I want to believe” (February 28, 2021), What if we really are this queer? (July 18, 2020), “Television culture and temporal connectedness in social isolation” (May 15, 2020), “At the end of the day” (June 20, 2020), “Pigeon standoff” (June 16, 2019), “I identify as tired” (May 27, 2019), “A poem on the underground wall” (February 6, 2018), and “Wandering cloud” (April 17, 2017).

From Ido in Autismland, “Autism and Occupational Therapy” (September 21, 2020), Blast from the Past, A Speech I Delivered in 2015 (July 20, 2021), “All Without Words, an Autism Inspired Musical Compilation” (May 7, 2021), “No Dog Training for Humans” (January 24, 2021), “Silent Advocates” (October 11, 2019), “Brain Alive in a Vegetative State?” (July 1, 2019), “Communication is a Human Right” (April 5, 2019), “Disney Characters No More” (November 14, 2019), “Exploring Why Standard IQ Tests Fail People with Nonspeaking Autism” (January 11, 2019), and “Scientists Try to Find Ways to Demonstrate that Nonspeakers with Autism Understand” (February 1, 2019).

The Age of Autism’s blog’s elements in my data are: Home page, Disaster Preparedness (September 26, 2021), “Deaf Ears And Exposed Arms” (October 02, 2021), “The Pandemic of Special Education” (October 26, 2021), “Cure is a Four Letter Word” (July 22, 2021), “’Yet Another "RARE" Autoimmune Disease Caused By Vaccines’” (January 09, 2020), “Developmental Language Disorder Formerly Known As Speech Delay” (October 22, 2020), “Autism, Twenty-Seven Years Later and What Have We Learned? Part 1” (March 04, 2020), “Best Of: Are Your Family's Autism Services Adequate or Absent?” (July 01, 2019), and “This SEED Grows Precious Little for Autism and is a Budget Boondoggle” (January 05, 2018). Autism Adventures blog’s articles and pages: Home page, “SETTING UP FOR THE NEW SCHOOL YEAR” (Aug 9, 2021), “Where Do I Start?” (August 2, 2019), “Teaching Pattern Skills in the Classroom” (August 6, 2020), “Celebrations at School: Behavior Basics” (June 22, 2020), “Asking a Friend to Play: Behavior Basics” (October 30, 2020), “Interactive Behavior Tools for Distance Learning” (March 24, 2020), “It’s Okay to Make Mistakes: Behavior Basics” (Oct 20, 2019), “My Favorite Sensory Tools” (December 14, 2018), “Sensory Needs in the Classroom” (September 1, 2018).

Autism Citizen: Home, “COVID-19 and Autism” (February 21, 2021), “Learning to Cope” (June 16th, 2021), “Different Thinking” (June 8th, 2019), “Using His Moodle” (April 5th, 2019), “Autism in Court” (April 6th, 2019), “Fighting for Your Rights” (June 24th, 2019), “Coincidentally” (June 9th, 2019), “The Kids Grow Up” (August 23rd, 2018), and “We Do it For People” (December 1st, 2018).

The parts of Embrace Autism’s blog are: “Authenticity and Avoiding Rejecting” (January 14, 2021), “3 common questions asked after an autism diagnosis” (March 6, 2021) “Autism and Camouflaging November” (29, 2020), “The Bright Side of Being Autistic” (September 17, 2021), “Autism and Addiction” (April 2, 2018), “Autism is like Cake” (April 8, 2021), “Autism and Motor Control” (February 21, 2020), “The autistic experience of overwhelm” (November 20, 2019), “Autism & pain” (November 5, 2019), and “Why is autism seen as a disorder?” (September 19, 2018).

Using InBloom’s blog for my project, I included the: Homepage, The Power of the Unspoken (June 22, 2021), “High Functioning and Low Functioning: What’s in a Label?” (November 1, 2021), “The Difference Small Gestures Can Make” (June 18, 2021), “What to Expect During the Diagnosing Process” (Sep 11, 2020), “Redefining ‘Problem Behaviors’” (December 21, 2020), “Keeping Routines Going at Home” (June 29, 2020), “Getting Involved in

Your Kiddo's ABA Sessions” (Apr 1, 2020), “Assembling Your Support Team” (Sep 10, 2019), and “Regulation and Supervision in ABA” (Apr 16, 2019).

National Council on Severe Autism’s parts of blog in my project are the following: “Please respond to urgent need for evidence-based services for adults with ASD” (October 19, 2021), “The Dastardly Diversion of “’Differentlyabled”’ (September 21, 2021) “Sad but true: "Disability" usually excludes us” (July 20, 2021), “Will the Biden Administration Bring Hope to America’s Growing Population of Panicked Autism Families?” (November 11, 2020), “Advocacy community Conversation About Autism, Fire Safety and Emergencies, October 14 at 11am PT” (October 8, 2020), “A Renowned Physician Calls On Media to Acknowledge Autism's Brutal Truths” (August 17, 2020), “New Study Points to Grim Outcomes for Adults with Autism” (July 6, 2020), “A Tale of Two Autisms” (June 24, 2020), “When Special Autism Talents Don’t Make You Rich” (November 22, 2019), and “Autism and Guardianship: When It’s an Easy Decision” (November 5, 2019).

Appendix B: Color Coding Themes

Table 2: Color-Code Key for Themes.

Red: barriers/limitations
Pink: working towards something good, improvement in futures
Light Orange: well-being
Blue: constant struggles
Magenta: social and institutional concerns

Light Green: focusing on the future/movement in realistic ways
Yellow: aloneness
Light Yellow: environmental and personal struggles
Orange: focus on the enhancement of lifestyles
Sky Blue: advocacy for a positive future
Brown: Sense of urgency
Grey: emotional impacts of autism

The tables above show the themes from within subgroup comparison analysis and from utilizing grounded theory coding and the Labov Method. I used color-coding to coordinate any overlapping from the authors whose studies I used to collect my data's' themes to my own, as I wanted to determine the similarities/differences in themes among different authors, about different advocate subgroups. The reality highlighted applicability of many of the themes from the author studying only one subgroup, in that the themes applied to the narratives that the authors I included in my study told (from either all three subgroups in my analysis or a different one than performed by the author in their own study).

Table 3: Recent Literature, Individual-Advocates

Doktor
Role strain
Isolation when withdrawing from social support

Woodgate
Fighting all the way
Sustain the self and the family
Doing all that you Can

Hodgon and Phelps
Frustration with the Education System
Isolation

Boshoff
Isolation versus support
Balancing roles and needs
Personal impacts of advocacy
Benefits of advocacy
Barriers to advocacy
Advocacy involves working to create a better future
Advocacy as a coping strategy for anger
Life-long challenge

Table 4: Recent Literature, Self-Advocates

Danker
Supporting students with autism to enhance their well-being
Barriers to gaining well-being in school
Wide domains of student well-being)

Brown
Otherness
Destiny

Yergeau
Environmentalism (Surroundings)
Recovery
Surveillance

Kelly
Out of time
Limited futures
An ‘aware’ future

Table 5: Recent Literature, Group-Advocates

Kelly
An “accepted” future
A social future
Focus on improved well-being
Independence and opportunity
Limited futures

Hedges
Inconsistencies during the day
Communication difficulties
Relationship challenges
Inconsistencies between school and home environments

In Kelly’s study, the themes apply to self-advocates and group-advocates. For the sake of collecting thematic analyses for all three subgroups, I include this study as a part of the group-advocates’ recent literature.

Appendix C: Grounded Theory Coding Data from Online Blogs

Individual-Advocates

Autism Journey

Labov Method Element	Description
Abstract	Welcome page: Bold words, “the "journey” at the top of the page as displayed when first going to the website.
Orientation	Parts of drop-down menu: Newly diagnosed, BLOG, MORE, Submit a Story, Read more, FAQ's
Complicating Action	Descriptions of receiving a diagnosis creates tension for the author, and the perception of autism is not clear at first. There are "STEPS for a consideration on a journey" for intervention in autism.
Evaluation	Internal: She talks about the steps that her child makes, big or small, and how happy they make her. She had to "face the music “that her son was disabled and decided to try home-schooling. External: She describes telling people about her newfound outlook on disabilities “thanks to autism.” They make a collection of the "twists in an endless journey" that the author describes as the autism experience
Resolution	Most entries end with the author accepting whatever element of autism they are having trouble accepting. There are tons of encouragement to other mothers in similar situations.
Coda	Each part of the websites has a presentation of quick resources and answers to common questions. Patterns include connections with the autism community, communication, and acceptance

Autism with a Side of Fries

Labov Method Element	Description
Abstract	The opening page includes a list of followers on an unspecified social media, recent tweets, blog archives, a total page view count, most popular posts, and an About Me section that was extremely difficult to find, under the archives.
Orientation	There are pictures of fries on every page of the website with the twitter handle largely displayed as, @FrenchFryInc. The people in the stories are the "Kiddo" (the child), the author (the mother), and the father., Many of the entries have subtle allusions to settings with fries. MORE button is including the different social media options for sharing
Complicating Action	The author presents the daily challenges of an autistic child's parent. The experiences of being such a parent are described in the majority of the author's entries- about going out to dinner, staying home to quarantine during COVID-19, going to the beach, waiting for a treatment to work. There is a tone of annoyance with her situation, as most of the commentary describes problems with her home environment.
Evaluation	Internal: The author writes rhetorical questions that emphasize her reasons for being so stressed all the time. Writing about power outages, trips to funhouses, the doctor. External: The description of any solutions to problems are followed with pictures that are referencing that "it all worked out" alright. She tells a story after the story (like a Personal Statement), to conclude her thoughts that each day can be good.

Resolution	Most entries end with the author accepting whatever element of autism they are having trouble accepting. There are tons of encouragement to other mothers in similar situations.
Coda	Each part of the websites has a presentation of quick resources and answers to common questions. Patterns include connections with the autism community, communication, and acceptance

Marguerite Elisofon

Labov Method Element	Description
Abstract	The website to a picture of Marguerite, a link to her book, amazon links to her books, book reviews, featured media, Offers of consulting services (for a price), and links for more finance/promotions related concerns.
Orientation	Home, Book, Consulting, Blog, About, Medica, Samantha, Contact
Complicating Action	A recurrent problem for the author is worrying about her daughter she is gone. The author has twins with only one having autism, so this is a complicated point in the narratives highlighted in the blog entries.
Evaluation	Internal: The author lists the questions her daughter asks during COVID-19, insecurity, and uncertainty. She writes about the lessons her daughter teaches her, mainly about COVID-19. External: She recognizes her daily struggles that often come with neurodiversity. She uses examples from everyday news to describe the autistic perspective. Also includes commentary on the interaction between autism and COVID-19, racism, Trumpism, Memorials, etc. Mainly about realizations during and about COVID-19.

Resolution	The online entries often with a summary of having learned a lesson from her daughter. There is always a short familial lesson or metaphor to comfort other readers. Lots of the ends of the writings read like "survival guides" after discussing the different problems an “Autism Mom” may go through.
Coda	Patterns in the entry are promoting the advice on the blog over and over in different ways, lots of COVID-19-related advice, and involvement in the progression of autism research.

Confessions of an Asperger’s Mom

Labov Method Element	Description
Abstract	Home page opens with most recent blog post and includes archives. Also has book link to amazon score, Google Analytics, a link to GoodTherapy.Org, She uses bold and enlarged text to emphasize her mission to “not be the expert mom.”
Orientation	Parts of the website’s orientation include the "Cast and Crew" pictures, family photo section, and the drop down links to share her writing by email, Facebook, or Twitter.
Complicating Action	The author writes about how any happy "moment" has been taken away by autism. She describes the disfunction in her home, expressing her feeling isolated and in chaos. She also describes the problems working at home comes with and the strain that teaching her child has put on her marriage. She writes about the boundaries she tries to make even when the author knows that they will be broken.

Evaluation	Internal: frustration with her situation oftentimes, and there are few ways that she is able to maintain her mental health; She wanted to leave her family one week, and there are internal monologue inclusions with italics. External: There are typically expressions of revelations discovered after an event from one of the blog entries. The author is writing towards herself and those like her to keep going, and that is made obvious by the reasoning indicators for why the website is made.
Resolution	The endings of the blog entries almost always use the literary tool of flashback. There are small resolutions, rather than one large resolution applicable to every story, that the author identifies throughout each entry.
Coda	The patterns are the realistic depictions of the frustrations of motherhood. They are emphasized throughout the website. The author repeatedly emphasizes her current emotions and thoughts in between the narratives unfolding.

Life With Asperger's

Labov Method Element	Description
Abstract	The first page opens up to a list of her most recent posts rather than a separate welcome page. There is no sense of welcome or flashy links to books or promotions.
Orientation	About and Contacts, Definitions and Disclaimers, Further Reading buttons, and a drop down of "Archive and Labels." Each picture has a caption, making the blog entries easier to read or skim.

Complicating Action	Various complicating actions express in the worried thoughts as to what happens to children as they get older—more or less autistic. A challenge is being thrown in the world of disabilities after a child's diagnosis. Other. challenges include children trashing the house and bullying.
Evaluation	Internal: The mom writes about her internal struggle how to control emotions while still upset about changes their child is going through. External: The reader is allowed to draw comparisons to their own situations/challenges with the inclusions of a "how to" format in her writings.
Resolution	The end of the blog entries mention: lack of perfection, acceptance, and general "tips" for parents. Lots of the resolution details involve planning, preparing for challenges, and working against perfectionism.
Coda	The website is formatted in a "How To" survival guide for living with autism. Her style of is direct to the reading audience rather than story-telling.

Susan Senator

Labov Method Element	Description
Abstract	The books by the author are largely displayed. Excerpt/author's note is present in HOME page, summary about motivations, family life, recent works, etc.

Orientation	about, home, media, contact, "more.” Other parts of the orientation include archives, most popular blog posts, social media links, and mentions of the authors’ published books.
Complicating Action	She writes posts that include links to published articles on other sites. Other posts use metaphor to create action, or flashbacks of decisions about treatment, ABA, that the mother now regrets choosing. Internal thought actions of comparing her old family and now while advocating for autism rights. Comparing/contrasting old and new
Evaluation	Internal: The author commonly writes in stream of consciousness and thinks about how encourage readers to see her articles published moments from specific events like holidays to write about when ideas struck her, her perspective changed, etc. External: readers are meant to sift through these posts quickly and look at the author as a form of authority. Pathos is utilized for external realizations of sympathy, relatability, etc.
Resolution	The author uses thought consciousness of "I think, I hope, I Wish," to end the narratives. A wish or an expression of hope is meant to highlight to unfinished note of each part of the stories or to keep readers coming back to find out more. There is also often mention of what the author hopes to be true eventually and what she needs to do.
Coda	The websites’ entries are written like a diary with internal feelings emerging. There are more posts written, frequency-wise, than any other individual-advocate blog.

Self-Advocates

Autistic Not Weird

Labov Method Element	Description
Abstract	There is no clear “Welcome” page. The parts of the site that captures attention are ads and a large section of the opening page of the most recent articles according to date.
Orientation	Main, About Chris Bonnelo, Complete List of Articles (BLOG), Speaking engagements, The Autistic Not Weird Book, Contact Chris Bonnelo.
Complicating Action	Problems in the blog’s entries are descriptions of being bullied, being left out of the author’s age group in school and feeling like he is in his own self-fulfilling prophecy. The problems are addressed in how the author describes the ways he made it through the certain obstacle.
Evaluation	Internal: As readers, we are picturing about things happening to autistic people with striking imagery. He also encourages certain changes to be made in the autism community, such as enforcing fundamental human rights like privacy (Banisar and Davies 2003). External: The author switches to a past-tense lens to indicate he has learned from the event in the story. In most of the blogs, the new perspective the author has, along with how it helps the larger disability community, helps point readers towards the “so what” of the narrative Asking others to be better advocates, parents, siblings, teachers.
Resolution	Entries end with headers saying: “In Closing” to indicate the end of the story coming up. The author consistently includes a “summarizing sentence” to reiterate his main idea and links to petitions or

	organizations coinciding with the blog entry. The overall sense of the resolution is reaching out for support in his social media communities.
Coda	Patterns include being a role- model, “How-to,” formats, promoting honesty, and re-writing the narrative and collective identity of autism.

The Autistic Advocate

Labov Method Element	Description
Abstract	The title of the site is “Autistic People Have a Voice.” There is a welcome -note to the reader detailing the author’s intent for the website, which is to address the negative narrative of autism.
Orientation	Home, “autistic masking”, blog, online learning, work with Kieran, FAQs, and Support. There is also a list of books sold by the author**,** links to online school for autistic people, and consulting offered for getting jobs.
Complicating Action	Lots of the actual events are thought actions describing moments the author experienced. He watches a movie about Autism awareness and praises/critiques the movie. Lots of rhetorical language/speaking to reader/takes the moments he experiences and expands it for a much more detailed conversation about autistic narratives. another ex.: remembering moments when young and thinking that everyone had knowledge of autism thinking--this eventually backfiring and the thoughts that follow.
Evaluation	Internal: The author describes being mistaken in their abilities. He writes about the “reality” of autism and life, and there are

	interruptions between the stories plot to detail this portion of the author's reality. External: The author poses questions for the future of autism research. He challenges them, typically after describing his sense of an autistic reality, them to do better in their respective rolls.
Resolution	Most of the blog entries end with a variety of quotes from different self-advocates on the topic of the blog entry. This highlights the author's "so what" the narrative, as he dedicates his website to raising autism awareness.
Coda	Patterns: motivational, resourceful, authoritative, selling own resources and services, taking on the identity of all members of self-advocates to be a voice.

Autistic and Unapologetic

Labov Method Element	Description
Abstract	The top of the opening webpage has a variety of different links to articles saying: "Hot of the press! latest articles..." The dates of each article are also listed large block letters, looking like BuzzFeed, in order of date, and there are small descriptions next to pictures in each post.
Orientation	There is no drop-down menu. There are individual hyperlinks to get to each article. For each post, the setting varies, and the articles are from the point of view of the author.
Complicating Action	The beginning of the blog post's includes challenges that are about why neurotypical people feel different. Many of the plot points are

	around miscommunications or having interactions where the author feels less-than.
Evaluation	Internal: Descriptions of feeling the collective struggle of being autistic, explains the emotions that arise when feeling different arises so frequently, and explains tasks typically challenging for autistic people. External: The author ends his stories through his perspective with lists of his "tips." The tips are advice for addressing obstacles, supporting others, and making it clear that he is a resource within the autism advocates.
Resolution	The blog posts typically conclude with an expression that despite when neurodiverse people try their best and follow the "tips" in his articles, they do not always work out. He ends on a positive note by talking about a theoretical, but specific challenge such as using verbal communication, and encourages ways to face them.
Coda	Patterns include role model, encouragement, self-constructed identities

Faith, Love, and Hope

Labov Method Element	Description
Abstract	Title of the website large and prominent, with a small blog "summary" underneath it. The most popular blog post is included in the center of the front page with monthly archives from years down to 2013 are included on the sides. There are Facebook links, pages, Awards, and an About Me link. Links to other autism-websites are also included, written by other authors.

Orientation	Home, Resources, Videos, Blog, Point to Communicate, RPM Providers/Support groups. There is no reference in the 10 stories I select that has specific setting or time frame or characters outside the author.
Complicating Action	Most blog posts have problems related to the struggles in learning to accept the diagnosis autism diagnosis while being motivated to receive treatment.
Evaluation	Internal: After addressing the obstacles in the blog entries, the author uses italics to describe an interruption of the present for a stream-of-consciousness. Often expressed include feelings of frustration, phases of emotion, and grief. External: The external evaluations are typically at the end of the blog posts, so the author writes in a format that highlights the “So What?” that completes an evaluation. The author writes about the hard things she learned from the experiences in the story and suddenly stop when they are saying “The end.” Endings of the posts often relate to learning skills like perseverance and self-compassion.
Resolution	The end of the posts includes pictures of what the author is doing in the specific blog entry. The last parts of the entries encourage trying hard despite challenges because, “it will be worth it" or "it will happen soon.”
Coda	Patterns in the lessons among the endings of the author’s blog posts, role-modeling and the power of encouragement.

Chavisory’s Notebook

Labov Method Element	Description

Abstract	There is no large indication of a “welcome’ page. There are instead the monthly archives from 2010 on. Archives are in easily accessible locations on the site.
Orientation	The drop-down menu options About, Autism Resources, Links, and Quote collection.
Complicating Action	Complicated moments in the blog entries are any included memories of learning how different he [the author] is from others. There are many details from the author about what he is going to do to address the problem at hand. There are many moments where the author has an epiphany, his opinion changes, and then he figures how to re-learn the societal construction of the autism narrative.
Evaluation	Internal: Much of the author’s addressing conflict in the story relies on convincing the readers or persuading the audience to believe him. He addresses the importance of breaking down stigmas after receiving insults due to his diagnosis. External: In-between the author’s telling of the readers why they should believe the author. He writes persuasively by presenting bits of information on how misunderstandings have large impacts in the autistic community.
Resolution	The author finishes his blog entries with adequate information to support his factual claims. He displays a sense of authority and responsibility to community by speaking for the whole autism community towards the conclusion, or more specifically when he starts mentioning problems that happen in interactions between neurodiverse and neurotypical peoples’ misunderstandings.
Coda	Patterns in the online blog entries include education, spreading awareness of autism, and changing the narrative of the autistic community.

Ido in Autismland

Labov Method Element	Description
Abstract	Elements on the home page include a "my books" page. There is a ‘WHO I AM’ excerpt on the side of the first opening page. The author’s newest book is listed underneath.
Orientation	There is no drop-down menu. There is a list of archives. Included on the website are the autism treatment types, rhetorical questions ask to the reader, treatment professionals, interviews he did from 2020, and new communication rights toolkits. There is no consistent time frame of being written and there is no chronological order to the website’s organization.
Complicating Action	Parts of the author’s website include examples of. He uses much of his platform, in several different posts, to describe the suffering he went through under ABA and thus slashes its reputation as legitimate and safe treatment.
Evaluation	Internal: The author’s intent for his website is to have a platform for his content, show his abilities to function adequately in this world, and sharing the reality of feeling isolated and lonely when neurodivergent. External: The author uses flashforwards to provide insight after telling a story from the past. Many of these flashforwards are theoretical of the impact of societal disability reforms. He shares his speeches to encourage hope for parents or push back against the autistic stereotypes- the exact ones he critiques in his narratives.

Resolution	A lot of the blog entries include a recognition of the audience toward the conclusion. The author often says verbatim "thank you" to end the entries whether it the post is from a speech the author gives or not. in the entries that are from a speech the author gave not from a speech. He thanks the audience to note the blessings gained through his advocacy, mainly his ability to communicate with so many amazing people.
Coda	Recurrent vulnerability about his experiences being an autistic writer, and a public speaker. At least once per blog article conducts video interviews, speeches, YouTube video links, and other forms of communication to engage with the public and spread awareness about autism.

Group-Advocates

The Age of Autism

Labov Method Element	Description
Abstract	The website is set up aesthetically like a newspaper with a typewriting font. It is designed as a daily web newspaper of the "Autism Epidemic". The opening page includes an excerpt of information about the Autism Age 501c3 non-profit organization. Options for donations, vaccine-autism link page, contribution-donations, then an archive of recent to less recent posts.
Orientation	At the top: no drop-down menu: Home, Donate, Contact, special reports, science, email subscription, RSS Feed 2021, our mission.
Complicating Action	Many researchers undermine the abilities autistic people with communication or movement. The complications rise in the moments

	where the author believes the antagonists who diminishes the author's skills in life.
Evaluation	Internal: The website was made to open up the voices of people who understand the impact of autism, and who is not a parent. Autism is put in the context of other world events, like Covid-19 and economic changes, to highlight societal disparities in times of change. External-: For many advocates, preparedness is a large concern among people who need assistance with mobility or daily tasks.
Resolution	All ten posts I include have an ending with the author's expression of concerns over being prepared the next worst event to happen. There is a note of caution to each "ending."
Coda	Patterns include preparedness, accessibility, Covid-19, and policy updates.

Autism Adventures

Labov Method Element	Description
Abstract	This website is designed to model the look of a classroom. It framed with a classroom decor vide and pictures. On the front page there are classroom schedule suggestions behavior management skills.
Orientation	Home, Behavior Basics, Blog, Start Here, Shop, Contact
Complicating Action	The complicating details are when students struggle with adjusting to classroom skills or are dealing with behavioral issues.
Evaluation	Internal: The author writes the blog to describe the emotions that come with the interactions she has with her students.

	External: Toward the end of most blog entries I read, the author evaluates the skills she teaches her students and compares how they apply to other aspects of life.
Resolution	The end of the blog entries includes resources and links to other blogs. She uses a more concise writing style and uses bullet points to evaluate her classroom goals, such as using point scale rubrics. The resolutions summarize the end of the blog post.
Coda	The patterns in the blog's entries: attitudes focusing on improving and modifying on bigger picture.

Autism Citizen

Labov Method Element	Description
Abstract	The front of the opening page says, "Autism News" and the page has a title l "Autism Citizen." There are also links to the author's social media, and archives of stories.
Orientation	Home. Blog, About, Discover Autism, How to Help, Support Us, Contact.
Complicating Action	The author poses questions at the start of the entries with a prompt. The complicating details include details of children with unique stories of hardship, talent, or perseverance with their autism in their early in lives. The complications challenge questions like equality and opportunity.

Evaluation	Internal: The author writes about people's viewpoint that autism is the reason for many families' misfortunes. The author highlight that this is not the case. External: The later part of the blog posts includes the authors' mention of who can help urge advocacy change along, such as those who are in courts but do not understand autism, and to embrace them as equals. External evaluations also mention what Autism Citizen, the organization, does as an entity to support autistic people.
Resolution	The last part of each post is a spot for readers to donate to Autism Citizen. The authors urge other advocates to continue educating others about the condition of autism in the present day.
Coda	In most blog posts the authors are encouraging some form of reform in autism advocacy, mainly concerning identity and inclusion.

Embrace Autism

Labov Method Element	Description
Abstract	The title of the website says, "The ultimate Autism Resource." There is also space for the "Autism Quotient or the RAADS-R, which are tests that have been used to determine diagnoses for autism.
Orientation	The drop-down menu includes Home, About (Sub drop-menu- Dr. Engelbrecht and The Team), blog, powers, tests, assessments, contact, and search.
Complicating Action	Complicating events are small anecdotes and using metaphors for emphasis. They also include global issues, such as the need for autism awareness to be public knowledge.

Evaluation	Internal: The authors evaluate how people perceive autism in different social situations. External: The author mentions his motivations to address the challenges in the policy areas of autism advocacy.
Resolution	The resolutions are not an actual ending but instead the blog entries finish abruptly. Many of the remedies for society the authors recommend communication and exploration among different members of society.
Coda	All of the blog entries include mention of testing and treatment for autism, accepting personal flaws, and using uniquities to their advantage.

InBloom

Labov Method Element	Description
Abstract	The largest element on the front page are the most recent posts. There are no other elements besides the table of contents and the title for autism services, "InBloom."
Orientation	Options on the menu include Services, locations, parent resources, careers, all posts, blog, lists, special features, culture, More (LRP), Diagnostic Service.
Complicating Action	The author's complicating details explain the sensory stimulation for autistic people who go through unspoken challenges. Larger issues are connected to the blog to tie the current state of the disability community to global scaled issues.

Evaluation	Internal: The authors list the problems affecting the advocacy community, the autism narrative, and societal collective judgments about disability. External: The authors give methodical, medical, or behavioral reasons to support the reasons for doing what the author described as momentary strategies/responses to challenges.
Resolution	The posts always end with the "about the author" and bullet summaries of the contents. All of the posts end with providing encouragement and resources to get involved in the autism advocacy community.
Coda	Patterns in the blog include research and logic. The authors' writing tones are scholarly and professional.

National Council on Severe Autism

Labov Method Element	Description
Abstract	The homepage has a summary of the organization's mission statement and a place to sign up for NCSA news and updates. There is also an invitation to join the NCSA on various grassroots measures.
Orientation	Home, About, Autism Makers, Webinars, Severe Autism Film Series, Position Statements, FAQ's Blog, Resources.
Complicating Action	The posts mention peoples' various skills in comprehending and adapting to an autism diagnosis. They evaluate disability and health laws affecting the future of disability policy.

Evaluation	Internal: There are evaluations, in effectiveness and efficiency, on how different advocates [of no specific type of advocate in subgroup terms] use their resources to conduct social change. External: The authors recommend changes to address the crisis or difficulty at hand to better assist the families' enduring trauma.
Resolution	The conclusions offer links for websites to learn more autism along with a general summary of the main message.
Coda	The entries focus a lot on evaluating how an advocate performed. The tone was looking big-picture and concerned with the collective over the individual.

Appendix D: Frequent Terminology

Table 6: Individual-Advocates

Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
Page- 7 Link- 5 Recent- 4	Home- 3 Fries- 3 Share- 3	Home- 4 Challenges- 3 Learning- 2	Child-5 Writing- 5 COVID- 4	Future- 5 Readers- 3 Resolve- 3	Comments- 4 Connections-3 Questions-2

Table 7: Self-Advocates

Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
Links: 5 Recent: 4 Post: 4	Home: 3 Articles: 3 Advocate: 2	List: 4 Time: 3 Support: 2	Others: 5 Reasoning: 4 Better: 3	End: 5 Always: 3 Support: 3	Encouragement: 3 Voice :2 How-to: 2

Table 8: Group-Advocates

Abstract	Orientation	Complicating Action	Evaluation	Resolution	Coda
Autism: 11 Recent: 3 Classroom: 3	Home: 5 Contact: 4 Special: 2	Complicated: 7 Details: 5 Thinking: 4	Internal: 5 COVID: 3 Situations: 3	Always: 7 Autism: 5 Resources: 5	Autism: 3 Policy: 2 Medical: 2