The Rhetoric of Mental Health: An Examination of the Recategorization of Autism Spectrum Disorder in the DSM-5 and its Absorption into Public Discourse

Elsa Martin
University of Texas at El Paso, elsabonillamartin@gmail.com

Follow this and additional works at: https://digitalcommons.utep.edu/open_etd
Part of the Psychology Commons, and the Rhetoric Commons

Recommended Citation
https://digitalcommons.utep.edu/open_etd/692

This is brought to you for free and open access by DigitalCommons@UTEP. It has been accepted for inclusion in Open Access Theses & Dissertations by an authorized administrator of DigitalCommons@UTEP. For more information, please contact lweber@utep.edu.
THE RHETORIC OF MENTAL HEALTH: AN EXAMINATION OF THE
RECATEGORIZATION OF AUTISM SPECTRUM DISORDER
IN THE DSM-5 AND ITS ABSORPTION INTO
PUBLIC DISCOURSE

ELSA BONILLA-MARTIN
Doctoral Program in Rhetoric and Composition

APPROVED:

______________________________
Kate Mangelsdorf, Ph.D., Chair

______________________________
Lucía Durá, Ph.D.

______________________________
James M. Wood, Ph.D.

______________________________
Charles H. Ambler, Ph.D.
Dean of the Graduate School
Dedication

For Pily and Elio
THE RHETORIC OF MENTAL HEALTH: AN EXAMINATION OF THE
RECATEGORIZATION OF AUTISM SPECTRUM DISORDER
IN THE *DSM-5* AND ITS ABSORPTION INTO
PUBLIC DISCOURSE

by

ELSA BONILLA-MARTIN, B.A., M.A.

DISSERTATION

Presented to the Faculty of the Graduate School of
The University of Texas at El Paso
in Partial Fulfillment
of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

Rhetoric and Composition
THE UNIVERSITY OF TEXAS AT EL PASO
May 2017
ACKNOWLEDGMENTS

First and foremost, I want to give thanks to my family for all the love and support they have always given me. To my Mom, for always listening and taking an active interest in my research. To my Dad, for the microscope that instilled in me a wonder for knowledge. To my Brother, for being there when I needed you the most.

I would also like to give thanks to the members of my dissertation committee, who were integral at different stages of my progress. I will be forever grateful to my dissertation director Dr. Kate Mangelsdorf; your unwavering belief in me and my project gave me the confidence to keep going and push my limits. This project is also possible because of Dr. James Wood who inspired me since I was an undergrad and sparked the idea for this project. And, I am grateful to Dr. Lucía Durá for helping me find an academic home for my ideas.

I am also thankful for all the people that I met and worked with in the RWS program. In particular, I want to extend thanks to my cohort for all the arguments in class that shaped me as a scholar and for listening to me talk about my project for years. I also want to thank Consuelo for being a great research partner and friend.

Above all, I want to give special thanks to Levi and the girls (M. and B.). I am very happy that we got to do this together. Thanks for the understanding, encouragements, and for reminding me to take the time to enjoy life. Finally, thanks Thom and Thalia for being there for us.
ABSTRACT

This dissertation explores the discourse of mental health across genres and public spaces. The research of this project is situated within the overlap of the fields of Disability Studies (Brewer, Selfe, Yergeau, 2014; Brueggeman and Kleege, 2003; Kerschbaum, 2012; Lewiecki-Wilson, 2003) and Rhetorics of Health and Medicine (Keränen, 2013; Kopelson, 2009; Segal, 1994; Scott, Segal, & Keränen, 2013), a space that focuses on the rhetoric of mental health (Chrisman, 2008; Emmons, 2008; Hacking, 2009). Following the principles of these fields, this project deconstructs the recategorization of autism in the DSM-5, the media coverage it received, and the public reception of the information as a means to explore the discursive construction of the identity of people with Autism Spectrum Disorder. An ethnographic content analysis was conducted in order to analyze and compare a variety of genres, including the DSM text itself, academic articles, newspaper articles, blogs, press releases, and online comments. The research shows that, even though the recategorization of autism is widely accepted, concerns about the impact of the changes are abundant. Furthermore, an analysis of the perceptions of people with ASD suggests a reluctance to reconcile the identities associated with each end of the spectrum into one and this unease often leads to conflict surrounding conceptions of disability and mental health. The findings of this dissertation highlight the need to continue to explore how we talk about mental health and the impact it has on the lives of people who live with a disorder.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .................................................................................................................. v

ABSTRACT ........................................................................................................................................ vi

TABLE OF CONTENTS ................................................................................................................... vii

LIST OF TABLES ............................................................................................................................ x

LIST OF FIGURES .......................................................................................................................... xi

Chapter

1. INTRODUCTION ............................................................................................................................. 1
   1.1 Overview .................................................................................................................................. 1
   1.2 Research Questions ................................................................................................................. 3
   1.3 Methodology ............................................................................................................................ 5
       1.3.1 Subquestion 1 .................................................................................................................. 5
       1.3.2 Subquestion 2 .................................................................................................................. 6
       1.3.3 Subquestion 3 .................................................................................................................. 9
   1.4 Project Boundaries ................................................................................................................... 10
   1.5 Chapter overview .................................................................................................................... 12
   1.6 Key terms .............................................................................................................................. 14

2. LITERATURE REVIEW .................................................................................................................. 18
   2.1 Overview ................................................................................................................................. 18
   2.2 The Gap in RWS ...................................................................................................................... 18
   2.3 Disability Studies ...................................................................................................................... 21
   2.4 Rhetoric of Health and Medicine ............................................................................................ 26
   2.5 Rhetoric of Mental Health ......................................................................................................... 31
       2.5.1 Mental Health Research within RWS ............................................................................ 33
       2.5.2 Mental Health Research outside RWS ......................................................................... 36
   2.6 Summary ................................................................................................................................. 40

3. RECATEGORYIZATION OF ASD IN THE DSM ........................................................................ 41
   3.1 Overview ................................................................................................................................. 41
   3.2 History of the DSM and ASD ................................................................................................. 42
3.2.1 The DSM .............................................................. 42
3.2.2 The DSM-5 and the Current Situation ......................... 46
3.2.3 Autism Spectrum Disorder ........................................... 49

3.3 Methodology ......................................................... 52
3.3.1 Sampling ................................................................ 54
3.3.2 Research Protocol .................................................... 55
3.3.3 Qualitative Software ............................................... 56

3.4 Analysis ............................................................... 57
3.4.1 Codes ..................................................................... 57
3.4.2 In-Vivo Coding ....................................................... 64
3.4.3 Code Frequencies and Patterns .................................. 67

3.5 Discussion ............................................................. 68
3.5.1 Construction of Disability .......................................... 68
3.5.2 Recategorization of ASD .......................................... 73
3.5.3 Silence in the DSM-5 .............................................. 78

3.6 Summary ............................................................... 81

4. REPRESENTATION OF ASD IN PUBLIC MASS MEDIA .......... 83
4.1 Overview ............................................................... 83
4.2 Autism in the Media .................................................... 84
   4.2.1 ASD Recategorization Media Coverage ......................... 87

4.3 Methodology ........................................................... 89
4.3.1 Sampling and Protocol Adaptation ................................ 89
4.3.2 Sampling Procedure ................................................ 94

4.4 Analysis and Coding .................................................. 95

4.5 Discussion ............................................................. 98
4.5.1 Media Coverage Conversation .................................... 98
4.5.2 Media Framing of Recategorization ............................... 103
4.5.3 Construction of Identities .......................................... 105
4.5.4 ASD News Coverage Breakdown ................................. 109

4.6 Summary ............................................................... 114
LIST OF TABLES

1. ASD recategorization documents sampled for Stage 1 ..............................55
2. Main coding structure for Stage 1 ...........................................................57
3. Media article covering the recategorization of ASD
   sampled for Stage 2 .................................................................................. 92
4. Main coding structure for Stage 2 ..........................................................95
5. Breakdown of comments sampled for Stage 3 .......................................121
6. New code groups added during Stage 3 .................................................126
7. Most recurrent codes of Stage 3 .............................................................134
LIST OF FIGURES

1. Breakdown of timeline of events surrounding the recategorization of autism and the media coverage sampled for Stage 2 ........................ 89

2. Representation of words in quotations found in the sample for Stage 3 ...................................................................................... 142
1. INTRODUCTION

1.1 Overview

I began my academic career in the field of psychology, where the inclination to study rhetoric developed over time from the conversations I had in my courses. As a student in a Clinical Psychology MA program, I was inducted into deep conversations about diagnoses, the function of labels, and how they can impact the lives of the people who receive them. My professors, and other professionals in the field, were concerned with the effect of diagnosing someone with a mental health disorder. Throughout the program, our classes began to focus less on memorizing definitions of disorders and more on the moral and ethical impact that the labels have on the lives of patients. I learned there was an awareness of the effects of our diagnostic system and how these were interpreted by the rest of the public. There was also an awareness of the nuances and caveats attached to the diagnostic system in place, a system that was viewed more as a guide than as a prescription. It was at this point that I realized that this awareness is not necessarily perceived or shared by those outside of the field of clinical psychology. Due to this, diagnostic labels become public without the necessary context to understand their implications. Because of this realization, I became interested in exploring how the way we talk about mental health impacts the lives of people that live with a disorder. This academic interest eventually led to the pursuit of this question in the field of Rhetoric and Writing Studies (RWS).
The Diagnostic and Statistical Manual of Mental Disorders (*DSM*), a seminal text that includes the standards and classifications of mental disorders, is published by the American Psychiatric Association (APA), and revised every few decades. The revision of the *DSM-IV* was in progress during my time in the MA program, and discussions over the proposed changes to the manual were prevalent both in the field and in class. Conversations over the revision continued over the years and grew to include not only insiders to the field of mental health but also the public. Although concerns over the validity and potential impact of the changes were front and center, what interested me the most was the way the revision of certain disorders would impact the perception of the people living with them.

Now, four years after the publication of the *DSM-5*, this dissertation explores the ways in which the identities of people with a mental health diagnosis are constructed through the language used to label and describe a disorder. The process begins with the *DSM* and how disorders are classified and defined by the scientists and researchers of the field of mental health. This language then travels from the *DSM* to the hands of the public in various forms that include news, popular media, and other social forms of communication. Once that language is absorbed by the general public, it shapes the way people with a disorder are perceived and how their identities are constructed. This dissertation explores each one of these steps through an analysis of the *DSM-5*, scholarly articles, APA materials, news articles, advocacy websites, and public comments.
1.2 Research Questions

The fifth revision to the DSM was published in May 2013 and sparked rich conversations about what it means to change the way mental disorders are conceptualized. Change doesn’t come very often to texts like the DSM, especially extensive change like the one seen in the fifth revision. As a result, the publication of the DSM-5 provided a kairotic opportunity to study the way the revision of an influential diagnostic text affects social perceptions of mental health. For this reason, this dissertation seeks to answer one central research question:

How do changes in an authoritative text like the DSM get absorbed by public discourse through media and in turn contribute to the discursive construction of identity of individuals living with a mental health diagnosis?

This question encompasses a very large area given that the DSM is a substantial text that covers all psychological disorders. Therefore, this dissertation focused on addressing this question by using one specific disorder, Autism Spectrum Disorder (ASD), as a way to narrow down the focus in order explore the different aspects of the issue. I chose this disorder because, given that it was one of the most controversial changes made to the DSM in the latest revision, it has been heavily portrayed in public discourse in the last few years.

In addition to this approach, the complexity of the question itself also required a more nuanced approach that analyzed the different processes that take place from the time a disorder is revised to when it finally reaches the general
public. Therefore, the main research question can in essence be divided into three specific subquestions:

1. How does the new recategorization of the Autism Spectrum Disorder in the *DSM* construct our understanding of the disorder and the individuals living with the diagnosis?
2. How is the recategorization of Autism Spectrum Disorder absorbed by public discourse and disseminated through mass media?
3. How does the presentation of the recategorization of Autism Spectrum Disorder through mass media contribute to the discursive construction of identity of individuals living with this diagnosis?

These three subquestions provide the frame for this dissertation by exploring the way the changes to the *DSM* lead to the social construction of the identity of people diagnosed with ASD. The answers to these subquestions are meant to build upon one another and together provide a more complete understanding of the issue.

Based on the subquestions, the analysis of this project is divided into three major stages. The first stage of the analysis focuses on assessing how ASD was recategorized in the newest revision to the *DSM*. Specifically, the language used in the fifth revision of the *DSM*, and a selection of literature on the subject, are analyzed in order to assess how the new autism spectrum was framed by professionals in the field of mental health. The second stage of the analysis explores how the recategorization of ASD was portrayed in the media through news and advocacy websites. This part of the analysis focuses on studying popular media
artifacts that made significant contributions to the dialogue about ASD. Finally, the third stage addresses how the representation of the recategorization of ASD in public media was absorbed by the general public and reflected on the perceptions of the identity of individuals diagnosed with this disorder. This final stage consists of an analysis of online comments made by the public on websites where the issue was reported. More details on the structure of this dissertation are presented below.

1.3 Methodology

The methodology for this dissertation is divided into three stages designed to address each of the subquestions for this project. Although the methodology has a unified core structure throughout the dissertation, each stage required a specialized approach. Therefore, instead of having a single methodology chapter, each chapter presenting one of the stages of analysis contains its own methodology section that describes the approach used in each case and how it fits within the overall structure of the project. The following is a summary of the methodology employed for each major stage of analysis.

1.3.1 Subquestion 1: How does the new recategorization of the Autism Spectrum Disorder in the DSM construct our understanding of the disorder and the individuals living with the diagnosis?

In the first stage of the methodology, the DSM text is analyzed in order to unpack its language and identify gaps between it and the content of a sample of professional literature surrounding the recategorization of autism. Similarly to the
work of Wilson (2003) in his analysis of the evolving metaphors of disease in science, I identify key language in the recategorization of ASD in the fifth revision of the DSM. Then, these terms and their context are deconstructed to explore how the official definition of ASD constructs our current understanding of this psychological phenomenon. These key terms are also used as a starting point for the next stages of analysis.

Aside from the language of the DSM, I also analyze the silences of this text. That is, based on the seminal work of Glenn (2004) and Ratcliffe (2006), I explore the ways in which silence is employed by the creators of the DSM and its implications to our understanding of ASD. It is my belief that just as the language employed in the classification of ASD is important, so is what is not being said and the reasons for the silence. In order to identify silence in the DSM text, I also analyze articles written by members of the DSM-5 task force, documents published by the APA, and a sample of academic literature on the recategorization of ASD because they were important parts of the conversation about ASD within the field of mental health. Incorporating these other texts allows me to identify what was being said in the conversation about ASD among professionals but was omitted from the actual DSM text.

1.3.2 Subquestion 2: How is the recategorization of Autism Spectrum Disorder absorbed by public discourse and disseminated through mass media?

The second stage of analysis required an ethnographic content analysis of several media artifacts depicting public discourse about ASD in order to encompass
the context of the online setting where these documents were published. Ethnographic content analysis (ECA) combines strategies commonly used in ethnographic methodologies with quantitative content analysis in order to discover and analyze “emergent patterns, emphases, and themes” (Altheide & Shneider, 2013, 23) in media artifacts such as online materials. This approach, also defined as reflexive analysis of documents, involves participant observation in the selection of topics, methods of study, data collection, analysis, and interpretation in order to incorporate the overall context of the material and how it relates to the people who create, use, and participate in the medium (Altheide & Shneider, 2013, 23). ECA was appropriate for the analysis of online materials related to the DSM because it seeks to not only analyze the text itself but also how it is constructed by people and the culture it resides within. This type of analysis seeks to understand the underlying cultural structures surrounding the online spaces where the artifacts selected were found.

In accordance with ECA, the actual media outlets incorporated into the analysis were sampled based on major search engine results about ASD in order to find the sites most relevant according to participants. That is, I use major search engine results to discover the sites and sources of information about autism that were most commonly used by individuals seeking information on the topic. The web articles are evaluated based on their relevance and contribution to public conversations about the issues. My goal is to identify the sites of information that individuals were most likely to find and use when learning about ASD. Google’s
search engine allowed me to filter engine results by time (anytime, past hour, past 24 hours, past week, past month, or past year); I use this feature to narrow down my results to the sites that were visited before and after the publication of the *DSM-5*. Google’s search engine also allowed me to choose sites that have been most visited so that I could get results that have actually been selected by people searching for this information. The media artifacts that depict or relay information about ASD are analyzed in order to evaluate how the information from authoritative sources, like the *DSM*, was portrayed to the general public.

Furthermore, based on ECA, my aim is to identify similarities and differences between the documents selected and how these represent information about ASD and reflect the specific cultural context (Altheide & Schneider, 2013, 27). I then identify the recurrent concepts portrayed by different artifacts, the role of the formats employed, and the visual imagery used in the approach to ASD. For example, I identify the more recurrent rhetorical appeals made when portraying this information based on their use of format, visuals, and references to specific people. I also identify common patterns and narratives used as well as their implication and contextual significance. Based on preliminary sampling of news coverage about the recategorization of ASD, for example, two of the most common themes found in these stories are the scientific validity of the recategorization and the personal impact to families with children with an ASD diagnosis. Both of these themes are constructed with different imagery and meaning which was assessed by
analyzing the images included in the articles and sometimes even the titles given to the stories.

1.3.3 Subquestion 3: How does the presentation of the recategorization of Autism Spectrum Disorder through mass media contribute to the discursive construction of identity of individuals living with this diagnosis?

In the last stage, I analyze the public comments, published in some of the media artifacts analyzed in the previous stage, that depict the opinions from the general population about the recategorization of ASD. This last step of the analysis follows the same ethnographic content analysis approach as the previous one. This part, however, focuses on exploring the way the comments absorbed the information about the recategorization and in turn constructed the identities of people with an ASD diagnosis.

In order to assess how the identities of people with an ASD diagnosis were constructed in these comments I use the work of Kershbaum (2012) on the study of difference. Kershbaum (2012) defined markers of difference as “rhetorical cues that signal the presence of difference between one or more interlocutors” (616). In other words, I identify the words and phrases that people used to differentiate themselves from others that they consider to be part of a different social category. As people differentiate themselves from others, they are essentially constructing an identity for themselves and the other. For example, based on preliminary analysis of comments made in a news story about ASD recategorization, several individuals identified themselves as “parent[s] of a child with Asperger’s Disorder” to signify
that they have first-hand experience with dealing with caring for a child with this psychological disorder. This in turn created a context to their message that signifies that they have ethos on the subject as well as a real stake in the recategorization of the disorder. Similarly, “helicopter parent” is a marker of difference employed by several individuals that served to separate parents in general into different categories: one that is overly protective and prone to exaggerate and one that is “rational” and “normal.” These categories of difference are very relevant to the understanding of how the identities of people living with an ASD diagnosis are constructed through discourse. I use Kerschbaum’s markers of different as a tool to further focus my analysis of the content using ECA.

1.4 Project Boundaries

Given the ambitious nature of the questions asked in this project, it is important to acknowledge the boundaries of the research and how it is situated within the scholarship of RWS. One of the main limitations of this study is the need to create small but representative samples of vast amounts of public data. For instance, Chapter 3 analyzes the professional conversations within the field of mental health surrounding the recategorization of autism. However, it was not within the scope or resources of this project to analyze every single article published on the subject. Therefore, a representative sample of documents is created in order to analyze the themes of the conversation as well as the framing of the recategorization of autism. Chapter 4 focuses on an analysis of the media coverage of the recategorization from the time the changes to autism were first proposed to
the publication of the *DSM-5*. Because of the large number of articles on the subject, the principles of ECA are used to create a representative sample of the coverage during this period of time. Additionally, the goal of Chapter 5 is to identify the public perceptions of people with ASD. Provided that perceptions are a very abstract concept, and the general public represents a very sizable number of people, an extremely limited sample is used for this stage of analysis. Having to create limited sample sizes is an unavoidable factor of this project that is addressed by relying on theoretical principles of the methodology throughout all stages of analysis. Nevertheless, this also means that a different method of sampling can lead to differing results and this makes my findings non-exhaustive.

Furthermore, this project relies solely on public data which limits the applicability of the findings, especially the ones from Chapter 5. Online spaces have unique rhetorical situations that do not mimic other forms of communication. For example, although online spaces can encourage freedom of expression through anonymity, they are also susceptible to extreme bias. For this reason, the findings of this project are only a beginning and can be further fleshed out through continuing research in more rigorous study designs.

This project is also limited by my personal positioning within the field of mental health. My previous background in clinical psychology provides a particular framing for the qualitative analysis conducted in this dissertation. Although my insider status within the field is valuable to my ability to study the conversations within it, it also makes it possible for bias to exist. For that reason, I have been
mindful to begin this text by positioning myself between the fields of mental health and RWS.

Ultimately, the boundaries of this project serve as a reminder that this is a relatively new area of study and the insights of this dissertation highlight more directions of future research. Throughout this dissertation, future research areas are discussed in an effort to encourage more scholarship in the field of Rhetoric of Mental Health. This project is limited to studying the case of the recategorization of autism, but the same kind of research should also be conducted on the several other disorders that underwent revisions in the DSM. I look forward to both continuing and following more research in this area.

1.5 Chapter Overview

Chapter 2 presents a literature review that situates this project within the scholarship of the fields of Disability Studies, Rhetorics of Health and Medicine, and the emerging field of Rhetoric of Mental Health. The field of Disability Studies provides valuable foundation for this project through their study of how disability, even though it is a physical phenomenon, is constructed in our social and cultural understandings of ableness and impairment. The field of Rhetorics of Health and Medicine explores the impact of discourse on our understanding of illness and health which provides part of the theoretical framework for this project. Finally, I argue that the emerging field of Rhetoric of Mental Health fills a gap between these two fields that combines insights from both to study the ways in which mental health discourse impacts the social perceptions of people with a disorder.
Chapter 3, “The Recategorization and Definition of Autism Spectrum Disorder in the DSM”, opens up by positioning the DSM in terms of its background and relevance to the field of Psychology/Psychiatry. This provides the context for the revision process and describes the conversation within the field of mental health. I also include a section on background information about Autism Spectrum Disorder that provides context for the recategorization and following controversy in the field and media coverage. Chapter 3 includes stage 1 of analysis addressing subquestion 1. In this stage, I study the recategorization of ASD and how it framed the identity of someone with the disorder by analyzing the text in the DSM-5 as well as articles published by the APA, written by members of the DSM-5 task-force, and other scholars in the field of psychiatry.

Chapter 4, “The Representation of the Recategorization of ASD in Public Mass Media,” covers Stage 2 of analysis and addresses subquestion 2. First, I go over the process of selecting the media artifacts to be used in this chapter based on ECA. Then I analyze the selected pieces in order to identify common themes, patterns, imagery, and appeals made in the representation of the recategorization of ASD. This chapter describes the content of the selected media to explore similarities and differences in the different artifacts. Additionally, there is a comparison between the way people with ASD were portrayed by the coverage of the recategorization and the findings of Chapter 3.

Chapter 5, “Discursive Construction of the Identities of People with ASD Diagnosis,” covers Stage 3 of analysis and addresses subquestion 3. Based on the
previous chapter, I describe how venues of online commenting were sampled and analyzed. This chapter analyzes public comments about the recategorization of ASD in order to explore how the identities of those living with the diagnosis are perceived by the public. Markers of difference employed by online commenters are incorporated into the analysis as well as the principles of ECA.

Finally, Chapter 6 includes a discussion that brings together the findings from Chapters 3, 4, and 5 in order to answer this project’s overarching research question. This chapter discusses how the official definition of ASD was represented by public media and eventually contributed to the discursive construction of the identities of the people with the diagnosis. Additionally, connections are established between all parts of the analysis. This final chapter also provides a conclusion to the dissertation focusing on the implications of the project. Future questions, such as the analysis of other disorders in the DSM and their portrayal in public discourse, are addressed and set up a plan for future research that I plan to continue to do and that should be approached by other scholars in RWS. Ultimately, I go over how this dissertation opens up a unique space of inquiry that overlaps with Disability Studies and Rhetorics and Health and Medicine.

1.6 Key terms

I would like to conclude this introduction by discussing some of the key terms used throughout this dissertation. During the course of this project, I have made important choices as to how I use critical terms and what they mean for this study. These choices reflect not only my personal positioning but also the theoretical
framing of my work. Therefore, their discussion provides critical context of their use and meaning.

In this project the terms autism and spectrum are used interchangeably with ASD (Autism Spectrum Disorder). Although this is done in part to provide variety in the language, it is also true that each part of the diagnostic label is sometimes more appropriate in certain contexts than in others. For instance, spectrum is used when emphasizing that several previously distinct disorders are now included under one term is important, while autism is used when this distinction is not necessary for the context of the sentence or passage. This choice also reflects the current understanding of the disorder in the field of mental health. That is, that the several disorders that are now included in the spectrum are recognized to be, despite of their differences, manifestations of the same phenomena at different levels; this phenomena is best known as autism. For these reasons, the terms autism and spectrum refer to the diagnostic label of ASD and do not represent different concepts for the purpose of this project.

Another important choice made during this project is whether to refer to the revision of autism as either a recategorization, redefinition, or recategorization. At the beginning of this study, I used all three terms interchangeably. However, as I became more involved in the subject, I realized that these terms have different implications and don’t mean the same thing in all contexts. To call the revision a redefinition is to make the assumption that diagnostic labels are the absolute definitions of a mental disorder. This is not always the case or the view of all
professionals in the field of mental health because diagnostic labels are meant to be
guidelines for the treatment of disorders and, inherently, not absolute. The term
reclassification is more appropriate because it recognizes the *DSM* as a
classification system of mental disorders. Although this is accurate within the field
of mental health, this doesn’t necessarily fit the context within the field of RWS.
What I mean by that is that within the context of this project, in the field of
Rhetoric of Mental Health, the *DSM* is seen as a way to categorize people based on
their symptoms and this is a separate issue from the taxonomical system within a
field of study. For these reasons, the revision of autism is exclusively referred to as
a recategorization.

This dissertation also predominantly follows the conventions of the field of
mental health, specifically delineated in the *DSM* itself, of referring to people as
individuals with a disorder. In other words, people are referred to as having an ASD
diagnosis and not as being autistic. This is an important and ethical distinction
based on the understanding that individuals with mental health issues are people
and not one dimensional beings defined by their diagnosis. This convention is
upheld by the field of mental health, but it does not necessarily represent all of the
beliefs of other fields like Disability Studies. For this reason, the only exception to
this convention is made when individuals in the sample referred to themselves as
autistic, autists, or Aspies. I made this choice to respect people’s right to choose how
they define themselves. Therefore, I refer to people as autistic, autists, or Aspies
only when the individuals involved made this choice for themselves. Any other
times, I follow the convention of referring to people as living with, or having, ASD.
Finally, the term “classic autism” is perhaps one of the most complex ones of this
project that requires a bit of deconstruction. Classic autism is not an official term in
the sense that it has never been a label used in the *DSM*. Classic autism often
refers to the diagnosis of Autism Disorder in previous *DSMs* that has now been
replaced with ASD. This term, became more relevant with the advent of the
recategorization due to a need to recognize the difference between what is seen as
“classic” autism and the high-functioning end of the spectrum. In other words, now
that people with a previous diagnosis like Asperger’s or PDD-NOS are all
considered to have autism, classic autism is used to specify the ones with a
diagnosis of Autism Disorder before the recategorization. The prevalence of this
term in the sample made it a relevant part of analysis and yielded interesting
insights. One of the findings of this project is that the term classic autism has
evolved to not only refer to Autism Disorder but to encompass all of the traditional
symptoms of autism; repetitive motions, social and communication issues, sensory
sensitivity, etc. For the purpose of this dissertation, the term classic autism is used
to denote the low-functioning end of the spectrum.
2. LITERATURE REVIEW

2.1 Overview

This chapter presents a comprehensive review of the literature that situates this project within the fields of Disability Studies, Rhetorics of Health and Medicine, and the emerging field of Rhetoric of Mental Health. First, I present the research gaps in the field of RWS, identified by scholars, pertaining to the study of constructions of disability and health. Then, I provide an overview of the research in the fields of Disability Studies and Rhetorics of Health and Medicine that serves as foundation for the research in this project. Finally, I present a summary of the research that has been done surrounding mental health both within and outside of the field of RWS. The research discussed in this chapter presents the theoretical grounding of this dissertation as well as its positioning among the work of other scholars.

2.2 The Gap in RWS

Over the years, especially more recently, there was been a growing amount of work done on the subfields of Disability Studies and the Rhetorics of Health and Medicine within the field of RWS. Scholars in these two subfields have identified a need to use rhetorical theory to analyze the ways in which we talk about issues pertaining to disability and medicine. Rhetoric Review published the Representing Disability Rhetorically symposium issue in 2003 featuring articles on the way disability is portrayed and perceived. In this symposium, Tracy Ann Morse (2003)
argued that, “how we talk about these disabilities and how we interact with our peers or students who have these disabilities is not prevalent in our discussions of rhetoric” (154). Cynthia Lewiecki-Wilson (2003) also noted that although disability is a physical phenomenon, “what is disabling about impairments resides in culture rather than in a natural consequence of impairment” (158). That is, “disability is always experienced through the attitudes, social arrangements, and technologies of a particular culture” (Lewiecki-Wilson, 2003) and therefore, as rhetoricians, we need to investigate how we construct disability in our everyday lives. This is particularly important because these unconscious ideas about disability become ingrained in institutional language and communication practices in our society (Stremlau, 2003), and this in turn impacts the lives of people who do not fulfill the expectations of “normalcy” that are implied by these policies. Other disability scholars such as Scott Lunsford (2005) also argue that by not questioning the language we use surrounding disability, we “slip back into hegemonic unawareness” (330) that leads to taking for granted the terms and labels we apply to people we perceive as disabled.

Similarly to the developments in the subfield of Disability Studies, Judy Segal (1994) raised the issue that medical topics such as patient compliance ignore “rhetorical theory and [are] well ignored by rhetorical theorists” (91). In her seminal article, she further argues that “connections among compliance, persuasion, and rhetoric deserve further study” (Segal, 1994, 92). Segal (1994), one of the leading medical rhetoricians in the subfield, raised awareness for the need to study
medicine because of its position of power in our society (92). More and more, both science and medicine have come to occupy a position of power in society by becoming the leading authorities in our understandings of health and the human body. Although science and medicine are indeed very important for our growing understandings of the physical world, we cannot ignore that these understandings are socially constructed and subject to the issues mentioned above by Lundsford (2005) and Stremlau (2003). It is for this reason that Lisa Keränen (2007) has argued that as a field we are missing a “comprehensive account of medical discourse arising squarely from the rhetorical tradition” (442). Keränen (2007) pointed out that this endeavor has begun to be undertaken by a variety of scholars “ranging from anthropology and bioethics to rhetoric and composition studies” (442). I believe it is indeed very important for the issues of medical discourses to be approached from members of different disciplines in order to encompass the wide range of impact of medical discourse on our constructions of health and disability.

Scholarship from Disability Studies and Rhetorics of Health and Medicine identify important gaps in the field of RWS. These subfields have become the sites for critical analysis of the constructions of disability, health, and the human body. Through the work done in these subfields, we have begun to explore the ways in which mental health is socially constructed, but more work needs to be done in this area. In the following sections, I will provide an overview of the work done in these subfields, the ways in which that work informs the understanding of mental health as well as the ways in which it comes short. Then I will outline the way in which
several scholars within these subfields, as well as other disciplines, have begun to create a space for the emerging field of rhetoric of mental health.

2.3 Disability Studies

Disability Studies is a growing subfield within the discipline of RWS. Leading scholars in this area have focused on investigating the social construction of disability and how that impacts the way we perceive people with disabilities. I believe that this work is incredible important for understanding mental health as well. Lewiecki-Wilson (2003) argued that disability is “material and embodied, as well as culturally made” (158). This argument, as well as disability studies as a whole, has been met with the critique that it ignores the fact that disability exists in the natural world and the phenomena is real and not constructed. However, disability scholars believe that both the social and medical models of disability are required in order for us to critically assess our views on disability and how they can be harmful and isolating for people with disabilities. Issues such as, “outright discrimination and unequal access to health, wealth, and education” (Lewiecki-Wilson, 2003, 159) are complex consequences of the dynamic interplay of the social construction of disability that need to be challenged.

Other scholars like Chrisman (2008) argue that , “physical and mental disabilities have always been cast in the dichotomous role of normal/abnormal, acting as the standard for measuring deviance, deficiency, freakishness, and undesirability” (24). This perception of disability then constructs the social
perception of disability that impacts the ways in which people with such a label are recognized and treated. Similarly, Morse (2003) explained that references about disabled people are underlined with deep social conditioning that portrays disabled people as “defective, deformed, or developmental in some way and [in] need [of] accommodations” (155). So, even if disability does exist as a physical phenomenon and something that should be explained through a scientific lens, it is also interpreted through social constructions of ‘normal’ and ‘ableness’ (Lindblom & Dunn, 2003, 169). It is in these constructions that disability is defined in our culture. As Lindblom and Dunn (2003) present in their article, “it is not my wheelchair that makes me disabled, but the stairs into the building” (169).

Another aspect of disability construction that is explored in this subfield is the idea of subjectivity and the disabled person. According to Lewiecki-Wilson (2003), the assumptions we make about subjectivity in the field of RWS and society as whole lead us to perceive disabled people as non-autonomous individuals who are not capable of speaking for themselves. What Brueggemann and Kleege (2003) call “rhetoric’s powerful ‘will to speech,’” is our tendency to over value speech as a sign of the subjectivity and agency of a person (158). That is, we have come to expect, and demand even, that a rhetorician should be able to speak and speak well. However, what about the deaf person who does not speak? Or, the disabled person that cannot express themselves1 through traditional speech?1 In the past, the speech of individuals with disabilities has received little attention or recognition as

1 Themselves is used here as an indeterminate pronoun in order to avoid the prescription of gender.
a valuable form of self-expression and knowledge building. However, work within the field of Disability Studies seeks to challenge this tendency by actively focusing on the speech of those with disabilities. For example, Chrisman (2008) focused her study on recovery by analyzing the personal narratives of people with mental disabilities. Chrisman’s work raises the argument of giving agency and voice to people with disability to speak for themselves as a way for us to learn more about disability in general as well as how it impacts the lives of people.

Another important area of study in this field is to question our use of labels and the language we use to describe disability and the disabled. Brueggeman and Kleege (2003), scholars with disabilities themselves, raise the issue with labeling that is imposed onto people by claiming that these are “terms [they] would never come to like or choose to call [themselves]” (177). Medical terminology commonly applied to disability such as “chronic, degenerative, progressive, profound, and incurable” (Brueggeman and Kleege, 2003, 175) has a real impact on how those conditions are perceived and understood in society. Therefore, society chooses to label certain individuals as impaired, regardless of whether the person feels any impairment. These labels then lead to material conditions that impact the lives of people from an early age. Brueggeman and Kleege both describe the ways in which their education was impacted by issues of accommodation and inclusion. Both women had to deal with issues of passing and managing the stigma associated with being impaired. Today, they still challenge the imposition of labels by stating that they prefer to think of themselves as “problem-solvers, as opportunists, and as
careful strategists of social and educational spaces” (Brueggeman and Kleege, 2003, 179).

Lunsford (2005) also warns us that we must not take for granted terms like handicapped or differently-abled, within our own scholarship (330). According to Lundsford, these words create realities and we must pay attention to them (331). Terms like the ones outlined by Brueggeman and Kleege (2003), “not only ignore individual identity by labeling people collectively but also maintain that the person is the disability itself” (Lundsford, 2005, 331). Lundsford argued that we need to complicate these terms, within ourselves and as a field, so that we can become sensitive to their uses. The key is that we “cannot stop questioning authority” (Lundsford, 2005, 332), which is a critical advice to follow when exploring not only issues of disability in general, but also mental health.

The field of Disability Studies has coalesced into a deep exploration of issues of disability as they relate to language, social constructions, understanding, power dynamics, agency and subjectivity, identity, and education. This space of rhetorical inquiry within RWS has become an important site for challenging our ideas of normative experience. Most importantly, scholars of this subfield argue that the study of disability is an opportunity to rethink practices in our daily lives (Titchkowsky, 2000; Wilson & Lewiecki-Wilson, 2001; Wood, Dolmage, Price, Lewiecki-Wilson, 2014). Disability then becomes a critical lens to be used by scholars, teachers, and even students (Wood et al., 2014). This approach requires that we not only “accommodate” others into normative experience but that we
transform the experience itself (Brewer, Selle, & Yergeau, 2014). Brewer, Selle, and Yergeau (2014) apply this critique to the field of RWS itself by challenging our own practices of accessibility in our scholarship. Challenging our own practices asks us “to examine complex and intersecting politics around identity and participation” (Brewer et al., 2014, 151). It is this kind of inquiry that needs to be applied to not only disability in general but also issues of mental health, specifically.

All of the issues raised by disability scholars are true also of mental health and the way we perceive and talk about people living with mental health disorders. However, there are a few key differences between disability and mental health. Some scholars such as Lewiecki-Wilson (2003) have chosen to “group mental illness and severe mental retardation under the category of mental disabilities” (157). I do not agree with this generalization because I think it blurs out some key distinctions between disability and mental health issues. Although there are several implications about the way we perceive disability that are shared with mental health issues (such as the stigma of being perceived as damaged or defective), there are key differences with the way these labels impact the image of a person. Being labeled as having mental health issues incorporates a different level of stigma that does not just make assumptions about the ableness of a person’s body but also the credibility of their character. A person with a mental illness diagnosis is not only seen as less capable but they may also be perceived as alien, disingenuous, fraudulent, weak-willed, and even violent. A person with a physical disability, such as hearing impairment for example, is less likely to be doubted or perceived to be
faking than a person living with a mental disorder such as depression. Depression, unlike physical disabilities, is often associated with a weak will or faulty character. Because mental health issues are directly linked to a person’s mind, I think more scholarship is needed to question the ways in which the identities of people diagnosed with mental disorders are socially constructed.

The field of Disability Studies has focused on theorizing the social model of disability, however, there has been less work on mental health as a primary category of analysis (Chrisman, 2008). Chrisman (2008) argued that “the reality of mental illness (and disorder) is not just a phenomenological experience, or even an epistemology, but also a complex of biochemical and physiological material reality” (1) that has become a reluctant subject in the field. Disability Studies provides a valuable base of inquiry and critique necessary to begin the exploration of mental health issues by challenging our ideas of what it is to be normal, able, and included. However, a study of mental health requires the incorporation of different approaches to explore the complexities experienced by those who live with mental health issues. A multidisciplinary approach, such as that found in the field of Rhetorics of Health and Medicine, needs to also be incorporated.

2.4 Rhetorics of Health & Medicine

Just like Disability Studies, the subfield of Rhetorics of Health and Medicine is important in the study of mental health discourses. In the 90s, Segal argued that rhetoricians had been notoriously absent from conversations about medicine and
science. Even when important medical topics such as patient compliance rely strongly on persuasion, there was no application of rhetorical theory to the issue (Segal, 1994). Instead, these conversations are held mostly among medical professionals, whose work impacts the lives of people (Kopelson, 2009). Kopelson, following the steps of Segal, began investigating the way in which the medical field discussed important issues such as patient’s rights to information and research. In her article she argued that “the changing medical landscape of e-health remains underexplored by scholars in rhetoric and writing studies” (Kopelson, 2009, 356). This blind spot is significant because it is in these medical discourses where the identity of the e-patient, the patient who uses the internet to research health topics, is constructed by professionals that occupy a position of power (Kopelson, 2009, 357). The texts analyzed by Kopelson (2009) construct the identities of these patients ranging from the “misinformed nuisance” to the “true medical ‘expert’” (356) which in turn inform the way patients will be perceived and treated by their health providers (359). This research is very relevant to understanding how the identities of those with mental health issues are also constructed both by professionals in the field as well as the rest of society. Chrisman’s (2008) work analyzed such perceptions held by medical professionals in her study of Reader’s Digest’s article “41 Secrets your Doctor Would Never Share (Until Now)”. This analysis sought to look into how the perceptions held by medical professionals have an impact on the lives of their patients by leading to treatment decisions as well as communication practices. This work also showcased how the identity created by the
medical community about their patients actually impacts the way patients approach medical treatment and institutions. Kopelson’s and Chrisman’s work emphasize the importance of exploring the ways in which constructions of health and individuals with health issues by the medical field has a very real impact on people’s lives and health as well as how they are viewed by others in society.

The work of Rhetoric of Health and Medicine seeks to analyze the ways in which Medicine embodies a position of power with relevant impact in the ways we view life and people (Heifferon & Brown, 2008; Scott, Segal, & Keränen, 2013). Keränen (2007 a) argued that even small operational documents used in medical settings can have a great impact in relationship between medical professionals and their patients. In her study, she analyzed the way the “Patient’s Preferences Worksheet” serves as a way to regulate discourses of life and death in a medical setting. The worksheet was designed and is used to establish end-of-life procedures based on patient preferences. Medical professionals fill out the worksheet with their patients to decide what kind of resuscitation procedures are to be used in case of trauma. Although the form is seen as one small part of the larger amount of paperwork routinely required in medical situations nowadays, Keränen (2007 a) argued that the way these artifacts “articulate the terms of end-of-life decision-making [...] are largely unexplored” (180) by the RWS scholars. For this reason, she calls for more rhetorical analysis of these instances where medical discourses and practices play an important role in the lives and deaths of people. Code status, as well as other medical discourses, are sites for rhetorical analysis although they do
exceed the strictures of the academy (Keränen, 2007 a). Rhetorics of Health and Medicine then provide a space for critiquing the impact of Medicine as a field in a position of power to create realities through discourse and practice.

Another important contribution to the field from Keränen (2011) is her study of the rise of biodefense and the construction of biological risk across political, scientific, and cultural rhetoric. Keränen (2011) demonstrated that phenomena such as biological risk is created through a complex intersection of political, technical, and cultural discourses that create a “site where rhetorical scholars may grapple with the consequences of large-scale organizational rhetorics of science and medicine” (452). In this article, Keränen (2011) traces the way in which the perceptions and discourses created by experts in the fields of medicine and science are not only absorbed into political and popular discourses but they are also influenced by them. For example, fictional novel Cobra Event (Preston, 1997) “purportedly persuaded President Clinton to conduct a review of germ threats” (456). All in all, Keränen (2013) showed that issues like biological risk, which is seen as a political and scientific reality, are constructed through complex discourse which she calls “amplified rhetoric” (462). Similar to the sociological model used in Disability Studies, social construction plays an influential role in the understanding and perceptions of various medical issues across contexts and population with real life consequences. Also, it is important to look beyond the field of Medicine into the representations created through popular media to understand complex ideas such as biorisk. Representations on popular movies and fictional novels are just as
important in creating the perceptions of risk that will in turn support political discourses on the topic. Rhetorics of Health and Medicine then call for more attention to the “interplay among science, technology, medicine, and their globalized publics” (Keränen, 2013).

Although several of the questions being raised in the field of Rhetorics of Health and Medicine apply also to issues of mental health, I think there are key differences that call for more specific research in to how mental health discourse impacts the lives of those that live with a psychological diagnosis. Mental Health as a field has been distinctly separated from Medicine for some very important reasons. Although over the last few decades there have been great advances into the understanding of psychological phenomena, the fact still remains that most psychological disorders cannot be traced back to purely physical, chemical, or genetic causes. In fact, there is a strong understanding that sociological and developmental factors play a very important role in the development of psychological disorders in addition to physical/genetic predisposition. Therefore, in addition to the medical model of understanding mental health we need to employ rhetorical theory to explore the way discourse influences the way people with psychological disorders are constructed in our society. Similarly to the gap in Disability Studies, medical disorders do not share the same kind of stigma that is associated with mental health issues. Mental health disorders are often perceived as less reliable, or even less real, than purely medical diseases like Diabetes or Cancer. There are no definitive blood or other medical tests to prove the existence of
disorders like Depression, Autism, or Schizophrenia (to name a few). This often leads to a belief that mental health professionals are less capable or even suspect, and more importantly, that people living with mental health disorders might be faking, cheating, acting up, or just not as good as “normal” people. Our social constructions of mental health, mental disorders, and people diagnosed with psychological issues play a very important role in our understandings of “normal” and “sanity” that in turn lead to the construction of people’s identity. It is for this reason that I believe there is a gap in our research concerning mental health, a gap I am interested in exploring in this dissertation.

2.5 Rhetoric of Mental Health

The work that has been done in the fields of Disability Studies and Rhetorics and Health and Medicine is both fascinating and very important. However, it does not always address issues of mental health, specifically the ways in which we talk about mental health. Although there has been work done in these fields that applies directly to mental health, there is a need to carve a new space for this specific kind of inquiry. The rhetoric of mental health is an emerging subfield with its roots in the work done in both Disability Studies and Rhetorics of Health and Medicine. Scholars that contribute to the study of mental health attempt to carefully situate themselves between these two fields while also trying to create a new space. This new space is necessary to provide the bases of new questions as well as focusing on the specific circumstances surrounding issues of mental health.
I believe it is important to investigate both the language that is used to describe people with mental disorders as well as the way it constructs the identities of people living with these conditions. In addition to the issues already mentioned, the widespread availability of the Internet and public media have led to increasing speeds of information dissemination that impact the way we understand mental health. Nowadays, certain disorders have become buzzwords in public discourse. People can find information online easily and use it to self-diagnose or diagnose those around them. Online quizzes (Emmons, 2008) to diagnose psychological issues are not just easily available through online search engines, but featured in magazines and popular websites. That is not to say that the increase in dissemination of psychological material is necessarily bad, however. This increased availability of information has led to unprecedented public access to the latest revision process of the Diagnostic and Statistical Manual of Mental Disorders (DSM), the official collection of mental disorders in the United States published by the American Psychiatric Association (2013), unlike the previous revisions of the text. If anything, this has opened the door for more public conversations about mental health and the way that people are categorized and labeled. The changes of certain disorders, such as Autism Spectrum Disorder, featured in the recent revision of the DSM sparked great public dialogue about the nature of categorization and the most importantly the impact these changes can have on the lives of people who live with the diagnosis. I believe there is a lot of room in the field of RWS to begin investigating how mental health issues are categorized and
defined, how public discourse portrays psychological issues, and how this portrayal actively constructs the identities of people who have been diagnosed (whether professionally or not).

2.5.1 Mental Health research within RWS

The rhetoric of mental health, though still emerging as its own subfield, has been increasingly approached by scholars within RWS in the past few years. Chrisman’s (2008) dissertation represents one the emerging bridges that attempts to carve a new space of inquiry for mental health. Chrisman positions herself within the field of Disability Studies while attempting to open up a new space for deep inquiry into mental health. She argued that, “psychiatric disabilities are mentioned [within Disability Studies], but do not receive the same attention as other disabilities” (Chrisman, 2008, 2). In her work, Chrisman critiques the way in which the medical model of disabilities dismisses, erases, and silences the narratives of those people with mental disabilities.

This is an argument that has been made by other scholars in regards to physical disabilities, however, Chrisman (2008) emphasized that the perception of mental disabilities is different because the narratives from people with mental health issues are often regarded as “seemingly uncomfortable, disturbing, or unintelligible” (22). Similarly, Prendergast (2001) has also argued that “insanity is a discursive construct, expressed, reinforced, and sometimes subverted by public discourse, the discourse of experts, and by institutional structures...” (47). That is,
there are “fissures” in the arguments made about disabilities in general that fail to account for the experiences of people with mental disorders (Prendergast, 2001, 46).

Other scholars have also begun to look into the narratives of people with mental disorders in order to capture the ways in which they are perceived in relation to the narratives of “normal” and abled people. Levy (2009), for example, examined the way in which people self-identified as “manic-depressive” use narrative to “negotiate identity and selfhood, epistemic and embodied experience, and political subjectivity...”. Levy argued that memoirs written by people identified as manic-depressive became a way to legitimize manic-depressive illness both culturally and scientifically, so much so that “bipolar memoir” became a genre of its own in the 1990s (2). Personal narrative then can be seen as a powerful discursive tool used to construct our social understanding of mental illness and the identity of those who live with it. Narratives from people with mental disorders, unlike the physical disabilities in general, have to address a very specific kind of “stigma and shame that surrounds mental illness in contemporary culture” (Levy, 2009, 3). This discursive negotiation of what it means to be identified as having a mental illness is critical to our understanding of the rhetoric of mental health.

Disability Studies has not been the only field to address issues of mental health, some scholars within Rhetorics of Health and Medicine have also approached this area. Emmons (2008) positions herself within the rhetorics of medicine while discussing the impact of psychiatric and medical categorization and diagnosis in the understanding of illnesses such as depression. In her work, she
argued that self-assessment tools geared towards the diagnosis of mental disorders are “important recent rhetorical interventions into US health care” with critical impact to the discourse of mental health (Emmons, 2008, 159). These rhetorical devices, commonly used by the Pharmaceutical industry, play a role in the social construction of depression as an illness as well as the construction of the identity of someone with depression. According to Emmons (2008), self-assessment tools are part of a complex rhetorical relationship between the public, business industry, and mental health experts that create the narrative of mental health. This is a critical area that requires exploration because it leads to the discursive construction of identity of people with depression. Emmons concludes that the self-assessment tools designed by pharmaceutical companies essentially construct the identity of a person with depression as a female who is socially isolated. This in itself creates a social perception that contributes to the fact that women are more likely to be diagnosed with depression than men.

Finally, some scholars position themselves between both subfields to tackle questions about disability within a medical context. Johnson (2013), for example, examines the ways in which autism is socially constructed at different levels of discourse. For instance, an analysis of the so called autistic epidemic highlights a complex situation that encompasses “changing diagnostic criteria, greater cultural visibility, and intense parental, school, and medical surveillance” (Johnson, 2013, par. 1). The combination of all of these elements highlights the need to continue to
study the ways in which mental health can be constructed in both social and medical contexts.

The work of scholars within RWS on the rhetoric of mental health shows that there is a strong base in current scholarship for the exploration of mental health issues in discourse. Both Disability Studies and the Rhetoric of Health and Medicine provide strong methods of inquiry that can be adapted and expanded to study mental health. However, other disciplines have also made interesting contributions to this area as well. An emerging field for the study of the rhetoric of mental health would become an important space for interdisciplinary collaboration.

2.5.2 Mental Health research outside RWS

RWS is not the only discipline that has approached issues of mental health. Important contributions have been made, and continue to be made, in other fields such as philosophy and education as well. Hacking, a philosophy scholar, has made critical contributions to our understanding of categorization and perception of people identified as having mental health disorders. In his seminal work “Kinds of People”, Hacking (2007) analyzed the ways in which scientific classification leads to the creation of new types of people by creating new ways of existing and experiencing life. Hacking argued, similarly to scholars in Disability Studies, for the social model of creating identities for people. That is, although the physical phenomenon of mental illness (or other examples such as race, ethnicity, etc.) might exist in the natural world, it does not technically exist until it is identified, named,
categorized, and explained through institutions of power such as the sciences (Hacking, 2007, 293). Hacking (2007), whose work is influenced by Foucault’s (1988) work on nominalism, described the complex system behind the making up of people as:

In the case of kinds of people, there are not only the names of classifications, but also the people classified, the experts who classify, study and help them, the institutions within which the experts and their subjects interact, and through which authorities control. There is the evolving body of knowledge about the people in question — both expert knowledge and popular science (295).

Another important contribution from Hacking is that the name and classification alone is not enough to create the identity of kinds of people, the “looping effect” is also important. Hacking described the looping effects as: “the way in which a classification may interact with the classified” (286). That is, it is not only the label given to people that constructs their identity, but they ways in which people are treated by society because of the label and how people view themselves as labeled. This represents the complex relationship between expert knowledge and popular knowledge that was discussed by Emmons (2008). Hacking’s work then provides the frame to analyze the social construction of mental illness as a rhetorical process that leads to the creation of identity for people who are perceived or labeled as having a mental disorder.

Aside from his work on the construction of identity through science categorizations, Hacking (2007) also has studied they ways in which popular culture and discourse contribute to the formation of identities for people with a mental
health diagnosis. Even though categories are often created by experts in positions of power and influence, such as medicine and psychiatry, the labels given to people are also constructed by the ways in which they are perceived and experienced through popular discourse. Hacking (2009) identified once such example by analyzing a persistent narrative of autism, the alien metaphor. According to Hacking (2009), “a persistent trope in some autism communities is that autistic people are aliens, or symmetrically, that non-autistic people seem like aliens to autists” (44). This recurrent narrative tells a lot about the social perceptions of autism as well as the way that people with autism perceive themselves in relation to society.

Hacking (2009) explained that in one context, the alien metaphor has been used by parents of children with autism to describe their children as being substituted by “non-human” entities (44). The implications of this interpretation of autism are telling to the kind of identity that is constructed by society and imposed upon the lives of people living with the label. The label of alien comes with complex negative connotations from the different contexts in which the word is often used, such as an illegal alien/foreigner. These connotations in turn become part of the dynamic construction of autism in society. Conversely, Hacking also (2009) discussed other instances of the alien metaphor that have a very different context and impact. According to Hacking (2009), the alien metaphor has also been used by people with autism, figures such as Temple Grandin, as a way to describe how they perceive the rest of society. To Grandin, non-autistic people seem as if they were aliens from Mars, for example (Hacking, 2009, 44). In this context, the alien
metaphor challenges the idea that people with autism need a cure and instead proposes the idea that “normal” people are the ones that are different from them. Both metaphors can be found in numerous instances of popular discourse such as films and novels and contribute to the construction of autism as much as scientific discourse. Hacking’s work indicates that in order to understand how mental health, and the identity of those living under this category, we need to explore the complicated relationship between both expert and popular discourse. The emerging field of rhetoric of mental health would then become a prime place for the rhetorical critique of this complex relationship and the implications to the lives of people.

Aside from Hacking, other scholars from different disciplines have also addressed issues of identity construction that could become integral bases to rhetorical inquiry about mental health. In the field of education, scholars such as James Gee have addressed the issue of identity construction. In his work, Gee (2000) asserted that, “when any human being acts and interacts in a given context, others recognize that person as acting and interacting as a certain ‘kind of person’” (99). This supports the idea that identity is dynamically constructed through complex societal systems that have real life impact in the way people are perceived and how people experience life. Gee (2000) also makes a very important assertion about identity as being the way someone is “recognized as a certain ‘kind of person,’ in a given context (100). Gee’s interpretation of identity is the kind of concept I am trying to approach in this dissertation. That is, the identity that is perceived/given through social interactions and not necessarily a person’s sense of self. This is an
important distinction to make, and a valuable approach to the study of the rhetoric of mental health.

Additionally, Gee identified different perspectives on identity that represent different ways in which an identity comes to be recognized in society. Gee (2000) identified these perspectives as natural, institutional, discursive, and affinity as a way to analyze their implications and origins. Although each of these perspectives is related to the others in complex ways, they also help to differentiate the different systems that bring out their recognition. For example, the institutional perspective of identity refers to the kinds of identities that are perceived through their recognition by institutions with power such as science (Gee, 2000, 102). In the case of mental illness, the identity of someone as having a mental disorder is recognized through the classification from the field of Psychiatry and Psychology, reflected in texts like the DSM. Gee’s contributions to the understanding of the social construction of identity provide relevant basis for the continued exploration of this issues as they are related to the rhetoric of mental health.

2.6 Summary

The emergence of the rhetoric of mental health as a subfield of study within RWS comes about as a combination of the efforts of scholars in a myriad of disciplines. Scholarship from Disability Studies, Rhetoric of Health and Medicine, as well as other fields such as Philosophy and Education has begun the construction of a new place of inquiry. I believe that these different fields have made great
contributions to our understanding of what mental health is and how we talk about mental health but they also have several limitations. These limitations then create the exigence for a new area of study that aims to deconstruct the ways in which we perceive the phenomenon of mental illness as well as the ways in which we construct the identity of the people who live with a mental diagnosis. This dissertation will continue to reinforce that bridge between these different disciplines in the formation of a field of rhetoric of mental health, such as previous scholars have done before me.
3. RECATEGORICATION OF ASD IN THE DSM

3.1 Overview

This chapter consists of the first stage of analysis of this study that deconstructs the way the recategorization of autism was presented in the DSM-5 and in a sample of academic literature. The chapter begins by providing essential background information on the DSM, its revision process, and Autism Spectrum Disorder (ASD). This context situates the DSM within the overall field of mental health and serves as the foundation to the analysis conducted in this chapter. Based on the literature review in Chapter 2, this chapter sets the foundation for the research methodology to be used in later chapters. Several sections of the DSM, relevant to ASD, are incorporated into the sample of this part of the analysis together with a selection of academic literature published during the revision of the DSM-5. Then, these texts are analyzed in order to study the way in which the recategorization was framed and how this in turn constructed an identity for people with ASD.

The findings from this chapter serve as the structure to the second and third stages of analysis in later chapters, and therefore create a sort of framing for the overall study. The coding structure presented in this chapter is used in the next couple of chapters as well. With this in mind, this chapter sets the tone for the rest of the project and becomes the context for the analysis of the media coverage of the recategorization of autism and its absorption into public discourse.
3.2 History of the DSM and ASD

3.2.1 The DSM

A few years ago, Michael Strand (2011) argued that it is easy to overlook the origins of artifacts that serve very important functions such as the Diagnostic and Statistical Manual of Mental Disorders (DSM). There is a tendency to assume that the reason for the DSM’s creation was based solely on the need for a classification system of mental disorders. However, understanding the origins of such an influential artifact requires us to look at the rhetorical context, the social/political climate that existed prior to the creation of the DSM-I in 1952. According to Joshua Clegg (2012), the history of the DSM is intricately linked with the development of the field of mental health that we know today in the United States. Due to the focus on this chapter, the following is a very brief recounting of the history of the field of mental health and the DSM in this country.

Before the creation of the DSM-I, the field of mental health in the U.S. was in the process of becoming an autonomous discipline distinct from that of medicine (which was a more established and legitimate field at the time). The psychoanalytic movement had been gaining force from the early 1900s, and sought to capture jurisdiction over mental health by establishing an independent field of study based on clinical treatment (Strand, 2011). Around World War II, American psychiatry had adopted a strong psychoanalytic frame in the treatment of war-related psychological trauma which was contrary to the current classification systems in place that were more based on the medical model (Clegg, 2012). In response to this,
the Office of the Surgeon General, chaired by Brigadier General William C. Menninger, produced a document called Medical 203, which would later become the basis of the first *DSM* (Clegg, 2012). Medical 203 “invoked the psychodynamic theory that had risen to prominence in the war” (Clegg, 2012, 365), and was an argument for the direction the field of mental health would take for the next few decades. Although some of the category names from Medical 203 had been changed, the language, description of psychotic disorders, and categories were either very similar or identical to the ones eventually published in the *DSM-I*.

According to Clegg (2012), the appearance of the *DSM-II* in 1968 was partly a response to the success of *the International Classification of Diseases (ICD)*, which is an international manual created by the World Health Organization that attempted to create a more uniform classification system of disorders. The *DSM-II*, however, was not much different from the first version of the manual and contained only a few significant changes to the original text (Clegg, 2012). Most importantly, the psychodynamic theoretical framework remained the same.

*DSM-III* is regarded as one of most drastic and influential changes within the modern field of mental health. Similarly to how Medical 203 and *DSM-I* were artifacts with argumentative force used by the psychoanalytic movement to

---

2 Although both the ICD and DSM provide classification systems for mental health disorders, there are significant differences between them which have led to my decision to only focus only on the DSM for this study. Unlike the DSM, the ICD is a comprehensive classification system that includes conditions and diseases related to all body systems, not just those associated with mental health. Furthermore, the DSM provides essential criteria and definitions of disorders that are used by clinicians in the diagnosis and treatment of mental illness, whereas the ICD only provides a code system that facilitates an international common language. Therefore, unlike the ICD, the DSM has overwhelming influence on the current perceptions and theoretical understandings of the field mental health, making it an essential part of this study.
influence the field of mental health in the U.S., the *DSM-III* would serve as an argument by the diagnostic psychiatry movement. During the 1960s, several changes to the political, economic, and social climates in the country led to psychoanalysis to come under scrutiny. The growth of third-party payment for health services (insurance) as well as American health programs (such as Medicare and Medicaid in 1966) had enormous impact on the field of mental health. The categorization system used by the *DSM* and psychoanalytic practices did not work well with the new systems of insurance and reimbursement (Clegg, 2012; Strand, 2011). Also, social/cultural critiques of psychoanalysis and the definition of mental illness, starting with Foucault’s (1988) *Madness and Civilization* in 1966, further reinforced the call for changes to the conceptualization of mental health. These factors then created the rhetorical situation that would lead to a data based movement and the creation of the *DSM-III*, both efforts led by influential psychiatric figure Robert Spitzer (Clegg, 2012).

The *DSM-III*, in 1980, featured a complete revamping of the classification system seen in its predecessors. Early *DSM*s were under attack for their lack of empirical bases and their inclusion of controversial diagnostic categories such as homosexuality (Clegg, 2012). Additionally, the early *DSM*s were based on a psychodynamic theoretical framework that was based in unverifiable explanatory mechanisms that were not linked to biological bases as in the medical model. This rose the question “how could a diagnostic manual, like the *DSM*, become a pluralistic diagnostic tool, one amenable to the multiplicity of therapeutic and
political contexts reflected in the American mental health professions?” (Clegg, 2012, 368). That is, although psychoanalysts comprised a large number of mental health professionals in the country, there were also clinical psychologists and psychiatrists that found the manuals unsuitable to their practice. This gave rise to the drive for a “theoretical neutrality” that would base the manual on evidence based research and field trials instead of any theoretical frameworks (Clegg, 2012). “DSM-III itself acknowledged that for most disorders ‘the etiology is unknown’, and so a theoretical form of classification was unwarranted in any case” (Clegg, 2012, 368). Therefore, Spitzer’s movement “successfully advocated for a return to the symptom-based, medically oriented, and empirically justified form of psychiatric diagnosis” (Clegg, 2012, 369) that had been present before the creation of Medical 203 and the early DSMs, and that was used by the ICD.

The changes to the DSM, at the end of the day, exemplify the ideological changes that took place in the field of mental health in the 1980s. Not only was the DSM-III introducing a different way to categorize mental illness but it was also creating a new meaning for it. DSM-III (1980) argued for the discontinuation of referring to people as “a schizophrenic” and instead advocated for adopting the practice of using “individual with Schizophrenia” (6). This reflects the current ideological standings of the field of mental health today, where disorders are understood to be entities or manifestations of illness in people and not the identity of the person. According to Strand (2011), the arrival of the DSM-III marked the end of the psychoanalysis hegemony established by earlier versions of the manual,
and perhaps it now also marks the beginning of a different kind of hegemony.

“What diagnostic psychiatry offered was a form of clinical practice that, significantly, remained medical and also rendered psychoanalysis obsolete” (Strand, 2011, 287).

*DSM-IV* and *DSM-IV-TR* continued to make changes/updates to the categorizations and criteria of the *DSM-III*, while maintaining the same theoretical ideology about mental health in the previous version. The manual emphasized culture specific approaches to disorders and made an “explicit endorsement of the bio-psycho-social model of disease” (Clegg, 2012, 367) that is very much still in place today. According to the revision task force, the main contribution of the *DSM-IV* was the way it was revised and not so much the changes that were made. This revision established the practice of using literature reviews, data re-analysis, and field trials as the bases for revision of the *DSM* (Clegg, 2012). This practice has been continued in the latest revision of the *DSM-5*.

3.2.2 *The DSM-5 and the Current Situation*

The fifth revision to the *DSM* has been a long process that began in 1999, but it also has been quite innovative for the field of mental health. Following the steps of *DSM-IV*, the revision process has involved addressing the perceived limitations of previous *DSM*, collection and assessment of a broad part of the literature, and an analysis of primary and secondary research. In addition to this, however, the most recent revision to the *DSM* was open to global discussion among members of the
mental health field and took into account the comments from patients, families, and other members of the community. It is this incorporation of a global discussion, via a website with updates and space for comments, which has proven to be quite interesting as it represents the first time since the inception of the manual that the public has been allowed to enter the conversation. This has prompted heated debates and conversations in all sorts of mediums and by a variety of individuals.

As the revision process progressed, the DSM-5 Task Force, composed of 13 mental health professionals acting as chairs for each of the diagnostic groups and a number of experts in the field, posted drafts of their proposed diagnostic criteria in order to get feedback from the mental health community in their official website (APA, 2017). The posting of the proposed criteria caused a lot of excitement and mixed feelings in the mental health community. At the time, I was working on my master’s degree in clinical psychology and the proposed updates to the DSM were a hot topic in our graduate classes. Professors approached the drafts with care and hesitation and we shared many conversations about what the changes would mean for our field. It was at this time that some of the most controversial changes began stirring heated conversations not only within the mental health field but also among the public. Proposed changes to the categorization of personality disorders and pervasive developmental disorders received mixed reviews; some of the professionals in the field believed that updating of the categories was indeed needed but were not quite convinced that the DSM-5 Task Force was heading in the right
direction. The public also began to enter the conversation as concerned parents voiced their fears about the changes in diagnosis that might affect their children.

All in all, it is clear to see that the transparency of the revision process had a significant impact in the final version of *DSM-5*. Several of the changes that had been proposed or discussed, such as the recategorization of personality disorders, ended up being rejected based on the negative feedback received. It was also possible to see the arguments made (and later rejected) in favor of adding controversial diagnosis such as pedohebephilia, coercive paraphilia, and parental alienation syndrome (Strait, 2014). Similarly to the revolutionary revision process of *DSM-IV*, the revision process of *DSM-5* introduced a more inclusive and public methodology for making changes to the manual. Although the changes made in *DSM-5* were not as extensive as the ones in *DSM-III*, the latest revision’s contribution is the precedent of transparency in the process.

Just as it is easy to forget the motivations and origins of texts like the *DSM*, it is also easy to believe the narrative that all changes and revisions have been made solely on the bases of empirical data and research. Throughout the history of this manual, there have been personal, social, and political concerns that have played important parts in the development of the field of mental health. Clegg (2012) argued that “the final product of any revision process will reflect the assumptions, interests, and commitments of those who occupy the seats of influence — that is, it will be at least as much a political product as it will be a scholarly one” (369). Later on in this chapter, the ideological arguments made in the *DSM* will be
analyzed in order to discover the meanings of mental illness it creates, as well as the constructed identities of individuals diagnosed with mental health disorders.

3.2.3 Autism Spectrum Disorder

This chapter focuses on the recategorization of Austin Spectrum Disorder (ASD) from *DSM-5*. Even though it is a relatively new disorder, ASD has a rich history that will provide the context for the recent recategorization. The following is a brief history of the discovery and development of ASD.

The term “autism” was coined in 1910 by German Psychiatrists Eugen Bleuler, a little over 20 years before its modern usage was established. Although the term autism was coined by Bleuler, he was using it to describe some of the symptoms of patients with schizophrenia and not the disorder we have come to know as ASD today (Kuhn, 2014). Bleuler came up with the term based on the Greek word “autos,” meaning self (Chown, 2012, 2263), to describe the “withdrawal of the patient to his fantasies, against which any influence from outside becomes an intolerable disturbance” (as quoted in Kuhn, 2014).

Today, we attribute the discovery of ASD to Leo Kanner and Hans Asperger, a discovery riddled with strange coincidences and a bit of controversy. In 1943, Kanner published a study describing a unique syndrome he identified as “Autistic disturbances of affective contact” (Wolff, 2004). Later on in the same year, Asperger published his own study of four cases described as “autistic psychopathy of childhood” where he identified the disorder as being recognized in childhood and
lifelong (Wolff, 2004). There is no known connection between the two scholars, although due to both of these papers being published in the same year by German psychiatrists, there have been claims of possible plagiarism (Chown, 2012; Lyons & Fitzgerald, 2007). Kanner’s work received a lot more attention than Asperger’s since his work was published in the US with a wide audience. Asperger’s work was published in Germany and was relatively unknown to American audiences until Lorna Wing brought it to the forefront in 1981 (Wolf, 2004). Both Kanner and Asperger identified autism as being a developmental disorder (identified in infancy) marked by social issues. Wing, expanding from Asperger’s work, further developed our understanding ASD and focused on “high-functioning” autism. Wing defined Asperger’s Syndrome (1981) and has been influential in the current understanding of autism as a spectrum disorder (represented in the recategorization of ASD in DSM-5) (Wolff, 2004).

Besides the work of these scholars, the development of ASD as we know it today has been influenced by social, political, and cultural shifts in the last few decades. Autism began receiving more attention after it was included in the U.S. Developmental Disability Act of 1975, which provided financial support and special education services for people with the disorder (Wolff, 2004). Infantile autism was the first form of the disorder to appear in the DSM in its third revision (1980), while Asperger’s Syndrome was added until the DSM-IV. According to Wolff (2004), “Cultural shifts as well as research findings have influences our concepts of autism and the education and treatment offered to affected people” (205). One of these
shifts was the influence of psychoanalysis in the field of mental health. Kanner, like many in the field of mental health at the time, was influenced by psychoanalysis theories when he first identified and treated this disorder in children. This led to an attribution of the disorder to poor parenting, which resulted in expensive and extensive treatment of children and their parents. Although research has disproved those allegations, they still influence the way the public perceived the disorder for many years (Wolff, 2004). Public understanding of ASD has further been expanded due to the writings of parents of children with autism and individuals with the disorder as well. These publications present a personal perspective of the disorder that expanded the boundaries of Autism to include Asperger’s Syndrome. Finally, the recent vaccine controversies surrounding ASD have had an impact in the public understanding of the disorder. Although there is no evidence of a link between autism in a variety of vaccines (such as MMR in the UK), several parents continue to opt out of vaccinating their children and claim vaccination as a cause for their children’s diagnosis (Wolff, 2004).

The latest evolution of autism was its recent recategorization of the disorder that appeared in *DSM-5*. Autism was identified to be a developmental disorder; that is, a disorder identified in childhood with ongoing effects throughout the person’s life. In the *DSM-IV-TR*, autism was placed under the Pervasive Developmental Disorder (PDD) category which was composed of five subtypes: Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) (APA,
According to the *DSM-5* Task Force, all of the disorders under the PDD category, except for Rett’s Disorder, were placed under one spectrum labeled Autism Spectrum Disorder (ASD) with differing levels to identify the functioning of the individuals diagnosed. One of the reasons for the change was that there was a clear diagnostic difference between PDD and non-PDD conditions, a difference that was not always distinguishable between the disorders under the PDD category (Kurita, 2011). Because of this, it was the belief of the *DSM-5* Task Force that the four original diagnoses are in fact different levels of the same disorder (which they have labeled Autism). This has prompted some doubts as to whether high functioning children diagnosed originally under Asperger’s Disorder and PDD-NOS will meet the new criteria at all. Parents, of children diagnosed with Asperger’s Syndrome or another high functioning autism diagnoses, were concerned about their children not meeting the new criteria for diagnosis and as a consequence losing access to precious resources such as insurance coverage, specialized resources for children with learning disabilities and developmental disorders, specialized school programs for children with mental health problems, and others.

### 3.3. Methodology

This dissertation seeks to answer one main research question:

*How do changes in an authoritative text like the DSM get absorbed by public discourse through media and in turn contribute to the discursive*
As mentioned in previous sections of this dissertation, the main research question of this project has been divided into three subquestions. These questions were crafted to answer specific parts of the main question and are used as key elements of analysis. This chapter focuses on answering subquestion 1:

*How does the new recategorization of the Autism Spectrum Disorder in the DSM construct our understanding of the disorder and the individuals living with the diagnosis?*

The context given at the beginning of this chapter situates the *DSM* as an authoritative text that significantly influences the course of the field of mental health in this country. It also emphasizes the importance of recognizing the context and conversations within the field that surround revisions to the *DSM* and redefinitions of mental health disorders. The recategorization of ASD sparked a vigorous conversation amongst mental health professionals in this country which was more visible than other similar conversations in previous revisions to the *DSM*. Because of the open forum approach through the *DSM-5* revision website, the conversation about ASD expanded to include not only the members of the *DSM-5* Task Force but also other professionals in the field, academics, and even graduate students in mental health programs (like I was from 2009-11). In order to answer subquestion 1, I felt it was necessary to not only analyze the text of the *DSM-5*, but also the academic conversations that were published about the recategorization of...
ASD. To achieve this, I sampled several key documents in this conversation along with materials published by the APA. Details about the sampling and analysis are given below.

3.3.1 Sampling

Given the fact that the conversation about the revision of ASD was very broad and extensive, I felt it necessary to use only a sampling of it in this part of the dissertation. In essence, this conversation happened beyond just the writings of academics in journals as it also took place in classrooms, during coffee breaks, through phone calls and correspondence between colleagues, in private conversations, online forums, and beyond. To attempt to cover a significant amount of these voices was beyond the scope of this chapter. Instead, I choose a specific sampling of academic writings because they reflected the thoughts of professionals in the field and I believe these thoughts are a representation of the conversations these individuals had with colleagues and students. In addition to these documents, a few select sections of the DSM-5 that were relevant to ASD were also included in the analysis. Table 1 presents the sampling of documents included in this part of the analysis.
Table 1

ASD recategorization documents sampled for Stage 1

<table>
<thead>
<tr>
<th>Document</th>
<th>Author</th>
<th>Date</th>
<th>Publication Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application of <em>DSM-5</em> criteria for ASD to three samples of children with <em>DSM-IV</em> diagnoses of Pervasive Developmental Disorders</td>
<td>Huerta et al.</td>
<td>2012</td>
<td>Academic Journal</td>
</tr>
<tr>
<td>What are the stakes? An analysis of the impact of the <em>DSM-5</em> draft autism criteria on law, policy and service provision</td>
<td>Ne'eman &amp; Kapp</td>
<td>2012</td>
<td>Advocacy Report</td>
</tr>
<tr>
<td>Sensitivity and specificity: <em>DSM-IV</em> versus <em>DSM-5</em> criteria for Autism Spectrum Disorder</td>
<td>Tsai</td>
<td>2012</td>
<td>Academic Editorial</td>
</tr>
<tr>
<td>Insurance Implications of <em>DSM-5</em></td>
<td>APA</td>
<td>2013</td>
<td>Online Statement</td>
</tr>
<tr>
<td><em>DSM-5</em> Preface</td>
<td>APA</td>
<td>2013</td>
<td>DSM Section</td>
</tr>
<tr>
<td><em>DSM-5</em> - Introduction</td>
<td>APA</td>
<td>2013</td>
<td>DSM Section</td>
</tr>
<tr>
<td><em>DSM-5</em> - Use of Manual</td>
<td>APA</td>
<td>2013</td>
<td>DSM Section</td>
</tr>
<tr>
<td><em>DSM-5</em> - Forensic Use</td>
<td>APA</td>
<td>2013</td>
<td>DSM Section</td>
</tr>
<tr>
<td><em>DSM-5</em> - ASD</td>
<td>APA</td>
<td>2013</td>
<td>DSM Section</td>
</tr>
</tbody>
</table>

3.3.2 Research Protocol

Following the methods outlined by Altheide and Schneider (2013), a research protocol was created prior to the analysis of the documents in this section. The research protocol is a “list of questions, items, categories, or variables that guide data collection from documents (Altheide & Schneider, 2013, 44). Given the reflective nature of the analysis, part of the protocol was created ahead of time to highlight important information to the analysis (such as recording the date, site of
publication, and author credentials) and to ensure I was asking the right questions. The other part of the protocol came from the analysis itself to ensure that emerging patterns from the data were incorporated into the protocol. For example, as the documents were being analyzed and coded, additions to the protocol were necessary to capture the different framings of ASD and its recategorization in the texts. A copy of the protocol can be found in Appendix 1.

3.3.3. Qualitative Software

I used ATLAS.ti (version 1.0.21 (91)), an extensive qualitative software, to analyze the documents and materials in this dissertation. The process involved uploading each document into the program and using the various commenting and coding features to document the items in the research protocol. This software allowed me to attach the research protocol to each of the documents via a commenting box in the interphase. The protocol was copy/pasted into the commenting box for each document and filled out. This was similar to a process of stapling the protocol sheet on top of physical documents as has been done by other researchers (Altheide & Schneider, 2013). Using the software features, I created a set of coding categories based on the research protocol that were used to highlight specific places within the documents. ATLAS.ti also supports in-vivo coding, which was necessary to track emerging patterns and concepts throughout the analysis. The coding capabilities allowed me to create groups of codes which functioned as an easily accessible way to categorize and organize codes. ATLAS.ti was also used to
compute code co-occurrence tables to analyze the relationships between certain groups and individual codes.

3.4 Analysis

3.4.1 Codes

This part of the analysis yielded a total of 7 groups containing 41 unique codes. Table 2 provides a list of the codes created in this stage of the analysis, organized by group as well as the number of occurrences for each code.

Table 2

*Main coding structure for Stage 1*

<table>
<thead>
<tr>
<th>Code</th>
<th>Occurrence</th>
<th>Code</th>
<th>Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Context</strong></td>
<td></td>
<td><strong>Recategorization</strong></td>
<td></td>
</tr>
<tr>
<td>spectrum</td>
<td>9</td>
<td>valid</td>
<td>28</td>
</tr>
<tr>
<td>disorder</td>
<td>5</td>
<td>problem</td>
<td>16</td>
</tr>
<tr>
<td>social problem</td>
<td>1</td>
<td>solution</td>
<td>12</td>
</tr>
<tr>
<td>disease</td>
<td>0</td>
<td>necessary</td>
<td>10</td>
</tr>
<tr>
<td>fake</td>
<td>0</td>
<td>invalid</td>
<td>6</td>
</tr>
<tr>
<td>medical</td>
<td>0</td>
<td>unnecessary</td>
<td>0</td>
</tr>
<tr>
<td>DSM</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>valid</td>
<td>28</td>
<td>recategorization</td>
<td>51</td>
</tr>
<tr>
<td>invalid</td>
<td>6</td>
<td>DSM revision</td>
<td>26</td>
</tr>
<tr>
<td>classification</td>
<td>1</td>
<td>ASD</td>
<td>23</td>
</tr>
<tr>
<td>guideline</td>
<td>1</td>
<td>Asperger's</td>
<td>14</td>
</tr>
<tr>
<td>description</td>
<td>0</td>
<td>PDD-NOS</td>
<td>21</td>
</tr>
<tr>
<td>Ethos</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>clinician</td>
<td>16</td>
<td>disability</td>
<td>53</td>
</tr>
<tr>
<td>MH professional</td>
<td>14</td>
<td>eligibility</td>
<td>32</td>
</tr>
<tr>
<td>scholar</td>
<td>4</td>
<td>resources</td>
<td>28</td>
</tr>
<tr>
<td>parent</td>
<td>1</td>
<td>policy</td>
<td>26</td>
</tr>
<tr>
<td>autist</td>
<td>0</td>
<td>insurance</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>58</td>
</tr>
</tbody>
</table>
During the development of the research protocol, several factors had to be taken into consideration in order to address subquestion 1. To answer this question, it was important to get a good understanding of the recategorization of ASD by analyzing the language used to describe it in the *DSM-5* and other academic texts in the field of mental health. The first step to do this was to track the use of the words *autism* and *ASD* in the texts and assess the assumptions and implications of the term being made by the author(s). The history of the *DSM* and Autism as a disorder show that ideology plays an integral role on how disorders are developed and defined within the field. For example, psychoanalytic ideology lend to the assumption that autism was caused by cold parenting instead of having a physiological bases. It so then follows that shifts in ideology are an important factor to consider during the recategorization of a disorder within the *DSM*. For this reason, it was important to note the assumptions being made when the terms *autism* and *ASD* were used. This led to the creation of a group of codes designed to assess the context of the terms, the codes included in the Context group are: *disease, disorder, fake, medical, social problem, and spectrum*. These terms were chosen based on preliminary observations of the different ideological understandings on the

<table>
<thead>
<tr>
<th>Codes created during the coding process with at least 10 occurrences</th>
</tr>
</thead>
</table>

- autism
- ASD
- disease
- disorder
- fake
- medical
- social problem
- spectrum

* DSMS attached with the meaning of social context.
disorder both within the field of mental health and in public awareness of the disorder. The code *disease* was used when ASD is framed as being a physiological disease (caused by physical anomalies or environmental causes) and sometimes with the implication that ASD can be cured. The code *fake*, was used to identify the instances when ASD is seen as something that can be faked or invented by parents, children, or mental health professionals. The code *medical* was used when ASD was framed as being a disorder based on physiological causes that can be treated by using pharmacological treatments. This ideological standing usually also assumes that ASD is a psychiatric disorder more so than a psychological one that should be treated primarily through the use of drugs treatments instead of therapy. The code *social problem* was used to identify instances where ASD was framed as being a social problem that should be addressed through policy and/or social practices. For example, this is a common ideological assumption when claims are made about ASD cases being on the rise as a consequence of social practices like vaccination. Finally, the code *spectrum* was used when ASD is represented as being a spectrum disorder encompassing a range of symptoms and levels of impairment. This was one of the crucial ideological changes that led to the recategorization of autism into ASD.

Another important set of ideological frameworks assessed where assumptions about the *DSM* itself and its role within the field of mental health. Subquestion 1, specifically asks about the impact that a change to a text like the *DSM* can have on the understanding of a phenomena such as autism. In order to analyze this impact, it is important to identify the way the *DSM* is perceived in each of the documents
used in this analysis. For this purpose, the code group DSM including the codes classification, description, guideline, invalid, and valid was created. The code classification was used when the text identified the DSM as being a set of classifications of disorders. That is, a form of organization of disorders based on their symptomatology and characteristics. The code description was used to identify instances where the DSM is perceived to be merely a description of psychiatric phenomena with the goal of providing a uniform description for practitioners within the field. This kind of ideological framework emphasizes the DSM as a collection of symptoms associated with a disorder without giving any theoretical explanations for the phenomena. The code guideline was used to identify instances where the DSM is seen as merely a guideline to be used by mental health professionals only. This ideological standing usually argues that the DSM is not meant to prescribe diagnoses or treatments; instead it should be a guideline for trained practitioners which should also use their judgement and experience when making choices about a specific individual. The code invalid was used to identify arguments made against the validity of the DSM as a whole or the validity of the research used to establish the definitions of certain disorders. Finally, the code valid was used to identify arguments that supported the validity of the methods used in the creation and revision of the DSM. This code was also used to identify instances where the DSM is seen as a necessary (valid) practice within the field of mental health.

Another key factor of subquestion 1 is to the matter of the recategorization of pervasive developmental disorders into a unified spectrum disorder (ASD). In order
to capture the conversation about this recategorization, the sampling of documents used in this study included not only the text of the *DSM* itself but also academic articles written by professionals in the field of mental health. The code group Recategorization was created in order to track the way the recategorization of ASD was portrayed throughout the documents; the codes included in this group were *invalid, valid, necessary, unnecessary, problem, and solution*. The codes *invalid* and *valid* were the same ones used to track the arguments made about the *DSM* in general. These codes appear in both groups because arguments against or for the validity of the recategorization of ASD can be also interpreted to be arguments against for the validity of the *DSM* as a whole. The codes *necessary* and *unnecessary* were used to track arguments made about the necessity to recategorize pervasive developmental disorders into one spectrum. These codes were developed because they capture a key difference between arguments for or against the recategorization; that is, even when the recategorization is seen as having validity based on research, it does not necessarily mean that the recategorization in the *DSM* was necessary. Arguments about the necessity to reclassify this group of disorders are usually more centered on the purpose of the *DSM* within the field and impact it can have outside of the field as well (e.g. impact on insurance practices). The code *solution* was used to mark instances where the recategorization was perceived to be the solution to a previously existing problem or set of problems. Even though some arguments made in the text do not necessarily identify the problem that existed prior to the recategorization, the assumption that a problem
existed is evident in the assertion that the new classification provided a better process of diagnosis. These instances were included under the code *solution*. Finally, the code *problem* was used to identify the instances in the text where the recategorization was perceived to create new problems. This code was not meant to create a dichotomy when paired with the code *solution* because it was not used to mark references to problems solved by the classification. Instead, the code *problem* was used to specifically identify new sets of problems that might or will arise due to the changes made to the classification of pervasive developmental disorders.

The last group of codes that was pertinent to this part of the project was developed to track the framing of the authority (ethos) of the arguments made in the conversation about the recategorization of ASD. One of the factors found to be important in this project was the relevance of the source of arguments made in this conversation. That is, the research questions in this project attempt to identify the nuances of how a disorder like ASD is perceived as the information of the recategorization travels from the experts in the field of mental health to public knowledge. For this reason, the group Ethos included *clinician*, *mental health professional*, *journalist*, *parent*, *scholar*, and *self*. The code *clinician* was used when arguments are either made by clinicians (professionals that work directly with individuals diagnosed with ASD such as therapists, clinical psychologists, and psychiatrists) or are made based on the information or opinions of clinicians in the field. The code *mental health professional* was used to identify arguments that attributed their ethos to any mental health professional (this includes any
professional that works within the field including psychiatric nurses, school counselors, etc. even if they are not necessarily psychologists or psychiatrists). The code journalist was used when arguments were attributed to a member of the press or media or someone reporting on the issue. This code was developed to track the arguments made by individuals that did not do the primary research on the recategorization but are reporting on the research and making arguments based on that. Although the word journalists was used, this does not exclude individuals who are mental health professionals or individuals who are not journalists per se. For example, a mental health professional reporting on the process of the revision to the DSM would be marked by this code because they are not basing their argument on their personal research or experience but more on their observations of the process itself. The code parent was used when the ethos was attributed to the parents of children diagnosed with any of the pervasive developmental disorders. The code scholar identified arguments that were attributed to researchers in the field of mental health who are not practitioners or clinicians. This code was developed based on the key distinction within the field of mental health between clinicians and researchers (the latter tend to work in research labs as opposed to doing therapy). Finally, the code self was used to identify the arguments that are attributed to individuals who have been diagnosed with a pervasive developmental disorder (whether they fall within the new recategorization of ASD or not) and usually denote personal experience similar to that of the ones identified with the parent code.
The groups of codes outlined before were all developed based on research and preliminary observations I made while developing this project. These may be considered planned codes that were set before the analysis of texts was conducted. They encompass the framework set for this analysis however, given the reflexive nature of this methodology, other codes were developed based on the observations made during the analysis as well. The following section outlines some examples of these codes and the rationality for their inclusion in the analysis.

3.4.2 In-Vivo Coding

Ethnographic content analysis (ECA) is a reflexive methodology that combines content analysis with observations (Altheide & Schneider, 2013). Therefore, setting parameters for the research protocol ahead of the analysis was just as important as the parameters that emerge during the observation process. In the process of analyzing the sampled texts in this project, certain patterns began to emerge that required the creation of new codes. New codes then required me to go back to the documents and follow these patterns as well. Although many codes emerged during this part of the process, this section will outline only a selection of these codes. The codes featured here serve as an example of the kinds of decisions that were made for inclusion of new codes as well as the rationale for their creation.

One of the factors coded prior to analysis was arguments made about validity of the research used in the DSM and the recategorization of ASD (coded as valid or invalid). However, once the analysis was underway, new patterns emerged in the
way that members of the field of mental health addressed the issue of research. During the analysis of DSM texts, there was a tendency to specify research as scientific. This lead to the development of the code scientific in order to identify words and references to science such as scientific validity, experiments, studies, and objective research. I believe this was a significant distinction in the language to track because it is tied to the arguments within the field of mental health that support the notion that mental health is a science just like the field of medicine. It was interesting to note that references to science were prevalent in the DSM texts as well as other academic texts.

Once the code scientific was created and used in the analysis another important pattern emerged; data and research were not only specified to be scientific but also objective. The code objective was developed to track the specific instances where objectivity was mentioned in the texts. For the most part, objective was often coded in conjunction with scientific, but this was not always the case. References to objectivity were often used as a qualifier for research and data that is seen as valid in the context of the DSM and the recategorization of ASD. Similarly to the pattern identified for the scientific code, objectivity is also a relevant word in the argument for mental health as a field of science. Using the word objective is significant because of the implications made against subjective data and research.

In the previous section, a description of the group of codes designed to identify claims to authority and ethos in argument was provided. During the coding of these specific instances, there was a need to include other codes as well. One of
the new codes that arose in this area was advocate. The code **advocate** was used to track the arguments and contributions to the conversation from individuals that are part or represent advocacy groups related to autism. There was a need for a new code because advocates are not always necessarily mental health professionals, parents, or individuals with a diagnosis related to ASD. Often times, advocates are policy makers that are influential in this area. Similarly, the code **private** was created to track the instances of attributions to regular members of the public (private citizens) that do not fit any of the parameters of the other codes already mentioned here. This became an important thing to track considering that the revision of the **DSM-5** was shared to the general public via a website. Also, the **DSM** makes a point on highlight that they took the opinions of the general public via the website.

Identifying the ways in which the **DSM** and the academic conversation about the recategorization create an understanding of the disorder and the people living with an ASD diagnosis was a very important part of this project. Originally, when developing the research protocol, the code group to track the context of the word autism and ASD (described above) was designed to identify the assumptions made about the disorder. However, as the research progressed, new codes emerged that addressed more specific patterns related to the understanding of the disorder and the creation of identity of individuals with the disorder. It became necessary to not only track the context of the words autism and ASD but also to identify their connection to people’s lives. The code **ASDdisability** was created to track any
instances in the text where ASD was identified as being a disability for the person diagnosed with it and descriptions of the ways in which ASD might be disabbling to a person. This code became very important to understanding the ways in which the texts observed create a perception of people with ASD as being limited in everyday life. According to disability studies research, noting the instances that mark people as disabled is critical. Similarly, the codes ASDidentity and MHIIdentity were created to highlight the instances where individuals with an ASD diagnosis or any mental health issues, respectively, are described. These instances, in essence, construct the idea for all the individuals who have a diagnosis. These three codes became important when tracking descriptions of behaviors and characteristics of people with an ASD diagnosis, and were grouped together under the name Identity.

3.4.3 Code Frequencies and Patterns

One of the objectives of subquestion 1 is to understand how the expert conversation about the recategorization of ASD constructs our understanding of the disorder. The text of the selected documents was coded to track the patters and concepts of the conversation. By looking at the most commonly used codes in this section of the analysis, the codes with the higher frequencies give us an idea of what the conversation focused on as well as the ways in which it constructs our understanding of ASD. The following is a discussion of the most commonly used
codes and their relevance and impact to the expert conversation on the recategorization of ASD in the *DSM-5*.

### 3.5 Discussion

#### 3.5.1 Construction of Disability

The most commonly used code in this stage of the analysis, by a large margin, was *disability*. *Disability* was used to code every instance in which there was a description or definition of disability. Looking at the quotes that were tagged with this code, I identified the ways in which disability was constructed in the selected texts as well as the different arguments made about it. The *DSM*, in particular, argues for making a clear distinction between mental disorder and disability. In their Forensic Use statement, the *DSM* (APA, 2013) defines disability as “impairment in social, occupational, or other important areas of functioning” (25). They further argue that “assignment of a particular diagnosis does not imply a specific level of impairment or disability” (25). The need to make this distinction stems from the implications of a text like the *DSM* and the way it is used in more than a clinical setting. That is, the *DSM* is meant to be a collection of mental disorders and their diagnostic characteristics; however, diagnosing an individual with a specific disorder does not necessarily establish that they are impaired or disabled.

The *DSM* makes this argument about disability in their Forensic Use statement because it is an issue with real and sometimes legal consequences. Even
though the primary purpose of the *DSM* is to provide a unified diagnostic system for mental health professionals, it is also often used in forensic matters such as custody or criminal cases. The *DSM* merely provides a unified understanding of the various manifestations of mental health phenomena but it relies on the expertise and judgement of a trained professional to actually reach a diagnosis. The Forensic Use section states that the *DSM* is not developed to serve “...all of the technical needs of the courts and legal professionals” (APA, 2013, 25). The danger in equating disability and impairment with a mental health diagnosis is that this association could be used to make a forensic case against the faculties of a person. Therefore, according to the *DSM*, a mental health diagnosis is not a disability or impairment but the manifestation of a psychiatric phenomenon. Disability is defined as an impairment that may sometimes be a result of a mental health issue.

Although the *DSM* makes a strong argument about disability and mental health, there is a salient contradiction when it comes to ASD in particular. In the case of ASD the *DSM* (APA, 2013) states,

> The essential feature of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restrictive, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criterion C and D) (53)

The diagnostic features of ASD specifically indicate that there must be impairment in order for a diagnosis to be warranted. However, the section on ASD also argues that ASD is not a disability, but the disorder can be disabling to some people. In the ASD section of the *DSM*, it is further specified that one of the criterions for the
disorder requires that the impairment “must cause clinically significant impairment,” (APA, 2013, 55) not just impairment. This juxtaposition of seemingly contradictory statements is perhaps a product of the recategorization of autism into a spectrum disorder. As it was explained earlier, the Pervasive Developmental Disorders were recategorized into ASD because they were found to be the same disorder in a spectrum of impairment (such as Asperger’s being perceived as a milder form of autism). This evaluation was a result of careful research and consideration for the classification of these disorders. Nevertheless, the fact remains that now a set of disorders which might have carried different connotations in terms of disability have been grouped together. The DSM does indicate that the extent and manifestation of the impairment varies from person to person along the spectrum, however, the label of impairment and disability has already been applied in some form. This poses a contradiction of the Forensic Use statement in that diagnosis of ASD must necessarily always indicate some form of impairment in functioning, and that is enough to create a disabled identity for the people who are diagnosed, regardless of where they fall on that spectrum.

Another possible explanation of this contradiction can be found in the similar arguments about disability that were observed in the academic documents outside of the DSM (also tracked under the disability). One of the articles acknowledges that one of the common critiques of psychiatry is for pathologizing normality (Bolton, 2013). That is, many of the diagnostic criteria in the DSM can be perceived as normal things that people do. The problem arises when a line has to be drawn
between being shy and uncomfortable in social settings and having a clinically significant social impairment or disability, which is part of the diagnosis for ASD. The debate over what is to be considered disability and impairment is also relevant to arguments about overdiagnosis of a disorder. One of the arguments for the recategorization of ASD was that the classifications in the *DSM-IV* caused overdiagnosis problems and the new classification was meant to help reduce those issues. By adopting a spectrum classification, impairment levels play as much of a relevant role in diagnostics as symptom criteria. The goal, according to Bolton (2013) is to not diagnose individuals who have no impairment. However, the implication of this is that diagnosis must necessarily imply impairment and disability. This becomes another example of the inherent contradiction in the construction of disability when it comes to ASD in particular. This example can perhaps also be a result of the recategorization of ASD as a spectrum, given that one of the reasons for the change was to address the overdiagnosis/misdiagnosis issues of the *DSM-IV* classifications.

Contradictions like these happen because diagnosis is not a simple matter and the field of mental health recognizes that a diagnosis can and does impact a person’s life. For this reason, the expert conversation about ASD often focused on definitions of disability and their role in the diagnosis of patients. This in turn produces a perception of disability in connection to ASD and, I argue that they are also establishing a perception of who a person with the diagnosis is, from their behaviors to their place in society. When the *DSM* lists the behaviors and symptoms
required for an ASD diagnosis, they are also effectively describing the behaviors of a person who is or will be diagnosed with ASD. This is perhaps an unavoidable fact of psychiatric diagnostics, one that does not go unnoticed within the field. However, the implications of a diagnosis are not just limited to the field of mental health because they also exist outside of it. Professionals in the field seem to be aware of the contradictory and difficult ways in which disability and impairment interact with diagnostics. This, on the other hand, does not mean that people outside of the field are aware of the nuances of diagnostics.

Based on the instances marked with the code disability, a diagnosis of ASD is commonly linked to disability and impairment. There are subtle contradictions in the way disability gets linked to a diagnosis but, at the end of the day, a disabled identity is constructed around the diagnosis. Based on the quotes under this code, the recategorization of ASD is an effort to curtail the diagnosis of individuals who are not impaired. The criteria listed in the DSM highlights that significant impairment must be present for a diagnosis. All this leads to the assumption that having an ASD diagnosis is a label of disability. The problem with that is that there are individuals diagnosed with ASD disorders that have argued against the label of abnormality or disability. According to Hacking (2009), people with Asperger’s and autism have expressed that they are not abnormal, just untypical. Just because their neurology might be different from the typical, doesn’t mean they are impaired or disabled. The implications of ASD as a spectrum make it hard for the neurodiversity movement to establish that there is room for difference without
become lacking or dysfunctional (Hacking, 2009). Diagnosticians might be aware of the nuances that come with a diagnostic label, but the label exists outside of the field of mental health. People have to live in the real world with the label, among people who are not diagnosticians or privy to the conversations in the field of mental health.

3.5.2 Recategorization of ASD

After disability the most recurrent code used was recategorization, which was used to track all instances that discussed the recategorization of ASD. This code is somewhat less organic and more dependent than other codes in the analysis given that this study is focused on the recategorization of ASD. The texts selected for analysis were chosen because they were part of the conversation about recategorization. So it was somewhat not surprising that this would be one of the more frequent codes used. However, what is interesting about this code is not specifically how many times it was used but its co-occurrence with other codes. Looking at co-occurrence allowed me to track the way the recategorization was framed and presented in this conversation.

Of the reoccurring codes, there was a group of codes that were related to explaining the recategorization of PDD disorders into ASD. Once again, these were not necessarily surprising, but do outline the way the recategorization was presented. Recategorization was often coded with codes ASD, Asperger’s, DSMRevision, and PDD-NOS. Asperger’s and PDD-NOS were two of the main
disorders from the *DSM-IV* that were absorbed into ASD (in conjunction with others). Interestingly, the *DSM-5* only mentions these disorders a couple of times and only when explaining that they are now part of ASD. Most of the instances of these two codes come from the academic articles and texts discussing the recategorization. These articles not only report that the disorders have been recategorized, but make arguments about whether or not this will cause issues with diagnostics. That is, the academic conversation outside of the *DSM* focused more on investigating whether individuals with Asperger’s and PDD-NOS diagnoses would be included in the new diagnosis of ASD. Aside from these codes, it is also no surprise that discussion of the recategorization often co-occurred with discussions of the *DSM*’s revision. This was to be expected, given that the recategorization of ASD was one of the most drastic changes in the recent revision and recipient of much attention.

Aside from the co-occurrences mentioned above, *recategorization* was paired with other codes that shed light into the framing of the issue. *Recategorization* appeared most commonly with the code *problem*, which was used to track discussion of problems arising from the recategorization of ASD. Interestingly, the recategorization of ASD was not paired with any mentions of possible problems in any of the *DSM* or APA materials in the sample; instead, this pairing only occurred in documents critical of the recategorization’s effect on diagnostics and policy. Huerta et al. (2012) argued that although not very prevalent they did find 186 cases in a sample of 2,130 children who did not fit the new diagnostic criteria. Articles
like this one are scrutinizing the new diagnostic criteria and highlighting that some individuals with previous PDD diagnoses will not meet the new criteria and this might pose potential problems for them.

In the advocacy report by Ne’eman and Kapp (2012), it is argued that being reclassified out of an ASD diagnosis into a different diagnosis (such as Social Communications Disorder) makes it “significantly difficult” (3) to qualify for the Individuals with Disabilities Education Act (IDEA) that provides assistance for students. The pairing of the codes recategorization and problem led to arguments about the potential negative impacts to the population that had a previous PDD diagnosis. The advocacy report also makes an argument about eligibility, which was another of common pairing with the code recategorization. One of the most common framings of the recategorization of ASD was that it creates an issue of eligibility. The codes problem and eligibility are much related in this conversation and often appear together in the advocacy report. One of the arguments highlighted by these codes is that, since IDEA focuses on intellectual and multiple disabilities, students with higher IQs are less likely to have accessibility to the ASD diagnosis and with it eligibility for assistance under this policy. These arguments were not made by the APA or the DSM-5 Task Force, but instead they were made by scholars and advocacy groups. However, it is important to know that the APA does make an argument about eligibility, in a separate statement to the DSM, which focuses on insurance implications for the DSM-5. In this statement they address issues of eligibility in general and as it relates to the ICD (editions 9 and 10) but not
necessarily relating the *DSM-IV* or ASD specifically. Therefore, when looking at the issues coded under *eligibility* and *problem*, there is a disconnect between the argument being made by the APA and the ones made by critical scholars and advocacy groups.

The last two most common code co-occurrences with *recategorization* were *valid* and *invalid* (*valid* appearing twice as much as *invalid*). From the quotes that were tracked with this three code combination, it is clear that the conversation centered on the validity of the recategorization of ASD as it relates to its ability to produce more accurate diagnoses and its basis on research and academic literature. Overall, both the *DSM* and several academic articles argue that the new diagnostic criteria is more accurate than then one in the *DSM-IV* (APA, 2013; Huerta et al., 2012; Ne’eman and Kapp, 2012; Tsai, 2012). There are also several claims that a unified ASD spectrum diagnosis is supported by recent research and our understanding of the phenomena. These arguments are often accompanied by data from studies comparing the diagnostic validity of the *DSM-IV* to the *DSM-5* criteria. The arguments made about the invalidity of the recategorization were very similar to the ones about validity except that these (coded specifically as *invalid*) were made by scholars only and not the *DSM*. Scholars like Tsai (2012) and Huerta et al (2012), in spite of concluding that the new diagnostic criteria is valid, cite previous studies that critique the new classification and report that several children will no longer meet the criteria for ASD. Even though both the APA and mental health scholars reach similar conclusions about the validity of the new classification, *DSM*
materials seem reluctant to even discuss the critiques of ASD whereas scholars openly include these reports in their literature reviews. The only message from the *DSM* is that the recategorization is valid, based on data and research, and will improve diagnostics. There is an overwhelming silence in the *DSM* about the people that will not meet the new criteria for ASD. There doesn't seem to be any mention of the individuals, as few as they may be, that will fall between the cracks.

Analyzing the co-occurrences of the code recategorization with other codes unveils two distinct framings of the recategorization of ASD into a spectrum disorder. One of the framings is that the recategorization is a necessary change that was adopted based on critical research that supports the spectrum classification and will lead to more accurate diagnosis of this disorder. The other framing is that the change to a spectrum disorder will necessarily lead to some individuals with previous diagnosis not fitting in the new criteria and this will cause eligibility issues with resources they already had or would have had access to. I believe that these two framings represent the two major attitudes about the recategorization of ASD that lead to the conflict associated with this issue. The conflict arises in that these two framings are used as arguments against each other. That is, the validity of the recategorization is questioned because it will lead to people with a previous diagnosis not fitting in the new criteria. However, I argue that these two framings are not mutually exclusive. I think both of these positions are correct and point to a difficult reality. Even though the recategorization may be a valid change that will improve the accuracy of diagnosis, it doesn’t change the fact that changes in the
way these disorders are diagnosed will impact people with previous diagnoses. This is a natural consequence of change that does not negate the validity of the recategorization. The *DSM* and APA materials present only the first framing of validity but fail to acknowledge the inevitable consequences of change. The scholars that argue about issues of eligibility are not arguing against the validity of the recategorization, but they are acknowledging that some people will be negatively impacted during the transition. Ideally, improved accuracy means that future diagnoses will be better able to reflect the psychological phenomena of ASD. But change doesn’t happen overnight, so some people will be in a difficult position of being excluded from an ASD diagnosis and/or being reclassified under a different category. So, the two overall framings of the recategorization of ASD are not conflicting but do point out that changes in psychiatric diagnostics always impact the lives of people.

3.5.3 Silence in the DSM-5

The silence on the possibility that individuals may not fit in the new criteria of ASD is not the only silence in the *DSM-5*. To find potential silences in the text of the *DSM-5* (following the work of Glenn, 2004) I separated the sampled texts in this chapter into text created by the APA (the *DSM* and Insurance Statement) and those created by scholars and advocates (academic conversation) and then looked at the discrepancies in code distributions. That is, I looked at the most recurrent codes that appeared in one group of texts but not the other. These groups of codes present
an overview of the kind of conversation that is being had in each type of document and, most importantly, where these two sides of the conversation fail to communicate.

The academic conversation, academic and advocate texts, had the following as the most recurrent codes: *eligibility, resources, policy, PDD-NOS, problem, MHIdentity, invalid, misdiagnosis, expert, impact, validity, harm, transparency, and controversy*. This list of codes actively described the conversation being had by these authors about the recategorization of ASD. The three most recurrent codes, *eligibility, resources, and policy*, are all addressing not whether the ASD classification was a good idea or not but the potential implications to the individuals living with this group of disorders. That is not to say that academics do not discuss the merits of the recategorization or its validity, but they are also focused on thinking about the social implications of such a change. The consequences of recategorization, according to this side of the conversation, are inevitable and independent of the necessity to recategorized Pervasive Developmental disorders. They call attention to the fact that some individuals will no longer fall under the diagnosis of ASD and this change will have tangible consequences in their lives related to their eligibility and access to resources they may have already had or the changes to be eligible for these in the future.

On the other hand, the APA texts did not focus on these external consequences to the recategorization of ASD. Instead, the list of most recurrent codes present in only these texts were: *SX (symptom), developmental, scholar,*
comorbidity, and innate. Given this list and the codes previously mentioned to be in the APA texts, there is an indication that this side of the conversation focused solely on explaining, supporting, and presenting the recategorization of ASD. There are arguments about the necessity and validity of the new diagnostic criteria as well as the increased accuracy of the diagnosis. However, they do not directly address the people that might no longer fall under an ASD diagnosis or a diagnosis altogether. The silence in the *DSM-5* is related to the consequences of the new classification as they impact the lives of people. This may be due to the nature of the *DSM* and its purpose in the field of mental health.

As mentioned in the previous section, two framings of the recategorization are being presented in this analysis and the silence in the *DSM* is due to the fact that they only address one of these framings and not the other. It could be argued that it is unfair for the *DSM* to only frame the recategorization based on its validity without addressing the unavoidable consequences. However, it could also be argued that addressing the consequences of changes in diagnostics is outside of the scope and purpose of the *DSM*. Based on the origin and rhetorical purpose of the *DSM*, outlined earlier in this chapter, this text serves a very strategic purpose in the field of mental health. The *DSM* can be seen as an argument for psychiatry and psychology as a science based on rigorous research. The goal of the *DSM-5* taskforce was to review the research of the past few years and revise the *DSM* to reflect it. One of the principles of science is that it is based on the continuous research and observation of phenomena, so it would be inappropriate to allow the impact of said
research to influence it. Perhaps the DSM fails to address the consequences of the recategorization of ASD because they should not influence the science behind it.

Nevertheless, the silence in the DSM does not transfer to the rest of the academic conversation about the recategorization. Academics and advocates address both of the framings of ASD and are critical of both the validity and consequences of its categorization. At the end of the day, the DSM has an integral role in the field of American mental health but it does not encompass the entirety of the discussions within in. The DSM has very real and complicated constraints based on its position in the field and its purpose. These constraints lead to certain silences that are filled in by the rest of the academic conversation in the field.

3.6 Summary

Based on the analysis presented in this chapter, the recategorization of ASD continues to construct what it means to be diagnosed with ASD. The understanding of ASD comes from the experts in the field of mental health that study and research these phenomena. The DSM presents an authoritative standing on the definition of ASD and the criteria used to diagnose it in this country. However, academics and advocates also take part in the creation of an understanding of ASD. According to the DSM, ASD is a developmental disorder that is present since early childhood and continues for the rest of a person’s life. Diagnosis of this disorder requires for there to be significant impairment, which then implies that all individuals diagnosed with ASD have impairment in one or more areas of their lives. ASD is understood to
involve impairments in social communications and interactions and a presence of repetitive behaviors, interests, and activities. This understanding of ASD then describes what a person diagnosed with ASD is like and the way they behave. Even though ASD is meant to refer to a spectrum where individuals will fall in different levels, one overall label is applied with diagnosis. This label inherently implies a form of disability.

The analysis of selected texts within the *DSM-5*, academic articles, and advocacy reports indicates that there are a lot of conflicting ideas and perceptions of the recategorization of ASD. This reflects the complicated nature of diagnostic science and the way it impacts the lives of individuals. I think it is evident that the field of mental health is very aware of the nuances and caveats associated with the diagnosis of a mental health disorders. What I would like to explore next is whether this awareness of the complications also exists outside of the field of mental health. As it has been argued in this chapter, a mental health diagnosis exists in the real world and it is shaped by what is said in texts like the *DSM* but not necessarily what is said by the rest of the conversation. After all, academic articles and advocacy reports are addressed to members of the field of mental health and not the general public. The next two chapters will explore how the recategorization of ASD is absorbed into public discourse.
4. REPRESENTATION OF ASD IN PUBLIC MASS MEDIA

4.1 Overview

This chapter focuses on the second stage of analysis of this study which explores the media coverage of the recategorization of autism. The first section of this chapter provides an overview of the presence of autism in media over the years. Given that autism is a relatively new disorder, popular media has played an important role in the dissemination of information about the disorder which in turn impacts the perceptions of the public. In Chapter 3, the analysis of the *DSM* and a sample of academic literature published during its revision revealed that the language used in these texts actively constructed the identity of those with an ASD diagnosis as people suffering from pervasive impairment throughout their lives. This chapter continues this research and analyzes how a sample of media websites absorbed information about the recategorization and reported it to the public. Using the coding structure developed in Chapter 3 as a base, this part of the analysis deconstructs the language used in 19 online articles discussing the recategorization. Then, I discuss the implications of this language and the way that it constructs the identities of people with ASD.

Although this chapter presents a cohesive analysis, with its own specific methodology and discussion, it is also a part of the overall research project. Chapter 3 first explored the ways the recategorization was framed by the *DSM* and scholars in the field of mental health. This chapter is focused on studying the way this information is presented by media sites before and shortly after the publication of
the *DSM-5*. Then, in the next chapter, the analysis will continue to investigate how the language of the media coverage of the recategorization was absorbed by the public.

### 4.2 Autism in the Media

As the awareness of Autism rises, so does the existence of fictional characters in media with autistic traits. Media reflects attitudes and issues that are important to the public at the time and, in many ways, it is no surprise that characters with mental health issues are presented and explored by a variety of media. For example, one of the earliest depictions of ASD in media can be traced back to a 1969 movie featuring Elvis Presley as a doctor treating a child with autism. Although the depiction is not accurate to the current understanding of the disorder, it is a good representation of the perceptions surrounding the disorder at the time. In this movie, autism is caused by bad parenting (the “refrigerator mother” theory) and is curable with the right amount of care and affection (Wolf, 2012). This representation of the disorder is nowhere close to the ones we see in media today, as our collective awareness and knowledge of autism develops further. However, all depictions of mental health disorders in media, regardless of accuracy, are valuable as a way to understand and document the public perceptions surrounding mental health at the time.

Over the years, fictional characters with autistic traits have been featured in literature, movies, television shows, and even video games. Often times, characters
are not officially diagnosed by the creators of the story but instead identified by fans, viewers, advocates, etc. For example, even though Sheldon Cooper, from *The Big Bang Theory*, has not been officially diagnosed as being on the spectrum in the show, he is one of the most popular television characters identified as having Asperger’s. The heated debates over Sheldon Cooper’s mental health have become a critical argument about the responsibility of show creators to portray accurate representations of people with a disorder. That is, creators of the show have commented that Cooper has some characteristics in common with people with Asperger’s, but they are reluctant to identify the character as such because it creates a burden to be both accurate and sensitive about the disorder. This has been perceived as an unjustifiable avoidance of responsibility that is there even if a character is not officially diagnosed by the creators (Koyanagi, 2015). This is relevant because it signals to the public’s increased awareness and interest in the ethical portrayal of mental health issues in the media they consume.

Another thing to note is that characters with autistic traits are moving from their brief supporting roles to become protagonists and leads (as in the case of *Bones, Sherlock, and Community*). This is significant because leads of television series get more character development and, when they are in the spectrum, get to show a more nuanced representation of ASD. For example, after a lot of debate, it is mostly accepted that lead character Sherlock Holmes, from *Sherlock*, is in the higher functioning end of the ASD spectrum. The depictions of Holmes in the series show a nuanced portrayal of the character that highlights both the issues he
encounters with understanding social cues and boundaries as well as his undeniable sense of empathy to those around him (a trait that is often overlooked in casual portrayals of autism) (Hughes, 2012). More importantly, the conversations about Holmes are examples of vivid engagement of the public with ASD that showcase the perceptions surrounding the disorder.

These representations of autism in media are important not only because they increase awareness and engagement with the disorder, but also because they reflect the reality of the many individuals living with this diagnosis. Lisa Bascom, an autistic woman, advocate, and writer, argued about the importance of seeing “someone who moves like you” (Bascom, 2012, par. 6). When you are part of a minority with a mental health disorder it is not very common to see a representation of yourself in media, but it is important because media increases awareness and proliferates perceptions of mental health disorders like ASD to the public. If media representations of ASD are a reflection of current social perceptions, then it follows that current social perceptions mirror those seen in media. Therefore, in order to identify the perceptions about ASD following the recategorization in the DSM-5, I will be analyzing the way the change was presented in news media, the first media genre to approach the subject in the advent of the release of the new version of the DSM.
4.2.1 ASD Recategorization Media Coverage

One of the most important factors in the research for this chapter was establishing a time range in media coverage of the recategorization of ASD. Although including a large number of articles on the subject is important to study the coverage of the recategorization, the range that is used to limit sampling is more relevant when it comes to understanding the way the issue was covered by the media. According to Ethnographic Content Analysis (ECA), data gathering should be reflexive and the time range to be covered needs to be based on the question and phenomena to be studied (Altheide & Schneider, 2016). Before starting the sampling for this chapter, I conducted preliminary searches to get a broad idea of the coverage surrounding the recategorization of ASD. I took note of the date, title, publication, and focus of each of the articles included in this preliminary search. It was during this first investigation of the coverage that three distinct clusters of articles were identified.

The coverage of the recategorization can be divided into three clusters according to the date and focus of the article (shown in Figure 1). Once I had identified the clusters, I compared the dates to press and news releases from the same time period by the APA and DSM organizations. The first cluster goes from December of 2011 to May of 2012, with the bulk of the articles being published in January, 2012. Based on the contents of the article, I identified that this cluster was specifically reporting on the announced changes to ASD. This range of time also coincides with the APA’s press release in Dec 2, 2011 with an update of the
development process of the *DSM-5* (American Psychological Association, 2011) and the *DSM*’s news release in January 20, 2012 announcing the proposed changes to autism disorders and the establishment of ASD (American Psychiatric Association, 2012). Up until around May of that year, various media sources continued to report the proposed changes to the disorder. The second cluster centers specifically on December of 2012 and coincides with the APA’s announcement on the approval of the previously announced changes to autism on December 1, 2012 (Psychiatric News, 2012). During this time, various media sources reported on the impending changes to the *DSM* in regard to autism disorders. Finally, the third cluster starts from May of 2013 to December of 2013. This cluster in coverage coincides with the release of the *DSM-5* in May of 2013. The media coverage in this cluster focused on the now published changes to the way autism is categorized and diagnosed according to the *DSM*.

Identifying these clusters of dates prevalent in the coverage of ASD was helpful not only for establishing a range for sampling; the clusters were also helpful in identifying the press releases from the APA and *DSM* that inspired the coverage by the media. Also, most importantly, the clusters became significant factors during the analysis in this chapter. When articles were compared against each other based on the cluster they fell into, clear differences in the content of the coverage were found. These results will be presented later in the discussion of this chapter.
4.3 Methodology

4.3.1 Sampling and Protocol Adaptation

As mentioned in the previous section, a lot of preliminary research was used to create adequate sampling of articles for this chapter. The main goal of this chapter is to answer Subquestion 2:

*How is the recategorization of ASD absorbed by public discourse and disseminated through mass media?*

In order to answer this question a detailed search of media coverage of the recategorization of ASD in the *DSM-5* was conducted. According to Ethnographic Content Analysis (ECA; Altheide & Schneider, 2013), the search for artifacts to be

---

*Figure 1. Breakdown of timeline of events surrounding the recategorization of autism and the media coverage sampled for Stage 2.*
included needs to be reflexive and based on a clear research protocol. The research protocol for this chapter centered around three factors: the coverage of the recategorization of ASD from the time it was announced to the publishing of the DSM-5, the most visited articles during the specified time period, and articles viewed by American users. Given the needs and constraints for this research question, the research protocol was used to create an advanced Google search to limit the results to the most relevant media articles on the subject, according to the factors mentioned.

The Google search parameters were set to reflect the research protocol for this chapter. The search focused on articles that were published between December 2011 and December 2013, covering all of the three coverage clusters described in the previous section. I chose this range because it adequately encompassed the coverage of important APA and DSM press releases with news on the recategorization of ASD. I also decided to collect articles after the publication of the DSM to include coverage of the changes shortly after they went into effect. Secondly, the search was limited to articles that had been visited (clicked on by Google users) and organized from most visited to least. This was an important part of the search because it was imperative to focus only on articles that had been widely read by users. My goal was to include the articles that were most read by people who were learning about the recategorization online. Lastly, the search focused only on those articles that were accessed by American users. The reason for this limitation is that the DSM is predominantly used in the United. It was also important to limit my sample to a
manageable size, and limiting results to the American public would allow for more meaningful representation.

Another important decision made in terms of sampling was about the kind of artifacts that would be included as part of the coverage of ASD. Initially, I foresaw only focusing on major news reporting on the issue from well-known publications. However, during the preliminary search of the media coverage, I realized that there was almost an equal representation of news media and advocacy organizations coverage on the issue. In addition to the major news reports, such as The New York Times, that were often viewed by users, articles from advocacy websites such as Autism Speaks were also commonly read. Therefore, I decided to include both of these kinds of reports based on how often they were viewed by users.

Finally, the sample size was chosen in order to fit the scope of this chapter. The coverage of the recategorization of ASD was significant and it would have been difficult to cover it entirely for the purpose of this chapter. Therefore, based on the three factors of the research protocol, I choose to use the top 19 most visited articles about the topic. The sample evenly covers the three clusters of coverage on the recategorization and also evenly represents news media and advocacy articles. I made the decision to use these 19 articles because the search results after them began to fall in relevance and did not exactly match the focus of the search designed for this chapter. Information about the articles sampled can be found in Table 3.
### Table 3

*Media articles covering the recategorization of ASD sampled for Stage 2*

<table>
<thead>
<tr>
<th>Document</th>
<th>Title</th>
<th>Author</th>
<th>Date</th>
<th>Publication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media 1</td>
<td>Answers to frequently asked questions about <em>DSM-5</em></td>
<td>n/a</td>
<td>n.d.</td>
<td>Autism Speaks</td>
</tr>
<tr>
<td>Media 2</td>
<td><em>DSM-V</em>: What changes may mean</td>
<td>n/a</td>
<td>2012</td>
<td>Autism Research Institute</td>
</tr>
<tr>
<td>Media 3</td>
<td>Normal or not? Saying goodbye to Asperger's</td>
<td>Parry</td>
<td>2013</td>
<td>Live Science</td>
</tr>
<tr>
<td>Media 4</td>
<td>You do not have Asperger's: What psychiatry's new diagnostic manual means for people on the autism spectrum</td>
<td>Lutz</td>
<td>2013</td>
<td>Slate</td>
</tr>
<tr>
<td>Media 5</td>
<td><em>DSM-5</em>: Autism spectrum disorder diagnosis</td>
<td>n/a</td>
<td>2012</td>
<td>Raising Children's Network</td>
</tr>
<tr>
<td>Media 7</td>
<td>Asperger's Syndrome dropped from American Psychiatric Association manual</td>
<td>n/a</td>
<td>2012</td>
<td>CBS News</td>
</tr>
<tr>
<td>Media 8</td>
<td>How will the <em>DSM V</em> changes in autism affect people?</td>
<td>Robinson</td>
<td>2012</td>
<td>Psychology Today</td>
</tr>
<tr>
<td>Media 9</td>
<td>Redefinition: Autism, Asperger's, and the <em>DSM-5</em></td>
<td>Anderson</td>
<td>2012</td>
<td>Interactive Autism Network</td>
</tr>
<tr>
<td>Media10</td>
<td>DSM-V goes forward: Major shift in diagnostic criteria for Autism Spectrum Disorder approved</td>
<td>Bortfeld &amp; Steck</td>
<td>2012</td>
<td>Talk About Curing Autism</td>
</tr>
<tr>
<td>Media 11</td>
<td>The DSM-V: Changes for autism and research</td>
<td>Nebel</td>
<td>2013</td>
<td>The EJBM Blog</td>
</tr>
<tr>
<td>Media 12</td>
<td>The proposed DSM-5 changes with regard to ASD</td>
<td>Winner</td>
<td>n.d.</td>
<td>Autism Support Network</td>
</tr>
<tr>
<td>Media 13</td>
<td>Changes to the DSM autism diagnostic criteria</td>
<td>Tull</td>
<td>n.d.</td>
<td>Association for Science in Autism Treatment</td>
</tr>
<tr>
<td>Media 14</td>
<td>Psychiatric Association approves changes to diagnostic manual</td>
<td>Falco</td>
<td>2012</td>
<td>CNN</td>
</tr>
<tr>
<td>Media 15</td>
<td>New definition of autism will exclude many, study suggests</td>
<td>Carey</td>
<td>2012</td>
<td>The New York Times</td>
</tr>
<tr>
<td>Media 16</td>
<td>Criteria for Autism in the <em>DSM-V</em></td>
<td>Miller-Wilson</td>
<td>n.d.</td>
<td>Love to Know</td>
</tr>
</tbody>
</table>
Once sampling was complete, the research protocol that was used to record valuable information from each artifact in the previous chapter was slightly modified to fit this chapter. One of the major adaptations to the research protocol in this chapter was in regard to the date for each article. Unlike the publications that were analyzed in the previous chapter, media articles are not always clearly dated in the same way. Advocacy articles do not always have a clear publishing date and news articles often have two dates reported, the initial publication and the revision dates. For the purposes of this chapter, I used the publication date instead of the revision one because it would most accurately reflect the content of the article. That is, if an article was published in January 2012 about the announced changes to ASD but was later updated in May, it still more accurately reflects the themes that were relevant during January.

Another notable addition to the research protocol was including a record of any images used in the articles. Unlike research publications, media articles can often be accompanied by images. I thought these images would be relevant to the content and themes found in the articles and therefore were carefully saved, labeled, and eventually coded in the analysis.
4.3.2 Sampling Procedure

Once the sampling of the articles for this chapter was complete, it was necessary to find a way to record and prepare them to be uploaded into the coding software. For the purpose of this project, and future expansions of this area of the research, I wanted to save all the articles in a way that would be coded easily, captured the entire article as it appeared on the website, and preserved visual material including images, adds, social network links, etc. I conducted a search for software that would allow me to capture the material in this way, as traditional methods such as printing and saving the web page as a pdf did not accurately capture the articles (and it was important for the research to save the articles as they would appear to users). After an extended search for adequate software, I settled on Abduction!, a Firefox browser add-on program that captures exact screenshots that include elements such as recommended articles, ads, relevant links, images, social networking links, etc. The screenshots were preserved as lossless image compression (PNG) files that were easily uploaded to the coding software (Atlas.TI).

Another issue that I had to consider was the need to use a different browser that was not associated with my private use. While conducting the preliminary search for this chapter, I realized that the ads that were included in the articles were targeted to my private browsing history. That is, the ads were targeted to content that I view personally or based on my demographic information, and would
not accurately reflect the kinds of ads that would be used for other users. I wanted to avoid getting targeted content in an effort to get the most accurate representation of what other viewers were likely to see. Unfortunately, the possibility that users viewed their own targeted content is of course very high. But, given the nature of online browsing, it will have to be enough to get as close as possible to ads and suggested links that are targeted to the content of the articles. Therefore, I limited my work to a browser, *Firefox*, I don’t use personally and I used the private browsing feature.

4.4 Analysis and Coding

In this chapter, I continued to use the existing coding structure that was developed during Chapter 3 (Table 2). Given the purpose of this project, it was important to maintain a coding structure throughout the three stages of analysis. This would make it possible to maintain focus on the same themes and key-words as well as the comparison between all three analyses. Although the coding from the previous analysis was used here, there were some additions and adaptations made for this chapter (found in Table 4).

Table 4

*Main coding structure for Stage 2*

<table>
<thead>
<tr>
<th>Code</th>
<th>Occurrence</th>
<th>Code</th>
<th>Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Context</td>
<td>Recategorization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>spectrum</td>
<td>17</td>
<td>valid</td>
<td>49</td>
</tr>
<tr>
<td>disorder</td>
<td>1</td>
<td>changesa</td>
<td>26</td>
</tr>
<tr>
<td>social problem</td>
<td>1</td>
<td>problem</td>
<td>20</td>
</tr>
</tbody>
</table>
The changes made to the existing coding structure were not extensive and were done only to adapt to the new types of documents and language used in the analysis of media coverage of ASD. One of the main additions to the coding structure was a new coding group for images in the media articles. I believe that the images included in the media articles are very important to the overall impact and meaning of the piece. Therefore, it was relevant to code the visual elements...
included in each of the artifacts. Not all of the articles sampled for this chapter included an image, but the ones that did were coded according to the content of the image. The codes included in this group were: *child*, *disabled-adult*, *DSM book*, *expert image*, *graphic*, and *pop culture*. The *child* code was used when an image, always a stock image, of a child was used in the article. Interestingly, all of the images of children used featured a “normal” looking boy focusing on toys. Among all the images used, only one article used a real image of a person diagnosed with ASD. The image featured an adult woman with visible disability and in the care of her mother (this image was coded as *disabled adult*). The code *DSM book* was used to code images that used a picture of the *DSM*’s front cover or a book in general. The code *expert image* was used when the picture of an expert in mental health, quoted in the piece, was used in the article. The code *graphic* was used when a digital graphic was used as an image. For example, one of the graphics included in the sample was a drawing of an umbrella. Finally the code *pop culture* was used for one of the images that featured alleged autistic fictional character Sheldon Cooper, from *The Big Bang Theory*. Since there were only 13 images included in the sample, it won’t be possible to incorporate them heavily into the analysis of this chapter. However, given the relevance of visual cues, the images will be important to the discussion of themes and perceptions in both this chapter and later on in the dissertation.

Aside from the new group of codes for images, there were some codes added to pre-existing groups in the coding structure. These codes were added to include
themes that had not been present in the previous chapter. The code *bible* was added to the DSM label code group developed in the first stage of analysis. This code group included codes that described the ways in which the *DSM* was referred to (previous codes include: *document, guideline, handbook,* and *manual*). During the analysis of media coverage of ASD, the *DSM* was referred to as the “bible” of psychiatry in several occasions. The codes *Asperger’s Identity, Aspie,* and *NOS Identity* were added to the Identity code group. The additions became necessary because the media coverage on the recategorization of ASD often specified notions to the identities of people previously diagnosed with Asperger’s and PDD-NOS. Finally, the codes *changes* and *new criteria* were added to the Recategorization code group. This group was used in the previous stage of analysis to record the way in which the recategorization was presented in the sampled texts. During the analysis of the media coverage around the subject, these new codes were needed to capture the language by media. These were all of the additions made to the code structure developed in the first stage of analyses. These additions will be carried on into the third stage of analysis as well.

### 4.5 Discussion

#### 4.5.1 Media Coverage Conversation

Based on the codes most commonly used in the analysis of the media coverage of the recategorization of ASD, the conversation centered around the recategorization and its validity and impact to people previously diagnosed with
Asperger’s and PDD-NOS. Similar to the *DSM* and academic texts analyzed in the previous chapter, the most commonly used code in this sample was *recategorization*. The recurrence of this code is, of course, to be expected since the articles were sampled for their coverage of the recategorization of ASD. However, the significant combinations of this code with others will be presented further down in the discussion.

The second most common code found in this sample was *impact*. This is very significant as it indicates that the media conversation focused heavily on the impact of the changes done to categorization of autism in the *DSM-5*. This code was used to track instances in which the possible or definite effects of the recategorization would have on previously and newly diagnosed individuals were mentioned in the articles. Often, there was a sense of fear and anxiety over the impending changes to come and their effects on the lives of those previously diagnosed with an autistic disorder. For example, one of the quotes marked under *impact* stated, “There is real mistrust on the part of some, who suspect the new criteria were designed to exclude higher-functioning kids from a diagnosis and thereby deny them services” (Parry, 2013). This quote is a good representation of the fact that the discussion of these kinds of doubts was present in the coverage of the recategorization and often alluded to. Although not all of the discussions of impact were negative, and some ranged from positive to hopeful, the overall majority of the quotes marked under this code were addressing negative impacts to those with previous diagnoses. Some information sites assured parents that services should not be interrupted, “your
child should not receive a standard re-evaluation and re-consideration of treatment unless [sic] a clinical or legal reason to do so” (Autism Speaks, n.d.). But there was still a widespread fear that even if services were not terminated they would likely be at least interrupted or jeopardized. Overall, this common code highlights the interest in anticipating and discussing the impact of the recategorization on the lives of individuals, suggesting that thinking of the consequences might be more relevant to the public than the relevance for the need to change the way autism is categorized.

The third most common code used in the media conversation was Asperger’s, just slightly less common than impact. I believe it is very significant to see that the media coverage of the recategorization of ASD focused so heavily on Asperger’s, a disproportionate emphasis given that there were 3 more disorders that were absorbed into the spectrum. This code was used to identify all of the instances in which Asperger’s was mentioned in the articles. Several of the mentions were simple descriptive passages that explained that the previous diagnosis of Asperger’s (as well as PDD-NOS and Childhood Disintegrative Disorder) was incorporated into ASD. However, a large number of the quotes marked with this code discussed specific issues that may or have arisen for people previously diagnosed with Asperger’s. For example, one of the quotes stated, “The Asperger’s community is well-established, and changing the name may be inconvenient and bothersome” (Miller-Wilson, n.d.). Looking at all of the mentions under this code, I argue that the media focused heavily on the fact that Asperger’s, a now widely recognized
disorder, is now being disposed of its official status. There seemed to be uncertainty on what this would mean to the people that identify as having Asperger’s (sometimes calling themselves Aspies).

The fourth most commonly found code in this chapter was *valid*. This code was used to highlight all of the instances in which the media reported on the validity of the recategorization of ASD. Given that the opposing code *invalid* was hardly used in this sample, it is clear that the media conversation presented an overall positive view of the recategorization by citing arguments for its validity from experts on the subject. In fact, the code *expert*, used to code references to expert opinion, was the sixth most commonly used code in this sample and was used in conjunction with the code *valid* 21 times. Most of the quotes marked by the code *valid* discussed either the process that was undertaken by the *DSM-5* experts to revise the definition of autism or on the evidence that supports the recategorization. For example, one of the quotes from a spokesperson from the *DSM-5* presented in one of the articles marked by this code stated, “The criteria showed excellent reliability -- that is, different clinicians evaluating the same child usually came to the same diagnoses...” Given the content of the quotes under this code, the validity of the recategorization was not heavily contested by the media and was instead overwhelmingly positively presented and attributed to expert decisions. That is not to say that the media did not report on the controversies attached to the recategorization of autism, but the coverage prevalence of validity critiques was brief in comparison with reports of the validity of the change.
Finally, the fifth most commonly used code in this section of the analysis was *PDD-NOS*. This code was used to track any mention of the PDD-NOS (Pervasive Developmental Disorder, not otherwise specified) disorder in the sample. PDD-NOS was introduced as part of the description of the disorders that were absorbed into the autism spectrum. In fact, out of the 45 quotes tagged by this code, 42 of them were also tagged with the code *Asperger’s*, given that these were the two disorders commonly discussed when in reference to the recategorization. Unlike the extensive emphasis on the impact on the identity of people with an Asperger’s disorder, there were only a few instances about the impact to people with a previous PDD-NOS. These discussions centered predominantly on the possibility of interruptions of services for people with this previous diagnosis. Given the content of the material under this code, I believe it is somewhat evident that the media conversation centered on the two most widely recognized autism disorders that were absorbed into ASD. In fact, the coverage of the recategorization often revolved around the displaced disorders, although the main focus remained on Asperger’s specifically.

Given the most commonly used codes in the media coverage analysis presented here, I argue that the recategorization was presented to the public as a valid change that would inevitably impact the lives of people diagnosed under ASD. I believe it is very interesting that the validity of the change was presented as separately from its potential impact. That is, even though the recategorization was overwhelmingly presented as valid and based on research and expert opinion, this did not retract from the discussion of the potentially negative impact it can have on
the lives of people with previous autism diagnoses. Given that expert opinion was heavily referenced in discussions of validity, it is possible that the issues of validity were left to the field of mental health because of their expertise and power over the decision. In other words, given that the experts would ultimately get final say (and be the most prepared to have a say), I believe the news coverage over the recategorization focused more on being critical on the potential impact and how that should be dealt with. This suggests that discussions about impact would be more relevant to the public than a critical review of the research in support for recategorization.

4.5.2 Media Framing of Recategorization

The discussion of the most commonly used themes in this chapter highlighted the most prevalent themes present in the media coverage of the recategorization of autism. A similar pattern was present when analyzing the co-occurrences with the code recategorization. The codes that most co-occurred with recategorization were: Asperger’s, impact, valid, problem, PDD-NOS, and expert (in order of the most common). Most of these codes show the same pattern of occurrence as the overall for the entire sample except for the code problem. Overall, it seems that the recategorization was framed as being valid and supported by expert opinion even though it would also have a significant impact in those with a previous diagnosis of Asperger’s and PDD-NOS. This reflects the overall message of the media coverage. However, the recategorization was also presented as a cause of problems. The code
problem was used to highlight all of the instances in which the recategorization was presented as the cause of a potential or actual problem. This was different from the code impact which was used to highlight all potential effects, whether they were positive or negative. Therefore, although the validity of the change was not necessarily questioned, this did not distract from the problems that may or have arisen because of it. It is significant that both of these perspectives were equally represented in the media coverage.

A deeper exploration of the code problem, provides more insights into the discussions of potential effects by the recategorization. The code problem appeared in conjunction with the following codes: insurance, services, Asperger’s, advocate, and lost diagnosis. Looking over the quotes marked by these codes, the problems with the recategorization were presented as having to do with insurance coverage, access to services, and a loss of identity associated with the displaced diagnoses. Interestingly, most of the discussion about these potential problems came from autism advocates, and to some extent parents, who were particularly worried about the impact to the identity of people with a previous autism diagnosis, especially the identity of people with Asperger’s.

Another thing of note regarding the framing of the recategorization is that the displacement of Asperger’s disorder was the most common theme. In fact, several of the sampled articles used the disappearance of Asperger’s from the DSM as the main commentary or description surrounding the recategorization. This is evident especially when considering that 6 of the article titles in the sample
revolved around Asperger’s, such as: “You Do Not Have Asperger’s” used in the Slate article (Lutz, 2013). This suggests that perhaps those with a previous Asperger’s disorder have the most to lose from the change. After all, Asperger’s is not the only disorder that was absorbed into the spectrum, but it is the most heavily discussed one. I believe this might have to do both with the higher awareness of this disorder amongst the public (more so than the other disorders included in the spectrum) and the perception of it applying to highly functioning individuals. That is, individuals with Asperger’s are commonly portrayed as highly intelligent and somewhat quirky or eccentric in popular media representations. So it might be harder for most people to see someone who is not so different than everyone else grouped into the spectrum of people that behave much more differently than the norm. I argue that this highlights the importance of perception and the construction of identities of people with an ASD diagnosis.

4.5.3 Constructions of Identity

One of the most important goals of this project is to explore the ways in which the identities of people with a mental health diagnosis are constructed through media. In order to analyze this, I took a very close look at any mention that described a person with an autism disorder. In essence, every time there is a description of typical behaviors for a person with autism, an identity for people with the diagnosis is being constructed. For example, when an article describes that repetitive motions and lack of eye contact are symptoms of autism, the reader forms
an image in their mind of a person with this label. If they have never met a person
with the disorder in person, this may very well be the only way in which they
perceive autistic people to be. Therefore, all of these descriptions of people with the
disorder were coded under the identity code group. As was discussed earlier in the
chapter, new codes Asperger’s Identity, Aspie, and NOS-Identity were included into
this group based on the analysis of the media coverage.

Overall, the identity created for people under the ASD spectrum was as that
of having a disabling disorder. Based on the identity code group, the most recurrent
codes were diagnosis, recategorization, ASDDisability, and Asperger’s Identity. This
collection of codes somewhat echoes the construction of ASD identity found in the
expert conversation analyzed in the previous chapter. That is, people diagnosed
under the autism spectrum are presented as having a disabling disorder that is
pervasive throughout their entire lives. The one major difference between the media
and expert constructions of identity is that the media coverage specifically discussed
the identity of people with Asperger’s as separate to that of those with classic
autism.

One of the biggest differences between the expert conversations surrounding
the recategorization of autism and its news coverage is the focus on Asperger’s. In
the expert conversation, analyzed in the previous chapter, individuals at all levels
within the autism spectrum diagnosis were presented as having significant
impairment characterized with social, developmental, and behavior problems. The
media coverage of the recategorization, however, often included a discussion of
Asperger’s identity as different from that of individuals with an Autism diagnosis before the recategorization. In fact, this difference is presented as one of the harmful impacts of grouping all developmental disorders under one spectrum. This is exemplified in one of the quotes from one of the articles sampled: “The label Asperger’s at least gives observers the impression of intelligence and ability. But when most people think ‘autism,’ they think of someone who should be institutionalized” (Lutz, 2013). This quote came from guest blog from a teenager with Asperger’s and discussed the differences in perceptions attached to each of the different diagnostic labels. The label autism comes with a lot more stigma than Asperger’s, and hence there are different perceptions to the identities associated with each.

I argue that the media coverage sampled in this chapter actually constructed two perceptions for people with ASD, an autism identity and the now lost Asperger’s identity. I believe both of these constructs are imperative for understanding how the identities of people with ASD were portrayed by the media. Looking at the quotes marked with the code ASD Identity, a person with a diagnosis of autism is presented as having significant issues in social contexts, lacking or having abnormal speech, performing repetitive behaviors, and hyper or hypo reactive to sensory in aspects of the environment. This echoes the definition for ASD given in the DSM-5, which requires there be significant impairments in social contexts and repetitive behaviors. However, when looking at the quotes under Asperger’s Identity, an Asperger’s diagnosis is presented as being “almost cool to
have…” (Lutz, 2013). The identity of people with Asperger’s disorder is presented as being high-functioning and having mild social issues, high intelligence, quirks, and vast knowledge in narrow subjects. In fact, people with Asperger’s are perceived to be not very far off the norm and their impairments are seen as eccentricity instead of mental issues (as is often portrayed in popular media discussed earlier in this chapter). There is a big contrast between the two identities being presented here, and this contrast is carefully crafted into the narratives of several of the articles in the sample. Although I argue that both of these perspectives are oversimplified, they are nonetheless being presented as opposite ends of the spectrum for ASD with the caveat that now there won’t be a distinctive label to identify each anymore.

Given the intertextuality of the material sampled for this chapter, the images used in some of the articles became an important factor in the construction of the identity of people with ASD in the media coverage. Although there were not a lot of images used, I believe that the few images present make powerful arguments about people with autism. There was a total of 13 images used in the articles sampled. About half of the images were either pictures of the DSM book or graphics related to autism (for example a graphic of an umbrella with “Autism” written on it). The other half was images of people and I argue that these give some insight into the perceptions surrounding people with ASD. One of the images was of an expert in the field cited in the article (there is an image and a video of her giving a presentation). One image was of Sheldon Cooper, the fictional character from The Big Bang Theory. Four of the images were stock pictures of boys, aged 5-7 years old,
usually playing with toys. And finally, there was only one real image of a person with an actual ASD diagnosis, an adult woman with her mother. I argue that these images reinforce the identity constructed for people with autism, but not necessarily Asperger’s. Autism is mostly associated with children, since this is the most common age for diagnosing the disorder. It is also of note that all the images were of relatively normal looking boys, but there were no girls included. The image of the woman also corresponds to this construct given that she shows visible impairment and is in the care of her mother. The only image that is most associated with the identity constructed for people with Asperger’s was the picture of Sheldon Cooper, a fictional character. It was interesting to see that the images used represent the perception of “classic,” overall, and further highlight the fact that this image doesn’t fit everyone that is now diagnosed under the spectrum (Images available in Appendix 2).

4.5.4 ASD News Coverage Breakdown

After analyzing the way the coverage of the recategorization of ASD presented the topic to the public and the constructions of identity of individuals with ASD, I became interested in analyzing how the coverage itself was structured. By that I mean, I wanted to know if there were differences in the content of the articles sampled based on whether they were a news or advocacy publication or based on the date cluster the article represented. To do this, I used publication kind (news/advocacy) and date cluster (Figure 1) as filtering variables and compared the
number of quotes and code occurrences in each kind of article. The results were surprising.

When I began this part of the analysis I expected to find differences between the news and advocacy articles in terms of their content and message. I hypothesized that since each publication kind has different exigencies and agendas, these would color the content of the articles. This however, was not evident in my comparison of the articles. Although news articles had higher numbers of code occurrence, these differences dwindled when controlling for the number of quotes for each kind of article. That is, there were a total of 238 quotes marked in news articles compared to 163 quotes in advocacy articles. This, I believe, is mostly due to factors such as article length and genre and does not reflect the relevance of the content for each kind of article. Therefore, instead of comparing the number of code occurrences per article kind, I compared the overall percentage relative to the total number of quotes. When doing this, the differences in code occurrence become minimal. Consequently, unlike my initial hypothesis, news and advocacy articles presented parallel coverage of the recategorization of ASD. They both prioritized discussion of Asperger’s, impact to people with previous diagnoses, and the validity of the recategorization.

Although there were no significant differences in the content of news and advocacy articles, comparisons between the three date clusters showed thematic deviations between the articles. As was discussed earlier in the chapter, the three date clusters identified in the sample represent three milestone events in the
recategorization timeline (announcement of changes to ASD, approval of recategorization, and DSM-5 release). To analyze the progression of the coverage, I compared the code occurrences between the articles in each date cluster and noted differences in code appearance or mention. Overall, the first cluster, responding to the announcement of changes to ASD (American Psychiatric Association, 2012), had high incidences of the codes controversy, expert, impact, insurance, and validity. The incidence of these codes decreased in the second cluster and dwindled in the third. The second cluster, responding to the approval of changes to ASD (Psychiatric News, 2012), had a high incidence of the code service (with limited appearance in the first cluster and no mentions in the third cluster). Finally, the third cluster, responding to the release of the DSM-5, had high incidences of the codes Asperger’s and problems. The use of these two codes increased overtime and peaked in the third cluster.

Given the differences in code occurrence based on the date cluster, I was able to assess the changes in the conversation relating to the recategorization of ASD. Once the changes to the DSM and autism disorders were announced, the media coverage focused heavily on discussing the controversies associated with the recategorization. There was a heavy emphasis on the potential impact, especially when it comes to insurance coverage, as well as references to expert opinion and validity. Overall, the discussion of the validity of the changes was very crucial in the first cluster but decreased sharply in the second and third clusters (25 mentions in the first cluster, and 7 and 6 mentions in the second and third clusters).
respectively). This is a very interesting trend that suggests validity was discussed only when the changes were announced and still in progress. This was also a period of time in which people were invited to comment on the proposed changes through the *DSM-5* website. Once the changes were approved by the APA, however, the discussions of validity decreased to the point of being mentioned only in passing. Given this change in the conversation, it is possible that validity was assumed given the approval of the APA or that critiques of the validity seemed less relevant once the changes had been set in stone with no chance of changing.

In December of 2012, the changes to ASD were approved and there were some shifts in the coverage of the recategorization. Although the conversation following the approval continued the discussion of the themes in the first cluster (such impact and expert opinion on the matter), there was a decline in the occurrence of these topics. More so, it seems as if the conversation began to slowly shift toward a discussion about the changes to services available for people with previous diagnoses under ASD. Several of the advocate articles included advice on how to approach any reclassification of services and news articles reported on the likelihood for service interruption or loss. This is interesting and suggests that after the changes to ASD were approved, there was an exigence to discuss how the now inevitable changes would be handled by those with a previous disorder. It is also at this point that discussions of the impact to people with Asperger’s began to rise in the conversation.
Finally, once the *DSM-5* was released in May of 2015, the coverage shifted heavily to discuss Asperger’s disorder and the problems that may be encountered by people with the new diagnosis. Occurrences of Asperger’s in the media coverage increased steadily throughout the timeline and became the most common topic after the release of the *DSM-5*. It was at this time that several of the article titles referred to Asperger’s specifically. Given the Asperger’s was definitively at the core of the coverage of the recategorization overall, it is interesting to see this trend. Although Asperger’s may not have been the first issue of concern when the changes to ASD were announced, it certainly became so once the changes were approved and followed through. The conversation about potential problems arising from the new *DSM* often focused on the displacement of people with Asperger’s. Given this trend and the rest of the analysis in this chapter, I argue that Asperger’s became the central point in the discussion of the recategorization of autism predominantly because it is the most visible of the absorbed disorders and the one associated with a strong identity and community of people.

Overall, the progression of the conversation shows the shifts in thinking and concerns around the recategorization of ASD. It seems that media coverage shifted given the status of the changes to ASD. As the changes to autism went from proposed, announced, and finally published, the concerns in the articles changed accordingly. Following the proposal of the changes the discussion centered on the question of validity and potential impact to people with an ASD diagnosis. At this point, the changes were still progress and subject to change, so there was an
emphasis on discussing whether the changes were a good idea and consideration of how they may impact people. Once he changes were approved, the conversation made a drastic change from being critical of the changes to discussing the practical issues to come. Finally, the release of the *DSM-5* triggered a wave of concern over the displacement of people with Asperger’s and the community they have built in the previous decades. Given this progression, it is clear that the media coverage responded to the timeline of events in the process of the recategorization. I also argue that the official release of the *DSM-5* marked a final end to Asperger’s as a diagnosis and brought to the front issues with the loss of identity.

4.6 Summary

Public knowledge and perceptions of mental health are heavily interconnected with the information and perceptions presented through mass media. For people not privy to the expert conversations within the field of mental health, media coverage of the recategorization is the first source of information. The goal of this chapter was to answer the question of how the media coverage of the recategorization presented the issue to the public. Given the analysis in this chapter, I argue that the recategorization was presented as an overall valid change that would have undeniable impact on the lives of people with a previous autism diagnosis. Even though the change was seen as valid and based on strong research, this did not detract from the fact that people’s lives will be affected in more ways
than one. This same duality was present but never acknowledged in the expert
conversations about the recategorization.

Furthermore, media coverage of the changes to autism actively constructed
not only an identity for people in the spectrum but also one for those with
Asperger’s. The identity of people in the autism spectrum is presented as that of
someone with a significant disability that permeates their life. Significant social
and behavioral issues are associated with an autism diagnoses, and individuals are
perceived to be severely impaired and unable to lead a “normal” life. However, the
media coverage of the recategorization also constructed an Asperger’s identity that
heavily contrasts the one for autism. People diagnosed with Asperger’s are
perceived to be highly functional, self-reliant, highly intelligent, and somewhat
eccentric. There is such a contrast between these two identities that the question
arises of what to do when they are both labeled ASD. I argue that both of these
constructed identities represent artificial ends of the spectrum and echo the
uncertainty of how to categorize people that can fall in such a wide range. In reality,
not all people with Asperger’s are the same and they may experience different
impairments in the same way that not everyone with an autism diagnosis is the
same. There are two distinct identities being constructed, a classic autism and an
Asperger’s one, and there is conflict when they are combined into one single
diagnosis. I believe the conflict comes from the uncertainty that arises when a
single label, ASD, becomes associated with two different and opposing identities.
5. DISCURSIVE CONSTRUCTION OF THE IDENTITIES OF PEOPLE WITH ASD

5.1 Overview

In the last couple of chapters, I have investigated the recategorization of autism and the ways in which it was covered by news media in the United States. There have been a number of insights in these chapters that now serve as the foundation of this one. This dissertation strives to uncover how the identities of people with a mental health diagnosis are constructed by the definition of the disorder in the DSM and how it is disseminated through mass media, especially during a time where a disorder is going through a significant recategorization. The first step in this investigation was to analyze the way the recategorization of autism in the DSM-5 actively constructs the understanding of the disorder and, with it, the identity of the individuals with the diagnosis. Findings from Chapter 3 suggest that the language used in the DSM, and by mental health researchers in the literature leading up to its revision, specifically constructs the identity of those within the ASD spectrum as suffering from pervasive impairment in their everyday lives. This impairment is a necessary condition for getting a diagnosis, and therefore indicates disability for the people who have it. Chapter 4 looked at the coverage of the recategorization in the most visited news media and advocacy websites leading up to the release of the DSM-5. An analysis on the language used to describe the disorder shows that individuals are indeed presented as having disabling impairment. However, there are two specific levels of impairment highlighted in this sample; a higher level of disability associated with classic autism and a lower
level associated with Asperger's. I argue that these findings show that the disabled identity constructed through the *DSM* is indeed absorbed into the coverage of the recategorization, but the media differentiates this identity from the identity of people with a previous diagnosis of Asperger's.

With the developments from the previous two chapters, this chapter outlines an investigation into the public response to the coverage of the recategorization of autism, and how the construction of the identity of people with this diagnosis is embedded within it. The language and narratives used to describe people with ASD will be analyzed and deconstructed to find the discursive construction of identity in the context of this recategorization.

### 5.2 Comment Analysis

Exploring the public understanding of ASD, and the perceptions of the identity of people with this diagnosis, is by far the most challenging endeavor of this dissertation. This is mostly because the scale of the research needed to make such an assessment is much larger than the scope of this dissertation permits. Therefore, in order to strike an effective balance for this research, this chapter will analyze a sample of comments responding to the news of the recategorization to provide a glimpse into the public reaction to the news coverage of the recategorization and their perceptions of people with this disorder. This approach is based on previous research done in the fields of critical and disability studies.

The internet, without a doubt, has become one of the most revolutionary communication advances in human history. It not only allows for the almost
immediate transmission of information, but also provides a space for public
discussion that gives users a maximum freedom of expression (sometimes veiled by
anonymity). It is this public forum that gives researchers an unprecedented
opportunity to study the ideas and perceptions of large groups of people. Tardy
(2009) employed such an approach to analyze a public debate over the
establishment of English as the national language of the United States that ensued
in the comments of a web news article on the subject. This research examined “the
ways in which dominant texts and ideologies within [a] corpus of text are taken up,
dropped, and perpetuated through linked genres…” (Tardy, 2009, 265). Through the
in-depth analysis of these comments, Tardy (2009) was able to identify the different
kinds of narratives that emerged in this debate, and how these narratives reflect
the positioning and perceptions held by the public on a sensitive topic. This
approach will be replicated in this chapter as a way to explore the ideologies and
subjectivities present in the dialogues that ensued in the commenting sections of
media articles covering the recategorization of autism.

Furthermore, the research in this chapter is heavily informed by the
literature of the field of disability studies. In the seminal Rhetoric Review
symposium “Representing Disability Rhetorically”, several scholars argued for the
need of further investigations on how disability is constructed through attitudes
and social arrangements and how these then become ingrained in our society
(Lewiecki-Wilson, 2003; Morse, 2003; Stremlau, 2003). Lewiecki-Wilson (2003), for
example, argued that although disability has in part physical manifestations, a
disabled identity is a social construct that is tied to the views and perceptions held by a community. Another important argument from this field of study is that labels used to categorize people have a significant impact in how people are perceived by those around them, and therefore a critical part of a social identity (Brueggeman and Kleege, 2003). The disability studies research sampled here, and in the literature review of this dissertation, functions as a structure for the analysis and discussion of this chapter. This research will focus on identifying the social perceptions and labels used to construct the identity for people with an ASD diagnosis, an identity that has been identified as disabled in chapters 3 and 4.

Finally, the methodology for this chapter was also based on the work of another noted scholar in the field of disability studies. In 2012, Kerschbaum introduced the concept of Markers of Difference (MODs) as “rhetorical cues that signal the presence of difference between one or more interlocutors” (616). MODs are relevant keywords and phrases used by a person to separate themselves from the other. Kerschbaum (2012) argued that “marking difference in intimately tied to the display and recognition of identities” (628-629). Therefore, analyzing MODs allows us to study the way in which people create an identity for themselves that is distinct from the identity of the other. This chapter will identify MODs present in comments and analyze the ways in which they create a sense of self and the other as well as the identity of people with an ASD diagnosis. The way MODs were coded in this chapter, and how they were used in analysis, will be discussed in later sections of this chapter.
5.3 Methodology

This chapter represents the third step in the dissertation needed to answer the overarching question. Therefore, this chapter will address subquestion 3:

*How does the presentation of the recategorization of ASD through mass media contribute to the discursive construction of identity of individuals living with the diagnosis?*

The methodology for this chapter will build upon the structure established in Chapters 3 and 4 with some significant changes and adaptations.

5.3.1 Sampling Process

The first step to this part of the research was to identify a sample of comments that provides an adequate scope for the purpose of this chapter. Given that the focus would be analyzing the public reaction to the coverage of the recategorization of autism, it was necessary select comments made on media articles that discussed this specific topic. There are more website articles that covered the subject of the recategorization than the ones sampled for Chapter 4. However, analyzing comments from articles that have not been analyzed in this dissertation created a significant problem for their analysis. This is so because having a concrete understanding of the content of the articles that comments are responding to is absolutely necessary in order to have the relevant context to analyze them. The articles sampled for Chapter 4 have been thoroughly analyzed in terms of content and framing, therefore, this provides the necessary context to the
conversation held by commenters in response to these articles. For this reason, the comments sampled for this chapter were extracted from 6 media articles from Chapter 4. These were the only articles in the sample that featured comments.

The sample size used was decided according to the scope of this chapter. Although comments from all of the 6 articles identified in Chapter 4 were used, not all comments were incorporated in the sample for this chapter. All of the comments of 5 out of the 6 articles were used in the sample. Not all of the comments from the 6th article were selected in order to keep the sample size manageable. That is, from the 642 comments available in the 6th article, only the first 175 comments were included in the sample. These comments encompass a large part of the initial conversation that took place on the day the article was released, and spanned a total of 3 pages of the comment widget used by the website. In total, 224 comments were sampled for this chapter (shown in Table 5).

Table 5

Breakdown of comments sampled for Stage 3

<table>
<thead>
<tr>
<th>Document</th>
<th>Title</th>
<th>Author</th>
<th>Date</th>
<th>Publication</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media 3</td>
<td>Normal or not? Saying goodbye to Asperger's</td>
<td>Parry</td>
<td>2013</td>
<td>Live Science</td>
<td>15</td>
</tr>
<tr>
<td>Media 4</td>
<td>You do not have Asperger's: What psychiatry's new diagnostic manual means for people on the autism spectrum</td>
<td>Lutz</td>
<td>2013</td>
<td>Slate</td>
<td>3</td>
</tr>
<tr>
<td>Media 8</td>
<td>How will the DSM V changes in autism affect people?</td>
<td>Robinson</td>
<td>2012</td>
<td>Psychology Today</td>
<td>8</td>
</tr>
<tr>
<td>Media 15</td>
<td>New definition of autism will exclude many, study suggests</td>
<td>Carey</td>
<td>2012</td>
<td>The New York Times</td>
<td>175a</td>
</tr>
<tr>
<td>Media 18</td>
<td>Autism criteria critics blasted by DSM-5 leader</td>
<td>Gever</td>
<td>2012</td>
<td>MedPage Today</td>
<td>3</td>
</tr>
</tbody>
</table>
Once the sampling of the comments for this chapter was complete, a method for capture of this content needed to be used to get the material into the qualitative research software (ATLAS.ti, 1991). Following in the steps of the previous chapter, the Firefox browser add-on program Abduction! was used to capture the comments of 3 of the articles used in this chapter (Evans, 2013). This program saves sections of websites into png files that preserve the exact screenshot of the material that is easy to import into ATLAS.ti. Unfortunately, I was only able to use this effective method on the websites that did not use widgets to display comments. Therefore, I copied and pasted the text from these comments into a word processing program and then converted the file into a pdf for easy upload into ATLAS.ti. In the end, the result was the same in terms of the coding features of ATLAS.ti and this didn’t have an overall effect on the process. This was possible mostly because, unlike the analysis of a website article, the analysis of comments relies solely on the text and there was no need to preserve visual elements for the purpose of this chapter.

5.3.2 Comment Sample

As far as the sample for this chapter, most of the comments included came from news media articles from websites like The New York Times. Only one of the articles used for this chapter was an advocacy website, a blog that featured comments. It would have been interesting to have a more balanced sample in terms
of news versus advocacy sites for this sample. However, this was not possible mostly due to the difference in genres between these two types of publications. That is, advocacy websites do not often feature commenting features in their web articles (perhaps because they are more focused on providing information than a forum for discussion). All in all, the advocacy blog provided with some interesting distinctions between the comments posted for each genre that will be discussed later on in the discussion of this chapter.

Comments in the sample ranged from short answers, comprised of a couple of words, to elaborate responses spanning a couple of paragraphs. For the most part, most of the comments were complete ideas addressing the article itself, the recategorization of autism, or the subject of autism in general. Special attention was used to code the comments that were responding to other commenters in the thread. No distinguishing features such as user name, time-stamp, or user location were taken into account in this chapter, as this was not part of the scope of this project. However, there is no doubt that analysis of these elements would be an interesting project for the future.

5.4 Analysis and Coding

As was mentioned in Chapter 4, an overarching coding structure and procedure has been used throughout the entire dissertation, although specific adaptations have been used in each of the three major chapters. The shared structure allows for the ability to maintain a stable analysis throughout the three stages of this project, while the flexibility of the methodology ensures that each
stage adapts to the needs of each specific subquestion of the overarching research question. Although the procedure for coding in all three of the analysis chapters has been pretty much the same, there was a significant difference in this chapter. In Chapters 3 and 4, major code groups were established before the coding began to ensure the process was focused on addressing the research questions of this dissertation. Some codes were then added throughout the coding process to adapt to the subject material as is dictated by the principles of Ethnographic Content Analysis (ECA) by Altheide and Schneider (2013). In this chapter, however, the nature of the question required a slightly different approach. Although several of the major code groups (outlined in Tables 2 and 4) used in the previous chapters were also used here, all new coding groups in this chapter were created during the coding stage and were not planned ahead. The reason for this was that it was not possible, or appropriate, to anticipate what the public response would be to the article without biasing the process. Therefore, I allowed the language in the comments to guide the new coding groups created for this analysis (presented in Table 6).

This stage of the analysis incorporated the following existing code groups from Chapters 3 and 4: context, identity, recategorization, author, and subject (Tables 2 and 4). These major code groups have been the backbone of the coding structure for this dissertation and have allowed for consistency in the analysis of the subject. The Context code group has been used to track the context surrounding ASD to assess the perceptions and understanding of the disorder. For example, in
this chapter this code group highlights whether a commenter perceives ASD to be a curable disease as opposed to an incurable disorder, or a social problem to be addressed by social policy aside from a medical problem in need of research and expert judgement. The Identity code group has been integral for tracking all the instances where people with an ASD diagnosis are described. These descriptions then become part of the discursive construction of identity of people with an ASD diagnosis. In this chapter, the Identity code group has been used to construct an identity for people under the general ASD diagnosis, people with a previous diagnosis of Asperger’s, and people who are perceived as being disabled or heavily impaired. The code group Recategorization has been used throughout the three stages of analysis to analyze the way the recategorization of autism is framed in the sample. The major codes under this group that were used in this chapter include valid, invalid, problem, and solution. This code group has been integral in the analysis of the reception to the news of the recategorization and how this impacts the perceptions of people with ASD. The code group Author has been used throughout this project to identify the writers of the several artifacts that have been analyzed. In this chapter, this code group has been used to track every time a commenter identifies themselves as being either a person with autism, a parent to a child with autism, an advocate for an autism cause, a mental health professional that has worked with people with ASD, etc. Finally, the Subject code group has been used to track the specific subject being discussed in the sample. Although the material being analyzed in this dissertation is all focused on the recategorization of
ASD, this code group has been used to highlight the specific subtopics associated with this issue. For example, in this chapter, commenters have referred to specific subtopics such as Asperger’s, PDD-NOS, ADD, and ADHD, in addition to autism. The continued use of these major code groups has been important to maintain a stable coding analysis that ensures that meaningful comparisons can be made between Chapter 3, 4, and 5.

In addition to the existing code groups from previous chapters, this chapter featured the development of a new set of code groups necessary to analyze the sample of comments (shown in Table 6). New code groups were established during the coding process as they became necessary to track the content of the different conversations and discussions held by commenters. The only code group that was planned ahead of the coding process was MODs. However, the codes within this code group were strictly created during the coding process as they arose in the narratives. These codes will be discussed in the next section.

Table 6

New code groups added during Stage 3

<table>
<thead>
<tr>
<th>Code</th>
<th>Occurrence</th>
<th>Code</th>
<th>Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Article Response</td>
<td>Keywords</td>
<td></td>
<td></td>
</tr>
<tr>
<td>critique</td>
<td>14</td>
<td>mild autism</td>
<td>21</td>
</tr>
<tr>
<td>like</td>
<td>4</td>
<td>ADD</td>
<td>8</td>
</tr>
<tr>
<td>dislike</td>
<td>1</td>
<td>ADHD</td>
<td>5</td>
</tr>
<tr>
<td>negative</td>
<td>63</td>
<td>vaccinations</td>
<td>4</td>
</tr>
<tr>
<td>positive</td>
<td>31</td>
<td>epidemic</td>
<td>3</td>
</tr>
<tr>
<td>nuanced</td>
<td>21</td>
<td>quack</td>
<td>3</td>
</tr>
<tr>
<td>quotations</td>
<td>21</td>
<td>shrink</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>revisionism</td>
<td>1</td>
</tr>
</tbody>
</table>
The new code groups developed for this section of analysis were Article Response, Attitudes, Conversations, Emotions, Keywords, and MODs. The Article Response code group was created to track all instances where a commenter expressed their opinion about the article they read. The code like was developed to track all instances when a commenter clearly expressed that they liked the article very much either because it was well written, informative, relevant, accurate, or in alignment with their own perception of the recategorization of autism. This code can be likened to the “like” feature often present in news media articles in the form of a “thumbs up” button. But, unfortunately, it was not appropriate to count those “likes” numbers into this analysis because not all articles offer this feature and
when they do, a thumbs down option is not present to balance the feedback from readers. The code dislike was used to track all instances where a commenter clearly stated they didn’t like the article because it was poorly written, inaccurate, too brief, or unaligned with their perception of the issue. The code critique was developed through a need to identify comments that, regardless of whether they liked the article or not, actively critiqued a specific aspect of the article. For example, some commenters critiqued the lack of relevant sources, sufficient facts, or development on the topic as well as a biased approach to the reporting from the author of the article. This code group was used to assess the overall response to the coverage of the recategorization of autism by the readers. Although the response to the news of the recategorization itself is analyzed using code groups Attitudes and Recategorization, this code focused specifically on the response to the media coverage itself and the way they issue was framed by the media.

The code group Attitudes was developed to analyze the overall response of commenters to the issue of the recategorization of ASD. The codes under this group were developed based on the different attitudes identified in the comments when referring to the subject of the recategorization. Although the code group Recategorization has been used throughout the dissertation to assess the perceptions of the topic, the distinct set of codes in this new code group was necessary because commenters, as opposed to more objectively inclined scholars from Chapter 3 and journalists from Chapter 4, are more open to express their personal attitudes about the subject. Therefore, this code group was challenging in
the sense that attitudes are more abstract concepts that are not directly identified by commenters but must be inferred from their tone. There were a total of 9 codes created in this group: hope, positive, “quotations”, dismissive, uncertainty, nuanced, negative, loss, and disappointment. Most of these codes are self-explanatory, so I will not discuss them here specifically, but others require a bit of a description. The codes positive and negative refer to the general attitude of the commenter toward the categorization. These can be described as highlighting those commenters that were glad, happy, or grateful for the recategorization and those who were upset at the news, respectively. The code “quotations” was developed to track all of the instances of quotation mark use by commenters. At first, I was sure that the trend of using quotation marks was relevant, although I didn’t particularly know in what way. After analysis, I realized that quotation mark use in the sample was predominantly a sign of sarcasm, mistrust, and skepticism targeted at the terms in quotations. This then became an interesting attitude expression in the comments. The code nuanced was developed to track comments that expressed a nuanced opinion about the recategorization by recognizing two or more valid attitudes and complexity. The rest of these codes will be further described as they become relevant in the discussion section of this chapter. Overall, this code group was a very interesting one that provides a great deal of insight into the understanding of the public in response to the news of the recategorization.

The code group Conversation was used to identify comments that were responding not only to the article they read but to a specific commenter before them.
Not all commenters respond to other comments, but a good amount of them did and made it necessary to track. Conversations were identified when the comment mentioned the username of the person they are replying to, the website allowed replies to specific comments, and through context. This code group is composed of the following codes: confrontation, insult, rebuttal, correction, fact drop, and agreement. The code confrontation was used to identify whenever a commenter would argue against another. These comments expressed disagreement with the arguments or comments made by another person. The code insult was used when disrespectful language was used in a reply that escalated the conversation from a simple confrontation to a personal attack on the other user. For example, “your opinion on this matter is both racist and idiotic” (Carey, 2012). The code rebuttal was used to track a reply to a reply. That is, commenters that were engaged by another person sometimes came back and responded, and these were tracked as rebuttals when they were engaging in the argument. The code correction was used when a reply to a comment was not arguing against an idea but correcting a fact, assumption, or assertion made by a commenter. The code fact drop was developed to track comments that would incorporate quotes and or other facts from relevant sources as evidence for their arguments. This ranged from a small statistic reference to a large quote of a text like the DSM. Finally, the code agreement was used to identify comments that expressed specific agreement with the comment from another user. Agreements ranged from short statements like, “I agree,” to more developed responses that expressed agreement and then provided their
contribution to the argument, or further examples in line with those of the other user. The code group Conversation does not necessarily become relevant in the analysis of identity construction, but it does provide valuable context to the tone of the conversations held by the commenters in the sample.

The code group *Emotions* was created to identify comments that expressed feeling a particular way about an issue. Unlike the attitudes coded in a previous code group, emotions are not constructs that can be inferred with accuracy from reading an internet comment. Therefore, I was careful to limit my use of these codes to comments where the author directly mentioned feeling a specific way about the issue of the recategorization of autism. This code group included the codes: *hope*, *fear*, *anger*, and *sadness*. These codes are self-explanatory and do not require a specific description. Each code refers to a specific emotion referenced by at least one comment. Overall, this code group wasn’t very prevalent in the sample, but it did highlight a difference between the expression of opinion and attitudes and the expression of an emotional response by commenters.

The code group *Keywords* was developed in order to organize any keywords that were used in the comments that highlight specific related issues to the recategorization of autism. The keywords identified under this group were interesting but did not fit into any of the other code groups. The codes included in this group are: *quack, ADHD, revisionism, mild autism, vaccinations, ADD, shrink,* and *epidemic*. Some of these codes were not very relevant and mentioned only a couple of times, but others highlight important themes relevant to the topic. The
codes *quack* and *shrink* represent a somewhat negative perspective of mental health professionals, used as a way to denote distrust in their judgement or value. The codes *ADHD* and *ADD* indicate that these disorders are commonly associated with autism and were sometimes incorporated into the discussion. The similarities between these disorders and ASD are that they are commonly diagnosed in children, impact education, and require resources associated with the school system. The code *vaccination* refers to the controversial claim that vaccines can cause Autism, a fact that has been disproved but is still prevalent among large communities of parents. The code *epidemic* became relevant because this was a common argument made about the validity of the recategorization of autism. Some commenters often cited the recategorization as a solution to the epidemic of diagnosis, while others argued that there is a real epidemic of the disorder that requires attention. Finally, the code *mild autism* was developed to track every instance of a distinction made between classic autism and a milder form, now all under the spectrum. This concept was further explored by other codes, but I decided to maintain this keyword code to track the usage of the word “mild” specifically because I find it to be a very telling language choice. Overall, the Keyword code group became useful in tracking the prevalence of related topics of issues to the subject of the recategorization. Given that some of these codes were not very prevalent in the sample, they are not very significant in the analysis of this chapter. Nevertheless, I believe that these keywords serve to open up future directions in research of this subject that are worthy of study.
In addition to the codes groups described above, the code group MODs was developed to analyze the markers of difference used by commenters in the sample. This code group was established following the guidelines of the work of Kerschbaum (2012). Kerschbaum (2012) provided the following guiding questions to identify markers of difference:

- How do individuals position themselves alongside others?
- How are individuals positioned by others?
- How do individuals acknowledge similarities and differences between themselves and others?

These questions were used to identify and code the MODs used by commenters to both distance themselves from others and to describe them. There were a total of 21 MODs identified in the sample, although 10 of them were used only a couple of times and were not relevant for this analysis. The following is a list MODs codes, developed during the coding stage of analysis, which were significant in the analysis of this chapter: insider, neurotypical, Autism vs Asperger’s, not a parent, Asperger’s vs Autism, bad parent, and Autist vs Doctor. In addition to these new codes, Kerschbaum’s (2012) guiding questions also identified the code group Author as fitting the definition of a MOD and was therefore incorporated into this group as well. The reason for this is because the code group Author, as explained above, was designed to track all instances where people identify themselves in a particular way (such as a parent to a child with autism or a person with the diagnosis), and in doing so they are marking a difference between themselves and others that impacts the credibility of their arguments. Further descriptions of the codes in this group
will be presented during the discussion section below, in their own section, where they will be more effective to the content of this chapter.

5.5 Discussion

5.5.1 Public Concerns

The most efficient way to begin to explore the data of this chapter is to first take a look at the overall concerns expressed by the public comments to the coverage of the recategorization of autism. Looking at the most prevalent codes of this sample, found in Table 7, provides a good idea of the themes and issues raised by commenters, as well as a good overview of the analysis of this chapter in general. The list of codes that appeared a minimum of 20 times in the sample represents six code groups that were very relevant to this analysis: Context, Attitudes, Conversation, Identity, Recategorization, and MODs. Three of these code groups were created in the analysis of Chapter 3 and were used in Chapter 4 as well, and the other three code groups were created during the analysis of this chapter. The following in an exploration of the insights gained by looking at the most used codes in this sample and how they represent the concerns of the public.

Table 7

<table>
<thead>
<tr>
<th>Code</th>
<th>Occurrence</th>
<th>Code</th>
<th>Occurrence</th>
</tr>
</thead>
<tbody>
<tr>
<td>negative</td>
<td>63</td>
<td>ASD Disability</td>
<td>29</td>
</tr>
<tr>
<td>services</td>
<td>46</td>
<td>parent</td>
<td>29</td>
</tr>
<tr>
<td>confrontation</td>
<td>41</td>
<td>agreement</td>
<td>28</td>
</tr>
<tr>
<td>autism</td>
<td>38</td>
<td>solution</td>
<td>26</td>
</tr>
<tr>
<td>problem</td>
<td>38</td>
<td>insider</td>
<td>25</td>
</tr>
</tbody>
</table>
The most prevalent code in this sample, by far, was the Attitude code *negative*. This code tracks comments that expressed a negative attitude toward the recategorization of autism. Although the opposite code *positive* was also within the list of most prevalent codes, there is a marked disparity between the number of occurrences between the two. Hence, it is accurate to say that the majority of public comments expressed being concerned about the recategorization and viewed it as negative in variety of ways. Furthermore, an analysis of the co-occurrence shows that *negative* was most often coded in conjunction with top codes *services*, *problem*, *invalid*, and *impact*. These four codes are part of the Recategorization code group, which tracks perceptions about the recategorization, and therefore gives us an idea of the top reasons why the changes are seen in a negative light. Looking at the quotes marked with the code *negative* provides insight into this assertion. For example, several of the commenters with a negative attitude toward the recategorization were concerned with the accessibility to services: “Since resources are limited, those with a supposedly less severe disability such as myself will likely lose what little support we are getting” (Robinson, 2012). Others believed that the changes to the *DSM* would lead to a series of problems such “excluding the higher
functioning kids means that schools will have to do more to make regular classrooms hospitable to them without IEP-based accommodations” (Raising Children Network, 2012). And many questioned the validity of the recategorization itself; “It seems to me that a diagnosis should be scientific not some vague sets of rules” (Raising Children Network, 2012). Overall, it is clear that there were significant concerns with the recategorization of autism. Interestingly, validity, thought important for several commenters, was only one of the concerns given about the recategorization, and different forms of impact were more often cited as the reason for their unease at the news.

Similarly, looking at the list of prevalent codes shows the other side of the equation, the comments that expressed having a positive attitude about the recategorization. Although the code positive was not as prevalent as its opposite, its appearance on the list in conjunction with codes solution, valid, and misdiagnosis is evidence that there was a significant minority within the comments. That is, a significant proportion of the comments believed the recategorization was a good thing because they viewed it as a solution to an existing problem, a valid change in the definition of autism, and/or an end to over diagnosis. Some of the quotes coded under this set of codes give some explanations to the kind of arguments made by these commenters. One of the main arguments seen in these quotes is that the recategorization would fix the problem of ambiguity in the previous DSM. For example, one comment argues that “tightening up the diagnostic criteria will bring more order and clarity” (Carey, 2012). Other comments argue for the validity of the
change by pointing out that the *DSM* is an objective endeavor that seeks the best understanding of a phenomenon, regardless of the impact that may have (Carey, 2012). Finally, another common argument made in favor of the recategorization was that it would end the misdiagnosis of autism. A commenter said, for example, “good, maybe now social awkward and autistic won’t be synonymous” (Carey, 2012). I believe that the fact that there was a strong prevalence on both sides of the argument, for and against the recategorization, shows that the subject was very polarizing. There may have been a majority who believed the recategorization was a bad idea, but there was also solid support for the changes. I argue that this is probably one of the main reasons why ASD was one of the most reported changes featured in the *DSM-5*.

Another significant insight, from the list of most prevalent codes in this chapter, is that the code *Asperger’s* was used almost as many times as the code *autism*. The code *autism* tracked all of the instances where the general diagnosis of autism was mentioned in the comments, be it in the forms of autism, ASD, the spectrum, etc. The fact that Asperger’s, one of the diagnoses absorbed into ASD, was just as prevalent as autism in the comments shows that it was perceived as an integral part of the conversation surrounding the recategorization. This was also the case in the analysis of the coverage of the recategorization from Chapter 4, where the media focused on Asperger’s as a major point of emphasis for the changes to the *DSM-5*. Given that Asperger’s was not the only disorder to be incorporated into the spectrum, it shows that this is by far the source of the most contention with
the recategorization. An overview of the quotes shows that Asperger’s is perceived to be parallel to autism, undeniably related but never converging with one another. This is exemplified by the way several of the commenters feel the need to refer to ASD by using both names; “...undoubtedly there are financial pressures influencing this vote about autism/Asperger’s” (Carey, 2012). This also, once again, highlights the glaring omission of other disorders incorporated to the spectrum (such as PDD-NOS which was only coded 10 times in this sample). A further exploration of the quotes marked under the code Asperger’s, show that several commenters expressed a marked benefit at having a specific label for Asperger’s, such as a comment that expresses “I was so happy that my son would be able to benefit from the diagnosis [of Asperger’s] and from the network of Aspies as he grows up” (Davide-Rivera, 2012). This quote, among others, argue that regardless of the validity of the recategorization of autism, there are undeniable reasons why having a distinction between classic autism and Asperger’s is beneficial to people with the diagnosis, benefits that go beyond just access to resources. The trend of highlighting the parallelism between Asperger’s and autism goes far beyond just the use of the two terms, and will be further discussed in relation to other findings of this chapter.

5.5.2 Reception of the Recategorization of ASD

Overall, the sample of comments analyzed in this chapter showed a variety of views regarding the recategorization of autism. As discussed previously, most of the commenters expressed a negative attitude toward it while a strong minority held a
positive attitude. These two points of view represent the extremes of a spectrum that also included other attitudes that were relevant to understand the overall reception to the news of the recategorization. These other points in the spectrum were identified through the codes: nuanced, quotations, uncertainty, dismissive, hope, loss, and disappointment. Of these different attitudes coded in the sample, the last four were only quoted a handful of times at best. Therefore, this section will explore the other most common attitudes to the recategorization, aside from the negative and positive codes.

Throughout the coding process of this chapter, there were attitudes toward the recategorization that were difficult to categorize at first. I began to track most of these comments under a variety of codes like neutral, complex, and understanding. However, upon review of these codes, it became apparent that they had more in common than not, and these comments were then all recoded under one unified code, nuanced. Commenters that exhibited a nuanced attitude toward the recategorization demonstrated a complex understanding of the issues surrounding it. They often rejected black and white notions about the issue, and recognized that opposing views were equally valid and important to consider. The following comment is a good example of a nuanced attitude found in the sample:

Services should be based on need and not diagnosis. Autism, like many behavioral disorders, is likely to be an overarching term for a variety of seemingly related diseases or conditions. To understand its causes and eventual cures or specific treatments, medical scientists need to be able to sort out the different types first. This is hard to do if all patients are lumped together for other purposes such as eligibility for benefits. (Carey, 2012)
A breakdown of this quote shows that the author is careful to acknowledge both sides of a variety of common arguments made by other comments in the sample. The main argument of this quote is that both the need for a scientifically valid categorization of disorders and a system of resources for people who need them are equally important. In doing so, the commenter argues that it could be possible to address both issues by separating them from one another, that is, to separate the eligibility for services from the professional categorization of disorders, like the *DSM*. This is a very complex position. Furthermore, the commenter also actively acknowledges that autism is sometimes perceived by some to be a disease, and a condition by others. Similarly, the commenter recognizes opposing perceptions of autism as either a curable disease or a condition requiring lifelong treatment.

Comments like this exemplify that there is definitely a middle point in the spectrum of attitudes toward the recategorization. Most comments may have either seen it in a positive or negative light, but a good portion were able to position themselves in the middle and recognize that there is a complexity to the issue that requires a more nuanced understanding of the arguments being made in this conversation.

The code *quotations* was at first used to track all instances of quotation use, that were not related to quoting exact words from another commenter or source, in the comments. After careful analysis of the comments marked by this code, I found that quotations were often used as a way to cast doubt on the word or words within the quotation marks. This in turn became an interesting way to gauge the attitudes of the commenter toward the issue of the recategorization. Unlike the other codes
under the group Attitudes, the code *quotations* is not associated with a particular view of the recategorization. That is, comments marked by this code represent a variety of perspectives ranging from negative to positive. So, even though this code doesn’t highlight a particular attitude towards the recategorization, it does provide some insight into a common issue seen in the overall sample; there is undeniable distrust of the terms associated with the field of psychology/psychiatry. Figure 2 represents a word cloud composed of all the words that were in quotations in the sample. At a quick glance, it is clear that there is a very specific theme to those words. The words are often labels to psychological disorders (autistic, Asperger’s, syndrome), words associated with psychology (introverted, shy, normal), or words used through the diagnostic process (substantial, standards). I argue that this finding is very relevant in the understanding of how words and concepts are absorbed by the public. The use of quotations in this sample suggests that although commenters use the terms created by the field of psychology, they do not accept them wholly and without question. The fact that autistic was the most quoted word in the sample is evidence that this is not a concept or term that is truly understood by the general public. I believe that this overall unease with the words and terms of the field of psychology colors the way in which the general public absorbs information about the recategorization of autism, and this is an interesting direction for further research.
Finally, the code *uncertainty* was used to track all the cases in which commenters expressed apprehension and doubt about the recategorization of autism. As evidenced by the code *nuanced*, not all commenters aligned themselves with either the positive or negative spectrum of views about the changes to autism. In the case of this code, commenters were uncertain of what was to come with the changes to the *DSM*. The doubts present in these comments echo some of the arguments made for and against the recategorization, but acknowledge that this is something yet to be seen and not a certainty. Uncertainty was almost always expressed with the posing of questions such as the one by this commenter: “What
support will there be for people who are left out of the new diagnostic categories, but who are not able to function independently?” (Carey, 2012). Another example of a question is, “What are the implications for that change in our view of the human condition?” (Carey, 2012). Overall, this code reflects the complexity of the issue and highlights a disconnect between the general public and experts within the field of psychology. Similar to the insights from the quotations code, I think this code highlights the imbalance of power between the public and the authorities within the field of psychology that have power over the categorization of disorders. It is evident that this fact does not go unnoticed in the comments and leads to uncertainty as to why changes had to happen and what is to come as a result.

An analysis of the attitudes held about the recategorization of autism shows that the issue is not only polarizing but also highly complex and enmeshed in politics of power. The overall majority of a negative attitude toward the changes to the autism categorization does not eclipse the positive attitude, uncertainty, complexity, or distrust exhibited by the commenters in the sample. I argue that understanding these attitudes is integral to the study of how the identities of people with autism are constructed because they reflect lenses that color public opinion on the subject.

5.5.3 Conversations among Commenters

As evidenced by the previous section, the subject of the recategorization was polarizing and in turn this influenced the conversations among commenters in the sample. For the most part, most instances of commenters addressing one another
were categorized as confrontations. The code *confrontation* highlighted instances of not only disagreement but antagonistic arguments between commenters. For instance, one commenter replied to another “Someday you might find yourself on the other side of this issue and find your own heart and a little compassion to boot. Shame on you...” (Carey, 2012). This comment was part of a series of responses by several people to one comment, most of them with a similar tone. It is safe to say that most of the confrontations featured arguments against the ethos of a commenter. For example, “Spoken like someone who truly has NO clue what children and their families go through...” (Carey, 2012). Confrontations, then, featured disagreement among commenters that was focused on the character of the person, and not always about the facts of the issue. This shows that questions related to autism are a very personal matter, and commenters often felt personally attacked by comments that were either insensitive or dismissive of their concerns. To me, this is in partly due to the fact that mental health issues are by nature associated with the self and personality of a person. Therefore, comments like “It’s time for a more specific set of diagnostic tools, and time to get a lot of greedy people off the government dime,” were often perceived to be a direct attack to the integrity of parents of children with autism or people with autism themselves (Carey, 2012).

Aside from confrontations, a good portion of the conversations in the sample were coded as *corrections*. These types of comments did not focus on being antagonistic, like *confrontations*, but instead sought to correct a fact or idea from a previous commenter. These kinds of comments often incorporated either research
from outside sources, like the *DSM* or a mental health expert, or first-hand experience to correct something they disagreed with. For example, a commenter stated, “as an Early Intervention therapist with 19 years experience with Autism, I can honestly tell you that I have rarely worked with a kiddo who has already has a diagnosis of Autism that didn’t have it” as a correction to the assertion of gross over diagnosis of the condition (Carey, 2012). Analyzing corrections in the sample was useful in the sense that it highlighted a dichotomy between the use of personal experience or expert opinion as valuable support for arguments made about autism. That is, even though mental health expert opinion has a clear value in the arguments made about this subject, first-hand experience with the disorder was also often presented as being just as valid or sometimes more so. This trend is even more apparent when analyzing the conversation in the comments of an advocacy blog, to be discussed in a later section.

Finally, although confrontations and corrections prevailed in the conversations among commenters, there was still a substantial amount of agreement reflected in the sample as well. Often, agreements not only reinforced the views of their parent comments, but they also furthered developed those argument with their own experience or knowledge. For example, some comments began by expressing agreement, “Well said! Asperger's is heartbreaking; it is outrageous to pretend it does not exist,” and then they went on to further develop the argument, “Just ask parents and young people about the future of such
children” (Carey, 2012). Overall, agreements in this sample functioned as a way to support the ideas of others, something that is common in online commenting.

A look at the conversations in the sample showed that most of them featured disagreement between the commenters. This not only further highlights the polarizing nature of the subject, but it suggests that, when it came to responding to another commenter, people were often more motivated to respond against those that attacked their views than those who shared them. Perhaps this is true of most polarizing conversations on the internet, and something to be studied later. For the purpose of this project, this analysis serves as evidence that there was a lot of disagreement between commenters in the sample and that it was often taken personally by those with a first-hand experience of the disorder. I argue that this reinforced the argument that when it comes to issues of mental health, it is hard for people to disassociate themselves from the arguments made.

5.5.4 Views of Autism

The next section of analysis focused on studying the context surrounding autism in the sample. As has been done in Chapter 3 and 4, the code group Context, analyzed the ways people perceive autism and how this impacts their understanding of the disorder. Understanding the views of autism is necessary in order to analyze the perceptions of people with an ASD diagnosis; therefore, this section of analysis provides valuable context to the overall goal of this chapter.

In this sample, the majority of mentions of the disorder refer to autism as a spectrum. This is interesting because it suggests that at least this part of the
recategorization has been absorbed by the general public, who have adopted the
term to describe the disorder. Furthermore, an analysis of the quotes under the code
*spectrum* reveal an interesting trend; even though spectrum is often used as an easy
way to refer to the entire set of developmental disorders now absorbed into ASD, it
is not used as a replacement from more specific terms like Asperger’s or classic
autism. That is, I found it very interesting that commenters that used the term
spectrum often also felt the need to specify other terms within it during their
discussion. For example, comments like, “I do believe Asperger’s should remain on
[the] Spectrum but, it seems more different from classic Autism and high
functioning individuals can’t relate,” show a conflict between recognizing autism as
a spectrum and combining previous diagnoses under one label (Parry, 2013). In
order words, accepting the recategorization of autism as a spectrum is not the same
thing as discontinuing the use of the other diagnostic labels that have been
eliminated from the *DSM-5*. Commenters often support both ideas in their
arguments, accepting the recategorization into a spectrum while at the same time
refusing to let go of the distinct labels within it. Perhaps this is something that will
fade with time, and years from the release of the *DSM-5* this will not be the case
anymore. However, as far as the conversations held during the revision of the *DSM-
IV*, the duality of recognizing both the spectrum and disorders within it was very
prevalent.

This duality trend seen with the use of the term spectrum is further
reinforced when analyzing the code *mild autism*. During the coding process of this
sample, it became apparent that there was a need to track all of the instances where commenters referred to the concept of mild autism. This concept was present in a variety of different forms and language such as high-functioning autism, Asperger’s, high-end of the spectrum, etc. Analyzing the quotes under this code reveals that commenters often see a stark difference between each end of the autism spectrum, and this difference is hard to ignore. For example, one mental health professional commented, “I’ve met a few kids who inexplicably carry this [Asperger’s diagnosis] ... and they seem to stand in marked contrast to classically autist children” (Carey, 2012). However, regardless of this difference, commenters do not argue against recognition of a spectrum. The main issue seen in the comments is that because mild autism is so different from what has come to be known as classic autism (the acute end of the spectrum), confusion and misunderstandings can lead to the misrepresentation of people in the spectrum (misrepresentation that can impact the eligibility for services). For example, a commenter said, “the fact that some higher-functioning people can lead independent lives doesn’t mean that other people on the autistic spectrum don’t legitimately need help” (Carey, 2012). The problem, it seems, is that grouping mild autism under the wide label of ASD blurs the fact that people in the spectrum need varying levels of support and treatment. People close to the classic autism end of the spectrum argue that those with mild autism do not need the level of support needed at the other end, while individuals closer to the high functioning end reject a label that suggests that they do not have the ability to live full and fulfilling lives. This
contrast between the ends of the spectrum is further discussed in the section for MODs.

The next most prevalent code deconstructing the context of autism in the sample was *social problem*. *Social problem* was an interesting code that, although created at the beginning of this project, became particularly significant in the analysis of this chapter. The code tracks all instances in which autism is presented as being a social construct that needs to be addressed in a social context. This can take several forms, ranging from being a health issue in need of support through funding and research to a social phenomenon related to who gets access to resources. The fact that autism is often seen as a social problem in this sample suggests an attempt to separate the issue from a purely psychiatric concern to the hands of social policy. In other words, instead of seeing autism solely as a psychiatric disorder falling within the purview of the field of psychiatry for treatment and study, autism is perceived as something that should also be addressed by social means. When viewed in this way, the recategorization of autism is seen to be a change in language with the purpose of impacting these social practices, and not only to further the scientific understanding of a psychiatric disorder. For example, one commenter argues:

These “experts” have had enough time to figure out what causes autism and which treatments are most effective. Why don’t [sic] they just be honest and fess up that this new “definition” is really a cover for cutting programs since health insurers are nervous about now having to cover therapy for it in NYS [New York State]. The idea in the pipeline is to pass on more costs onto parents already (Carey, 2012).
This comment highlights a feeling of distrust about the motivations to change the categorization of autism. The argument made by this and other commenters is that changing the definition of autism is not just something that advances the study of the disorder, but something that actively changes the way autism is handled in social terms. Therefore, a discussion of the value of the recategorization of autism is often riddled with concerns of whether or not the social impact is positive or negative. This stands in marked contrast to the views from the field of mental health analyzed in Chapter 3, where value of the recategorization is seen as depending solely on whether or not the research supporting it is valid and how well it furthers the understanding of the psychiatric disorder.

Finally, the fourth most prevalent code used to study the context of autism was disability. An analysis of the quotes associated with this code shows a common trend in the sample to argue that ASD is disabling. Reading the context of these comments made me realize that this argument is a response to comments that say autism is over diagnosed and/or not a real disorder. For example, a commenter replying to one of these allegations stated, “Asperger’s is not a mild form of anything. It is fiercely disruptive, and has the capacity to utterly wreck the lives of most who suffer it” (Carey, 2012). Another interesting insight from this code is that the argument for disability is often made by parents as a way to make the case that they are not overreacting or seeking a diagnosis on a whim. Instead, parents argue that ASD causes significant impairment in the lives of their children and families and, therefore, access to resources is paramount. Perceptions of ASD as a disability
play an important role in the creation of identities for people in the spectrum. Parents may be making a case on why their children need access to services, but they are also creating a narrative that paints the identity of their children in a particular way.

Overall, the context surrounding autism in this sample provides a basis for understanding the perceptions surrounding people with an ASD diagnosis. The major codes analyzing context show that autism is perceived as a spectrum, a collection of distinct disorders like classic autism and Asperger’s, a social problem, and a disability. Although at face value these different views of the disorder may seem to be contradictory, I argue that they exemplify the issue is multi-layered and that more than one perception of it is valid.

5.5.5 Markers of Difference

Marker of difference (MOD) codes were created to analyze the ways in which people identified themselves and others in the sample. There were a total of 21 MODs identified, but this section will focus on discussing the most prevalent ones. MODs are integral in the analysis because they are the words or descriptions used by commenters to construct identities.

The most prevalent MOD in this sample was to self-identify as a parent of a child in the autism spectrum, marked by the code parent. Commenters that identified themselves to be parents often did so as a way to strengthen their arguments by citing their first-hand experience with the disorder. One example of this is the following comment:
As the mother of a child with PDD-NOS and therefore someone who has become very familiar with these disorders and the kind of rigorous diagnostic evaluations that people in the spectrum must endure, I strongly disagree. My son had no fewer than five evaluation before he received his official diagnosis (Carey, 2012).

In this comment, a mother implies that people who are not parents don’t know how difficult it is to obtain eligibility for services or that the process is not legitimate. In making this assertion, the commenter and others who made similar arguments are both creating a narrative of themselves as a concerned parent that has struggled to secure care for their child and a narrative of the other who cannot empathize because they are not parents to a child with ASD. This same argument was identified in the sample in two forms: identifying oneself as a parent (marked as parent) or identifying another commenter as not being a parent (marked as not parent). Although in essence both of these MODs are making the same claim, I found it interesting that some commenters went beyond identifying themselves to actually make claims about the identity of another person. For example, in a direct reply to another comment, a commenter said, “[...] there is such a thing as abnormal. If you had an autistic or developmentally disabled kid you’d know it” (Carey, 2012). I argue that this is a more aggressive version of the parent code because, instead of making a general statement about people who are not parents to an autistic child, these comments are making a very concrete claim about the identity of one specific person. The effect is the same, and a difference is acknowledged between those who have lived through this with a child and those who haven’t.
Another MOD that was associated with the parent/not parent MODs was captured through the code bad parent. These MODs are associated because, in most instances, attacks against parenting were either the inciting comment that led to a string of responses that featured the parent code, or they were reactions to these arguments. For example, the comment, “[...] the parent is in denial and cannot accept that they have a discipline problem,” was one of the ones that spurred a series of responses from parents. Commenters that used bad parents MODs did not necessarily identified themselves to be parents, but they did identified others as bad parents that create a problem of over diagnosis and abuse of resources. In other instances, the bad parent MOD appeared as a response from argument made by parents. The following comment was a response but it features the same argument as the previous one, “don’t listen to the self-serving helicopter parents! Autism exists, but it is relatively rare” (Carey, 2012). I believe that looking at all three MODs (parent, not parent, and bad parent) gives a more complete picture of the way in which parenthood was represented overall in the sample.

The next MOD found in the sample, marked under the code autist, identifies a commenter as being on the spectrum. While coding for this MOD, I made the decision to include people who claimed to have an official diagnosis, a self-diagnosis, or made no assertion as to either because the official standing of the diagnosis was not relevant in the analysis of how a person identifies oneself (even though this can impact the way others perceive them). This MOD was used similarly to the parent MOD in that it became support for the arguments made by a commenter. People
identifying themselves on the spectrum often gave descriptions of their own experiences with the issues being discussed by others. For example, a commenter explains, “As somebody who was diagnosed with Asperger’s before my Grade 12, I have been greatly helped by the services I have been able to access” (Carey, 2012). This in turn reinforces the argument that limiting eligibility to services will cause a negative impact in the lives of those on the spectrum because services are necessary for many of them. Another insight from this code is that people who identify as being on the spectrum have a unique perspective that nobody else can have; they experience the mental impairments that are not visible to others. For example, one of the commenters identified as having ASD makes this claim: “All the years of learning to just say, ‘Oh, I am fine,’ to questions no one really wants an answer to doesn’t mean our difficulties do not exists, just that a stranger does not see them” (Davide-Rivera, 2012). I believe this is an example of the way MODs can not only create the identity of a person but they also empower their view over that of others. In the case of the previous quote, the argument is that, because ASD is a mental disorder, only someone experiencing the disorder can know exactly what it feels like, and that means that other people who are not in the spectrum have no authority to deny their experience. I argue that this makes MODs powerful factors in the discursive construction of an ASD identity.

Another significant MOD used in the sample was coded as insider. This MOD was somewhat similar to the parent/not parent in that it was used to denote that the commenter had significant experience in the subject though their proximity,
familiarity, experience, or unique understanding of ASD. This MOD was interesting because it opened up the in-the-know bubble to include other people who are not necessarily parents of a child on the spectrum or a person with an ASD diagnosis. Unlike the previous MODs discussed above, the MODs used by insiders were less direct. For example, one comment stated, “I sincerely doubt you have ever met or spoken to any parents of autistic children” (Carey, 2012). The author of this comment doesn’t make a direct claim about who they are, but they do insinuate that they know at least one parent who has an autistic child. This assertion is enough for the commenter to support the rest of their argument. Another example of a comment that makes a similar indirect claim about the identity of another commenter stated, “I hope no one you love ever has to deal with a developmental disability” (Carey, 2012). This commenter makes the assumption that because someone else is not empathetic to the issues of families dealing with autism it must surely mean that they don’t have any family member that has gone through something like it. In essence, they are making the assertion that discounting the hardships of families dealing with autism is a sign that someone is an outsider. This kind of othering is powerful, and further supports the divisive nature of the issue of the recategorization.

The next pair of MODs highlights a continuation of one of the most salient trends of this entire chapter, the clash between classic and high-functioning autism. The codes *autism vs Asperger’s* and *Asperger’s vs autism* represent two sides of the same coin or, more fittingly, two ends of a spectrum. It was clear that several
comments made a point to remark on the differences between each end of the spectrum. Although some of these differences have already been tracked through other codes like *mild autism*, these MODs tracked specific instances where the differences between the ends of the spectrum were presented as a way to mark difference between people other than their diagnosis. For example, in the comment, “I have a 16-year-old with classic autism and have been shocked at some of the kids who have the label and are getting services as I can barely detect anything out of the ordinary” (Carey, 2012), the commenter not only described the differences between levels of autism but they also insinuate that people in the higher end of the spectrum are getting services that they do not deserve. This kind of language is divisive in a different level than just the range of the spectrum because it encompasses not only the children with autism but their parents as well. Similarly, a quote marked by the *Asperger’s vs autism* code remarked, “[...] I don’t even look like I have autism so not everyone believes me which is worse than having people care for you 24/7 I can assure you” (Robinson, 2012). Once again, the differences between the range of the spectrum are used to create different groups of people, groups that are in opposition to one another. Although these two codes were not as prevalent as the other MODs that have been discussed, I believe that these still shed a light on the trend of comparing classic and high-functioning autism.

Finally, the MOD *Autist vs doctor* was a very interesting and surprising one to find in the sample. The reason it was surprising and singular among the rest is that this MOD only appeared in the comments of one sampled article, the advocacy
blog. This code was developed to track all the instances where people with autism
remarked having more insight into their condition than mental health
professionals. For example, in a discussion of the new criteria for ASD, a person
with the diagnosis remarked, “I’m not surprised at all because it shows how much is
still unknown about autism. When I say unknown I don’t mean unknown to us
autistics but to the others” (Davide-Rivera, 2012). Comments like this highlight one
of the most important facts related to this topic, people in the spectrum have unique
insight that those outside it can never have (even the people who study the
condition). I believe this is one of the most drastic walls built to separate two groups of people, one that can’t be easily breached. Reading through the comments made in this blog made me wonder if the reason why this MOD only appears in this space it’s because it is perceived as a safe space by those with ASD. Given that only one of the advocacy articles sampled in this dissertation had a commenting feature, this is a hypothesis that can’t be proven in this project. However, it is a question worthy of further study.

In summary, the analysis of MODs in the sample highlights the differences between groups of people created by the commenters. The fact that three of the major MODs identified were associated with parenthood is evidence that parents are a big part of the conversations about autism because this is a disorder that is most often first diagnosed in childhood. This, for example, might not be the case for disorders associated with adulthood, like depression. Another major insight from the analysis of MODs is the construction of difference within and outside of the
spectrum. It is clear that there is an undeniable difference between each end of the autism spectrum. And the analysis of the comments in the advocacy blog shows that there is a definite division between those who are in the spectrum and those who are not. The insights from this part of the analysis then serve as the foundation of the analysis of the construction of an ASD identity.

5.5.6 Constructions of Identity

In Chapter 4, an analysis of the construction of identity for people with ASD in the media coverage of the recategorization identified two distinct identities being constructed, one for classic autism and one for Asperger's. A similar analysis of identity construction in this chapter yielded similar results, although these were more complex in nature. The codes *ASD Identity* and *ASD Disability* (part of the Identity code group) were among the most prevalent in this chapter, indicating that perceptions of people with ASD were a significant part of the conversation analyzed. In addition to these two codes, the code *Asperger’s Identity* was also a fairly used and focused on specific descriptions of people on the higher end of the spectrum, the one associated with an Asperger’s diagnosis. An analysis of the comments marked by these codes, and how the codes interact with one another and other codes in the sample, allows us to piece together the ways in which people with ASD are painted by public comments.

At first glance, one of the most salient details when looking at the code distributions of the Identity codes is that the codes *ASD Identity* and *ASD Disability* overlapped a third of the time. That is, of the total 35 and 29 times each code was
used, respectively, 11 were coded together. In contrast, there was no overlap between the codes *ASD Disability* and *Asperger’s Identity*. These code distributions suggest that ASD in general is perceived to be a disability, but these perceptions don’t necessarily encompass people with a previous diagnosis of Asperger’s. However, even though a quick overview of the comments in the sample might support this finding, I found that a closer reading of the comments reveals a more complex state of affairs.

In order to take a much closer look at what was being said about people on the spectrum, I went through each comment and wrote down all of the descriptions about people with autism used by commenters. I was extremely detailed in this step, and was careful to write all the keywords that create a picture of the people being described. I first focused on analyzing all of the comments that were tracked by the code *ASD Identity* which tracked all instances of descriptions of people with ASD in general (including both ends of the spectrum). Then I made note of the similarities between the narratives in the comments and found three major trends; (1) descriptions of impairment, (2) need for services or support, and (3) snapshots of the everyday lives of people with autism. The first and most salient trend focused on describing a type of impairment or problem associated with autism. Many of the comments discussed developmental delays, social problems, rituals, language issues, sensory issues, deficits, disability, debilitating conditions, and stigma associated with the disorder. A common example of this is exemplified by the comment, “my teen son is non-verbal, cannot sign, is on risperdal, functions at
about an 18 month old level [...]” (Robinson, 2012). The second trend argued that people with autism need a variety of services and support, often times throughout their entire lives. Many of the comments that fit this trend argued that ongoing support is valuable for both adults and children in the spectrum, as well as their families. For example, one parent made the argument that their autistic child “will need to be constantly supervised and cared for, forever” (Robinson, 2012). Finally, the third trend featured comments that contained descriptions of the lives of people with ASD, often times from people who identified themselves as being on the spectrum. The following comment is one of the best examples of this kind of narrative:

I am the one who won’t ever get a job, will never go to a concert without fear of sensory overload (can’t even walk down the street without medication without having it) and epileptic seizures, won’t ever drive, date or have any connection with a human being. I won’t ever be able to tolerate change or live without routines, stop with the stimming or not have explosive meltdowns. And I barely talk unless medicated too, and when I talk I can barely make any sense. I have all that but to people I don’t even look like I have autism... (Robinson, 2012)

I believe this particular comment encompassed a good summary of the kinds of descriptions of people with ASD present in the comments. One of the most interesting details of this quote is that the person is describing a set of impairments that are very pervasive in their lives, but they also contrast this with the fact that these impairments are internal and invisible to others. Looking at the three trends as a whole gives us a complete image of a person with ASD as constructed by the comments. The identity of a person in the spectrum is either an adult or child that
experiences a variety of impairments, both visible and invisible to others, and often requires services and support throughout their lives. Communication, social, and sensory problems are part of the list of impairments described, and impact the quality of life of the individuals. It is important to note that these kinds of descriptions are usually associated with classic autism, but in this sample they apply to the overall perception of someone with a general ASD diagnosis.

The next step in the analysis of identity construction was to analyze the text of all the comments marked by the code *ASD Disability*. The comments tracked by this code specifically framed an ASD diagnosis as a form of disability. Following the steps detailed above, I took note of all the words and phrases used to describe autism in this context. At a simple glance, there are a lot of similarities to the descriptions provided in the previous paragraph describing impairments of the disorder. The main difference was that impairments were specifically defined as disabling and pervasive. For example, one commenter described the spectrum as “a true neurobiological disability” and that the kinds of impairments associated with it require medical attention (Carey, 2012). Another difference is that the comments under the code *ASD Disability* often included words that emphasized the level of impairment. That is, words like serious, constant, persistent, and severe were used to emphasize that degree of disability experienced by people in the spectrum. For instance, an Autistic Support teacher claimed, “I have students who range from fairly high-functioning to severely disabled, nonverbal with clear cognitive impairments” (Carey, 2012). This particular quote also highlights a tendency to
specify that disability is more present at the more acute end of the spectrum, and therefore more associated with classic autism. Another commenter made the same distinction; “a child with moderate-to-severe autism might have been kept home or institutionalized as mentally retarded” (Carey, 2012). Consequently, the analysis of the code *ASD Disability* showed that people with ASD, especially the ones at the more acute end of the spectrum, are perceived as having a disability that permeates their entire lives.

Finally, I analyzed the language used to describe individuals who are in the high-functioning end of the autism spectrum, marked by the code *Asperger’s Identity*. Although, technically, all descriptions of someone in the higher end of spectrum are part of the overall perceptions of people with ASD (and were included in that analysis), I decided to analyze these separately due to the other findings in this and the previous chapter. That is, throughout the sample there has been a consistent emphasis on making a distinction between classic autism and high-functioning autism/Asperger’s, an emphasis that was present in the descriptions of people with ASD. Therefore, an analysis of the comments that address high-functioning individuals gives us insight into why these two groups of people are perceived as distinct from one another. The most surprising finding in this part of the analysis was that descriptions of people with Asperger’s/high-functioning autism are remarkably similar to those associated with classic autism. People on the higher end of the spectrum are described as having pervasive social, communication, and sensory issues as well as needing a range of services and
support throughout their lives, just like the descriptions of people in the low end of the spectrum. For example, a commenter explained, “Asperger’s is viewed as mild and not very disabling, but my son had a breakdown due to the social and sensory torture he endured for only a few short weeks at a secondary school” (Davide-Rivera, 2012). Comments like this reinforced the idea that Asperger’s, although considered to be in the high-functioning end of the spectrum, still represents a variety of impairments that are very disabling to the people with the diagnosis.

So, if people at both ends of the spectrum are perceived so similarly in the sample, why is there such a distinction between them? The analysis of the code Asperger’s Identity revealed two answers to this question; (1) people with Asperger’s feel like outsiders in the ASD community and (2) they provide a counter narrative to the idea that people in the spectrum can never live normal lives. Throughout this chapter, the conflict between people at each end of the spectrum has been discussed in the analysis of codes mild autism, autism vs Asperger’s, and Asperger’s vs autism. A summary of that conflict is that even though Asperger’s is accepted as part of the spectrum, the question of whether they deserve the same kind of support like people in the lower end causes animosity between the two groups. Based on several of the quotes that have been presented throughout this chapter, I believe the key to this animosity is that the impairment experienced by people in this higher end of the spectrum is more internal and not as visible to others like the kind of impairment associated with classic. That means that people with Asperger’s, who appear more “normal” than others in the spectrum, are often doubted and accused of taking
advantage of the services meant for people with more severe impairments. This rejection from the ASD community is one of the reasons why people with Asperger’s have felt the need to create their own community and identity. This was explained by one commenter:

It is also worth noting that Asperger’s is an identity for us Aspies. We have spent lifetimes feeling like outsiders. Our identity is a powerful source of strength. “Autism Spectrum Disorder” feels too clinical to express all that. It may seem a silly point of contention, but the emotional effect of stripping a group of people of an identity term is nonetheless real. (Lutz, 2013).

Aside from feeling like outsiders, people in the higher end of the spectrum provide a counter narrative to the one that paints them as disabled and nothing more. In the advocacy blog, a safe haven for people with Asperger’s, several commenters argued that despite their impairments they are able to live full and successful lives. Several of the commenters who identified themselves as having Asperger’s talked about having children, going to college, and having a professional career, something that seems unlikely when reading some of the other comments stating that people on the spectrum can’t lead normal lives. The commenters also argued against the idea that being successful is incompatible with an ASD diagnosis. For instance, one commenter asked, “I wrote a book that is doing well, I write for answers.com about autism, does this mean I am no longer autistic because I have some degree of success?” (Davide-Rivera, 2012). Interestingly, this argument was not limited to only those who are in the higher-end of the spectrum. The same commenter also argued that people like Temple Grandin (an autistic woman that fits the classic autism box) is also very successful and this does not cancel out her diagnosis.
(Davide-Rivera, 2012). So, the reason why people with Asperger’s, despite their similarities to the rest of the spectrum, are perceived as distinct is that they often straddle the line between autistic and normal, with invisible impairments and seemingly normal lives, and this has led to the need to claim a name and community of their own. This, I argue, is why the distinction cannot be ignored or erased and permeated the conversations among the commenters in this sample.

5.6 Summary

To summarize this chapter, the analysis completed showed that the public response to the recategorization of autism was complex, multifaceted, and permeated with divisions between groups of people (such as parents vs non parents, autistic vs non autistic, insiders vs outsiders, high end vs low end of the spectrum, etc.). One of the findings was that although a majority of commenters expressed disagreement with the changes to autism, many others also expressed positive or nuanced views as well as uncertainty. Another finding was that Asperger’s was found to be an integral part of the conversation and a term often mentioned in equal standing to that of autism and ASD. The analysis also highlighted the use of MODs used by commenters to both strengthen their positions and diminish those of others as well as a way to create an identity for themselves. Together, these findings provide the necessary context to understand the ways in which people with ASD are perceived by the public.

The major finding of this chapter was that even though two distinct identities are being constructed, one for classic autism and one for Asperger’s, both are
blended together to create a cohesive identity for all people in the spectrum. The comments analyzed in this sample discursively construct the identity of people with ASD as a person with several disabling impairments, both visible and invisible, that needs continuous support. This identity applies to everyone in the spectrum. Nevertheless, the collective identity created for people with Asperger’s before the recategorization of autism has survived the revision of the DSM and now lives within the identity of people with ASD as a caveat of sorts; even though all people in the spectrum have disabling impairments and need continuous support, some in the high-functioning end of the spectrum are able to lead fulfilling and successful lives. The caveat is not always recognized in the sample of comments, but it is definitely there. Furthermore, the findings of this chapter show that, overall, people with an ASD diagnosis are perceived as disabled, no matter where they fall on the spectrum.
6. DISCUSSION AND CONCLUSION

6.1 Overview

The main research focus of this project was to explore the ways in which changes to the *DSM* were disseminated through media, absorbed into public discourse, and in turn contributed to the discursive construction of identity of people with a mental health diagnosis. The case of the recategorization of autism in the most recent revision to the *DSM* was chosen as the most effective way to explore this issue because of the extent and visibility of the changes. In order to analyze this research question, an ethnographic content analysis (ECA) was conducted to study the *DSM* text, media articles published on websites, and public comments on the subject.

This study was situated within a gap that exists between the fields of Disability Studies and the Rhetorics of Health and Medicine, the emerging field of Rhetoric of Mental Health. Over the last couple of decades, the field of Disability Studies has emerged to address how disability is constructed in our world through social structures and discourse. The work in this field has become increasingly influential and has led to major changes in how we view and address issues of disability, especially within higher education itself (Guest Pryal, 2017). The field of Disability Studies provided valuable structure to analyze the ways in which mental health diagnoses can be perceived as disabilities and in turn create disabled identities for the people that carry a diagnostic label like autism. Similarly, the field of Rhetorics of Health and Medicine has become integral to the exploration of how
discourse about medicine has real and crucial implications on how we view and
treat disease (Keränen, 2007; Kopelson, 2009). The theoretical framework for this
field has also been incorporated into this project in order to examine the way mental
disorders are categorized and how this impacts the lives of people with these
diagnoses. Although both of these fields appropriately frame some important
elements of the current study, mental health disorders have unique circumstances
that require a more targeted approach. That is to say, unlike diseases like cancer or
disabilities like deafness, mental health disorders are intrinsically related to a
person’s identity because they primarily impact the mind instead of the body.
Therefore, to study the way mental health is socially constructed and the way it
becomes enmeshed with a person’s identity, there is a need to take into account the
connection between the mind and identity. This gap in the research is addressed by
the emerging field of Rhetoric of Mental Health, and this dissertation aims to fit
within this new area of study. The complexity of the questions addressed in this
field is best addressed through interdisciplinary collaboration and create a space for
a variety of methodologies. With this goal in mind, this project brings together
works from a variety of disciplines and fields, utilizes a mixed methodology
approach, and encourages others to explore this topic from different perspectives.

Coming into this project, I knew that the recategorization of autism was
going to be an important subject of research in the coming years. However, I never
quite expected how important the subject would be outside of academia as well.
While working on this project, I have been lucky enough to participate in
discussions about autism with a wide range of people, from colleagues to family and friends. I was surprised more than once when the mention of the topic of my dissertation was met with enthusiastic curiosity and interest. From these conversations I gathered that people were very often interested in the recategorization, and surprised that Asperger’s Disorder had been incorporated into the spectrum. This same interest was found in my research and analysis of public comments. Questions about autism are relevant, I realized, because they are important to many people; be it because they know someone on the spectrum, are on the spectrum, or because autism is linked with education issues that are salient for many parents, educators, and communities as a whole. Hence, this study brings to the foreground public concerns regarding mental health that require further research.

By and large, working on this project has been a very enlightening process that has raised many questions and shifted some of my own perceptions about mental health. Although coming from a background in the field of psychology provided me with a unique insight into the workings of the diagnostic process, it has also become clear to me that I harbored many assumptions about mental health that were put to the test during this study. For instance, analyzing the language and word choices in the sampled texts forced me to also reflect on how I describe issues of mental health. Consequently, a discussion of my choices became a part of this dissertation and was addressed in the introduction. This and other moments of
personal reflection have led to the project presented here, and it is my hope that the insights of this study motivate others to reflect as well.

6.2 Discussion

6.2.1 The Recategorization of ASD

Throughout this study, an analysis of the recategorization of ASD has provided an effective context to the impact of diagnostic labels on the construction of identity. Although it is not the label itself that changes who people are (Hacking, 2007), the way labels are understood and constructed impacts the perceptions of people. This project has explored the way in which several diagnostic labels have changed in the most recent revision to the *DSM* to become a unified spectrum. This change has been extensive and has followed a complex path from the change in the *DSM* to public discourse.

The analysis of the recategorization of autism began in Chapter 3 with an exploration of the changes in the *DSM-5* and the professional discussion of them in the literature. This stage of the analysis revealed the existence of a dual and parallel framing of the recategorization by the field of mental health. On the one hand, the *DSM*, as an authoritative text with the goal of providing a classification of disorders for practice and diagnostics, framed the recategorization of autism as a valid change that better reflects the scientific understanding of the disorder. The *DSM-5* constructs autism as a spectrum disorder that combines the previously separate diagnoses of Asperger’s Disorder, Childhood Disintegrative Disorder, Autistic Disorder, and PDD-NOS. The text of the *DSM-5* focuses only on
highlighting that the recategorization was based on years of careful and objective research that supports the new understanding of the disorder. On the other hand, a second framing can be found in the professional conversations about the recategorization published around the time of the revision. Professionals in the field of mental health, aside from discussing the validity of the changes, framed the recategorization in terms of its potential impact to the lives of people with an existing diagnosis. That is, the experts in the fields of psychology and psychiatry were often concerned with the conundrum of reconciling the impact to the lives of people with the necessity to advance psychiatric science. Changes to the classification of disorders do not happen in a vacuum, and it is impossible to separate them from the real life consequences from revising a text like the *DSM*. Changes to the categorization of autism were necessary, but that also meant that people would fall between the gaps during the transition to the new diagnosis. Therefore, even though these two framings of the recategorization were equally important and present in the expert conversations of the field of mental health, they remained parallel to each other and never able to converge. This duality of framing was very salient in the literature published during the revision of the *DSM* but, because of the limited scope of the *DSM* text itself, only the framing of validity is actually present in the *DSM-5*. Consequently, reading the *DSM-5* without the context of the literature published around it results in an incomplete story that fails to represent this inherent conflict between validity and impact.
The analysis presented in Chapter 4 explored the way the recategorization of autism was presented by the media coverage of the issue. For this stage of the analysis, I sampled the most visited web articles and advocacy websites that reported on the recategorization of autism between November 2011, when the changes were announced, and December 2013, seven months after the publication of the DSM-5. This part of the analysis revealed that, although the same duality of framing was present in the media coverage, the parallel framing was constructed in a different way. Specifically, the media coverage sampled in this chapter reported two framings of the recategorization; one of validity from the DSM and experts in the field of mental health, and one of impact from advocates and parents of children with autism. Therefore, even though both framings from Chapter 3 were also found in this part of the analysis, their sources were different and hence came with different contexts. Overall, both news and advocacy website presented the recategorization of autism as a valid change, heavily supported by references to the DSM-5 text and the testimony and quotes from experts that were involved in the revision process. However, media coverage also framed the recategorization as having the potential to impact the lives of people with a previous diagnosis by endangering their eligibility and access to services. This second framing was only attributed to advocates, parents with children of autism, and people with autism and, therefore, did not reflect that several professionals in the field of mental health voiced identical concerns in the literature published during the revision of the DSM-5. This disconnect between these two parallel framings served to widen the distance
between them, and gave the impression that professionals within the field of mental health were not concerned with impact at all.

The third stage of the analysis, presented in Chapter 5, focused on studying the way the framing of the recategorization presented by media coverage was absorbed by the public and reflected in the comments published on select websites. In order to fit the scope of this project, a small but representative sample of public comments was collected from the websites identified in Chapter 4 to accomplish the goals of this chapter. According to the analysis of this sample of comments, both of the framings presented by media sites were identified within the comments to these articles, but they were not necessarily mirrored by public opinion. An analysis of public comments revealed that the majority of people viewed the recategorization as a negative change, often questioning the validity reported in the media. Although the framing of validity was present in public comments, it was overshadowed by heavy concern about the potential impact to people with a previous diagnosis. That is to say, that the second framing, the one focused on impact, was by far more relevant to commenters. Individuals with an ASD diagnosis, parents and educators of children in the spectrum, and other advocates voiced their concerns about impact and steered the public conversation to focus on this framing over that of validity. Because of this imbalance, the gap between these two parallel concerns widened even more and led to animosity and extreme divisiveness between groups of people.

The analysis of these three sites (the DSM, media coverage, and public comments) revealed two parallel framings of the recategorization of autism, one of
validity and one of impact. The way these two framings were constructed, and who they were constructed by, influenced the conversations about the recategorization and provided the context for the construction of the identity of people on the spectrum. The fact that these two framings do not converge suggests that they are not mutually exclusive. In other words, the recategorization of ASD can be valid without negating the reality of its impact. This conflict, reflected in the literature about the recategorization, leads to the divisiveness seen in the public comments analyzed in this project. When viewed from the perspective of the field of mental health, it is extremely important to continue to revise the DSM to reflect the current understanding of psychological phenomena and research in the field, even if this has a negative impact on some people caught in the transition. When viewed from the perspective of people on the spectrum, and those close to them, concerns about the impact of the recategorization are front and center because they have the potential of changing their lives in very real and meaningful ways, even if the change is valid. Both perspectives have merit, but only a small number of commenters were able to concede the importance of both. Consequently, the conflict emanating from this duality of framing regarding the recategorization is integral to the understanding of how the identities of people in the spectrum are constructed.

6.2.2 Constructing the Identity of People with ASD

One of the main goals of this research study is to explore the ways in which we talk about mental health and their effect on the public perceptions of people with a mental disorder. This is an important research goal because, although
mental health disorders are real phenomena their context is a social construction. The stigma associated with some mental health disorders is caused by the language we use to define, describe, and discuss them, not the existence of the disorder itself. Scholars such as Wilson (2003) have argued that disability has been conceptualized as an error, something that has gone wrong with the body, through the language used to describe it in the medical field. This construction of disability is then transferred into the identities of people whose bodies have been identified as defective in some way. The *DSM* is one of the most influential texts in the field of mental health in the US, and the language it uses to describe mental disorders impacts they ways in which they are socially constructed. For this reason, this research project investigated the ways in which the recategorization of autism in the latest *DSM* has contributed to the construction of identities of people with the disorder.

In Chapter 3, the text in of the *DSM-5* was analyzed in order to deconstruct the recategorization of autism. As discussed earlier, the recategorization consisted of the combination of four previously separate disorders into one unified spectrum, ASD. According to the *DSM-5*, autism was recategorized into a spectrum because the four disorders involved weren’t that different from one another, and research showed that they were in fact different representations of the same underlying condition. Because of this, the disorders were recategorized into a spectrum with differing levels of impairment, and individuals with any of the previous four diagnoses are now grouped together under one label. According to the new
diagnostic criteria, someone with ASD is characterized as having a life-long condition that causes impairments in two areas of their lives. The first area is social communication and it is described as having difficulty with verbal and non-verbal communication, ability to form and maintain relationships with others, establishing emotional connections with others, ability to relate to peers, lack of eye contact, etc. The second area is described as restrictive and repetitive patterns of behavior, interests, and activities which can range from repetitive motions, sensory sensitivity issues, insistence on routine, and intensity of focus, among others. In order to receive a diagnosis, there must be a history of impairment in these two areas and the impairment must be significant, present from early childhood, not caused by other forms of disability. Once diagnosis is conferred, a person is placed in one of three levels of severity that are based on the amount of support required. The levels of severity range from “requiring support” to “requiring very substantial support” (APA, 2013). Given the way ASD is constructed in the DSM, it is clear that the diagnosis is irrevocably linked with severe impairment that requires at least a minimum of support to overcome. Consequently, the diagnostic criteria for ASD constructs an image of a person with the disorder as someone who struggles with social communication, performs a variety of strange behaviors, and is in need of constant support. This in turn becomes a disabled identity for the person with the diagnosis, regardless of where they fall on the spectrum.

This construction of ASD in the DSM-5 was reflected in the way the news was presented by the media. In the new diagnostic criteria, impairment is not only
a big part of the diagnosis but a requirement, and this particular point heavily influenced the way media coverage approached the subject. In Chapter 4, an analysis of the sampled media coverage of the recategorization of autism showed that there was an overwhelming focus on the impact to services and support for people affected by the changes. I argue that this focus on services is a result of the presentation of ASD as a disability marked by a need of services in the *DSM-5*. Because impairment was front and center in the diagnostic criteria for ASD, media coverage focused on issues like insurance coverage and eligibility for services when presenting the topic. Similarly, the emphasis on impairment and need for support sparked particular interest on the fate of people with Asperger’s. Media often presented people with Asperger’s as highly functional individuals, where their impairments are seen more as quirks and eccentricities that contribute to their almost genius representations in popular culture. Therefore, this view of a highly-functional group of people clashed with the heavily disabled identity being presented by the new *DSM*. This clash led to a concern of whether people with Asperger’s would qualify for the new diagnosis and whether they could be grouped with the rest of the spectrum. Due to this, the media coverage of the recategorization was not able to reconcile the identities of people with Asperger’s and classic autism into one and ended up presenting both. This presentation of separate identities for people on the spectrum is a good example of the general unease of grouping two groups of people perceived as widely different into one single identity.
The last stage of analysis of this project focused on studying the general public's reception to the coverage of the recategorization of autism. One of the main findings reported in Chapter 5 was that public comments absorbed the media's unease of grouping people from each end of the spectrum together under one diagnosis. Commenters were often concerned with the impact of grouping people with such a wide range of needs under one diagnosis, citing issues that may arise related to insurance coverage, access to services, and education needs. Similarly to what was seen in media reports, the analysis of comments about the recategorization of autism argued for the existence of two distinct identities within the spectrum, one for what has come to be known as classic autism and one for the high-functioning end of the spectrum (often called mild autism). However, unlike the perceptions seen in the media regarding Asperger’s as far from a disability, commenters argued that both ends of the spectrum experience impairments that lead to a need for support. In other words, the point of contention seen in the comments was not whether one end of the spectrum was disabled while the other one was not, but that a single diagnostic label erases the significant differences in levels of impairment experienced throughout the spectrum. This concern was highlighted the most in the comments from people who identified themselves as being on the spectrum, especially the high-functioning end. This group of commenters advanced a counter narrative to the one of disability by arguing that people with mild autism, although they do experience a variety of impairments like the rest of the spectrum, have the ability to live rich and fulfilling lives. And,
furthermore, the use of a single label can be useful in a clinical setting but it is a
disservice for people on the spectrum when it is used to blur their identities into
one. All in all, the analysis of public perceptions of the recategorization of autism
showed that a unified label of ASD can be both useful and harmful, depending on
the context. That is, in terms of validity, a unified label can have benefits when it
comes to treatment and research but, at the same time, a unified identity
perception of everyone in the spectrum can be harmful and a form of erasure of
diversity.

To summarize, this dissertation has studied the way the identities of people
with ASD were constructed by the *DSM-5*, disseminated through media, and
ultimately absorbed into public discourse. In the *DSM-5*, the ASD label is
intrinsically associated with a significant level of impairment in social and
behavioral areas as well as a definite need for some kind of support, which in
essence created a disabled identity for everyone on the spectrum. This perception of
people with ASD was absorbed into the media coverage of the recategorization, but
it was only applied to the people on the spectrum that fit the stereotype of classic
autism and not to the ones with a previous diagnosis of Asperger’s. As a result of
this, two perceptions of identity were disseminated through mass media; one for
classic autism that denotes a person with significant disability and in need of
substantial support; and one for people with Asperger’s that describes a person who,
although eccentric or quirky, is highly functional to the point where they need
minimal services, if any. Finally, even though these two very opposite identities
were somewhat reflected in the perceptions of the general public, these were more complex than the ones in the media coverage. The perceptions of the public showed that within the spectrum, and this overall identity of disability, people with classic autism are seen as severely disabled to the point of not being able to lead normal or fulfilling lives (a tragic life) while people with mild autism are seen as having the possibility of overcoming their disability and leading a semi-normal life. The sometimes stark differences between the two ends of the spectrum are a source of contention that reflects the difficulties of establishing an overarching diagnostic label that covers such a wide range of people. The fact that the identities for classic and mild autism tend to blend more than not is also a cause of conflict.

6.3 Conclusion

6.3.1 Implications to the field of RWS

This study is situated in a very new area of research that focuses on the rhetorical constructions of mental health. Thus, the research presented here is meant to be a foundation for more work to come. Additionally, even though several aspects of this project could be situated within either the field of Disability Studies or the field of Rhetorics of Health and Medicine, I argue that bringing together their combined insights is a great beginning for a new area of study that focuses on mental health. Issues of mental health will always be intrinsically linked with disability and medical rhetorics, but their unique circumstances require a more targeted approach that encourages collaboration with other disciplines. The study of medical rhetorics will continue to be fundamental to research on the development,
categorization, and definition of mental health issues. Similarly, the study of constructions of disability will continue to be integral to the study of stigma associated with mental illness as well as concepts of ableism. Nevertheless, the study of the rhetorics of mental health is a unique space that explores the undeniable connection between the mind and identity and challenges conceptions of neurotypicality. The findings of this project show that a mental health diagnosis is more than just a diagnostic category for psychological treatment; a mental health diagnosis actively shapes and constructs a way of being, a form of existence for the people who carry it. Diagnostic labels impact people’s lives in very real ways that can range from the type of education they have access to, the jobs they are able to pursue, to the kinds of relationships they form. And, narratives from people with a mental health diagnosis counter our ideas of what it means to be a normal person, a person with a normal brain. These complex questions are not, by any means, new. But, they are being addressed in relative isolation by scholars in several fields and disciplines that don’t have much contact with each other or a sense of community. Therefore, I argue that the emerging field of Rhetoric of Mental Health fills a gap that will foster more research of these questions and, for this reason, projects like this one play an integral part of its formation.

Another important implication is that this project’s findings about the impact of the *DSM* in public discourse highlight a need to continue to study this kind of text. The field of RWS is perhaps the best suited for this kind of analysis because of its emphasis in multidisciplinary efforts. Texts like the *DSM*, because of their
professional nature, impact not only the perceptions of people within the field of mental health but also those outside of it. Because of this unique reach and potential for influence, the exigence to continue to study its language, assumptions, and implications is key to the study of rhetorical constructions of mental health. This study contributes to this research area and opens up the space for continuing analysis of the DSM and other psychiatric texts, whether those are in the form of traditional texts or non-traditional genres.

Additionally, the methodology and kind of data used in this dissertation showcase the importance of using mixed methods and public data within the field of RWS. The main reason why I chose Ethnographic Content Analysis (ECA) as the main methodology of this project was that it was designed specifically to study online spaces. Even though other qualitative and grounded theory methodologies can be adapted to include online research, I believe they don’t accurately capture the complexity of these spaces. ECA incorporates principles from ethnographic research because it recognizes that online spaces function as living communities with active members, sets of rules, distinct cultures, moral codes, etiquette conventions, etc. Therefore, analyzing public data requires us to be mindful of the online community in which it resides. Because of this, the research presented in this project incorporated discussions of a variety of details such as special attention to commenting widgets used in websites, commenting features like the thumbs up button, ads, social media buttons and their placements, visual elements, and more. These details may seem to be superficial and unrelated to the content or data being
analyzed, but in reality they cannot be separated from it. The structure and principles of ECA require the researcher to step back, take into account all of these details, and adapt the research protocol based on data itself. This reflexivity can be challenging at times but it is also allows the researcher to analyze a variety of genres at the same time. For these reasons, I believe that a lot of different areas within RWS could benefit from incorporating ECA into their research of online spaces, and I hope this project showcases one example of how this methodology may continue to be used in the future.

Yet another implication of this research is the need to incorporate more voices of people with mental health diagnoses in our understandings of mental health construction. The field of RWS has made robust efforts to recover and empower the voices of those that have been marginalized in the past. This is evidenced by the development and importance of subfields focusing on feminism, women’s studies, queer theory, African-Americans, Latin@s, etc. In the same fashion, this project argues for the creation of a space to recover and empower the voices of people who are not neurotypical. Some of those voices were found within the samples analyzed of this study and should continue to be brought to the forefront. Within the field of RWS, such spaces are beginning to appear and should continue to be supported and empowered (Lee, 2014; Levy, 2009). For example, the Speakers Bureau is a small organization that travels to high schools and college classes and shares personal narratives about the varied experiences of mental disability (Uthappa, 2017). In doing so, they are helping to reconstruct the
perceptions surrounding mental health by providing their own narratives. The research presented in this dissertation supports these efforts as well as encourages more researchers within RWS to explore the ways in which people with a mental health diagnoses reconstruct their identities and counter the concept of the “normal.”

To sum up, the insights, methodology, and research presented in this paper have many relevant implications for the field of RWS. The combination of theory and methodological approaches is a good example of the ways in which research can be adapted to explore complex issues. This study analyzed a wide range of materials and different genres of discourse which required a flexible methodology like ECA. In addition, the analysis of large amounts of online information in this project reinforces the fact that multimedia has become integral to research in the field of RWS. I look forward to continue to contribute to the emerging field of Rhetorics of Mental Health as well as collaborating with scholars in other fields and disciplines.

6.3.2 Areas of Future Study

Given the positionality of this study in a relatively new area of research, the work presented here is only a beginning. This project explored the ways in which disability and impairment become enmeshed with the identities of people who carry a mental diagnosis by focusing only on the case of autism in order to narrow the scope of this dissertation. I believe that in the future, this same kind of research should be conducted with other diagnoses and kinds of mental health issues. The recent revision of the DSM provides a unique opportunity to study diagnostic labels
during a time of change. This opportunity was very enlightening in the case of autism, and I believe it will be equally so for the other disorders that were revised in the *DSM-5*. For example, when I was first starting this project, I considered the idea of focusing on the elimination of the bereavement clause to the diagnosis of major depression in the *DSM-5*. This case was interesting to me because the reasons for the change were related to our conceptions of grieving. That is, in the *DSM-IV*, depressive symptoms were excluded from diagnosis when they appeared within two months of the death of a loved one. This clause has now been removed based on the understanding that bereavement can last more than two months, and that it is a significant source of stress and affliction for a person. Changes like this one should be analyzed in order to study our understanding and assumptions about grieving and depression. Some scholars, like Rehavia-Hanauer (2011) have already begun to explore some of these other changes. Therefore, in the future, I hope to continue my research and analyze the revisions of other disorders in the *DSM*.

Another future area of study highlighted by this project is a need to continue to research the narratives of people on the spectrum. As I researched this subject I became interested in the narratives from people like Temple Grandin, a noted advocate of people with autism. Another important document analyzed in this dissertation was the blog of a woman with ASD that serves to both educate and advocate for people on the spectrum. The narratives of these women are powerful and provide a unique perspective into the lives of people with ASD. One of the most interesting findings for me was the idea that people with ASD are not necessarily ill
but just made differently than others. Unfortunately, the scope of this study did not allow for further exploration of these narratives, but this is something I would like to pursue in the future.

Finally, the analysis of a small sample of public comments in this study serves as a starting point for further research. Because of the limited scope of this dissertation, I was not able to focus exclusively on the analysis of public perceptions of ASD. However, given the insights gained in this project, I would like to do a more extensive study of perceptions of ASD online. Particularly, I would like to focus on blogs authored by people on the spectrum and analyze more of their content. In my experience during this project, these kinds of blogs are safe spaces for the ASD community and therefore a great window into their views. Studying the narratives of people on the spectrum is not only a great way to learn their personal perspectives but it is also a way to empower their voices.
REFERENCES


Garcia Winner, M. (n.d.). The proposed *DSM-5* changes with regard to ASD. *Autism*


Hughes, C. (2012, June 20). BBC’s Sherlock, Asperger’s Syndrome, and sociopathy. 


Strand, M. (2011). Where do classifications come from? The DSM-III, the


APPENDIX 1

Research Protocol

1. Date:

2. Publication:

3. Location of Autism (in the document):

4. Genre:

5. Length:

6. Subject Matter:

7. Author(s):

8. Ethos:

9. Context of autism:

10. How is the word autism used?:

11. How is the recategorization presented?:

APPENDIX 2

Images from chapter 4

(Source: Parry, 2013)

(Source: Raising Children Network, 2012)
(Source: Jabr, 2012)

(Source: Miller-Wilson, n.d.)
(Source: Miller-Wilson, n.d.)

(Source: Miller-Wilson, n.d.)

(Source: Davide-Rivera, 2012)
(Source: Carey, 2012)

(Source: Anderson, 2012)
(Source: CBS, 2012)

(Source: Nebel, 2013)
(Source: Autism Research Institute, 2012)
(Source: Lutz, 2013)
CURRICULUM VITA

Elsa Bonilla-Martin grew up in the border between Cd. Juarez and El Paso, TX and graduated from a local high school in 2005. That fall she enrolled at the University of Texas at El Paso (UTEP) and eventually earned her BA in Psychology with a minor in Communication Studies in 2009. That same year, she was accepted into the Clinical Psychology graduate program at UTEP where she worked as a researched assistant in the Behavioral Medicine Laboratory, a teaching assistant for several statistics courses, and a clinical intern for the Nuevo Día Study. In 2011, she earned an MA in Clinical Psychology and entered UTEP’s doctoral program in Rhetoric and Composition in 2012.

While pursuing a doctoral degree, Elsa held several positions within the university and presented in various academic conferences. She worked as an Assistant Instructor teaching a variety of courses in the Rhetoric and Writing Studies Undergraduate Program (RWS-UP) and served as a tutor in the University Writing Center (UWC). She also served as Assistant Director for the UWC and the RWS-UP program. Finally, she is currently interning at the Center for Institutional Evaluation, Research, and Planning (CIERP) at UTEP where she is part of the Research and Communications team.

Contact Information: emartin3@utep.edu

This dissertation was typed by Elsa Bonilla-Martin