Composing the Autistic Self
Current and Emerging Autism Discourses

by

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INTRODUCTION

Ethical and Methodological Considerations

The project that I initially envisioned was inspired by an article by Francisco Ortega (2009) titled “The Cerebral Subject and the Challenge of Neurodiversity,” which investigates how autistic individuals describe their brains. Ortega suggests that through neurodiversity discourse, autistic people are sculpting new forms of citizenship that are defined by relationships with and between understandings of the mind, brain, and self.

As Ortega (2009) describes, autistic people understand their diagnosis as “neither a physical (bodily) disability, nor a mental illness,” but rather a “neurological disability” (p. 453). What fascinated me was how his interviewees inconsistently ascribed pride and antagonism to their brains and oscillated in the ways they described their brains and minds as well as their spatial relationships to the body. After reading this article, I grew very interested in how understanding of neurology may impact these discourses. In particular, I was interested in how information about neurology acquired from neurological research experiences may interact with knowledge about the mind, brain, and self that individuals had acquired from school, daily life, and involvement with neurodiversity movements. Ortega suggested that autistic people are beginning to view themselves as citizens in relation both to the state and to others through their distinct biology. I wondered if the institutional and discursive space of the research laboratory facilitated this self-understanding. I had planned to investigate these interactions at an autism research lab and document the discourse of the researchers in the absence and in the presence of research.
participants and their families. In addition, I planned to interview research participants about self-understanding and ideas about their minds, brains, and selves, and throughout research participation. Given this plan, the envisioned project was likely to be largely rooted in theory and language-analysis.

A number of circumstances brought me to the project presented here. Rather than observing a laboratory, I conducted interviews with individuals, gave questionnaires to their parents, and scoured autobiographies of autistic people. I headed into the interviews with the intention of coding for references to minds, brains, and selves, with a close awareness of neurodiversity and biomedical discourse and experiences. However, after some early reading and my first interviews, I realized that a more important project was evolving.

In the eleven years in which I have consistently interacted with individuals with disabilities through volunteerism, a local soccer program I founded, and employment, I have avoided the cultivation of the naïve yet widely held belief that all disabled people are happy and blissfully unaware of their surroundings including the words said about them while they “aren’t listening” and “can’t understand.” My rich personal relationships with disabled people reinforced my belief that they are really no different than non-disabled people. Despite these relationships, I still more or less accepted research claiming that difficulties with emotional cognition are one consequence of autistic neurology. The interviews and readings that have shaped this project, however, contradicted these former beliefs and demonstrated how important it is to acknowledge that autistic people, just like neurotypicals (or non-autistic people—discussion of language to follow), are impacted by their peers. Also, the
interviews and my reading asserted that autistic and neurotypical people’s psychological well-being are equally as fragile and susceptible to many of the same influences as anyone else.

I was troubled by how urgently I felt the need to assert these observations. I consider myself an ally of disability communities and disabled people; however, I wondered, as an outsider, is “needing” to present these research findings fundamentally paternalistic? Am I overestimating and misunderstanding the needs of autistic people and the ability of neurotypicals to advocate for these needs? I hope that my asking these questions will make an impression on the reader, and keep him/her constantly evaluating my role as an ally. This feels particularly relevant as I raise questions about how neurotypicals, society, and particular discourses create oppressive and dehumanizing environments for autistic people.

Although autism research has received significant federal funding in recent years, this funding has been most generously provided to research addressing etiology and cure. Less than 1% of funding is devoted to studies striving to support autistic individuals and improving their lives (Durbin-Westby, 2010). In addition, autism research has hardly touched upon issues of quality of life, despite the fact that some studies suggest autistic people may be up to 40% more likely to be depressed than neurotypicals and also have higher rates of anxiety, among other mental health difficulties (Robertson, 2010). In this thesis, I strive to focus on autistic voices and reach outside of the bounds of medicalized language and thought and examine the forces that have led to the subordination of this group.

In particular, by identifying the ways in which autism has been understood
historically, I explain how its modern understanding has come into being. Although the rise of neuroimaging and the increasing emphasis on biological explanations of behavior have greatly impacted how we understand autism, historical understandings still inform and direct biological research and explanations. In this thesis, I point to the ways in which personal narrative discounts many of the foundational understandings of autism and call for a focus on emotionality and personhood of autistic people. I hope that my efforts to focus on autistic voices and reach outside of the bounds of medicalized language and thought, my examination of the forces that have led to the subordination of this group, and my discussions with peers and academics invested in disability rights have made this project one that does more good than harm. What follows in the next several pages is a description of the language I will use in this thesis, my methods, a discussion of my positionality as a researcher and an ally, and an outline of the rest of this thesis.

A Note About Language

Disability communities are widely debating the usage of “politically correct” “person first” language.1 Person first language refers to the act of naming a “person” prior to a diagnosis; for example, “a person with a disability, autism, an Autism Spectrum Disorder (ASD),” etc. rather than “a disabled person” or “an autistic person.” Although many people view person first language as an important linguistic tool to assert the personhood of all people and all bodies, others claim that person first

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1 “Person first” language was first recommended in 1988 in a letter to the editor of Business Week in which it was suggested that this was a more humanizing way to discuss disabled individuals (“Letter to the editor: Supportive housing needs of elderly and disabled persons: hearing before the Subcommittee on Housing and Urban Affairs of the Committee on Banking, Housing, and Urban Affairs, United States Senate, One Hundred First Congress, first session on S. 566 ... the National Affordable Housing Act, June 2, 1989,” 1988).
language discounts the importance of disability to one’s identity and that it suggests that a diagnosis necessarily invalidates personhood and is something from which individuals should distance themselves. Allegra Stout, founder of Wesleyan Students for Disability Rights, puts it this way: “would you a say, ‘a person with boyness’ or ‘a person with blonde hair?’” The answer everyone always gives is “of course not!” Rather, you would say “a boy” or “a blonde,” because those are (relatively) stable and intrinsic characteristics of the individual. This example also points out that we do not insist upon person first language for value-neutral characteristics, but rather only for those from which societies wish to maintain distance. Put more aggressively, Tanya Titchkosky, a disability rights scholar, views “person first language as being apolitical and ‘dismembering disability from self’” (Shepard, 2010). Furthermore, language such as “autistic” and “disabled” aligns with the social model of disability which asserts that incompatible environments, rather than bodies, are disabling (Oliver, 1990). This model suggests that rather than people (innately) having a disability, something (generally, institutions), disables people, which thereby renders them in a disabled state. This is in contrast to the medical model which asserts that disabled people suffer from an organic and naturally impairment, which disables them, and are in need of fixing; in this model, the repulsion and rejection of disabled existence goes unchallenged (Michalko, 2002, pp. 47-48). Given these critiques, and this project’s goal to examine autistic identity and avenues for empowerment, I will refer to my interviewees and the authors whose works I read as “autistic” and “Aspergian” unless I am using a direct quote in which an individual has chosen other language. This language choice is a challenge for me, as I grew up with person first
language and never questioned it prior to coming to Wesleyan. But four years later, it is time to make it stick. ²

Following this logic and borrowing from the neurodiversity movement, I refer in turn to non-autistic people as “neurotypical.” Another reason I am choosing to refer to “normal” people with this exotifying term is to demonstrate the impact and awkwardness of labels (Valentine, 2012). Rosemarie Garland Thomson offers the word “normate” (2002) and Eli Clare (1999) suggests that we refer to “able-bodied” people as “enabled”—both these terms point out the constructed nature of disability (Shepard, 2010, pp. 13, 22). I struggle with how to make linguistic choices that acknowledge that there is not a strict binary between autistic and neurotypical people, and that there are many neuro“atypicalities” outside of autism. So, although reductive, rather than stumbling over words, I will use “autistic” to refer to people who identify with the diagnosis of autism, and leave “neurotypical” to describe all other people.

Another important language choice I make in this thesis is to avoid words such as “disorder,” “condition,” “disability,” and “different/difference.” All these words carry histories of oppression and I use them only when quoting a source or making a specific reference to the construction of autism as a disorder, condition, etc. Although this choice results in the repetitive use of the word “autism,” in an effort to shift away from viewing autistic people as somehow deviant and lacking personhood and agency, it feels like a meaningful and necessary decision. Also, I often substitute

² When interacting with or speaking about someone the “politically correct” convention is to use person first language. More importantly though, is to listen to the wishes of the person to whom you are referring.
in the word “diagnosis” to point to the scientific and cultural forces surrounding the creation of the category of autism.

Autistic individuals are often categorized as “low” or “high” functioning on the basis of verbal skills. “Asperger’s Syndrome” is a term associated with “high functioning autism,” and is defined as a “milder” form of autism in that language acquisition is not delayed and symptoms may appear less severe. Other than a brief discussion here though, I will not refer to people as “low” or “high” functioning. These labels do little for autistic people as a community. As Shepard (2010) suggests, the value attached to different positions on the spectrum results in a spectrum which “does not necessarily resolve the tension between adhering to and disrupting disability narrative” (p. 64), which is a goal of this thesis. Furthermore, as Yergaeu (2010) points out, the spectrum itself is “nonlinear,” and to place individuals on a line of developmental or verbal ability is a gross oversimplification of individuals. Therefore, I will indirectly discuss social implications of these categorizations, particularly that of “high functioning,” but aside form acknowledging the Asperger’s Syndrome diagnosis of many of my sources (both interviewees and autobiographical authors), I will refrain from identifying individuals with these labels. Indicating that I will not identify my participants with these terms is an important methodological note, as lively discussion occurs within autism communities about which autistic voices are most commonly heard. I feel that it is important for me to acknowledge that I am primarily reporting and analyzing the words of people about the most commonly articulated subset of autistic individuals—those on the “high end” of the spectrum.
Methods

Interviews

Wesleyan University’s Institutional Review Board granted me approval to conduct interviews (see questions in Appendix II) and administer questionnaires (see Appendix III) between May and August 2011 in the Washington, D.C. metropolitan region. In order to recruit interviewees, I advertised (see Appendix I for recruitment letter) through parent resource groups for parents of children on the autism spectrum and through a soccer program for children with disabilities that I founded in 2002. In addition to the five participants I acquired through this recruitment effort, I gathered six additional participants through personal relationships or referrals.

Participants

I had a relatively homogeneous sample. Nine of the eleven white-male participants reside in the well-educated and wealthy Washington D.C. metropolitan area. This area of the country is likely to have a higher incidence of autism, as cases of autism have been found to “cluster” in highly educated areas (Buchen, 2011). Perhaps the greatest heterogeneity in my sample was found in the range of ages of the participants—ten to twenty years old (Table 1). Three out of the eleven participants attend private school. Two of these individuals were part of the “Model

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3 I began to interview 12 participants, but have omitted one from discussion (Interviewee 008), as my communication with his mom was terribly confusing. We eventually arranged a phone interview, but she told me what to ask her thirty-year-old son and to try to evoke “yes” or “no” responses. When he got on the phone this proved ineffective and he quickly handed the phone to his mother. Although the mother did provide responses I do not include her data due to the absence of her son’s voice.

4 It was very difficult to find statistics for prevalence of autism in the Washington D.C. metropolitan area, or Virginia and Maryland. Perhaps this is due to the amorphous and broad definition of autism. In general, prevalence studies focus on particular cities rather than reporting statistics in each state. The Center for Disease Control has begun standardized prevalence studies through their Autism and Developmental Disabilities Monitoring sites, of which there are currently twelve (see Rice, 2006 for the most recent report from eleven sites).
### Demographic Data

<table>
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<tr>
<th>Interviewee</th>
<th>Age</th>
<th>School type (State)</th>
<th>How contacted</th>
<th>Relationship</th>
<th>Interview setting</th>
<th>Parent Age</th>
<th>Parent Science Education</th>
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<td>Private (MD)</td>
<td>listserv</td>
<td>soccer</td>
<td>living room</td>
<td>48</td>
<td>Master’s Degree</td>
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<tr>
<td>002</td>
<td>20</td>
<td>Public (VA) current college student</td>
<td>personal contact</td>
<td>camp co-workers</td>
<td>phone</td>
<td>49</td>
<td>Bachelor’s Degree</td>
</tr>
<tr>
<td>003</td>
<td>18</td>
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<td>personal contact (through 002)</td>
<td>camp</td>
<td>phone</td>
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<td>living room</td>
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<td>High school and college coursework</td>
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<td>High school and college coursework</td>
</tr>
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<td>N/A</td>
<td>living room</td>
<td></td>
<td></td>
</tr>
<tr>
<td>009</td>
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<td>13</td>
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<td>babysit/ coached sibling (012)</td>
<td>babysitter/ soccer</td>
<td>kitchen</td>
<td></td>
<td></td>
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<tr>
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<td>11</td>
<td>Public (VA) babysitter</td>
<td>babysitter</td>
<td>babysitter/ soccer</td>
<td>living room</td>
<td>45</td>
<td></td>
</tr>
</tbody>
</table>

**Table 1:** I interviewed subjects with a range of ages (mean = 13.8 years old, S.D. = 3.4 years), school experiences, and relationships to me. Of the mothers who answered the questionnaire and reported their age, the mean age was 46.4 years old (S.D. = 3.4 years). Despite their similar ages, they had a range of educational backgrounds in science. Blank entries indicate that parents did not provide the missing information.
Asperger’s Program” at Ivymount, which is devoted to educating autistic children and those learning disabilities (Appendix VI), while one of the eight individuals is currently enrolled at public school but had attended Ivymount. The eight remaining participants attended public school and receive varying levels of support in their classrooms.

I conducted all of the interviews but two at the homes of participants in a variety of settings, including kitchens, living rooms, home offices, and backyards. Depending on the participants’ interest, interviews lasted between fifteen and forty minutes. Two phone interviews with older participants (who I found through personal contacts) lasted around forty-five minutes. After interviewing the participants, I gave their parents a questionnaire, which they could complete at their leisure.

Parent Questionnaire

Interestingly (or perhaps not so surprisingly, as will be discussed), 100% of parents with whom I had contact were mothers. They were also the parent who completed 100% of the parent questionnaires. The mothers exhibited a range of response times to the questionnaire—some completing it within a day or two of the interview, and others, taking several weeks. Only one participant’s (Interviewee 003) parents did not complete the questionnaire.

The parent questionnaire probed several areas that I will not discuss in this thesis due to incomplete data. Some parents choose not to answer some of the multiple-choice questions for personal reasons. Questions that parents omitted

5 In retrospect this project would have greatly benefited from follow-up interviews with both interviewees and their parents.
included how they talk to their children about autism and where they gathered information about autism. I wonder if this could be attributed to mothers’ susceptibility to the effects of evaluation apprehension or demand characteristics. Demand characteristics are features of a study that may alert participants to the hypothesis of the study and result in them sculpting their answers to align with it (Cozby, 2009). Evaluation apprehension is the term psychologists use to describe the desire of participants to respond in a manner that they believe will make them “look good” (Trochim, 2006). Rather than trying to draw generalizations about how mothers learn about autism and discuss it with their child, I looked at parental reports in the context of their children’s responses. As the sample size was not large enough, in an effort to avoid making assumptions about correlation and causation, I did not fully utilize this information.

Autobiographies

In addition to interviews, I concurrently performed close readings of the autobiographical texts listed below. I choose these texts for a variety of reasons, ranging from availability to recommendations to the fame of the author. Availability was a particularly important factor in choosing a book, as I am doing a critique of popular discourse, and therefore sought out the most available books and well-known autistic authors. In the case of John Elder Robison and Temple Grandin, this decision means that I am citing figures who are rejected by many autistic people in order to emphasize voices widely read by the general population.

Rather than listing these books in alphabetical order by author, I have chosen to list them in the order in which they were read to provide an opportunity to recreate
my research process. I coded these texts for the same themes that I observed in the interviews and kept non-categorized notes and quotes for each book on the same page as the coded information. This approach challenged me to consider the narrative of each work as a whole. I chose to put these authors in conversation with my interview participants, because although many of the authors have different personal histories (especially given that many of them were diagnosed relatively late in life), and are much older than the interviewees, they discuss autism and their experiences so similarly that these variables do not seem significant enough to justify their separation.

When reviewing the list of texts below, I want to call attention to the “bias” in the autobiographies of autistic individuals, as we are only able to “hear” from those who have considerable verbal strength. The experiences and perceptions of/relationship with autism of the authors cannot necessarily describe those of individuals whose stories we do not read or hear. For a brief synopsis of each work and the rationale for choosing each text, refer to Appendix VII.


• *Parallel Play: Growing Up with Undiagnosed Asperger’s*, by Tim Page (2009)


Data Analysis

I took notes during the interviews to which I added additional details immediately afterwards. Upon completion of all twelve interviews, I re-read my interview notes, and then decided to code them for the following themes:

- brain as:
  - strength
  - self
  - accounting for personal experience of life
  - basis of autism
  - behavior
  - difference
  - bad
- disability construction
- diagnosis
- feeling misunderstood
- feeling lonely/different
- feeling anxious
- sense of annoying others
- discussion of emotions unrelated to other emotional categories (loneliness, difference, anxiety, etc.).

Then, in order to have a quick reference to the interview material, I compressed the notes that I predicted to be most useful for my writing into one half-page and paired it next to parent responses (see Appendix IV). Throughout the writing process, I referred to both the raw interview notes and these abridged notes with similar frequency (for full results of these questionnaires, see Appendix V).

Third Variables

I would like to acknowledge the many factors may have affected participant responses. In addition to the power dynamics and un/familiarity with the interviewer
will be discussed further below, some interviews may have been conducted at less than optimal times. Some individuals may have been more or less motivated or attentive given prior occurrences during the day—if they were just arriving home from an activity, and/or if particular medications were wearing off or at their strongest. In addition, sensory sensitivities set off by the interviewer or interview setting (such as smell or light reflecting from glasses) could have impacted focus. Consideration of these aspects does not invalidate my data, but reinforces the need for researchers to consider the particulars of individuals and environmental variables.

Another possible confounding variable may have been parents discussing the upcoming interview with their children. Parents had the following information from the recruiting notices (Appendix I):

I am writing to introduce you to a study I am conducting to examine how people with Autism Spectrum Disorders think about their minds, brains, and selves, and how this is affected by involvement with biomedical research and neurodiversity movements. My hope is that this research will shed light upon characteristics of empowering environments for people with Autism Spectrum Disorders. In order to complete my research, I am conducting interviews with children and young adults on the Autism Spectrum, and administering questionnaires to their parent(s)/guardian(s), regardless of their experience with biomedical research and/or neurodiversity.

Such an introduction may have prompted parents to discuss neurodiversity or research experience with their children before or after the interview, which may have impacted what information was provided in both the interview and the parent questionnaire.

Personal relations, power dynamics, and name recognition may have also impacted the interview process. For example, my familiarity with the Northern
Virginia parent disability community\(^6\) meant that some participants had known me at one time or were introduced to me as “Ariel from soccer.” It is possible that these individuals did or did not enjoy playing soccer, and were thus less or more inclined to talk with me, made them uncomfortable, or placed particular demands on their responses.

Two of the four (out of eleven total) participants with whom I had some level of relationship were from a family for whom I had babysat (one of these participants had also been part of the soccer program), and it is likely that this created an odd power-dynamic. I knew the other two from my work at a camp for children on the autism spectrum. One was an interning counselor “under” me, yet had been given significant responsibility, and has become a friend of mine. When we had recently seen each other, he expressed interest in being involved and agreed to recruit his friend (whom I also knew from camp). In addition to an uneven distribution of power due to prior relationships, being an adult neurotypical researcher was another distinct social power advantage over younger autistic participants. This is yet another factor that could have played into the participants’ comfort while talking with me and affected their responses. Given all of these factors of my relational identity, similarly to their mothers, it is possible that individuals (especially given their relative social positioning) were susceptible to the effects of demand characteristics and evaluation apprehension, as described above.

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\(^6\) I specify my membership in the parent community, as opposed to “the disability community,” as I was not involved with self-advocates or with disability political and identity groups. My role within my locale was that of someone providing a resource and support—something sought out by parents, not their young children. This is an important distinction to make, as many disabled adolescents and adults do not feel aligned with politics and views of their parents with regard to disability, and thus distinguish the “parent disability community” from “the disability community.”
Autism and Qualitative Research

The perceived difficulty in conducting qualitative research with autistic people perhaps stems from the very fact that autism is an incredibly heterogeneous category. Due to communication barriers,\(^7\) it can sometimes be difficult to glean information from interviews. Many autistic individuals have much more complex thoughts than they verbalize and therefore researchers cannot assume that apparent “simplicity” in responses reflects simplicity in thought or understanding.

Most research with autistic people therefore has focused on quantitative measures. Researchers attempt to operationalize complex qualitative constructs such as self-understanding and theory of mind, and construct quantitative instruments to assess these constructs. Researchers believe that this enables them to correlate interview data with other (presumably objective) variables, such as neurology and genetics. The greatest strength of qualitative research conversely is in that it avoids the reduction of individuals to a number. The small sample size in this study allowed me to process data in a careful way that accounted for individual characteristics and matched parental and participant responses. Rather than performing a computerized content analysis I was able to spend time thinking about each interview and parent questionnaire and think about how together, and in the context of my other data, they told an individual story. Although I do make generalizations concerning the participants’ responses, I base these generalizations on this careful analysis of interview content rather than a number deemed statistically (in)significant or a computer pulling out information. In a larger sample, such a holistic analysis would

\(^7\) This is a word chosen because it implies a communication failure that can be attributed to both parties (Abbott, personal communication, 2011-2012).
have been considerably more difficult given the time frame in which I had to complete this project. Therefore, this qualitative method enabled me to study and engage with individuals rather than aggregates of characteristics and responses. This, the same attention to individuality could be accomplished with a larger sample size with more time.

If a larger scale study were to be conducted, one solution to the challenge of the heterogeneity of the autistic population might be to have measures of participant’s cognitive abilities such as attention, memory, verbal and global IQ. This way, individuals with similar cognitive profiles could be compared and contrasted, which would theoretically be one step towards accounting for this heterogeneity. Using this information to mitigate the impact of cognitive variables could be seen as a means to collectively analyze, rather than individually examine large amounts of qualitative data. I argue that this would be a potentially dehumanizing solution, as individuals’ responses run the risk of being interpreted in numbers that may or may not accurately describe their abilities and cannot be clearly correlated with individual responses. A much better solution would be to conduct longer and repeat interviews, so the interviewer could get a better idea of the idiosyncrasies of each participant’s language and individuality. This is a methodology that can be extended not only to a larger sample, but also to autistic individuals with different modes of communication. In

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8 For example, one of my interviewee’s (001) used the linguistic construction “Asperger’s people.” Had I been correlating interview data with performance on verbal measures I may have looked to these measures to help interpret the meaning of this construction. Did my interviewee mean to imply that having Asperger’s Syndrome culturally distinguishes people? Or, when he said “Asperger’s people,” did he not realize what might be implied by this word order? Had he demonstrated high or low verbal performance I may have interpreted this response as more or less meaningful, respectively. However, this may have been counterproductive to my qualitative approach, which I argue by allowing for and welcoming contradictions, enables me to uncover nuanced and complex self-understandings.
other words, I propose that autistic people are no different than neurotypicals with regard to their suitability for qualitative and more holistic research.

**Why is this Neurotypical Writing About Autism?: Identities and their Boundaries**

Having worked with children with disabilities since age eleven, even founding a soccer program for disabled children and having become some sort of local “spokesperson” for the program, I came to Wesleyan certain that I knew everything there was to know about disability rights and being an ally. However, it only took few social science classes and conversations to completely put my views into question. At Wesleyan I took a step back from my volunteer work and began to question my role as an ally and my ability to talk about disability as an expert. I had figured that my years of experience working with people with disabilities made me an expert on them, or at least an expert about working with them. My first social science classes at Wesleyan challenged me to step outside of my experiences, analyze the factors that might have shaped them, and to apply this critical practice when considering the experiences of others. Wesleyan, therefore, gave me a huge jolt, and I started to question the meaning of the work I had been engaged with since age eleven. I realize now, that for the integrity of this project, I must fully disclose my role as an ally, a researcher, someone who has questioned her own disabled identity (or lack thereof), and a recognizable member (and actor) in the parent disability community in the Washington, D.C. area and at Wesleyan.

In particular, my own navigation of disability may have influenced this project. Throughout the past four years, I have struggled with concussions that have plagued me with continuous headaches for months, increased sensory sensitivities,
and altered my sense of safety and home in my body. Sometime around the beginning of my junior year, a friend who had taken a while to come to her own disabled identity, and with whom I have done most of my activist work at Wesleyan, starting asking me the question, “Why don’t you identify as disabled?”

I still struggle with this question. I wear glasses to block out fluorescent lighting that makes it difficult for me to focus and quickly tires me. My head injuries severely limit the activities in which I can participate with any sense of safety. I have a physical condition that often alters my ability to read and follow conversations, especially in crowded and loud rooms, or after physical exertion. Headaches are often a part of my daily life. Officially, I receive a “disability accommodation” from Wesleyan, even if it is simply having my living space prioritized for salting in the case of snow and ice, to prevent falls and further head injury. Most importantly, my head injuries have drastically altered my lifestyle, and I am still working to come to terms with this reality and I mourn for my old self. But, when first asked the question, “Why don’t you identify as disabled?,” and for the year that followed, I firmly identified as non-disabled.

I have learned that self-understandings of our bodies and selves are fluid and open to revision, and as I worked on this project in early November, I had a relapse of concussion symptoms and started to rethink my status as a dis/abled person. Between my need to rest, wear earplugs, shield my eyes from light, and my acute awareness of my delayed cognitive processing, I started to reconsider whether or not I have a disability. These days I borrow a term from English Professor Christina Crosby and say that I maintain an “elective affinity” with disability (Haraway, 1991). Maybe I do
no feel “disabled enough.” Maybe I do not feel disabled all the time. However, I also feel most comfortable sticking my fingers in my ears, admitting that I am having trouble processing on a given day, and asking for lights to be dimmed in spaces where others have disabilities, atypical sensory needs, and/or are invested in disability rights. Although I did not grow up with an Individual Educational Plan (IEP), generally do not experience adverse educational effects of my injury, and did not suffer the discrimination and medicalization that so many disabled people experience (Clare, 1999, p. 88), every day, the tiny precautions I take to protect my head become increasingly automatic and ingrained into my body.

So if I have some form of chronic impairment that causes me to modify how I interact with my environment on a daily basis, why do I not consider myself disabled? There is not an easy answer. In my resistance to acknowledge that in many ways I do meet criteria for having a disability, I have been forced to realize that I must have some unrecognized prejudice or shame towards the category of disability (Frank, 1986). I realize that for whatever reason, despite my lifelong involvement with disabled people, and my professional plans to continue this work, I distance myself from this category. I still have not figured out if this resistance stems from internalized prejudice, my denial of the ways in which my life has changed, or if I just do not feel “disabled enough.” It is likely a mixture of all of these factors and others. I do not yet understand.

In a sassy theoretical and practical essay, Melanie Yergeau (2010) insists that we stop creating bounded categories of identity. With reference to the harm done through autism discourses constructing binaries and de/valuing particular autistic
traits, she demonstrates how drawing circles around non/disabled bodies and people does no one any good. She asks the question, “Who is neurotypical?” and thus challenges the impermeability of identity groups. This concept is also present in the language used to describe outsiders to disability communities as “TABS” or “temporarily able-bodied,” as disability is a category into which most people enter (and possibly move out of) at some point in their lives. For me, this means that I can identify as “kinda-disabled” or “not-quite-neurotypical” and feel as if my unanchored identity resists conventional understandings of dis/ability. This is all to say that throughout my time working on this project, I have come closer and closer to accepting a disabled identity. My recent ambivalent identification as disabled speaks to both the fluidity of this category and to how this identity and category are co-constructed with in/compatible environments.

I still do not firmly identity as disabled, and ironically, despite my “sorta-disability,” in the context of autism I still identity as neurotypical. I have a sense of self that departs from neurotypicality, but severely devalue and resent my brain injury that has resulted in neurological difference, and feel that the ways in which I relate to my injured, and therefore different brain, departs from the nuanced relationship autistic people have with their brains that I have observed and describe in this project. Furthermore, despite sensory difficulties and processing delays on bad days, I have never had social isolation and medicalization imposed upon me due to these difficulties.9 Most of my symptoms are only apparent to me, and I am read as a

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9 A friend reviewing this work also pointed out that I do not have the many strengths associated with many “disabilities” (Abbott, personal communication, January 2012). This perhaps is another reason that I do not claim a disabled identity.
neurotypical, even though, due to my very real physical impairment and fragility, I do not feel neurotypical at times.

I have taken this space to discuss my identity, because all too often TABs and neurotypicals talk *about* people with disabilities rather than *with* them, or even simply listening. Although in many ways, my status as someone who is non-autistic yet writing about autism contributes to this oppressive practice, I feel that in some small way, by providing full disclosure, I ask the reader to keep my positionality in mind while you read. Furthermore, I believe that my identity as “kinda-disabled/chronically impaired” and “not-quite neurotypical,” and my process of reaching this identity is an important factor to keep in mind as you continue reading, as it may have colored the ways in which I was able to view disability and neurological differences and identities.

What is the Role of an Ally?

As a non-autistic person, I lean towards the stance that even as an ally, it is wrong for me to be making suggestions and decisions for and about autistic people. The disability rights movement adheres to the motto: “Nothing about us without us,” asserting the need for disabled people to be key players in decision making when it comes to issues that concern them. Although my research centered on the voices of autistic people and I consulted autistic people in addition to classmates and academics working within Disability Studies, I am not autistic, and my interpretations of and conclusions about these voices could be misplaced. I know that acknowledging my ambiguous role as a neurotypical researcher is not enough. Although I reached out to two autistic adults, Disability Studies scholars, and other allies, in retrospect, I realize
that it would have been most responsible to have shaped and conducted this project in collaboration with autistic people from its onset. Despite my best intentions, the worry that as a neurotypical doing this work, I am complicit to the very systems I work to dismantle persists.

However, upon the insistence of my thesis advisor, Professor Gillian Goslinga, I am taking a moment to consider reasons why I might be wrong about my concerns about my ability to do good work within the field of Disability Studies. I realize now, if a neurotypical were going to conduct this project, several steps required a certain type of neurotypical. Attaining approval to work with people with disabilities from Institutional Review Boards is not easy! As I will discuss how society views disabled people as less than full humans, and in need of protection, I question whether the IRB would have granted me permission to interview autistic youth had I not presented my many years of work with disabled people. Furthermore, access to participants might not have been as easy for someone else. As a founder of a soccer program in my county, I have done work at the regional and state levels with therapeutic recreation, worked at various summer camps, and worked as a tutor and social skills group assistant. This not only gave me easy access to listservs, but also helped me gain the trust of parents. Having some level of name recognition likely assured parents of my ability to engage with their children unsupervised.

One of the reasons that work with autistic people has not focused on interviews and has not been qualitative is that neurotypical scholars are hesitant to talk with autistic people, and doubt their own ability to have a conversation with autistic people. However, I do not feel that this is a legitimate concern, and never
have. For me, conducting an interview with an autistic person does not consciously feel that different from an interview with neurotypical people. I imagine that this derives both from years of experience and my knowledge that autistic people are full individuals. Hopefully, both of these factors combined to enable me to do this work responsibly.

Finally, there are the “technical” aspects of interviewing autistic people. I realize that the care I took in constructing literal questions that only addressed one subject at a time was important. Additionally, I gave participants an opportunity to sit, pace, stand, or play with a toy or object if that was how they felt comfortable. Similarly, I gave participants extended time to process and respond to questions before clarifying or repeating, as some autistic people have difficulty with verbal processing. I imagine these simple things were a result of my experience working with autistic people and enabled me to do this work that may have been difficult for others.

**Organization**

This thesis follows the construction of autism, beginning in the early-twentieth century. I focus on the ways in which scientific views of autism as a mysterious puzzle autism and how autism becomes desirable through what I call, following Nikolas Rose (2007), “hope technologies.” Chapter 1 establishes the construction of autism as a puzzle and uses this analogy to document shifts in cultural rhetoric regarding autism. In addition, I discuss pathology, building on the work of George Canguilhem (1991) and Rose (2007). Based on their work, I consider ways in which autism is expected to be managed, and how this emphasis on management
relates to citizenship. I use this chapter to document the ways in which society uses
tropes of hope and mystery to compose an autistic individual who can be recomposed
by experts who can access and solve the autistic body.

I should take this moment to note, that although eugenics discourse and the
theme of animality are omnipresent in disability and pathology discourses, and so
pervasive, that they even emerges when reviewing the titles of the autobiographies I
read, I have chosen not to discuss these topics in Chapter 1 (or the rest of this thesis),
as I find it counterproductive. Giving time to these discourses only legitimates their
place in disability history, and for this project, plays no role in how I propose to
reconceptualize autism and autistic people as fully human. This thesis is meant to be
an activist project, and although both eugenics and animality do have their places in
activist work, I do not feel I can do these themes justice within the confines of this
thesis. I believe these themes are most appropriate for sociologists and philosophers
and historians of science. Although the implications of these discourses are severe to
this day, I mention them only sparingly. Their dark histories and pseudo-scientific
links merit deeper discussion of scientific processes, distribution of knowledge, and
many specific cultural and social environments that I do not have the ability or time to
unpack.

Rather than continuing to unpack the historical processes that have
constructed disability, the rest of this thesis is focused on the present. Therefore,
Chapter 2 acknowledges discourses that influenced current neurological discourses,
but emphasize the current prominence and person-making power of neurological
discourses. To accomplish this, I trace the transition of autism from a psychological
to bio/neurological diagnosis. With regard to psychology, autism was defined as a
deficit in verbal and emotional intelligence and communication—all essential
characteristics of the normative human as constructed by Enlightenment philosophy.
I argue that psychological work figured autistic people as non-human. However, I
then consider the ways in which the emergence of neuroscience and the localization
of autistic symptoms to the body, and more specifically the brain, rectify personhood.
In addition, I examine the ways in which brain imagery plays an important role in
societal understandings of personhood and autism.

In Chapter 3, I explore the ways in which defining autism as neurological
leads to the essentialization of autistic people. Through testing and assessments,
science “uncovers” autistic difference and strengths, yet ascribes all of these
characteristics to the brain. It seems that the potency of scientific data, combined
with societal understandings of how the brain relates to the self, led to complex
autistic self-understandings that hinge on neurology. Although touched upon in
Chapter 2, Chapter 3 emphasizes the double-voiced (Higginbotham, 1992) nature of
neurological discourse, as it is deployed both to perform work of autistic speciation
and celebration.

In Chapter 4, I explore ways in which neurodiversity discourse influences
autistic self-understandings. In particular, I consider how individuals view
themselves as dis/abled relative to their environments. In addition, I explore how
autistic people view biomedical research and its role in constructing not only their
lives, but also autistic prototypes. I conclude this chapter by discussing the ways in
which autistic autobiographers have and continue to play a significant role in the
construction of autism narratives, or personal accounts, and I also consider in their work the emerging theme of emotionality. I relate autism narratives and emotionality to a close analysis of the difficulty my interviewees experienced when asked to describe their strengths and interests.

I conclude this thesis applying Ian Hacking’s (2006) people-making engines to autism. In doing so, I review my arguments in this thesis and string together the different forces involved in disability construction. Finally, I consider the ways in which allies and advocates should move forward, with a call to focus on autistic narratives and individuality.

**Future Directions**

The research I present in this thesis provokes several questions. With regard to autistic self-understanding, I would be interested in exploring the relationship between autistic narratives and autistic self-understanding. Interview questions related to this area may include:

- Have you read any books, blogs, or heard talks by autistic adults and/or other teenagers or kids? If so…
  - Did you agree with the ways in which they spoke about autism?
  - What would you add? Change?
  - Have you had experiences that are similar to those of these adults?
  - Did you feel like their books or talks helped you learn about autism? Yourself?

- Have you read books, magazine or newspaper articles or heard talks about autism written or given by autism “experts?” If so…
  - Did you agree with the ways in which they spoke about autism?
  - What would you add? Change?
  - Did you feel like their books or talks helped you learn about autism? Yourself?
  - How did you feel about these experts talking about autism? About autistic people?
• What do you think other people think about autism? About autistic people?
• What would you like people to know about autism? About autistic people?

Perhaps the responses to these questions could clarify if and how (openly, with criticism, reservations, etc.) autistic people consume autism narratives, and could be used to evaluate the role that these narratives play in the lives of autistic people. In addition, similar questions could be asked of parents including: “Do you communicate the information you receive from these sources to your child?”

In addition, to exploring how autistic self-understanding is influenced by autistic narratives, I am also intrigued by the ways in which autistic people relate to their minds and brains. Although this topic was discussed at length in this thesis, I wonder if different conclusions would result from asking interviewees more direct questions about how autistic people view their minds and their brains, and what influences these views. Related to this topic, I would be excited to teach participants about neurodiversity and the social model of disability and then conduct several follow-up interviews to see if their views change.

Although touched upon in this thesis, one might be interested in how societal views of autism differ from those of another particular diagnosis. Another area of inquiry may be the delegation of attention and resources to particular diagnoses. For example, as described, one mother wrote, “[Neurological differences are] not something we fixate on” (Parent 010). Although this parent says that neurological differences aren’t given much attention in her family, I wonder if the nature of these differences could contribute to this attitude. For instance, would she have a different attitude towards neurological differences that aren’t considered lifelong? Have
different etiologies? Symptoms? Parsing out the differences between attitudes and the level of attention varying differences receive in this household and others, may further contribute to knowledge about societal attitudes towards and understandings of autism and other neurological diagnoses. Finally, I believe that it is valuable to explore all of these questions cross-culturally.

Finally, I concluded this thesis for a call to action. In particular, I insist that neurotypicals attend to the voiced of autistic people and to view these people as individuals. One suggestion I make with regard to viewing and treating autistic people as such was to focus on the individual interests and skills of these people. Through feeling supported in their strengths and hobbies outside of academic and intellectual pursuit, perhaps autistic narratives will broaden to the point until “the” autistic narrative shatters under the weight of individual autistic narratives. I believe that such a change could perhaps lead to the recognition of autistic people’s individuality, which in turn could impact societal beliefs about (lack of) autistic emotionality. I would be excited to conduct a study evaluating the psychological impact of various types of supportive recreational programs on autistic individuals.
CHAPTER 1
Re/figuring the Autistic Puzzle

In this chapter, I will explore the trajectory of autism research since 1943, and how the “mystery” of autism has been “uncovered.” In particular, I will demonstrate how early understandings of autism, such as the “triad of impairment” theory still define the diagnosis today. In addition, I will use the analogy of a puzzle to discuss historical, psychological, and neurological understandings of autism. I will use this analogy to discuss technologies of hope (defined below) in the context of emerging views of pathology and ab/normality and how this plays out in (self- and other-) management of autistic people.

As early as the fourteenth century, the human body in Europe has been figured as an amalgam of parts to be decoded and sorted rather than as a singular functioning unit (Park, 2006, p. 95-115). This figuring originated with women’s bodies, which were hypothesized to hold secrets to be uncovered by physicians in order to learn about origins of life (Park, 2006, pp. 39-59; Terry, 1995, pp. 129-158). In the premodern period, it was believed that only male physicians could understand women’s bodies; this perhaps led to the lasting cultural belief that bodies are only legible to experts, rather than to the individuals who inhabit them (Park, 2006, pp. 52-59, 80-93).

Particularly when considering disease states, scientists and physicians have historically inquired into the body’s components and how they cooperate. Throughout history, “pieces” of the body have included factors beyond it, extending the puzzle to matters of spirituality, morality, and the physical and social...
environment. In *The Birth of the Clinic*, Michel Foucault (1973) details the transition from understanding disease as inclusive to family, climate, and geography in the middle of the 18th century, to legible in the space of the clinic itself at the turn of the century, to legible in the very tissues of the body by the 19th century. From this point onward, the medical gaze, which has privileged access to and knowledge about the body, has acted as a strainer of facts, dictating which characteristics of the body are incorporated into diagnosis. In the 19th century and thereafter, in order to parse characteristics relevant to diagnosis, medics must select those that they can compare to a norm located within the mechanized-anatomical body. Thus, in order to (re)compose a composite picture of the body, the medical gaze must first decompose it; however, this is only enabled by the cultural understanding that the body is decomposable in the first place (p. 94). By figuring the body as an amalgam of parts rather than a coherent functioning unit, the body was understood as mysterious and secretive, yet this construction also provided hope that the elements of this mysterious myriad of components could provide clues to its whole.

*Figure 1*. Although the National Autism Society of the United Kingdom no longer uses the puzzle piece symbol (Figure 1A depicts their current symbol), the puzzle piece has become the universal symbol for autism (Society, 2011). B. Although Autism Speaks, one of the largest cure-focused autism organizations, uses a single colored piece (Speaks, 2011), C. the multi-colored piece (Broussard, 2005-2011) is the most common. D. Adopting from cancer imagery, puzzle-piece ribbons (America, 2008) are very popular, and further contribute to cure-discourses by implicitly medicalizing autism and positing it as an invasive tragedy, similar to the way that bodies are “taken over” by cancer cells. To do this association, and puzzle-piece imagery justice requires an additional thesis.
Not surprisingly, Autism Spectrum Disorder advocacy and research organizations deploy the image of the body as a puzzle and the puzzle piece as their symbol (Figure 1 above). The puzzle piece, which is now as commonly recognized as the pink ribbon of breast cancer, was adopted in 1963 by the National Autism Society in the United Kingdom, an organization founded by parents of autistic children. At the time, they chose the puzzle piece because it stood out as a distinctive symbol (Allison, 1987). The selection of a distinctive symbol perhaps performed the work of rectifying the stigma of autistic difference and mystery. Today the puzzle piece epitomizes predominant approaches to the autistic body (and thus, to individuals), and works in synergy with current autism discourses that I call what (medical) discourse of hope and mystery. Many autistic individuals now view the symbol with resentment, saying that the symbol suggests incompleteness of autistic people/bodies:

Autistic individuals are puzzles? They are distorted, psychedelic minds? Exactly what is the message? Not that all people aren't puzzles, but to think one group is any more puzzling is a curious claim. How does this promote understanding? The claim that we are all part of the greater puzzle... no, a puzzle is a mystery. The message to me that autism and autistic people are strange, mysterious. (Wyatt, 2008, para. 4)

The problem is that a lot of the times it comes to mean that there are 'pieces' missing from us, and that suggests that we are less than whole, and thus less than human. This fosters negative stigma towards autistics, and promotes an ideology that because we are less than human, we do not require the same rights and freedoms as "real" humans. Which in turn, justifies abuses and human rights violations, neglect and murder towards autistics. Not to mention fosters a reluctance on the part of service providers to meet the needs of autistic individuals. (Becker, 2010, comment on blog entry)

Despite this pushback from some members of autism communities, as we will see, some autistic people themselves have come to understand their bodies as a puzzle to
understand and solve. Recently, autistic authors Temple Grandin and John Elder Robison explain several distinct characteristics of autism by referring to their brains and networks of neurons. Through neurological explanations of their emotional cognition, through their attention to detail, and through their behavior, these famous autistic authors participate in the project of piecing together the puzzle of the autistic brain (person). Despite their explicit rejection of a cure and normalizing technologies such as behavioral therapy and medication, Grandin and Robison implicitly support and proliferate (medical) discourses of hope and mystery. These discourses construct an image of the autistic person as a brain composed of localizable parts that can be managed and perhaps altered (through therapeutic and biomedical technologies) to achieve cure and normalization. The potential to achieve normalization leads to “hope” playing a strong role in autism discourse. I take “hope” to be a technology that mediates constructions of autism and subsequent technologies applied to autistic bodies and understandings. As scientific explanations posit autism as a potentially “curable” condition, the diagnosis becomes desirable. Subsequently, the possibility of cure leads to the allocation of technologies in order to actualize this potential.

Later in this chapter, I will explore how both neurotypicals and autistic people have become a part of this discourse, and will emphasize the evolution of the politics of belonging, citizenship, and management of autistic people.

**Whose Job is it to Manage?: Historical Understandings of Autism**

Figuring the body as a puzzle implies not only that the body is a mystery that can be solved, but that it is both predetermined with regard to its final form and passive in its trajectory towards actualization of this form. Modern (medical)
technology opens up the possibility of all bodies attaining a “normal” end form, granted that the correct puzzle solver and techniques are deployed. These techniques can be understood as efforts to manage the body, and in the case of autism, how the body needs to be managed has changed over time. These changes have been rooted in evolving beliefs concerning autism’s etiology and the techniques available to undercut the diagnosis’s ends and origins, and consequently, who the appropriate “solver” of the “autism puzzle” should be.

Interestingly enough, the identification of autism as a separate and unique diagnosis has its roots in schizophrenia. Schizophrenia provided an avenue through which autism could be identified because in the early twentieth century, few psychological diagnoses were granted to children. Schizophrenia was then well documented and an accepted reason to place children in asylums for treatment and observation. In the early twentieth century though, the diagnosis of schizophrenia was more broadly applied, which led to the institutionalization of children who today would neither be institutionalized nor diagnosed with schizophrenia, as evidenced by the number of childhood diagnoses of schizophrenia that were often removed and replaced with intellectual disability (or “mental retardation” at the time) in adulthood. As Eugen Bleuler had coined the term autism to describe withdrawn schizophrenic patients in 1911, children diagnosed with childhood schizophrenia provided the first context for the use of the word “autism” (Grinker, 2007b, p. 45). At this moment in history, the same techniques employed to “solve” schizophrenia were the only ones available to investigate autism. People with “autistic behavior” were not imagined to reach an “end form” other than the schizophrenic or intellectually disabled adult.
Management was the primary job of psychiatrists and psychologists who used the same medications and technologies prescribed to schizophrenic patients on autistic people. The idea of a complete “normative” human was not proposed as a realistic end for these children. Perhaps the subsuming of autism under schizophrenia contributed to the lack of research and probing of autism, in contrast to the attention the diagnosis would have been devoted had it been considered a unique category.

“Autism” was not defined as its own separate diagnosis until the 1940s when Hans Asperger and Leo Kanner described a set of patients who had strikingly similar characteristics. In his 1943 article, “Autistic Disturbances of Affective Contact,” Kanner highlighted aloneness, perseveration on particular activities or topics, “excellent rote memory,” “delayed echolalia,”\textsuperscript{10} atypical sensory sensitivities, specific and intense interests, repetitive movements, “good cognitive potentialities,” and the exceptional intelligence of subjects’ parents. Later, Kanner narrowed key characteristics of autism to aloneness and perseveration and hypothesized that other characteristics were secondary symptoms, or independent of autism. Soon after Kanner’s initial description of autistic children, Han Asperger (1944) independently published a study on “autistic psychopathy,” in which he described a population that significantly overlapped with that of Kanner’s. However, in addition to the unifying characteristics described by Kanner, Asperger documented that many of the children with “autistic psychopathology” had delayed or absent language and were clumsy. Although Kanner and Asperger described very similar populations, they disagreed on the learning style and thought processes of these children. Asperger suggested that

\textsuperscript{10}The repetition of heard utterances or speech (Gregory, 2009)
these children were “abstract thinkers,” who benefited from spontaneous play and learning, while Kanner claimed that his subjects learned best from repetition and had difficulty with abstract thought (Grinker, 2007b; Happé, 1994). Here, a disagreement could be imagined in regard to curative/solving technologies, as these hypotheses imply different educational needs.

Although Kanner did think that schizophrenia and autism were linked, he believed that autism was present from birth (a viewpoint which, at the time, contradicted beliefs about mental illness as inorganic), therefore suggesting that autism might not simply be a symptom of schizophrenia. Perhaps the description of autism as its own unique category is the greatest contribution of both Kanner and Asperger. The differentiation of autism from schizophrenia opened up the possibility to consider etiologies, curative technologies, and ends other than those previously proposed, thereby expanding and altering the predominant image of the autistic puzzle at the time.

While autism as a distinct diagnosis was first being studied and described in the 1940s and subsequent decades, psychoanalytical explanations of human behavior dominated psychological thought. This mode of thought led to the development and popularity of the “refrigerator mom” hypothesis in mid to late twentieth century, in which several prominent researchers claimed that cold and detached parents, possibly those with psychiatric disabilities themselves, were the cause of autism in their children, who were perhaps genetically predisposed (by parents) to autism. Kanner’s observation that highly educated parents were distant from their children and more likely to have children with symptoms of autism further contributed to the
“refrigerator mother” theory. Additionally, Bruno Bettelheim’s widely read book, *The Empty Fortress*, published in 1967, describes three autistic children and states the following hypothesis:

I would stress that the figure of the destructive mother (the devouring witch) is the creation of the child’s imagination; though an imagining that has its source in reality, namedly [sic] the destructive intents of the mothering person…I state my belief that the precipitating factor in infantile autism is the parent’s wish that his child should not exist (Bettelheim, 1967).

Popular media also reinforced this notion, including the movie *Change of Habit* (Graham, 1969), in which Elvis Presley connects with an autistic child by speaking of and giving love that the child’s mother presumably had not provided.

Fathers were also implicated in autism. During the 1970s, Leon Eisenberg documented the behaviors of fathers of autistic children and noted several symptoms of autism in the fathers. Rather than this observation lending credence to a genetic hypothesis of autism, it was instead used to support “bad parenting” hypotheses (Grinker, 2007b, pp. 74-75). Despite acclaimed researchers such as Asperger suggesting a genetic basis of autism, parent, particularly, mother blame was a predominant and worldwide-held etiological theory of autism for much of the 20th century (pp. 72-93). The practice was in fact so predominant, that Kanner (1941) even wrote a book titled *In Defense of Mothers: How to Bring Up Children in Spite of the More Zealous Psychologists* in which he posits psychological and medical authorities as “bullies,” and makes it clear that he never intended to implicate parents in the disorder when he chose to discuss parental characteristics. He wrote, “Because I reported some characteristics of some parents…I never said ‘parents did it.’ I hereby acquit you people as parents” (Shepard, 2010, pp. 50-53, quoting Kanner).
Remnants of psychoanalysis and mother blame remain even in relatively recent scientific studies, as the 1990s marked a time when relationships and affection were being investigated for their impact on the developing brain. Famous studies such as Harlow’s (1958) attachment studies further contributed to the belief that autism was the fault of poor parenting. However, the difference was that researchers around the turn of the century now had (privileged) scientific evidence to support their hypothesis. Other research surrounding child development continued throughout the twentieth century, and popular media and movements during the 1990s, such as Hilary Clinton’s activism surrounding the importance of parenting in the first three years of life, facilitated the creation of a folk neurology regarding the role of family environments on child development. These discourses implicated poor parenting as a cause not just of psychological variance, but of neurological and developmental as variance well (Grinker, 2007b, p. 88).

Although Asperger, and later Kanner, defended parents of autistic children and asserted that autism was not their responsibility (Shepard, 2010), by the late twentieth century, parents, and in particular mothers, were viewed as the masters of the autistic body. Thus, mothers were responsible for both stealing their children’s bodies (which were perceived to be innately, though no longer, normative) and the restoration of those bodies. Here, love, good parenting and psychological services were viewed as the tools that should be applied to achieve normative ends.12

11 Harlow (1958) evaluated rhesus monkeys raised with wire “mothers” that provided food versus soft wire “mothers” that did not. His studies documented “better” development in those monkeys that had been raised with soft “caring” mothers.

12 Today, mothers are still expected to facilitate the achievement of normative ends (Shepard, 2010, pp. 50, 83) using these same tools. The pressure that mothers experience to manage and work to “normalize” their children is a consequence of the technology of hope.
However, despite the predominance of mother blame throughout much of the century, further research led to new hypotheses about a potential biological cause and unified symptoms. In the 1970s, Sir Michael Rutter built on the descriptions of Kanner and Asperger to suggest four key characteristics that became the foundation for modern understandings of autism:

- Onset before 2.5 years of age
- Impaired social development
- Impaired communication
- Unusual behaviors such as repetitive and stereotyped behaviors (Grinker, 2007b, p. 109)

These four characteristics could be observed in a wide range of individuals and perhaps paved the path for conceptualizations of autism as a spectrum, or a set of puzzles, rather than a single one. The first explicit suggestion of the “autism spectrum” has its origins in the work of Stella Chess (1971), who in the 1970s assessed “developmentally delayed” children with congenital rubella. Although many children she assessed were blind or Deaf,13 she proposed that many of these “delayed” children who had difficulties with language and social interaction relative to their age-matched peers with typical hearing and vision had autism, and thus hypothesized that autism might exist in a wider variety of individuals than suggested by Kanner and Asperger. Chess’s work was supported by Lorna Wing’s 1981 studies, which led to the recognition of Asperger’s Syndrome and the broadness of the autism spectrum. In addition, Rutter’s demonstration that autism can be both familially correlated and exist in a wide range of people with diverse combinations of symptoms also played a role in understanding autism as a “spectrum” and possibly

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13 I choose to capitalize “Deaf” and “Hard of Hearing,” as many Deaf and Hard of Hearing individuals prefer this convention, noting that it highlights the cultural (and non-disabling) aspect of Deafness.
organic in origin (Grinker, 2007b, pp. 61-62). The work of these individuals coalesced in the broadening of diagnostic criteria by the 1987 release of the Diagnostic and Statistics Manual III-Revised (DSM-III-R), which in turn led to a rise in diagnoses (p. 139): in the past two decades roughly one in 10,000 to one in 80 children have been diagnosed in the United States (Rice, 2009).

Despite the concern about the “autism epidemic,” it is likely that there has not actually been an exponential increase in people who have the characteristics that are believed to compose “autism,” but rather, that the increase in diagnoses can at least be in part attributed to the changes in the social conditions surrounding autism. As described above, autism is a relatively “new” diagnosis, with it first being described in the 1940s, and officially distinguished from schizophrenia in the Diagnostics and Statistics Manual (DSM) only in 1980. Since then, the diagnostic criteria have been broadened. Table 2 provides a simplified summary of Richard Grinker’s (2007a) presentation of the evolution of the DSM definition of autism. This table documents the transition of autism from a component of schizophrenia, to a subtype of schizophrenia, and then Pervasive Developmental Disorder (PDD), to its own category. But although diagnostic criteria for autism has evolved, in many ways the “triad of impairment” including difficulties with socialization, communication, and imagination, which was identified by Wing and Gould in 1979 (Wing, 1993) still defines the diagnosis. The most significant change is that in the span of over fifty years, by the fifth DSM (released planned for May 2013), autism becomes its own category—now subsuming other diagnoses. Perhaps this can be understood as a morphing of autism from a part of a schizophrenic puzzle, to a mysterious puzzle
### Diagnostic Criteria

<table>
<thead>
<tr>
<th>Edition (Release)</th>
<th>Diagnostic Requirements</th>
<th>A. Social Interaction</th>
<th>B. Communication</th>
<th>C. Activities and Interests</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I (1952)*</td>
<td>N/A: used as a descriptor to describe schizophrenia as manifested in children</td>
<td></td>
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<tr>
<td>II (1968)*</td>
<td>N/A: a characteristic of childhood type schizophrenia</td>
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<tr>
<td>III (1980)*</td>
<td>Onset prior to 30 months Abnormal social interaction: delusions, hallucinations, loosening of associations, incoherence</td>
<td>Pervasive lack of responsiveness to other people (autism)</td>
<td>Gross deficits in language development If speech is present: peculiar patterns, included delayed echolalia, metaphorical language, reversal of pronouns</td>
<td>Bizarre responses to the environment, for example, resistance to change and peculiar interests in and/or attachment to objects</td>
<td>“Infantile Autism” was considered one of five Pervasive Developmental Disorders (PDD)</td>
</tr>
<tr>
<td>III-R (1987)*</td>
<td>• Meet 8 criteria, with at least two in each category (A through C) • Absence of Rett’s disorder or childhood disintegrative disorder</td>
<td>Qualitative Impairment in reciprocal social interaction: Lack of awareness of existence or feelings of others No or abnormal seeking of comfort at times of distress No or impaired imitation No or abnormal social play Impairment in ability to make peer friendships</td>
<td>Qualitative Impairment in verbal and nonverbal communication and in imaginative activity: No communication Abnormal nonverbal communication Absence of imaginative activity Abnormalities in speech production Abnormalities in speech content Impairment in ability to initiate or sustain conversation with others, even in the presence of intact speech</td>
<td>Markedly restricted repertoire of activities and interests: Stereotyped body movements Persistent preoccupation with parts of objects Distress over change in trivial aspects of environment Unreasonable insistence on following routines in precise detail Restricted range of interests and preoccupation with one narrow interest</td>
<td>First recognized as distinct diagnosis Diagnosis retained even if improvements were observed</td>
</tr>
</tbody>
</table>

Table 1. Diagnostic criteria for autism have changed throughout the years. The above table summarizes these changes.

1. "The condition may be manifested by autistic, atypical and withdrawn behavior..." (Gianetti, 2007, quoting DSM-IV)
2. Rett’s disorder is a PDD predominant in females and associated with a specific neurodevelopmental gene.
3. Childhood disintegrative disorder is characterized by a loss of communication and social skills around age three or four.
### Diagnostic Criteria

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</tr>
</thead>
<tbody>
<tr>
<td>IV (1984 and IV-TR (2000))</td>
<td>• At least six criteria listed under A–C • At least two criteria from A • At least one from B and C • Onset before 30 months of age</td>
<td><strong>Qualitative impairment in social interaction</strong> • Impairment in use of nonverbal behaviors • Failure to develop developmentally appropriate peer relationships • Lack of spontaneous efforts to share interests and enjoyment with others • Lack of social or emotional reciprocity</td>
<td><strong>Qualitative impairments in communication</strong> • Delay or lack of development of spoken language • Impairment in ability to initiate or sustain conversation with others, even in the presence of intact speech • Stereotyped or repetitive use of language or idiosyncratic language • Lack of spontaneous imaginative and social imitative play</td>
<td><strong>Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities</strong> • Preoccupation with one or more patterns of interest • Inflexibly adhere to specific nonfunctional rituals or routines • Stereotyped or repetitive motor mechanisms • Persistent preoccupation with parts of objects</td>
<td></td>
</tr>
<tr>
<td>V (May 2013)</td>
<td>• A &amp; B are consolidated into one category (listed under ‘A’ in this table); must meet all three criteria in this category • Must meet two criteria in C</td>
<td><strong>Qualitative impairment in social interaction, unaccounted for by developmental delays</strong> • Deficits in social-emotional reciprocity • Deficits in nonverbal communication • Deficits in developing and maintaining developmentally appropriate relationships</td>
<td></td>
<td><strong>Restricted repetitive patterns of behavior; interests, or activities</strong> • Stereotypes or repetitive speech, motor movements, or use of objects • Excessive adherence to routines and/or ritualized patterns • Highly restricted, fixated interests that are abnormal in intensity or focus • Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment</td>
<td>“Infantile Autism” was considered one of five Pervasive Developmental Disorders (PDD)</td>
</tr>
</tbody>
</table>

Table 1. Diagnostic criteria for autism have changed throughout the years. The above table summarizes these changes.

* Although no significant changes were made to diagnostic criteria, descriptors of social behavior, communication, and language development broadened. Furthermore, children diagnosed with PDD-NOS who had either social or (rather than only) communication delays and abnormalities could be diagnosed with ASD. PDD-NOS, or Pervasive Developmental Disorder-NOS, Not Otherwise Specified is a fluid diagnosis. In the DSM-III, “infantile autism” was listed as one of the three categories of PDD. The other categories included a later onset autism, while “Atypical Pervasive Developmental Disorder” was the third, more amorphously defined subtype. Later, the diagnosis of PDDs began to be applied to individuals who had characteristics of autism, but did not fit the diagnostic parameters. Eventually though, PDDs became understood as part of the “autism spectrum” (Gerlach, 2007, pp. 136-141).  
lacking several pieces, to one with several identifiable pieces. Disentanglement from autism’s historical association with schizophrenia, a highly stigmatized mental illness, in addition to the heightened understanding of autism, has made it an increasingly desirable diagnosis. It could be hypothesized that diagnostic criteria both asserting this distance from schizophrenia and other mental illnesses and pointing to a plethora of specific and observable and quantifiable (through the use of psychological assessments) symptoms is another reason that the prevalence of diagnosed autism has increased.

The localization, observation, and quantification of symptoms (particularly in the brain) of autism lead to the belief that cures acting on these specific symptoms may be in autism’s near future. Neurological data concerning autism in particular act as “hope technologies” because the brain is paradoxically viewed both as an essential and determinant component of people and as malleable (fixable) parts of people. It follows that many American parents desire Autism Spectrum Disorder diagnoses for their children. The view of autism as fixable and hopeful may be why, in several states, a diagnosis of autism is accompanied by relatively significant educational and medical resources (Grinker, 2007b, p. 134).

As anthropologist Nikolas Rose (2007) describes, hope can play an important political role with regard to funding for particular medical diagnoses, as diagnoses that are viewed as having the potential for normalization (i.e. cure) lead to a particular type of social, political, and economic organizing (pp. 135-136, 148). These types of organizing have a different character with regards to “hopeless” diagnoses, for which no avenue for normalization is currently envisioned. In addition, the concept of the
“autism spectrum” itself infuses hope into this diagnosis, because the inclusion of autistic individuals with a desirable combination and degree of autistic and neurotypical characteristics creates an alluring “ends” which parents, clinicians, educators, and individuals can strive and hope to achieve through management.

**The Question of Normality and Desirability: Contexts and Locations**

Beliefs about complete puzzles, their origins, and the appropriate and available (management) technologies to actualize these puzzles, are highly variable based upon not only scientific data and discourse, but also sociocultural contexts. This can perhaps be clarified by using the puzzle analogy as a framework to view theories of pathology. Today’s disability theorists such as Robert McRuer (2006) and Lennard Davis (2002) and those who laid a foundation for their work, such as philosopher of science, George Canguilhem (1991), discuss pathology and illnesses as pushing the boundaries of biology and broadening the range of life experience, rather than presenting biological and social catastrophe (Canguilhem, 1991, p. 89; Davis, 2002, p. 29). In other words, to be sick is to be incompatible with the environment (Canguilhem, 2011, pp. 118-119, 183), and/or that “to feel abnormal is to realize that certain activities, which have become a need and an ideal are inaccessible” (Canguilhem, 2011, p. 201). Here, Canguilhem, writing in the first half of the 20th century, lays the ground for the social model of disability that asserts that impairments, such as paralysis, are biological in origin, but that social worlds create and maintain disabiling environments. Therefore neither disability, nor health are absolutes. Or in other words, as Michael Oliver (1990) boldly states, “disability as a
category can only be understood within a framework, which suggests that it is culturally produced and socially structured” (p. 22).

Nikolas Rose urges us to consider the abiotic factors that led to an investment in localized organs upon which work can be performed as the totality of self. As our bodies have discursively transitioned from a functioning unit to distinct and transformable parts, they have become manageable and malleable. Rose explains that with regard to the brain, through the 20th century, psychological theories (concerned with the whole unit of the mind) did not sustain their potency as “truth discourses.” At this time, psychiatry turned towards viewing (concrete) brain abnormalities, rather than those of the (abstract) psyche, as the etiology of disease. This meant that the brain itself, in addition to its chemicals and its functions were viewed as facts, and could be invoked to explain pathology and sculpt strict scientific categories. Rose believes that views such as the “Mind is simply what the brain does,” and that, “mental pathology is simply the behavioral consequence of an identifiable, and potentially correctable, error,” in addition to the emphasis on the brain in psychiatry, leads to “a new way of seeing, judging, and acting upon human normality and abnormality. This enables us to be governed in new ways. And it enables us to govern ourselves differently” (Rose, 2007, p. 192). Thus, although now rooted in biological “truth”, this shift in how we view the human body and psyche performs powerful political (abiotic) work. As I will discuss further in this section, Rose’s stance, then, is that pathology is situated and that cultural ideals and shifting conceptions of the body have opened up biotechnological possibilities that play a significant role in contextualizing, and thus, defining bodies and persons.
Current understandings of disability have evolved based upon notions of “the norm.” Early biologists perceived disease and disorder as “experiments of nature” that were the result of humoral imbalances (this belief persisted even prior to the first century and remained intact through the eighteenth century), defects in intensity of biological processes (a belief in the nineteenth century), and, later in the nineteenth century, were seen as the boundary of normal human variation. Therefore, pathology and illness either were understood as homogenous with the norm/health or of continuous terms with health/normal biological activity (Canguilhem, 1991, pp. 40- 47, 76-77). Later, though, disease came to be understood as a category established in order to protect the “productive citizen” and, within particular economic and social environments, the bounds of moral and physical desirability (Foucault, 2004), Although historically, pathology has been understood to reside within and be defined by the individual, academics, such as Canguilhem, and later, anthropologist Rose (2007), and psychologist Mark Rapley (2004), as well as others, emphasized social factors that define pathology. They assert that individuals exist in relation to scientific inquiry and discourse, and that it is society (and perhaps specifically scientific, medical, and political authorities and institutions), rather than some veritable measure, that defines the norm. In this model, social forces often impose self-understandings of pathology upon individuals who recognize pathology/abnormality neither within nor as relevant to (them)selves.

Canguilhem (1991) offers the following explanations of the relationship between biological and social norms: “Social norms interfere with biological laws so that the human individual is the product of a union of subject [sic] to all kinds of
customary and matrimonial legislative prescriptions” (p. 159), and “The human race, in inventing kinds of life, invents physiological behaviors at the same time. But are the kinds of life not imposed?” (p. 175). For Canguilhem, biology and social norms co-construct each other. This becomes particularly true with the advances of biomedical technologies at the end of the twentieth century and, as we shall see, especially true in autism.

Rose, as we have seen, writing twenty years later than Canguilhem, insists upon the role of technology in defining health and the self (and therefore, implicitly, disability). He claims “biotechnology changes what it is to be biological,” as he describes biological being as equated to the “natural” or the “standard.” I believe this can also be stated: biotechnology changes what it is to be ‘normal’ or ‘healthy,’ which results in the consolidation of the category of disability.

In contemporary Western society, easy access (for a majority) to treatment and diagnoses makes it even harder to attain idealized bodies and minds, because as soon as the prior moment’s “ideal” is obtained, the standard for the “ideal” of the present is raised. Furthermore, ease in modification and treatment leads to an increasing number of bodies transitioning “out of” their disabled state, and justifies and maintains categorizations of people as disabled. The movement by many out of the category of disability renders those who remain “stagnant” in their bodies more recognizable due to reduced variation in the mainstream population and the implication that these individuals have more “extreme/irreparable” deviations. As theories of autism postulate its cause and fundamental characteristics, the route towards normalization of autism becomes both increasingly defined and accessible.
Therefore, those autistic (and all disabled) people not observed or perceived to position themselves on this route (be it through medical, educational, and/or psychological interventions) will increasingly stand out among the “normative” and “normative-yearning” population.

Rose describes a biotechnomedical and social landscape in which bodies can transition out of abnormality to normativity. However, any such transition relies upon the notion of stable and universal norms. In the absence of “pathological” and “normative” characteristics, how do individuals orient themselves relative to norms? In addition to identifying pathology as situated within the environment, Canguilhem (1991) suggests that normality is also situated according to the individual: “It is the individual who is the judge of this transformation [to sickness] because it is he who suffers from it from the very moment he feels inferior to the tasks which the new situation imposes on him” (p. 182). By viewing pathology as individually understood, Canguilhem opens up room for individuals to exist in space ignored by Rose’s scheme, in which individuals are either ab/normal or transitioning between the two states, with normality always accessible and desirable. Many autistic people, however, carefully toe the line of identifying as dis/abled. For instance, many individuals describe the difficulties they have with social skills or sensory hyper/hypo-sensitivities, but insist that they gain many strengths from autism despite other characteristics that society stigmatizes and perceives as disabling (Grandin & Johnson, 2005; Robison, 2007, 2011; Stefanski, 2011).

Removing autism, or any other diagnosis from the category of disability, does nothing to reduce ableism or stigma. Therefore, following Canguilhem, instead of
considering whether or not individuals view themselves as disabled, I propose that it would be more interesting, and perhaps more productive to consider how individuals relate to the concept of “normality.” For example, statements such as, “[autism is] an integral part of who I am” (Interviewee 002), and “a way of being,” (Robison, 2008, p. 5) point to the situated nature of normality. Author Jason McElwain’s (2008) explanation of autism and his personal experiences further reinforce this notion:

I’m used to people looking at me like I’m different. It doesn’t bother me. I don’t even notice it. When they ask me what it’s like to be autistic, I don’t know how to answer. It’s just how I am. It’s like asking someone what it’s like to be tall or short, or fat or skinny. It’s like asking a tomato what it’s like to be a tomato. It’s normal. It’s me. I don’t think I’m any different from anyone else, really, I don’t. I look at the world the same way as anyone else. I see myself in the mirror and how I look to other people. I think about things probably the same way you think about things. It’s just that the world looks back at me a little funny, like I’m a little different. But like I said, I don’t really notice it. I’m aware of it, but I try not to think about it because there’s too much to do without thinking all the time what other people are thinking. (p. 39)

Here, McElwain acknowledges that although others perceive him as “different,” he does not perceive himself this way. In fact, to him, autism is “normal.” Despite his insistence on normality, McElwain’s identification as autistic interpolates him as such (Althusser, 1971) and as “biologically atypical,” as to be autistic is to be biologically atypical in today’s social world. Therefore, Canguilhem’s notion of pathology as situated within the individual and statements like, “it [autism] is an integral part of who I am” (Interviewee 003) suggest understandings of selves as biological citizens.14 Interestingly enough, due to cultural understandings and valuation of “the natural,”

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14 Anthropologist Adriana Petryna (2002) defines “biological citizenship” as a mode of citizenship in which individuals adopt bio/medical labels in order to qualify as members of the state, benefiting from state protections, and taking on a particular (diagnosis-specific) social standing.
this biologicalization implicitly refutes pathologization—a point that I will explore further in chapters two and three.

Nikolas Rose (2007) also suggests that biotechnomedical technologies have brought us to an era in which “our bodies have become ourselves, become central to our expectations, hopes, our individual and collective identities” (p. 105). Thus, an autistic person becomes a particular type of brain, rather than a “broken” one. Identification through anatomy in autism (and other brain-based dis/orders) may go relatively unchallenged, as these days the brain occupies a privileged space when it comes to understanding “self.” This is especially true with the rise of brain imaging technologies and the public distribution of neuroscience research:

Most accounts that make use of these technologies write as if we can now visualize the interior of the living human brain and observe its activity in real-time as it thinks, perceives, emotes, and desires—we can see “mind” in the activities of the living brain. Hence, it seems, we might be able to use these images of brain activity in different regions to make objective distinctions between normal and pathological functioning. (p. 195)

Rose’s work suggests how autism, now categorized as neurological in nature, serves as a compelling case study for how we understand our active-selves as relating to our brains.

As I have discussed, in our current era the brain stands in for “self,” the distinction between the biological self and agency has actually not been demonstrated scientifically. While we have identified the brain as the key to the autism “puzzle,” an irony emerges in that this key opens up additional areas for exploration, as now a relationship between neuro/biology and agency must be solved. Therefore, autism also provides a way for neurotypicals to learn about themselves, as autism as an object of inquiry provides clues to neurotypicality. This is not only because
neurotypical and autistic brains and behaviors are contrasted in scientific studies, but also, as all humans do when they inquire about any object (Feuerbach, 1989), neurotypicals construct autistic pathology in their own image.

It seems possible that the rise in autism diagnoses is in part due to the reduction in stigma attributed to this *neurological* diagnosis, as in the United States, although ableism is experienced by people with genetic and “faultless” disabilities, there is a greater tendency to tolerate disabilities that we do not see as anyone’s fault compared to those to which blame can be ascribed to individuals or their decisions and behaviors (Jenkins, 1998). Therefore, because we now posit autism as biological, in that we can even locate a “disturbed” organ (the brain), all former and shameful beliefs of the diagnosis’s etiology and symptoms, such as bad parenting and poor conduct/self-restraint begin to diminish under the “truth” discourse of biology. Furthermore, the *neuro/biological* diagnosis of autism becomes *desirable* over diagnoses with overlapping symptoms. This diagnosis absolves parents and autistic people of the stigma of diagnoses such as intellectual disability (formally “mental retardation”)*15* or behavioral/conduct and communication challenges that are often confused with and/or are comorbid with autism.

Although neurological localization removes fault with regards to etiology, locating autism in a malleable (fixable) *part* of an individual, implores autistic people and their parents to work towards managing and fixing autistic brains. In other

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15 The use of the term “Mental Retardation,” is a very offensive and historically significant term to describe intellectual disability (typically an IQ scores less than 70), and was very publically challenged during the first decade of the second millennium. This effort was initiated by TABs and disabled participants at the Youth Activation Summit at the 2009 Special Olympics World Winter Games ("Spread the word to end the word overview," 2011). This term was officially replaced with “Intellectual Disability” on all United States documents by the signing of “Rosa’s Law” in October, 2010 (Diament, 2010).
words, despite the autistic puzzle being relegated to the domain of biotechnology, understandings of the brain as plastic\textsuperscript{16} implores autistic people and their parents to attain access to management and curative technologies and to actively engage in efforts to modify behavior. What then happens when individuals and families reject the sociocultural imperative to strive towards normality?

Management of the Malleable Self: Does Celebrating Differences Make One a Bad Citizen?

Neurodiversity movements have their origins in the late 1990s. As understandings of autism shifted away from psychology and towards neurology and genetics, whether or not autism should be “cured” increasingly became called into question by autistic people. The term “neurodiversity” seems to originate in the writing of autistic activists, scholars, and self-advocates, and while Judy Singer is often cited as coining the term “neurodiversity,” Jane Meyerding (1998) reports Singer as saying, “I am not sure if I coined this word, or whether it’s just in ‘in the air’” (Ortega, 2009, pp. 2-5). Although not all autistic people are aligned with neurodiversity movements and its discourse, those who are proclaim that their differences do not require curing, and that they experience life in distinct and desirable ways. To counter-act cure discourse, neurodiversity activists, in a kind of reverse gaze, may point to the flaws of neurotypicality and suggest that neurotypicals be cured—this move is meant to “demonstrate the absurdity” in efforts towards normalization (p. 432).\textsuperscript{17} These individuals may choose to construct identities around

\textsuperscript{16} Today, when scientists talk about the ability of the brain to change and make new connections throughout the life time, they use the word “plasticity.”

\textsuperscript{17} One example of this type of discourse comes from the “Institute for the Study of the Neurologically Typical”: 
atypical neurology, movement, speech, etc., and do not seek to alter the effects (behaviors, etc.) of their neurology to conform to society.

Are these individuals viewed as practicing important self-preservation strategies (Crocker & Major, 1989) or are these individuals viewed as defiant, and in turn further stigmatized for their decision not to challenge their biological reality? Perhaps in the past, people who made the best of their physical differences were viewed as having strong character, but as biotechnology opens up new interventions, it also prescribes a new type of personhood and “appropriate” responses to states of being viewed as pathological.

As discussed, Rose (2007) describes how [(increasingly) easy] access to diagnostic and therapeutic technologies, be it genetic testing, MRIs, psychotherapy, or pharmaceuticals, puts new pressure on good citizens to sculpt their bodies in order to attain the biological (and thus psychological) possibility of the “the good life”:

Making up biological citizens also involves the creation of persons with a certain kind of relation to themselves. Such citizens use biologically colored languages to describe aspects of themselves or their identities, and to articulate their feelings of unhappiness, ailments, or predicaments. (p. 140)

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What is "neurotypical"?
Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone and are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist on the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum.

What is the cause?
NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical to be typically smaller than that of an autistic individual and to have overdeveloped areas related to social behavior.

How common is it?
Tragically, as many as 149 out of every 150 individuals might be neurotypical.

Is there any treatment for NT?
There is no known cure for Neurotypical syndrome, however, many NTs have learned to compensate for their disabilities and interact normally with autistic persons (Larson, 2010).
In this age, when biomedical technologies provide opportunities for transformation (through management), identifying the self in biological (read: manageable) terms implicitly writes the self as malleable. This opportunity implores malleable individuals to sculpt biologically idealized bodies in order to attain their intended (= natural = biotic) state. Given this social responsibility, in our biotechnomedical age, is any person who does not procure the “real” (idealized) self disabled? Rose (2007) emphasizes that much of health today is about “how we conduct ourselves” (p. 26); meaning that even in absence of ideal biology, individuals are expected to strive for perfection by all means possible. He discusses how technologies of the self shape people into ideal forms, as “biology is no longer destiny” (p. 40). Here is where he discusses the shift from ‘implacable abnormalities to manageable susceptibilities,” that can be controlled, thus resulting in (ideal) “normal” bodies (p. 154). No longer is pathology “destiny” in that individuals are passive to the circumstances and realities of their bodies. Rather, individuals (if they have the financial resources) have agency over their bodies. What is interesting though, is that despite the now active individual working on a passive (biological) body, we still categorize people based upon their dynamic bodies, and thus, work done on the body can be seen as a “people-making” project (Hacking, 2006).

Aside from the present use of transformative technologies such as medications and therapies on individuals, individuals and clinicians manage future bodies through genetic screening and therapies, such as the selection of particular embryos for implantation during reproductive counseling. Perhaps most salient today is the belief that autism can be somehow “produced” by the combination of genes of intellectual
and “nerdy” parents, and the subsequent implication that these types of people should take caution when procreating. However, scientific research regarding this hypothesis has been inconclusive (Buchen, 2011). However, in the case of autism, though some technologies do promise a cure, none are reliably documented to have this capacity, nor do any exist for prevention. Therefore, for now, autistic people and their ranges of behavior and experiences are generally presumed to be natural (biological or environmental) accidents, rather than a result of negligence (of a child or reproductive caution) or improper care.

Parental blame for autism does persist in some places though, and many studies have suggested and searched for environmental and genetic causes of autism. Should these be uncovered, perhaps autism will once again be considered a choice, or at least a diagnosis that can be avoided. In the case of abiotic causes, attribution of “fault” for or “choice” of autism would be directed at management of symptoms and the environment rather than autistic existence itself. However, the dearth of conclusive evidence for any theories of autism’s etiology both reifies it as a mysterious diagnosis and imbues it with hope.

Defiant disabled individuals disrupt the process of people making and reject biomedical people-making technologies by asserting that their (non-“ideal”) bodies do not need to be managed, corrected, or cured.18 Rather, through neurodiversity and disability studies discourse (which is ironically often facilitated through computer technology), autistic individuals establish disability as within the bounds of normal human variation and even choose disabled bodies (Michalko, 2002, p. 48). Because

18 Ironically, it is the existence of these technologies that creates this political opportunity.
citizenship is dependent on labor and biological contributions of the “normal body,” those bodies that do not make an effort to conform and optimize labor and biological potential are not considered to be productive contributors to society, as in their rejection of normalization, they shirk their responsibility as citizens. Perhaps this is why schools and parents are expected to intervene on the disabled body—because many believe that the disabled individual should not be provided the opportunity to self-determine their behaviors and way of living. Disabled children begin the normalization process through parental and government-mandated management (via schooling), sometimes from birth. Through these early experiences, and the rigid structuring of society, which reifies the necessity of the perfect body, individuals are inducted into a mindset and/or routine of working towards normalization and mimesis of enabled individuals (Foucault, 2004; Michalko, 2002, p. 166). This process is assisted by the infantilization of disabled people, as they often grow up without the opportunity to make decisions for themselves (Clare, 1999), such that they are sculpted by “normal” (read: TABs) parents, teachers, peers, and caregivers (Abbott, personal communication, 2011).

If overt management by professionals and families is not enough to mold disabled people, their environments (physical and social) often evoke a sense of being disabled and a desire for intervention and normalization. This is perhaps best explained by referring back to the social model of disability (Oliver, 1990) and Canguilhem’s (1991) model of situated pathology. The social model of disability describes individuals as not organically disabled, but rather impaired—the body does not disable, rather incompatible environments produce disability. Therefore, it is not
unreasonable to expect that if a person who used a wheelchair grew up in a physically accessible town, he or she might not feel disabled. Or, at a social gathering of autistic people, such as the AUTREAT conference/retreat run for and by autistic people (Sinclair, 2010), autistic individuals may not be or feel disabled.

This chapter has discussed ways in which autism has evolved as a puzzle. When it was first conceptualized, autism was understood as a characteristic of schizophrenia, a mental disorder, which psychological therapies could “amend,” into an “improved” schizophrenic or intellectually disabled adult. Then, Kanner and Asperger’s identification of autism as its own category opened up possibilities for new ends, and in particular a normative adult. Initially, parents (and in particular, mothers) were hypothesized as both the origin/cause of autism and its “solver” who through the “technologies” of love and attention could achieve normality for their children. Starting in the 1970s, research suggesting that autism exists in a wide range of individuals led to movement away from parent blame and shifted responsibility to psychology, biology, and the environment—which could be seen as puzzles in their own right, and altered through the technologies of clinicians. Today, autism is more specifically understood as a neurological disorder with possible genetic and/or environmental foundations that are also appropriately managed and “solved” by experts and their technologies. Even though the autistic puzzle is no longer believed to originate with mothers, they are still a part of the “solving” (or treatment) process, as they are responsible for access to clinicians and services.

Although we have seen how norms and context construct a particular type of “able” person, the specific ways in which norms develop and how autism has become
desirable have not been fully discussed. The following chapter will describe the
evolution of normalized organs and how this has constructed a particular autistic
brain. I will also describe ways in which autistic and non-autistic people usage of
neurological discourse leads to its nature as a double-voiced tool that simultaneously
denies and confers autistic personhood.
CHAPTER 2
LOCATING DIFFERENCE: AUTISTIC SPECIATION

As I established in the previous chapter, understandings of the “normal” body are centered on the illusion of an attainable and ubiquitous norm. In the current era of technology, we also use the norm to prescribe technologies to reconfigure and transform bodies—as Rose demonstrates, self-management is now part of being human. Evaluations and prescriptions determining which bodies necessitate management rely upon testing that invokes (truthful) science and is therefore a powerful technology with regard to identity formation and sociopolitical classification. This results in scientific and medical testing becoming a basis of identity formation, and being an incredibly powerful technology in the process of people making. Today, though, testing is focused on those bodies that fall outside of the constructed “norm.” As argued in the previous chapter, continued cycles of testing throughout the twentieth century that identified “aberrant” characteristics in autism reified autism as pathological but more recently have led to the destigmatization of autistic people by localizing autism within the brain.19 As I will discuss in this and the following chapter, the neurological character of autism leads to narratives of both humanity and hope.

Michel Foucault (1973) describes how the medical gaze (which itself is a product of historical and sociocultural understandings of the body) selects particular characteristics as typifying bodies. The gaze is neither isolated nor stagnant, but

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19An exception to testing as an experience reserved for “abnormal” bodies is the testing of the “normal,” or “control” human subjects. There has been little work in this area, however through archival and field research of Institutional Review Boards, Laura Stark’s ("coy," : Stark, 2012) recent book documents the emergence and current character and treatment of the “human subject.”
rather it simultaneously and continuously works upon the environments within which bodies are understood. Today, because medical testing demands significant resources, its gaze is relegated only to those bodies that we understand as deviant. This spatialization transforms the very act of entering a clinic into the implicit acceptance of pathologization.

People are also evaluated on the basis of behavior, and although psychology had been studied for centuries, advances in neuroscience, and the establishment of psychological research labs in the second half of the nineteenth century, helped establish psychology as distinct from philosophy, and paved the way for psychological research and ab/normalities of behavior to be studied scientifically and clinically. This emerging field developed concurrently with the rise of institutionalization for the mentally ill, and an increasing number of individuals considered mentally ill were not only sent to these facilities, but were also studied there. In the second half of the nineteenth century, the clinical interest in behavior and psychology as a science led to the identification of several new pathologies and expanded the gaze outside of the body, to the psyche (Magoun, 2003).

**Boundaries of Personhood**

As discussed in the last chapter, autism was initially understood as a characteristic of schizophrenic children. These children were noted to lack specific social abilities and behaviors, particularly those concerning socialization and communication. Autistic individuals were dehumanized through both autism’s association with schizophrenia and Kanner’s and Asperger’s stigmatizing descriptions

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20 This is similar to how the medical clinic became defined as a place of medical inquiry and cure for somatic pathology. In *The Birth of the Clinic*, Foucault tracks how the clinical transformed from a place for bodies to die into a site of research and cure.
in the 1940s. In addition, the social implications of delayed communication and odd social behavior, which were associated with other disabilities such as intellectual disability and mental illnesses, further contributed to stigma. The link to schizophrenia is clear, as many people with schizophrenia exhibit atypical social and communicative behaviors, but it can also be hypothesized that communication deficits led to associations of autistic people with high stigmatized people with intellectual disabilities, despite Kanner’s assertion of “good cognitive potentialities” in the autistic population (Grinker, 2007b, p. 49). In addition, the framing of autistic individuals as lacking emotional capacities likely associated them with other people constructed as psychologically ill and predisposed to commit crimes.

Mid nineteenth century understandings of autism that focused on communication strongly established pathology. Although social understanding is often discussed as characteristic of autism, language and verbal communication differences are also important diagnostic criteria and play a large role in defining the in/humanity of autistic people. Autistic author Temple Grandin (2005) makes this point by emphasizing the social importance of language: “A lot of people are emotionally invested in the idea that language is the one thing that makes human beings unique. Language is sacrosanct. It’s the last boundary standing between man and beast” (p. 272). Therefore, a lack of, or disturbance in language, gets at what exactly it may mean to be human, something that autistic 26 year-old Sue Rubin has seemed to have internalized. Rubin says, “When I wasn’t able to communicate, I was a non-person” (Wurzburg, 2005). This is supported by parents’ many efforts to help their autistic children learn to talk and communicate above all else (Adams, 2005).
Autistic twenty-one year-old Jason McElwain (2008), who distances himself from autism, especially nonverbal autistic individuals, provides a vivid example of how highly verbal communication is socially valued. In his descriptions of desiring to be “normal” or “regular,” he focuses on the changes that he and those around him felt and perceived once he began to talk, especially in relationship to his brother. He wrote, “a year or two after I started talking, after I’d become a regular kid brother after all that time not talking and everything…I guess he [his brother] was surprised that I was just a regular person inside.” McElwain says of the time prior to beginning to talk, “I wasn’t really much fun to be around, I guess,” and reflects on the changes associated with verbal communication: “But then I started talking and everything changed. My personality changed—that’s what everyone said” (pp. 103-104).

It is unclear whether or not McElwain had previously valued communication and/or the change in him when he began communicating, or if his pride in communication stemmed from his parents’ emphasis on talking. However, it is evident that McElwain noticed and enjoyed the difference in how others related to him when he began talking. “Once I started talking, once I started interacting with other people, Josh [his brother] started to pay attention to me. Before that, I was just his autistic little brother. I was always around, that’s all” (p. 103). Thus, it seems McElwain devalued his nonverbal self, by saying he was “just [an] autistic little brother” (emphasis added), as if an autistic little brother were not even something to be paid attention or afforded social space. Perhaps, as his family encouraged communication and he observed that talking was valued, McElwain viewed verbal communication as defining worth and humanity, and subsequently worked to achieve
it. Most importantly though, is that both Rubin and McElwain seem to view verbal communication as conferring personhood, and subsequently imply the silent (nonverbal) body’s status as the “other” (non-human).

**Self-Knowledge is Humanizing: The Theory of Mind Hypothesis**

The most popular etiological understanding of autism, which plays a significant role in directing current biological research, is the psychological hypothesis of absence of Theory of Mind (ToM). The ToM hypothesis dates back to the 1970s, when Frith, Leslie, and Baron-Cohen suggested that autistic individuals lack the ability to interpret the intentions of others, or are “mindblind” (Happé, 1994). This theory was largely supported by false belief tasks21 in which most autistic individuals failed regardless of age and IQ. More advanced ToM/false belief tasks have been designed, and the results of these studies have suggested that perhaps autistic individuals are capable of primary non-mental representations, yet lack the ability to form mental representations that would enable them to pass false belief tasks (Happé, 1994, p. 46). Perhaps these results played a role in the eventual acceptance of autism as a spectrum, as the advanced false belief tasks resulted in a performance gradient supporting the heterogeneity of autism even within what was hypothesized as its core feature.

One of the strengths of the ToM/mindblindness theory is that it can explain the “triad of impairments” that is often used to describe autistic individuals:

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21 False belief tasks assess whether or not individuals are able to recognize that others may have mental representations of a situation that differ from their own. The most famous of these tasks is the “Sally-Ann” task, in which subjects are told a story in which one character moves a marble from one location to another while the other character is not present, and then asked where the absent character will look for the marble upon returning. In order to pass this task, subjects must say that the character will look in the original location, thus suggesting that the subject understands the thought process of characters (Happé, 1994, pp. 40-46).
difficulties with socialization, communication, and imagination (Happé, 1994, p. 18). The Theory of Mind hypothesis supports this descriptive scheme, as mindblindness could lead to an inability to understand individuals as free agents (social understanding), which could also lead to deficits in communication and imagination. However, the triad theory is not currently widely accepted in autistic, parent, scientific, and clinical communities, largely because autistic people form a heterogeneous population in which impairment in all three of these areas is not always present (pp. 35-36). Despite this criticism, the triad is still used to formulate theories and guide research because it does describe a large proportion of autistic people with some degree of accuracy (the influence of the triad theory can be tracked in the DSM criteria previously summarized in Table 2). Aside from its ability to explain the triad theory, additional support for the ToM hypothesis comes from studies that suggest deficits in mechanisms involved with social understanding and referencing, such as joint attention, gaze direction, and pointing to objects in order to gain others’ attention. Some assert that the development of these mechanisms underlie ToM, and therefore, their impairment in individuals with autism may point to the underlying causes of ToM impairments (Bowler, 2007). Thus, ToM itself becomes a puzzle within the autistic body (or mind) that can be solved by psychological experts and their interventions. However, access to experts who can perform these interventions is usually the responsibility of the parents. Although state supports do exist, these are resources that parents must request and in many cases, prove the need for.
The ToM hypothesis has been extended to support Kanner’s original descriptions of autistic children that emphasized “self-focus.” Assessments of ToM not only operationalized Kanner and Asperger’s descriptions of atypical social interactions, but eventually led to the understanding of autistic people as unable to understand both self and others, and subsequently as bodies with “absent” selves (Lombardo, Barnes, Wheelwright, & Baron-Cohen, 2007). Thus, testing which asserts atypical understanding of self and other not only serves to distance autistic people from humanity, but also locates their inhumanity in the psychological realm. As identification of autistic pathology relating to understandings of self hinge upon tropes of humanity, it is important to examine the psychological research that has used these differences to justify autistic speciation.

To this day, apparent lack of social understanding is a socially alarming element considered characteristic of autism. Although I present data asserting that autistic individuals are capable of conceptualizing their thoughts and feelings, I feel that it is important to review research that has claimed otherwise. For example, Frith and Happé (1999) suggested that “the logical extension of the Theory of Mind (ToM) deficit account of autism is that individuals with autism may know as little about their own minds as about the minds of other people,” and therefore can neither reflect on mental sates nor represent “thoughts and feelings as thoughts and feelings.” They made this suggestion in a paper which performed a brief literature review highlighting studies with autistic individuals who the authors believed appeared unable to understand both the differences between mental states and behavior and those between willed and involuntary behaviors. Frith and Happé’s paper also highlighted
three subjects who were able to pass false belief tasks to varying degrees, yet when prompted to describe their experiences at given moments, all described visual rather than emotional or mental experiences, and struggled not only with describing their mental states, but also with conceptualizing how this might be done. In order to assert further evidence of a lack of introspection and feelings, Frith and Happé used biographical accounts from some of the first autistic autobiographers, such as Donna Williams (1992) and Temple Grandin (1995), who wrote statements such as “My first ‘wants’ were comprised of those seen in others” (Williams, 1992). The proposition that autistic people not only lacked understanding of others’ minds, but also of their own, played an important role in the early trajectory of autism research, as it led researchers to investigate the ability of autistic individuals to understand and communicate about themselves.

Another way in which self-understanding has been evaluated in individuals with autism is through the “self-reference effect” (SRE), in which individuals preferentially remember words associated with themselves, rather than with others. The evidence is inconclusive as to whether or not this effect is present in autistic individuals, as Toichi’s group (2002) claims to observe no effect, while Lombardo’s group (2007) notes such an effect, albeit quite small compared to that of neurotypical controls. Toichi’s group seems to briskly jump to the conclusion that a defunct or nonexistent SRE relates to “a lack of self-consciousness in autism” (which is the paper’s title). Lombardo’s group, however, notes a deficiency in SRE as correlated with difficulty recognizing one’s own emotions (alexithymia) and being less self focused. SRE was also studied by Henderson’s group (2009), who found similar
results to Lombardo’s group, but noted that both age and social impairment were positively correlated with the degree of SRE deficit, thus suggesting a possible developmental delay that could be correlated with the “severity” of autism.

Earlier behavioral studies also supported the notion that autistic people lack self-consciousness and have atypical inner experiences and understanding of these experiences. For example, Dawson and McKissick (1984) developed a study in which they assessed autistic children’s self-recognition in a mirror, and its relationship to developmental landmarks such as object permanence and social imitation. Although they found that object permanence and the ability to imitate another person were unrelated to self-recognition, individuals with autism had different behaviors than non-autistic participants, in that they displayed less self-conscious behavior. Despite their ability to recognize themselves in a mirror, autistic children behaved less “coyly” and did not exhibit self-conscious reactions to seeing themselves in the mirror. Similar results regarding self-consciousness were observed in a study by Hurlburt and Happé (1994). Although this research focused on reports of inner experiences of adults with ASDs who performed differently in false belief tasks, they observed that all participants were uninterested in their performance relative to other participants, which was in stark contrast to the interests of typical subjects with whom Hurlburt had previously worked. Such behavioral reports of autistic people lacking self-consciousness are supported by neurological studies (as

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22 Object permanence is the conceptual structure that allows individuals to know that an object exists even when it is not visible. Generally this developmental landmark is achieved between eight and twelve months of age (Smith, Nolen-Hoeksema, Fredrickson, & Loftus, 2003). Social imitation is also reported to emerge early in life and is an important process in social learning, through which viewing and replicating the processes and actions of others leads to acquiescence of social skills (Toth, Dawson, Meltzoff, Greenson, & Fein, 2007).

23 Because “coyness” is seen as an indicator of shyness or modesty (“coy,” 2012), perhaps this is how the authors linked “coyness” to self-consciousness, or awareness of self.
will be discussed) and also by some of the hallmark symptoms of autism, such as
difficulty with eye contact and understanding social rules.

Hurlburt and Happé’s research (1994) provides yet another case of
psychological studies contributing to stigmatizing and what I believe are inaccurate
conclusions about autism and autistic people. They suggested that autistic people do
not have the tools to talk about their inner experiences in ways similar to
neurotypicals. Hulburt’s initial studies with neurotypical participants found that most
people describe a variety of inner experiences, including those that are verbal, visual,
unsymbolized thinking, and emotional. In addition, they reported group differences
in how people with a variety of diagnoses such as schizophrenia, depression, bulimia,
and borderline personality disorder, report their inner experiences. However, the
autistic group was particularly interesting, in that all five subjects, regardless of their
ability to pass false belief tasks, had difficulty understanding the task and only
reported visual images. Although they used a very small sample size, from which no
conclusions can really be drawn, studies such as these, bolstered by Temple
Grandin’s (1995) famous work *Thinking in Pictures*, assert that autistic people not
only lack typical inner lives and are incapable of understanding their own feelings,
but can not even conceptualize what neurotypical individuals would consider
“thoughts” and “feelings.” In this influential and pioneering autistic autobiography,
perhaps the most well known “conclusion” is that Grandin (often cited in a way that
generalizes Grandin’s works to all autistic people) thinks visually rather than
verbally. Given Hurlburt and Happé’s research asserting that inner experiences are
often verbal, when Grandin’s work is taken out of context, it seems that her visual
thinking can be seen as supporting Hurlburt and Happé’s claim that autistic people lack typical inner experiences and tools to understand.

The above review of psychological literature reveals that psychological assessments served to not only locate autism, but also to perform the biological work of speciation. In particular, by positing autistic people as lacking and/or having atypical communication, social skills, and emotions, psychological research has provided data distinguishing autistic people from neurotypicals in speciating terms. Due to cultural understandings of science as truth, published data provides justification for viewing autistic people as somehow less than or not-quite human. Although the work of speciation was located in psychological research in the twentieth century, as brain imaging was gaining prominence in the 21st century, understandings of autism began to shift towards the brain. This shift has resulted in new forms of describing, (de)valuing, and understanding autistic people which both reify autistic speciation and open up space for autistic personhood.

**Neurology as Humanizing**

Perhaps the best place to begin a discussion of neurological understandings of autism is with the brain’s place in Western society and a brief overview of how it has been studied. A brief understanding of scientific understandings of the brain perhaps is useful to understand its place in our society. Despite neurology captivating the interest of scientists for centuries, the first noted methodology of neurological inquiry is Franz Joseph Gall’s development of phrenology in the beginning of the 1800s (Magoun, 2003, pp. 5-9). Although not immediately embraced by American scientists, by the 1840s, The American Institute of Phrenology was established, and
the measurement of heads and attribution of mental ability to phenotype was widely accepted. Today phrenology is considered a pseudoscience, but Gall’s suggestion that thoughts, emotion, and personality traits originate in the brain influences hypotheses about brain function hold up today. Furthermore, Gall’s impact can be observed in social history, as his work perpetuated ideas about head size and intellectual ability that politicians, scientists, and laypeople alike deployed to oppress many groups.

In the nineteenth century scientists began to investigate the brain on a smaller scale, with societies of neurology and neuroscience putting resources into the study of nerves and neurons (Magoun, 2003, p.43). In addition, during this time, neurology and psychology were tightly intertwined, and the field of “psychobiology” emerged. Of particular interest to many scientists was comparative neurology. Many scientists undertook comparative studies that examined neurology across species and race.24 One role of comparative anatomy is the classification of nerves and the recognition that different types of nerves corresponded to different functions. One might imagine that this carved the path for early neurosurgery experiments, which were first conducted on primates in the first half of the twentieth century. These experiments served as a valuable supplement for case studies of individuals with brain lesions and helped advance knowledge about the brain’s function, mechanisms, and localization of mental processes. In addition, this work opened up the space to investigate how particular components of the brain are arranged and how they function and influence

24 With regard to race, early neurological research was deployed to assert the superiority of Caucasians. These studies reified the belief that the white brain was more complex than the black brain persisted through the early twentieth century.
mental processes and behavior. By studying the brain and quantifying its effects (mental processes and behavior), characteristics of the human were defined and quantified—therefore, the emergence of neurology introduced new ways to determine the boundaries of personhood.

Neuroscientific inquiry was aided by visualization techniques. In 1875, electrical potentials were observed in nerve cells. This led to the development of electroencephalography (EEG), which records the electrical potential of nerve cell firing. EEGs enabled scientists to map the activity of particular brain regions, and by 1930, EEG had been developed for use with humans. Its first uses were to diagnose epilepsy, but it was later used for diagnosing brain damage during World War II (Magoun, 2003, pp. 176-179). In addition, early studies of communication disabilities were studied with EEGs at the University of Iowa in the 1930s (p. 398). Because many philosophers posit verbal language as uniquely human, it seems that when used in this capacity, EEG could have served as a tool to evaluate personhood on the basis of brain activity. The brain as an organ upon which (restorative) work could be performed was established by the 1940s, during which scientists had determined that frontal lobotomies could cure schizophrenia (p. 258). The use of lobotomies to normalize and tame individuals is additional indicator that mid-twentieth century scientists and society viewed the brain as a conduit to attain idealized individuals.

In addition to significant scientific interest in the brain, psychologists and philosophers, including Descartes and Locke, have long been interested in the relationship between the mind and the brain. As a prominent American psychologist
William James stated, the connection between the mind and the brain is the “ultimate of ultimate problems” (Magoun, 2003, p. 331). Efforts to unravel this mystery have centered on consciousness, and popular discourse has struggled to determine exactly where the (uniquely human) mind and consciousness reside. Is the mind within the brain? Or are they one and the same? Is the brain the organ within which the mind resides, with the mind the seat of consciousness? Would this imply that particular regions of the brain are devoted to consciousness? If so, where does the mind fit in? These questions have been long debated and have resulted in a popular rhetoric in which the mind and brain are often conflated. How we view the mind and brain in relationship to consciousness has large implications for the construction and evaluation of human identities. Because the mind and brain are closely associated with consciousness, broken, abhorrent, and damaged minds and brains are seen to as related to atypical or even absent consciousness, which results in dehumanization.

Writing in the 21st century, Paul Rodriguez (2006) performs a careful semantic analysis of the ways that Western society discusses the mind and brain. He explains that although the mind and the brain are often substituted for each other, the brain remains concrete, while abstract meanings are attributed to the mind. In Rodriguez’s analysis, the brain stands for intelligence, an intelligent person, thinking effort, and a body part/organ that in and of itself “stands for a whole person” (including that person’s intelligence). Furthermore, Rodriguez suggests that in Western discourse, “the state of the brain equals the state of being,” the brain itself is “the experiencer of perceptions,” and “medi[ates] the mental state” (p. 311). Therefore, Rodriguez describes how Western discourse implicates the brain as the localized source of
individuality, intelligence, and difference, and citing anthropologist Joe Dumit, explains that the proliferation of brain imaging technology has increased the cultural significance of the brain.

*Spectacular Images*

Dumit (2004) explains how spectacular brain images, which suggest that neurological differences and processes are defined and visible, participate in neurological reductivism. He describes how these images are created, and how, although compelling, the researchers creating these images neither strongly support their commercial use, nor their use as tools to deduce facts about, or explanations of, human variation (pp. 46-60, 111-113). In actuality, these images are created is a process that results in the publication of non-representative images, which are consumed as prototypical of the people studied. This is because published images are usually not average scans, but extreme representations that are strategically selected and colored to accentuate the findings rather than accurately represent the average data; therefore, images derived from Positron Emission Tomography (PET)\textsuperscript{25} scans present simplified and exaggerated information relative to the data tables from which they derive. If truly average, or more representative images were used, the (culturally powerful) distinctions between pathological and typical brains would not be readily observable (p. 96). Furthermore, these images are probably not applicable to much of the population, as in an effort to maintain experimental control, usually only white, right-handed males participate in brain imaging studies (p. 61). Regardless, these images are uncritically consumed as fact and tellers of stories—the cause of behavior,

\textsuperscript{25} PET scans produce three-dimensional images of the brain’s use of radiolabeled chemicals (generally an analog of glucose). This information is generally used to determine metabolic activity and localize brain processes.
the use of nutrients, the etiology of difference—are all mapped onto the localization of color in ungeneralizable and statistically inaccurate figures.

The quick conclusions that are drawn from imprecise yet readily accessible images result in popularized discourse of brain-based behavior and difference, or “folk neurology” (layperson understandings of how neurological processes relate to behavior and individual characteristics) (Vrecko, 2006). The proliferation and potency of folk neurology can be attributed to our cultural privileging of science and our lack of skepticism regarding scientists’ ability to “see inside” the brain and understand its inner workings; in reality, scientists are currently only beginning to be able to find correlative data, which is far from the causative models that images may imply. Regardless, we consume the language of scientists through popular media and use it to assert our own knowledge about the brain and how people function. Our daily exposure and participation in neurological discourse reifies neurological explanations and potential avenues for discrimination. Therefore, brain imagery implies the ability to directly observe distinctions among types of humans in the very organ that defines them as such. Additionally, similar to the act of entering a physician’s office as a patient, being selected for neuroimaging indicates pathology, as research is another technology that employs the pathological to learn about and define the norm. Therefore, by making psychological hypotheses of difference visible, not only to the trained eye of the physician and researcher and his/her technologies, but also to the layperson, neuroimaging technology is a powerful tool in the production of neurotypical and autistic personhood. It follows then that the hope of “fixing” autism could be viewed as hope for autistic people to transition into full
humanity. Accordingly, funding for research is largely provided for studies that promise to localize and reveal autism, with the hope that eventually work can be performed upon deviant structures, mechanisms, and genes.

An example of autism being reimaged is through early studies reporting an increase in size of autistic brains. It has long been observed that autistic children experience an exaggerated growth spurt in head circumference prior to age three. Early brain imaging technology supported the hypothesis that somehow, autism was due to some sort of excess (Figure 2). Despite studies revealing that the early growth spurt in head volume often observed in autism is not a cause of autism, in lay understandings of the brain, a sudden increase in head size has become a cause for concern. The correlation of large heads and autism has been further investigated, and in recent years, it has been determined that this increased volume may be attributed to an increase in white matter (the parts of the brain that are mylenated, and thus conduct information more quickly than unmylenated “grey matter”) and neuroinflammation (Herbert, 2005). Despite these specific findings, images such as those below still persist and imply that large brains are correlated with autism. This figure places brains that are considered to be representative of autistic and “average normal” children side by side; the excess of the autistic brain is exaggerated by displaying it as darker26 than the “average normal” brain (which is set back relative to the autistic brain). The placement of a scale in the image authenticates this visual

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26 Culturally, dark is associated with “bad” or “evil,” while “light” is associated with “good.” Therefore, this coloration is yet another way that the image implies autistic immorality, and lack of personhood.
evidence of the autistic large brain\textsuperscript{27} by asserting that this difference is measurable, and suggests that the image is representative of quantitative data.

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{figure2.png}
\caption{Both layperson observations and scientific studies have proliferated the notion that autism is associated with an excess of brain volume (Magoun, 2003; University of California & Children’s Hospital, 2003).}
\end{figure}

Furthermore, the use of non-parallel labels in this image also performs speciating work. The authors label the autistic brain as such, while they describe neurotypical brain without an analogous diagnosis (which I suggest would be “neurotypical”) but rather is reinforced as normal (read: desirable) through the descriptor of “average.” Not only does this work to distance autism from the possibility of normality (desirability), but it is also reductive in its suggestion that although a range of brains could exist within the “normal” population (hence the need to indicate that the brain displayed is “average”), any autistic brain would be fully representative of any autistic individual.

\textsuperscript{27}This may remind one of phrenology’s claims that head size is indicative of particular characteristics, such as intelligence.
Images such as these associate autism with “excess,” which is culturally established as related to immorality, irresponsibility, and loss of control (or failure to manage)—all themes that play a role in the stigma attached to disability, and more specifically, mental illness. Thus, due to a specific observation about hypothesized neurological correlates of autism, autism is brought more proximal to cultural understandings of mental illness.

Other studies identifying particular regions and functions of the autistic brain as pathological through function magnetic resonance imaging (fMRI) point to absence rather than excess. The emphasis on absence shifts the “blame” of autism away from the individual, as absence is associated with a lack of agency, so no personal blame can be assigned (recall that absence was a theme in psychological hypotheses of autism). More specifically, recent fMRI studies report differences in brain activity with regard to facial recognition, accomplishment of executive functions, and false-belief tasks that can be associated with reductions in size and activity (G. Dawson et al., 2002; Frith, 2001; Muthukumaraswamy & Singh, 2008; Pelphrey et al., 2002). In addition, a whole neurological system has been implicated in the symptoms of autism.

In the beginning of the 21st century, research on joint attention28 uncovered the mirror neuron system (Ramachandra & Oberman, 2007). These neurons are believed to respond identically to performing motor movements oneself as to observing

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28 Joint attention is the monitoring of another person’s attention and the subsequent orientation of our own attention to the same object or location (J. H. G. Williams, Waiter, Perra, Perrett, & Whiten, 2005). This behavior which appears to exist without direct instruction, is observed in closely related primates (Subiaul, Barth, Okamoto-Barth, & Povinelli, 2007) and has been demonstrated to emerge early in human development. Infants as young as 6 months old preferentially look at eyes, and by 18 months, they follow the gaze of others (Williams et al., 2005).
someone else perform these movements. Mirror neurons have also been implicated in the social mechanism of gaze following—another “deficit” observed in autism. Reduced connections, activity, and structural abnormalities resulting in a “broken” mirror neuron system have all been proposed as a possible explanation for the social symptoms of autism (G. Dawson et al., 2002; Muthukumaraswamy & Singh, 2008; Nichols, Fox, & Mundy, 2005; Ramachandra & Oberman, 2007). Such studies and popular media reports project the idea of autistic individuals as having a fundamental difference in neurology that accounts for their disability.

Mirror neurons are just one example of a specific brain region that is described and understood as atypical in autism. However, mirror neurons provide an interesting case of a whole system being defunct, as opposed to hypotheses about subtle differences in connectivity and structure in specific parts of the autistic brain.

In the image published by *Scientific American* in their article first reporting findings about autism and mirror neurons in 2006, the authors included a figure titled “The Anatomy of Autism” (Figure 3). This image associates specific symptoms of autism with specific brain regions, thus visually suggesting that autistic brains are so different from those of neurotypicals that we can “see” autism in several regions of the brain, whether on relatively macro (such as that of the mirror neuron system) or micro (for example, expression of a particular gene in a particular region that alters the activity in another system in a specific context) scales. Furthermore, by

29 Gaze following is an important component of joint attention, and is characterized by attending to the direction or place in which another person is looking. It has also been documented as delayed or reduced in autism (Williams et al., 2005).

30 Ramachandra and Ostrand (2007) titled their paper describing initial mirror neuron studies “Broken Mirrors: A Theory of Autism,” and proposed that this system was responsible for autism, as the following was highlighted in the article “Mirror neurons appear to be performing precisely the same functions that are disrupted in autism.”
associating symptoms with particular regions and stating: “People with autism also have structural changes in the cerebellum and brain stem” (Ramachandran & Oberman, 2007), the figure leaves open the possibility that anyone, regardless of behavior, with deviation in these areas of the brain could perhaps either be autistic, or should be evaluated for symptoms of autism due to their brain structure.

**Figure 3.** Specific brain regions and their functions are implicated in autism. Oversimplified images suggest that abnormality in these regions and functions are intrinsically associated with autism (Ramachandran & Oberman, 2007).
Empowerment through neurology

Although neurological explanations are reductive, imply biological pathology even in the absence of pathological experience, and lend credence to speciation, they also enable autistic people and others with neurologically defined differences to derive a positive sense of self through learning about their distinct neurology. As the brain is understood as a causal, yet uncontrollable and self-defining agent residing within our bodies, it can function as a scapegoat for idiosyncrasies, pathologies, and even incidental mistakes and lapses in memory (Dumit, 2003, p. 40; Rodriguez, 2006, pp. 313, 323). Furthermore, it seems that due to the responsibility attributed to the brain for both favorable and unfavorable characteristics, many autistic individuals write about the relief of being diagnosed with atypical neurology (Bagatell, 2010). Such diagnoses imply that individuals who have been frustrated with difficulties and differences, be they social, cognitive, sensory, behavior and/or emotional, no longer need to blame themselves. Rather than enforcing the self-understanding of being unintelligent, socially “awkward,” or unable to conquer their emotions, neurologically-based diagnoses enable neurodiverse individuals to define their problems as neurological rather than personal. Shepard describes this as the “sense making” ability of diagnosis to “give order to a particular aspect of the self that was previously seen as negative” (Shepard, 2010, p. 11). For example, in “Thoughts on Finding Myself Differently Brained,” Jane Meyerding (1998) writes that as she learned about autism and neurodiversity, she began to think:

But now here came neurology and the possibility that my brain really was different. If my life matched the descriptions in these articles, then apparently I had a brain that was built to a somewhat different design than the norm. This was something I had to know more about. Did it mean I was wrong to
believe all humans are basically alike? If I could understand my life for the first time only by understanding how my brain was different from the majority of brains, how much did I really have in common with all those neuro-typicals (NTs) out there, compared to whom I'd been judged inadequate so many times? (para. 9)

Meyerding tells us that her self-diagnosis of neurological difference was an empowering way to reconcile her social difficulties, as the idea of neurodiversity helped her feel as if the judgments she had received were irrelevant productions of the neurological “other” (NTs). Through neurological discourse, Meyerding is able to assert her subject position as distinct from the reality of others and place her brain at the root of this difference, thereby removing herself from responsibility for her differences and difficulties, which were the cause of judgments by neurotypicals.

Neurological explanations of world views, such as, “My autistic brain interprets the world differently from a neurotypical brain” (Miller Wynn, 2008, para. 4), not only remove fault from individuals, but also serve as a tool for social recognition and identity formation. Bagatell (2008) wrote, “Having the [autism] diagnosis in hand was actually a relief. The label enabled Harold to better understand himself, gain insight into his strengths and challenges, and perhaps more importantly, locate others like himself” (p. 35, writing about a “key informant” in her study of an autistic community). In this case, a diagnosis of neurological difference provides a means not only for recognition and self-understanding, but also for social relationships and coalition building.

Thus, although neurological explanations of autism are consumed as if they assert true (biological) and stigmatizing differences, it seems that neurological testing and research have actually played a significant role in destigmatizing autism. Just as
psychological understandings performed the biological work of speciating, the neurological diagnosis provides avenues through which the autistic brain can be reincorporated into humanity. Therefore, hope discourse can perform psychological work by absolving individuals and their families of responsibility for autism by suggesting a typical psyche despite atypical neurology.31

Furthermore, testing which “uncovers” the intelligence and communication abilities of autistic individuals contributes to the destigmatization of autism and the subsequent sociocultural view of autism as desirable (relative to other diagnoses). Although for quite some time, autistic abilities have been considered an artifact of their deficits, a 2007 study put this view into question. Dawson’s group (2007) indicated that autistic individuals score an average of 30 percentile points higher on non-verbal measures of intelligence (Raven’s matrices) than on verbal measures (such as Wechsler scales). Further research by this group has revealed enhanced perceptual abilities and creativity in autistic individuals, thereby lending scientific support to lay observations of autistic strengths (Mottron, Dawson, & Soulieres, 2009). These examples of tests constructing autism as positive point to the dual function of testing.

In this chapter, we have seen how testing both reifies autistic people as non-humans and acknowledges and identifies their strengths. Furthermore, we have seen how testing performs psychological and biological work. Ironically, psychological tests have performed the biological work of produces an in-human autistic species,

31 The lack of control which parents and autistic individuals are framed to have over autism not only absolves them of civic responsibility, but also of moral judgment, as autism is not something over which they can exercise their will.
while biological tests have generally performed psychological work by locating autism in the brain, and thus removing blame from autistic people and their families. In particular, psychological tests have established autistic people as lacking important components of humanity, such as ability to communicate, socialize and understand both self and other. This has led to the creation of the autistic species. Neurological explanations of autism reify autistic people as distinct from humanity, but at the same time, neurological tests reveal autistic strengths and provide hope that autistic people may be recovered back into humanity through biomedical technologies. The nuanced and multilayered types and consequences of neurological discourse will be discussed in the next chapter.
CHAPTER 3
Diversity of Neurological Discourses

We have now seen how autism has been constructed as a mysterious neurological diagnosis imbued with hope. Although autism is constructed as a diagnosis that demands management (by self and others), its characterization as neurological alleviates stigma by deemphasizing fault and suggesting possibilities for cure. In this chapter, I consider the narratives of authors, mothers, and my interviewees in light of social landscapes that led to the uncovering of autistic strengths. This chapter describes the ways in which neurological discourse not only distances autistic people from humanity, but also creates space to celebrate their differences. I also demonstrate how this paradox leads to complex self-understandings and relationships to the brain.

Finding Intelligence

Although we today recognize that autism is not synonymous with lack of intelligence, many autistic people suffer because of the cultural belief that they cannot succeed in school. Due to cognitive assessments and school settings that rely on, assess, and preferentially value verbal skills, autistic students—especially prior to diagnosis—are often placed in special-education classrooms where they are unchallenged. Simultaneously with cultural narratives of intellectual deficiency, autistic people are also exposed to the reality that savant abilities provide the opportunity to gain social (and self) worth. Thus, assessments that parse out different types of intelligence have provided proof that autistic people may have significant areas of cognitive strength. Many autistic people have constructed their identities around this destigmatizing function of testing. Therefore, I was not surprised that
many of the interviewees and authors feel strongly about communicating the point that autistic people (even those who are not savants) are smart and cognitively gifted.

One of the later questions I asked in the interviews was: “What are three things you really like about yourself or are good at?” Relative to the other interview questions, most interviewees took considerable time responding to this question. In addition, many individuals did not provide three separate responses. The strengths and interests my interview subjects described are shown in Tables 3 and 4. I have also included strengths that were explicitly discussed and framed as strengths during the course of the interview or stated as interests/hobbies with a strong implication that the participant excelled at the hobby. Most often this type of discussion occurred when talking about neurodiversity and whether having a different brain was something in which to take pride.
### Participants’ Descriptions of Cognitive Strengths and Interests

<table>
<thead>
<tr>
<th>Strength</th>
<th>Interviewee(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>learning languages</td>
<td>001</td>
</tr>
<tr>
<td>learning quickly</td>
<td>001</td>
</tr>
<tr>
<td>keen focus</td>
<td>001; 002</td>
</tr>
<tr>
<td>absorbing information</td>
<td>002</td>
</tr>
<tr>
<td>math</td>
<td>003; 005; 007; 009; 010</td>
</tr>
<tr>
<td>science</td>
<td>004; 010</td>
</tr>
<tr>
<td>memory</td>
<td>003</td>
</tr>
<tr>
<td>problem solving</td>
<td>006</td>
</tr>
<tr>
<td>thinking/unique way of interpreting information</td>
<td>003; 007</td>
</tr>
<tr>
<td>history</td>
<td>004; 010</td>
</tr>
<tr>
<td>new ideas</td>
<td>010</td>
</tr>
<tr>
<td>reading</td>
<td>002; 004; 005; 010</td>
</tr>
<tr>
<td>making connections/finding commonalities</td>
<td>002; 003</td>
</tr>
<tr>
<td>between subjects/information</td>
<td></td>
</tr>
<tr>
<td>art</td>
<td>002; 006</td>
</tr>
<tr>
<td>playing the flute</td>
<td>007</td>
</tr>
<tr>
<td>smart</td>
<td>005; 011</td>
</tr>
<tr>
<td>video games/strategy</td>
<td>001; 004</td>
</tr>
<tr>
<td>interest in/knowledge concerning dinosaurs</td>
<td>011</td>
</tr>
<tr>
<td>computers</td>
<td>006</td>
</tr>
</tbody>
</table>

Table 3. In general, participants described cognitive and/or intellectual strengths and interests. Ages of these participants can be found in Table 1.

I understand all of the above strengths as being cognitive or “intellectual” and leading to success in school and cultural recognition of intelligence. In addition, many of these strengths can be “verified” or “uncovered” through testing that regularly occurs (for example, math tests in school) or is part of diagnostic or treatment programs (for example, IQ/“smart” tests, or assessments of memory or ability to “absorb information”). Table 4, below, reveals the relative dearth of “non-cognitive”

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32 I include strengths and interests such as art, music, and video games and strategy because Western culture typically considers abilities in these areas to reflect intelligence, even outside of the skills assessed by traditional aptitude instruments. The widespread application and lasting renown of Howard Gardner’s Theory of Multiple Intelligences (see [http://www.howardgardner.com/MI/mi.html](http://www.howardgardner.com/MI/mi.html)) is just one example of this trend.
strengths and interests described. In addition, some individuals did not provide a non-cognitive/academic strength at all.

**Participants’ Descriptions of “Non-Cognitive” Strengths and Interests**

<table>
<thead>
<tr>
<th>Strength</th>
<th>Interviewee</th>
</tr>
</thead>
<tbody>
<tr>
<td>saving money</td>
<td>001</td>
</tr>
<tr>
<td>empathy (noted as recently developed)</td>
<td>002</td>
</tr>
<tr>
<td>media</td>
<td>003</td>
</tr>
<tr>
<td>funny</td>
<td>006</td>
</tr>
<tr>
<td>sports</td>
<td>009</td>
</tr>
<tr>
<td>good eyesight</td>
<td>009</td>
</tr>
<tr>
<td>good trooper (being helpful at camp)</td>
<td>009</td>
</tr>
<tr>
<td>tall</td>
<td>011</td>
</tr>
<tr>
<td>interest in NASCAR</td>
<td>011</td>
</tr>
<tr>
<td>nice</td>
<td>011</td>
</tr>
</tbody>
</table>

*Table 4.* Few non-cognitive or intellectual strengths and interests were described. As can be seen, fewer than half of the interviewees even provided one such strength or interest. Ages of these participants can be found in Table 1.

During the interviews, participants spoke of being smart, learning quickly, or being particularly proficient at a specific subject as a characteristic of autism. In addition, eight of the eleven parents also noted the intelligence of their children, including one parent who despite being prompted to identify three of her child’s strengths, listed only “intelligence.” The idea of intelligence as a reason to value autistic people also appears in children’s books about autism. Often authors present autistic children as providing an opportunity for their peers to learn not just humility through their interaction with someone “less fortunate,” but fun facts about their particular interests (Stefanski, 2011, p. 3). For example, Stefanski writes, “A lot of kids with autism are really smart, even if they have language difficulties” (p. 8) and Robison (2011) tells us, “My Aspergian brain helped me soak up new knowledge at a rate few typical [neurotypicals] competitors could match” (pp. 242-243). In addition,
media representations, such as the title of Tammet’s (2006) autobiography, *Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant*, also assert the importance of autistic intelligence. Neurotypical students are not framed as resources (to be managed) for their peers, so why can’t autistic students also be included on the basis of their humanity?

I think that the way in which both authors and my interviewees emphasized their intelligences points to their view of intellect as “redeeming.” Furthermore, simply by providing “redeeming” characteristics, several authors suggest to us that their social experiences have made them feel devalued. Framing autistic people as universally intelligent and purporting their intelligence as a resource performs reductivist work by leaving out what makes them *individual* humans. The emphasis on valuing the intelligence of autistic people is proven paradoxical when we consider that early conceptions of autism centered on cognitive deficits.

**The Brain Makes the Person: Reductivist Discourses in Autism**

The figuring of autism as neurological is now omnipresent, as even books written for children instruct that autism is a brain-based diagnosis. In *Autism and Me: Sibling Stories* (Shapiro, 2009), the author’s note to the reader describes what it means for the characters to be autistic: “This means that their brains work in a different way from other people’s brains.” In the book, several siblings discuss their siblings’ autism in terms of their brain, using statements such as: “Something is

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33 This title also reinforces the belief in autism as (biologically) mysterious by suggesting that it would be necessary to go inside the *extraordinary* mind of an autistic person. Furthermore, the phrase “Born on a Blue Day” derives from a family memory, but perhaps suggests that there is something significant about the author’s birth that perhaps could have shaped his “extraordinary mind.” This stands out to me, because generally, in Western culture, the type of day on which someone was born is not considered particularly significant, especially in relationship to the mind and its character.
wrong with his brain, so he can’t talk.” “My brother Justin has autism. His brain
doesn’t work like other people’s brain.” In some ways, this seems perfectly benign,
especially because autistic people often choose to define autism in terms of
neurological differences. Consider the following examples of neurodiversity
discourse:\(^{34}\):

- “The main thing to understand about Asperger’s is that it’s a neurological
difference—a difference in the way our brains are made” (Robison, 2011, p. 247).
- “Asperger’s is a difference in our brains. It never goes away” (Robison, 2011, p. 253).
- “Autism is a disorder that effects how my brain works (Yes, it does work!)…My
dad, who is an electrical engineer and knows a lot about wires and circuits, told
me that having autism means that my brain is wired different from most kids’
brains” (Stefanski, 2011, p. 1).
- “My brain is different “(Interviewee 001).
- “I have a different brain” (Interviewee 009).

There is evidence that autistic people refer to their brains to interpret their
strengths, weakness, experiences and behaviors. The following quotes and tendencies
of authors serve as examples of this:

- “My strange behavior was described as ‘bad’ instead of being seen for
what it was—the innocent result of a neurological difference” (Robison,
2011, p. 11).
- “I would start by saying it [autism] is an incredibly different living
experience in terms of how I think” (Interviewee 003).
- Among other neurological explanations of experience, strengths,
challenges, and behavior, Robison (2011) discusses processing
nonverbal communication during a conversation: “It’s like I’m missing
half of the conversation, and I always have been. The left side of my
brain is running full speed, analyzing the words I am hearing. I don’t
have any impairment at all in my ability to make sense of people’s
speech. It’s the other side where I have problems. While the left side of
my brain is analyzing the language, the right side is supposed to be

\(^{34}\)All children’s books that I read that were published in the 2000s included a definition of autism
referencing neurological differences. These examples were chosen because they stood out as instances
of emphasizing brain differences as the cause of autism as an important point used to explain many
other facets of autism.
listening to the speech the way you’d listen to a song. My right brain hears the tone, the cadence, and the melody, but it doesn’t ‘read’ those signs or discern what my partner meant by sending them” (pp. 93-94).

- One example of Grandin (2005) ascribing autistic experience to her brain is her attribution of sensory and emotional experiences to the frontal lobes: “As a general rule, we have lower pain, higher fear, and lower frontal lobe control of the rest of our brain than nonautistic people. Those three things go together” (p. 190).

These quotes provide robust evidence that some proportion of autistic people understand themselves and their thought processes in terms of specifically autistic neurology. Although this provides an opportunity for autistic people to organize around neurological identities, it is also perhaps somewhat worrisome, given the enormous (and increasing) societal significance pinned upon the brain. As already noted in chapter 2, when people are defined as having different brains it is implied that they are a different species characterized by a particular anatomical difference(s) (perhaps as a result of genotype and/or interplay with the environment and genes) that result in essentializing behavioral and cognitive traits (phenotypes). Perhaps this is something that Stefanski (2011) has felt, as he feels it is important to follow up his definition of autism with, “Even though my brain is different, I’m still a kid” (p. 2).

Robison (2011) also feels the need to insist that autistic brains do work:

> Neurobiologists have not identified anything that’s missing or ruined in the Asperger’s brain. That’s a very important fact. We are not like the unfortunate people who’ve lost millions of neurons through strokes, drinking, lead poisoning, or accidental injury. Our brains are complete; it’s just the interconnections that are different. (p. 9)

Robison seems to establish his cerebral identity, yet locate himself as a different type of human. Canguilhem might suggest that here Robison posits autistic “pathology” as demonstrating the possibilities of the human body and experience. However, Robison achieves this at the expense of other marginalized and socially stigmatized
groups, such as the elderly (strokes), those posited as irresponsible and immoral (accidental injury and drinking), and individuals who exist with fewer neurons. In addition, as autistic Wesleyan-alum Charlie Abbott says that Robison “is WRONG in that many autistic people do end up suffering brain damage as a result of self-injury. These injuries can exacerbate existing symptoms of autism or create new symptoms” (personal communication, January 2012). Therefore, Robison not only achieves humanity by working within hierarchies of privilege and ability, but also by making assumptions about autistic people based upon his individualized experience, and consequently excludes autistic people who differ from him.

*Animal Brains*

Temple Grandin (Grandin & Johnson, 2005) also interprets autism and her behavior through knowledge of the brain. Interestingly, through neurological and evolution discourse, she places autistic individuals somewhere perhaps just beyond the stretch of human, as she writes:

> Autistic people’s frontal lobes almost never work as well as normal people’s do, our brain functioning ends up being somewhere between human and animal. We use our animal brains more than normal people do, because we have to…*Autistic people are closer to animals than normal people are.*” (p. 57, Grandin’s emphasis)

Grandin uses this analogy to animals to personally distinguish herself by saying, “I’m different from every other professional who works with animals. Autistic people can think the way animals think” (this is why she feels that she has been more successful than other professionals in her field). Despite aligning autistic and animal brains, Grandin does assert that autistic people are still essentially human:

> Of course, we also think the way people think—we aren’t *that* different from normal humans. Autism is a kind of way station on the road from animals to
humans, which puts autistic people like a perfect position to translate ‘animal talk’ into English. (p. 6-7)

Grandin’s discussion of human/“normal people’s,” autistic and animal brains is puzzling. It almost seems as if she herself perceives “normal people” to lay the boundaries of “human.” Although Grandin claims to reside within the spectrum of human, she also advocates for autism to be viewed as residing at its outmost boundaries, or at least the boundary closest to animal. She draws on evolutionary accounts of brain development and attributes her challenges to underdevelopment of the frontal lobe (which evolved in later primates) and her strengths to the subsequent compensatory efforts of her “earlier” “animal” brain (p. 56). This willingness to place herself on the animal side of the human/animal boundary could derive from many sources. Perhaps, being the rational scientist she portrays herself to be, she is simply not afraid to acknowledge her animal origins. Other reasons that she may accept this proximity could be her respect for and understanding of animals, or that her self-admitted/chosen denouncement of “typical” social and personal life makes animality appealing, or at least preferable to the humanhood claimed and experienced by neurotypicals (Sacks, 1995). Despite this movement, as a neurotypical reading her book, I could not help wondering why Grandin was so willing to talk about autistic people as being so far from humans and so close to animals. Throughout her book, every example of autistic difference is supported by at least one neurobiological experiment involving animals, autistic people, and/or neurotypicals, and is replete with supplemental information.

Although I have established that I find discussing animality counterproductive (see page 28) for this thesis, Temple Grandin’s discussion of her hybrid brain is
necessary to consider, as she provides an important example of the deployment of “truth technologies” of science. There is ambiguity in how to read Temple Grandin’s use of science and her project in general. I instinctively read her as making assertions that may be considered adversarial to many in the autistic community by contributing to neurotypicals’ perceptions of autistic people as somehow less-than-human (and from a discussion with someone who considers himself part of the autistic community, it seems that many autistic people feel similarly). Although I disagree with Grandin’s narrow view of autism and the ways in which she draws analogies of autistic people to animals, others may read her work as striving towards the expansion of sociocultural understandings of intelligence by insisting upon the value of visual intelligence (versus verbal) and drawing attention to the tenuous boundaries between humans and animals.

*Neurological Personhood*

Although other autistic people may not explicitly assert their phylogenetic difference, they use several of the same rhetorical strategies as Grandin to discuss their identity and stretch the bounds of neurologically-based personhood. Similarly to how society understands the brain to be the source of all human action—the center of “self,” our behaviors, and our health—many autistic people also attribute behavior, thought, emotionality, their strengths and weaknesses, and their overall experience of life to their brains. Although behavior, thoughts, and emotions can be described as related to cognition and intellect, even characteristics not commonly understood as brain-based were attributed to participants’ brains. For example, in response to how having a different brain could be a source of pride, one individual told me, “I have a
different brain, I don’t understand what people are talking about and doing,” and described his brain as “kinda weak.” However, he continued to say, “but other times it is good to have a brain that is different from others’ [because] I can jump really far”—and then he described jumping into his car from a ledge by his driveway—“I don’t think others can do that.” The participant continued to tell me that his different brain led to his ability to complete his “math work really fast” and his “long eye sight” (Interviewee 009). His response demonstrated either a deep understanding of the brain as controlling all of his body’s actions, or the view of his brain totalizing all aspects of self.

The above participant’s discussion of neurology was interesting in light of his responses to my question of what it is like to have autism, as he told me, “destructing my room and running away when I’m angry because that is the only way I can express myself…no one else does that, that’s autism.” Furthermore, he told me about being afraid of the police because he was worried that he would get in trouble, but that one time when a police officer came to his door, the interviewee “told him that I have autism, and then he was nice to me” (Interviewee 009). Contrary to his totalizing descriptions of his brain, in this instance, the interviewee appears to view autism as behavioral and as social currency rather than as a neurological condition. Although this participant did indicate an understanding of his brain as conferring specific strengths and weaknesses, he did not map behavior and communication onto the autistic brain. Perhaps this individual views himself as having distinct neurology by virtue of being a unique human (as we all are), rather than this being a characteristic of autism (and autistic brains). Given his inconsistent responses, it is
unclear if he understands the brain’s involvement in his every movement (such as jumping), behavior, and experiences, or if he is mapping all difference onto the brain as a way not necessarily to understand his autistic self, but to understand and be understood by others.

Other responses also obscure whether or not the people whom I interviewed viewed their selves as intrinsically tied to their brains, and specifically, their autistic brains. In response to my saying that some people think “that having a brain that works differently from others’ is something to be proud of,” he said, “I think it’s kinda true. I’m really smart in math, even though my mom says it [autism] makes my social skills not good” (Interviewee 005). This response suggested that this participant equates his brain to autism, and meshes his self-perception with his mom’s perception of himself. Furthermore, it is unclear if he views autism as defining his neurology, or his neurology as defining autism. Early in the interview he had told me that a researcher had shown him that individuals with High Functioning Autism have larger brains, so it seems that he had a grasp on the correlation between autism and neurological differences. Therefore, he is attributing these global characteristics (really smart at math, and his mom’s perception of his social skills) to autism and perhaps his larger brain. This interviewee may be shaping his self-view through autism, as he seems to have adopted autism as a stand in for his brain (and thus,

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35 His mom reported discussing autism with her son as only a social disability, and within no other terms.
36 Although excess brain volume was previously noted as a way in which autism was negatively constructed, here we see this younger individual viewing “excess” either with indifference, and perhaps even pride, as it could be hypothesized that he points to the larger autistic brain as the source of his (autistic and neurological) intelligence. We can see a tension in terms of whether or not size should be de/valued. Perhaps this can be seen as yet another aspect of autistic construction that is situated.
himself). I came to this hypothesis based on this interviewee’s comment, “My mom thought ADHD was me, but when my brother got diagnosed [she knew it wasn’t]…when I get crazy [hyper] that is autism” (Interviewee 005). I viewed this statement as suggesting that he was declaring that he is not ADHD, and therefore implying that he is autism. Furthermore, it seems that this may be something that he associates with specific individuals, as it appeared that because his brother had/is ADHD, then he cannot “be” ADHD, because his brother is occupying that space. Although I see this as evidence that this person sees autism and his autistic brain as integral in the production of self-concept, it is possible that the above quote was a grammatical quirk and not semantically meaningful in the way I have proposed.

Nonetheless, the above participant and several others see having a different brain as a source of both positive and negative characteristics. It is interesting that these respondents spontaneously discussed weaknesses and negative aspects of having a different brain, as the question primed them to speak about only the positive aspects of difference. Perhaps this reflects how deeply they have absorbed cultural messages of “difference,” especially neurological, as bad. In addition to this possibility, there appears to be a general correlation of interviewees’ views regarding neurodiversity with those of their parents.

One instance in which this was not the case was Interviewee 001. He discussed how he would experience success in a future job due to the strengths conferred to him by his autistic brain. However, his mother believes that neurological differences can be disabling:

Neurological differences can confer certain strengths, though they can also be very disabling; to say that people with autism are different, not disabled, is a
gross oversimplification. Some very high functioning people may not be
disabled, but many with autism are—especially in our society where social
abilities are the best predictors of independence and success. (Parent 001)

This mother also posits neurological difference (in particular, autism), as a double-
edged sword. She acknowledges that these differences can confer particular
strengths, but creates a hierarchy of “high” versus (the implied) “low” functioning
individuals on the autism spectrum. She emphasizes social abilities as those that lead
to success (in neurotypical society) and thus are the disabling aspect of the autistic
brain. It is open to interpretation whether or not she believes that autistic individuals
who have developed social skills are disabled. Perhaps she accepts the social model
of disability, as she locates the value of social skills in society, rather than as
compulsory for personhood regardless of the environment. Alternatively, she may be
devaluing the skills that autistic people have and suggesting that they are useless in
neurotypical society, while valuing her own (neurotypical) social “abilities” (Abbott,
personal communication, December 2011).

Although many participants’ views of autism aligned with that of their
mothers, self- and formal-education also shape the way that autistic people think
about autism. As noted, the child of the mother quoted above was one of the few
individuals whose view of autism drastically departed from that of his mom, as he
significantly emphasized the positive aspects of autism and how they would enhance
his future. Although he did acknowledge the challenges he experiences, he mostly
located these in the past; more specifically, he discussed currently having fewer
“meltdowns,” having his behavior under control, and the development of a self-
awareness of behavioral difficulties—none of which he explicitly associated with his
brain, despite having located a strength which he emphasized (learning quickly) within his “Asperger’s brain.” Not surprisingly, this individual was one of the three interviewed who either currently or previously attended Ivymount (Appendix VI), a school that specializes in teaching children with disabilities and has a “Model Asperger’s Program” in which the students read *Be Different* by Robison (2011) and *The Outliers*, by Malcolm Gladwell (2008) and discuss theories of motivation in order to identify the ways that autism can lead to later successes. Therefore, it is likely that his empowered stance on autism is more grounded in his education and reading, rather than derived from his parents. Given these descriptions of self, to some extent, it appears that the participants and authors latched onto neurological explanations of self and demonstrated nuanced valuation of their distinct neurology—taking pride in some aspects and showing ambivalence in others. In addition, although they do ascribe several characteristics of self to their brains, they are not completely willing to forfeit the totality of their beings to autistic neurology. Therefore, they resist the negative consequences of reductivist neurological discourses that simplify and rearticulates people into and as brains rather than individual and complex humans.

*Neurological Politics*

Despite resisting reductivism, Temple Grandin and John Elder Robison place significant interpretative power and valuation in their autistic brains. In many ways, I see this as demonstrating a commitment to neurodiversity discourse, which asserts

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37 This book discusses successes by “experts,” and many of these individuals exhibit the hyperfocus and concentration that many autistic people are described to have. Gladwell’s book is well known for outlining how people become experts. For example, he asserts that true experts must log 10,000 hours of practice in their field—something that comes effortlessly to many autistic people in their field(s) of interest compared to the neurotypical population.
that their distinct neurology is something of which they should be proud. Given Western privileging of science and biological explanations, and cultural fascination with the brain, locating difference in the brain (as opposed to another bodily system or the psyche) has been a smart political move for autistic activists and advocates. This is in part because the brain is generally seen as an autonomous organ that dictates the mind and actions of an individual. Thus, neurodiversity plays upon cultural understandings of personhood, morality, and science in order to excuse and, in turn, empower differences. This discourse also reduces the individual to a singular organ and can lead to the construction of limiting identity narratives that set up boundaries within autistic communities based upon adherence to particular narratives. Furthermore, this discourse can paradoxically contribute to speciation projects that justify discrimination from neurotypicals. Thus, neurodiversity discourse, which is both celebratory of autistic neurology and results in reductivism, acts as a double-voiced discourse which both oppresses and uplifts (Higginbotham, 1992).

Despite a lack of explicit articulation of discomfort with this reductivism, many autistic people and their allies do appear somewhat unsettled by the idea of placing value in anatomy. Interestingly enough, whether the interviewees regarded autistic neurology as something of which to be proud or were ambivalent about their neurology, their attitudes generally aligned with their mothers’ views. In some instances, children and mothers expressed implicit concern about localizing difference. Perhaps, this anxiety can be related to the outcome of prior localized (for example, genetics) and reductionist (for example, sex and race) conceptualizations of the individual.
In particular, one interviewee’s response to “Neurodiversity is a word that people use to talk about differences people have in their brains. They say that having a brain that works differently from others’ is something to be proud of. What do you think about this idea?” provides a good example of uneasiness with regards to differentiating people based upon neurology:

Yes, being unique. It really doesn’t matter if your brain is unique or not. It doesn’t matter how much grey matter you have, you shouldn’t treat people differently. I just want to integrate into society…I am proud to understand adult conversations…the way I see it, everyone’s brain is the same size.

(Interviewee 010)

This individual acknowledges his strengths and uniqueness and links both to his brain while also implying that his brain may pose a challenge to integrate into society (thereby implying some experience of social challenges of autistic neurology), despite his belief that brain anatomy should have no impact on how we see and treat each other. This participant appears unresolved as to whether or not his brain is a source of pride and strength, or sees it as something to overcome in order to be a participant in society. This participant’s comment led me to consider if he believes he must manage himself in order to “integrate into society.” By insisting on the equality of all people, he refers us to the social model of disability, in which all people should be equal social participants, such that society must accommodate them.

However, he also states his desire to integrate into society without implicating society as flawed, thereby suggesting that he feels, at least in this social world, it is his obligation to adjust himself in order to achieve the goal of integration. The above participant’s apparent indifference to different types of brains as conferring status/value/pride reflected his mother’s response to how she viewed neurological
differences: “[Neurological differences are] not something we fixate on” (Parent 010). This would have been an interesting point to pursue had there been a follow-up interview, as perhaps the detachment of value from neurology is not something that had persisted prior to repeated exposure to the idea of brain differences. Furthermore, it would have been interesting to hear more about how this mother spoke about neurology and if it varied depending on which brain differences she was addressing.

Another interviewee also cautioned against placing an inherent value on anatomy, as when asked, “Are you proud of your different brain?” he responded, “I don’t think it is necessarily a good or a bad thing. I think the good or bad thing is something humans made up. In science we don’t say something is good or bad, we say ‘this happens or that happens’” (Interviewee 007). To provide additional context, in previous questions during the interview it seemed as if this individual viewed autism with ambivalence, as he talked about his difficulties and his belief that others thought he was “weird,” but also seemed proud to “analyze stuff in a more objective way,” as he said, “I feel like I’m less worried about what people think about something and more like, ‘well does it make sense?’ That’s useful, well sort of” (Interviewee 007). Here, even in describing his strengths, the participant presents self-doubt. This response leads to the interpretation of his reaction to the definition of neurodiversity (described above), as objective (which he values over subjectivity), rather than reflecting his personal (subjective) feelings concerning his brain. Perhaps, this response indicates ambivalence based on “data” he has collected (from his life experiences) about the pros and cons of being autistic/his autistic brain and his
awareness of societal discourse surrounding neurological de/valuation.\textsuperscript{38} His objective stance and ambivalent reaction to the description of neurodiversity seems also parallel to his mother’s, as she responded by saying:

Some people use it as a source of pride. Others say it’s just a ‘cop out’—a way of giving people an explanation that can be used as an excuse. It is not sufficiently precise, so if you don’t have a real science background and/or it’s not used in a specific context, it can be meaningless. People generally use the same ‘parts’ of their brains to get through life. Those with neurological differences use different parts of their brains. Frequently that results in severe problems, socially and physically. Sometimes it can result in someone having real ‘skills’ (such as an amazing musician or, like my son, mathematician). I’ve learned that different parts of the brain are responsible for certain types of actions, but that other parts of the brain can be ‘re-trained.’ (Parent 007)

This participant’s mother has a very complex view of “neurodiversity” and valuation of neurological difference. First, she suggests that neurological difference should not necessarily absolve individuals of accountability for the functional consequences of brain difference (“others say it’s just a ‘cop out’—a way of giving people an explanations that can be used as an excuse”). Second, she locates neurological value as situated in particular contexts by pointing to the value of different brains in academic settings, and the challenges posed by the autistic brain in social situations, and of other brains physically (therefore, I inferred that she was writing not just about autism, but more broadly). She also separates the brains into parts that can or cannot function and/or compensate for difference and/or be normalized. Here, we see hope at play, as she suggests that the brain can be mapped and that this mapping can perhaps lead to normalizing (re-mapping) processes that

\textsuperscript{38} It feels pertinent to note that this participant placed significant value in the perceived objectivity of science. This may have greatly informed his beliefs about autism and autistic difference. His apparent ambivalence is aligned with the plethora of inconclusive and contradictory scientific studies and opinions to which he may be exposed.
functionally, although perhaps not physically, alter neurological differences. This statement demonstrates how (present or imagined) curative and managing technologies can be deployed to manage not the total person (brain), but the particular aberrant neurological components and/or to strengthen those components that are functional in order to compensate for (hide and effectively erase) those that are not.

As noted, this mother’s son also expressed ambivalence over brain valuation. Another participant’s response was somewhat similar, as he framed his brain as “kinda weak,” and attributed several strengths and weaknesses to his “different brain” (Interviewee 009). His acknowledgement of strengths and weaknesses derived from his brain in some ways and again paralleled his mother’s perspective. She had heard of neurodiversity and wrote, “I try to help instill the desire and motivation to make positive changes without the expectation of becoming ‘typical’ or ‘curing’ difference” (Parent 009). This response and the ways in which this mother reported talking about autism (as an identity, source of pride, source of difference, and as a social and learning disability) seemed to present a multi-dimensional view of her son’s brain, regardless of whether her child perceived his brain as specifically autistic or unique based on his inherent individuality.

These three examples suggested that children likely pick up on the views, ambivalent or otherwise, of their parents towards autism. It also seems that children are influenced by their parents’ attitudes towards neurological differences. One such individual responded to the definition of neurodiversity with, “That’s good I guess, I haven’t heard it before, but I think it is something to be proud of because you’re unique in your own way” (Interviewee 006). He had a mother who reported
discussing autism as an identity, source of pride, source of difference, and a neurological identity. In addition, his mother, who reported having heard of neurodiversity said:

    I think of neurological differences as an important contribution to society. Those with neurological differences often have great strength in a particular area, and may be responsible for progress in our human development and evolution. I hope that we can better understand these differences and how they manifest in various individuals, so that we may benefit from the great gifts that result. (Parent 006)

Here, we see his mother adopting neurodiversity, citizenship, and eugenics discourse in one statement. It seems clear that this mother feels positively about her son’s autistic characteristics, especially those that confer strengths. However, it is important to point out that she accomplishes this celebration through demonstrating autistic productivity by pointing to “great strength[s]” that do not necessarily inherently hold value, but are esteemed due to their potential for “progress in our human development and evolution” which may “benefit” society (Parent 006). In suggesting that the manifestation of these differences should be a topic of study, she also leaves room for eugenics discourses focused on replicating/producing these gifts (read: resources to be managed). The intermingling of these discourses in this single response is important to identify to acknowledge the ways in that neurodiversity discourse, even its progressive extension of personhood, draws its strength from the very discourses it combats.

    All these responses point to the careful navigation of normality and self-valuation by autistic people. Michalko (2002) explains this by describing the ways in which disability interacts non-linearly with biology and society:
Making something of the body is an activity conducted in the confusing space between nature and culture. The confusing space between the normal and abnormal is similarly the “work place” in which “societal stuff” is made of our impairments. It is within this space that concepts of disability are developed by society. Now developed, however, disability remains in this confusing space and disabled people are forced to live a life in this space, between nature and culture, normal and abnormal. Is it I who is abnormal or is it my impairment, my body that is? Or, is (n)either abnormal? Certainly something abnormal is going on since I am raising such questions. (p. 83)

Michalko’s “work place” is located in the intersection of biological discourse and societal values, cultural tropes, and political systems. Disabled people must either locate themselves in this liminal space or oscillate between the normal and the abnormal, the natural, and the cultural/constructed. This was clearly demonstrated through the ways in which interviewees and their mothers valued and devalued their brains, deployed neurological discourse, and provided societal evaluations. Additionally, Michalko suggests that despite complicated evaluations of self and impairment, in order to dissolve this dissonance disabled people become privy to narratives and technologies of hope that suggest that through present or future management they will be able to bring their bodies into normativity.

Another way to read Michalko is to note that he does not discuss the situated nature of reality. Canguilhem, McElwain, interviewees, and disability theorists such as Oliver, McRuer, and Davis might suggest to him that rather than experiencing something abnormal, Michalko is reflecting upon how opaque the relationship between society and individuals has become. As people and bodies enmeshed in our social world, the constructed nature of the norm becomes obscured in such a way that we find ourselves fighting for the same sociocultural space that, ironically, seems to emerge internally in those moments in which we escape from tropes of normality.
However confusing this navigation may be, perhaps as it continues to be practiced, the liminality of this space may dissolve.

Perhaps then, localization of autism to the brain opens up space for autism narratives that make autism desirable. It may seem as if viewing autism as a desirable diagnosis has led to the expansion of the category of “human,” but this is a false expansion, as autism becomes desirable and is brought into humanity in the image of neurotypicals. In other words, rather than broadening the bounds of humanity by incorporating the individuality of autistic people into the definition of human, autistic people are valued and figured as human only insofar as they embody the characteristics that are desired to neurotypicals and can meet neurotypicals on their terms. In particular, as has been discussed in this chapter, autistic desirability resides within a particular narrative of innocent and intellectualized brains. Therefore, rather than creating space for autistic individuals, this false expansion cements management of autistic resources as necessary for inclusion in society and results in the reduction of individuals to their distinct biology, leading to the consolidation of autistic experience into a single uniform and (hyper-intellectual) image. Luckily, autistic people today are augmenting these narratives with their own voices. In the following chapter, we will see how autistic individuals interpret neurodiversity for themselves and view themselves as unique people who participate in the world with both cognitive and emotional capacities.
CHAPTER 4
Neurodiversity and Activism

We have now seen how scientific and cultural discourse has constructed autism as a mysterious neurological diagnosis imbued with hope. The neurological nature of autism leads to it becoming a category that is both desirable and alienating. In particular the neurologicalization of autism produces a prototypical autistic person defined in neurotypical terms. In this chapter, through putting interviewees, mothers, and authors in conversation with each other, I point out the ways in which neurological discourse and autistic narratives work to construct autistic self-understandings and prototypes.

Embracing Neurodiversity

The concept of neurodiversity is rooted in the notion of cerebral citizenship (Dumit, 2003, 2004). In this sense, biosociality, or the speciation of individuals based on biological markers, is located in the brain such that individuals become defined and codified by their (a) typical brain structure and/or functioning. Cerebral citizenship thus implies the coalescence of diverse individuals under categories such as “depressed,” “autistic,” “schizophrenic,” “normal,” or “gifted.” This flattening occurs as a product of beliefs in biological bases for these “individual” differences. Therefore, the accumulation of brain research may lead to the biologicalization of individual differences. The potential danger of this reductivism to cause scientifically justified, and perhaps even medically mandated discrimination and social divisions has been explored; however, less attention has been given to how this discourse can lead to neurology serving as a source of celebration, unity, and pride for many people.
with mental/neurological differences. There is no better example of this than the growing neurodiversity movement and autism.

Ari Ne’eman, founder of the Autistic Self-Advocacy Network (ASAN), described first reading about neurodiversity as empowering, as the information he found on the Internet “validated things I had felt instinctively, but thought I certainly couldn’t be right about.” What were these things that Ne’eman had felt instinctively?—“I was an equal human being, and that working to be normal wasn’t a worthwhile use of time.” He explains: “I didn’t think that bullying and other unfortunate situations in school were my fault…I didn’t have any frame of reference to conceptualize it as anything but,” he continued, “the neurodiversity movement was important because by discovering it, it put the bad things in a context to blame something [outside of myself]” (Ne’eman, interview, September 16, 2011). Because neurodiversity discourse comes out of the social model of disability, this discourse perhaps helped Ne’eman believe that society was the cause of his difficulties, rather than himself. This shift and the availability of an established discourse, likely helped Ne’eman articulate his inherent sense of his own personhood. Ne’eman’s discussion of how neurodiversity discourse helped him understand his school experiences speaks to the power of positing all brains, and thus all people, as worthy of space in society. Discourse such as this turns difference into a way of situating oneself as valued in an equal world. Thus, viewing oneself as different based on neurology not only removes fault from the individual, but also demands others to accommodate and value these differences. This is a message that drastically challenges and puts into question
attitudes society exposes individuals to in their daily lives by asserting the need for autistic people to change and “overcome” who they are.

In conducting my interviews, I found that two (Interviewees 002 & 007) out of the eleven had not heard of neurodiversity. Similar to Ne’eman’s initial reaction, they responded positively to the explanation, “Neurodiversity is a word that people use to talk about differences people have in their brains. What do you think about this idea?” Responses included:

- I think it’s kinda true. I’m really smart in math, even though my mom says it makes my social skills not good (Interviewee 005).
- That’s good I guess…I think it is something to be proud of because you’re unique in own way (Interviewee 006).
- I think it is something to be proud of. You can do things others can’t…problem solving, knowing about dinosaurs, and I don’t seem to get as mad as some people (Interviewee 011).
- I don’t think it is necessarily a good or a bad thing. I think the good or bad thing is something humans made up. In science we don’t say something is good or bad, we say ‘this happens or that happens’ (Interviewee 007).
- I have a different brain, I don’t understand what people are talking about and doing…[my brain is] kinda weak…but other times it is good to have a brain that is different from others’ [because] I can jump really far…I don’t think others can do that…I complete my math work really fast…[and have] long eye sight (Interviewee 009).
- It doesn’t really matter if your brain is unique or not…it shouldn’t make you treat people differently (Interviewee 010).
- Knowing it is just a difference, not a disability gives you more confidence (Interviewee 001).
- As a grown-up I’ll probably like having this because it’ll help me make a lot of money, because when I like what I’m doing I focus really well…I’m looking forward to grow up and having more strengths than weaknesses. I’ll be competitive when working, because if I like my work, I can work for ages (Interviewee 001).

As previously discussed in reference to brain reductivist discourse, these responses, in combination with those describing brains and attributing value to them,

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39 Five parents had heard of the term (Parents 001, 005, 006, 007, and 009).
demonstrate that autistic individuals sometimes ascribe any difference they notice between themselves and others to their autistic brains. Furthermore, in the context of being introduced to neurodiversity, my interviewees articulated a sense of neurological or cognitive uniqueness, and were willing to latch onto the idea that these differences can be a source of pride. Thus, as with neurotypicals, autistic individuals may view themselves as cerebral citizens with some ambivalence, but perhaps with a slightly enhanced eagerness to find something positive about their anatomical difference that mainstream society perceives as problematic. This points to both the double-voiced and authoritative nature of neurology discourse previously discussed.

**Attitudes Towards Research**

Given reduction of all individuals to their brains, and the potential for this conception of individuals to produce new categories of existence and species, it is not surprising that many autistic people are somewhat wary of biological research. Attitudes towards research ranged from ambivalence to excitement and support, with no one opposed. Common concerns include the curative model that research follows, the use of the research findings, and results that figure autistic people distinct from humans.

The strongest statements were those concerning the goals and positionality of non-autistic researchers. For example, “They [neurotypicals] don’t understand what it feels like to have it, they don’t see the essence…It’s easier to do the brain

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40 There was a varying degree of research experience and awareness of having participated in research, with only two participants reporting research experience (Interviewees 003, 006, and 007), while these parents, in addition to those of Interviews 001 and 002 reported research participation.
research when you actually have the disorder” (Interviewee 001). Although Ne’eman himself has never participated in biomedical research, and describes his experience as a research participant as limited to filling out surveys online, he agrees, adding:

They [researchers] don’t care what we think when they’re designing the study, they don’t care what we think when analyzing the data, and they don’t care what we think when they’re publicizing the data, but very much want to work with us when they’re looking for people to prod and poke.

In addition, he views the trend of treating autistic communities as a pool of research subjects and little else as dehumanizing. He also says that ASAN passes along “close to none” of the solicitations they receive for research, noting that the possibility of a free diagnosis is the only upside of most studies.

Ne’eman is very involved in autism research, a member of the federal Inter-Agency Autism Coordinating Committee which “advis[es] on autism policy and research issues,” and a consultant on various projects. He is also highly involved with the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) and offers an alternative model in his description of ASAN’s collaborative research projects that operate under the model of “Community Based Participatory Research, whereby researchers and community members serve as equal partners throughout the research process” (AASPIRE, 2011; Ne'eman, interview, September 16, 2011). Although research has always been dehumanizing for its

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41 This reflects the stance of disability activists who demand, “Nothing about us, without us!”

42 It is interesting to consider how these surveys presume literacy, and therefore acknowledge the abilities of autistic people, yet also self-select for a certain type of autistic person.

43 As previously hinted towards, many adults find that receiving a diagnosis is explanatory of many of their previous difficulties. Not only does the diagnosis absolve them of social challenges, but also helps individuals access services (Bagatell, 2010; Meyerding, 1998; Page, 2009; Prince-Hughes, 2004; Robison, 2007, 2011).
objects of study, today the potency of scientific discourse and the proliferation of
brain imagery that projects research findings into the public purview and becomes a part of our daily lives justifies the magnitude of this skepticism and disavowal.

In a more neutral, yet still skeptical response, one eighteen-year-old participant described research as “a blessing or a curse.” This participant acknowledged that he had “benefited a lot personally in the form of medicine and therapy,” but denounced research aimed at a cure, by stating, “I am not in favor of a cure. Asperger’s Syndrome is an integral part of who I am” (Interviewee 002). Here, autistic individuals reject neurotypicals as the arbitrators of normality who determine the need for adjustment (cure) into normality (neurotypicality).

Despite these concerns about agency, many of the interviewees expressed their support of research as an opportunity to learn more about autism or to provide the opportunity for others (autistic and neurotypicals) to learn about autism through research.\(^\text{44}\) Responses indicating positive feelings about research included:

- “It is good to let people know more about autism, such as, ‘how is it diagnosed, how many types are there?’” (Interviewee 005)
- “People misunderstand what Asperger’s Syndrome is like, what having it is like, why they [Aspergians] do what they do… I like doing it, it gives people a chance to get to know how I am, so people find out more about autism” (Interviewee 006).
- Enjoyed the games and puzzle solving so much that tried to get the puzzle to play with at home; appeared excited when describing the details of the study (Interviewees 003, 006 & 007).
- Enjoyed being financially compensated (Interviewees 006 & 007).

\(^\text{44}\) It wasn’t explicitly stated whether the interviewees were interested in research as a bridge between neurotypicals and autistic people, or were interested in advancing their own knowledge about autism. One individual seemed to cite research participation as part of his early understanding of autism outside of its relationship to himself, as he said that as he participated in more studies he realized, “Oh, this is bigger than I thought,” and that participating helped him transition from feeling “indifferent” about his diagnosis to “[knowing I was] part of something bigger” (Interviewee 003).
• “I think it’s necessary to figure out how the human brain works. I will subject to being questioned. I am perfectly fine with autism research [sic]...It is very useful” (Interviewee 009)
• It is positive, because “people need help walking and talking” (Interviewee 011).

Therefore, both these positive responses and those that are more ambivalent, suggest that many autistic youth see research as personally rewarding, and as a means to educate others and help improve the lives of autistic people.

The cultural use of neurological research as material for constructing boundaries of personhood, and neurology as a lens through which to understand the totality of individuals, provide reasons to fear research leading to autistic marginalization and essentialization. Most importantly, even if research is enjoyable and provides help for some, those studies conducted with “cure” in mind are seen as a threat by some autistic people. Here, we come back to the question discussed in the first chapter of neurodiversity as reflecting improper citizenship. Therefore, one might hypothesize that “proper” autistic citizens would support research. However, as we have seen, today it appears that both autistic authors and my interviewees navigate a careful line between wanting to know more about their neurology and attributing their brains to themselves. They also position themselves (and others) as actors distinct from and unaccountable for, and even in some cases, uninterested in, their differences.

Perhaps this divided stance on research and accountability will lead to the splintering of autistic communities. Those who are interested in participating as “proper citizens” in mainstream society, eager for biotechnological interventions and understandings, may peacefully co-exist with researchers and many parent groups.
They may accept medical advice and societal pressure to not have children and may find themselves with cabinets full of medications. Their adversaries, however, will be those who are proud of their neurological differences, supporting research that perhaps advances biological explanations of autism, but rejecting cures and interventions. These individuals will assert their rights to live as autistic people and demand that society broadens its understanding of citizenship to that of contributors who specialize by taking advantage of their innate biology, rather than conforming to become another cog in the machine.

**Autism Narratives: Adding Emotions**

Autism research and cultural narratives of autism have worked to construct each other. As previously described, many scientific theories of autism have led to cultural understandings of autism. The ways that autistic people internalize and rewrite these figurings of themselves also have the potential to impact the direction of scientific research. We have already seen how popularized understandings of autism as a mysterious neurological diagnosis are based upon dominant scientific and cultural narratives, but it is also interesting to consider whether cultural narratives of autism have impacted individuals’ self-understandings as relating to autism (and other clinical categories/identities). Ian Hacking (2009) suggests that autobiographies by autistic authors have contributed to the cultural creation of a coherent autistic self, which has shaped autistic experience. He emphasizes the potency of autobiographical narratives by asking, “Are the autobiographies and other stories less telling what it is like to autistic than constituting it, both for those who inhabit the autistic spectrum, and for those who do not?” Given Hacking’s suggestion, how much of a role do the
words of autistic authors or of other media have in reifying the notions that all autistic people view autism as a core characteristic of themselves, and that their diagnosis is a more salient feature of self than any other personality or physical trait, challenge, or ability? Along these lines, is the message that autism invokes one coherent “autism experience” also constructed through these autobiographies? For example, Grandin and Robison provide evidence that this may be the case, as they emphasize autistic difference and how autism has shaped their experiences.

Although Hacking does lay a compelling argument that narrative plays a role in the construction of autistic self-understanding and a singular autistic figure, two distinct categories of narratives have been adopted. Just as some individuals gravitate towards person-first language, which foregrounds them as a person first, and a person who happens to have autism, second, some individuals write about themselves as if they see autism as simply one component of themselves.45 In doing so, they assert that they are more similar to neurotypicals than different. Other autistic individuals (similar to those who find person-first language offensive to their autistic identity) see autism as all encompassing in its influence on their life, such that it distances them from neurotypical human experience (consider Robison and Grandin). It would not be fair to say that the former distance themselves from autism and lack autistic-pride, or that the latter all believe that autism is a wonderful human difference. Rather, further study would be required in order to uncover any possible correlations between preferred language use and self-understanding. However, this comparison

45 For example, Page states in the beginning of Parallel Play, “I’m not going to put undue stress on my Asperger’s syndrome; it will be there, but not front and center, in part because that was only one element of what made me, and in part because I had no idea what it was until I was forty-five” (Page, 2009, p. 8).
demonstrates how different autism narratives may participate in other conversations in disability communities.

Regardless of which identity scheme they adopt, today’s autistic authors are interested in adding a new element to the autistic narrative that perhaps draws them closer to neurotypicals—emotionality. Several authors insist upon the presence of their emotions, as they feel autistic people are consistently regarded as, or criticized for lacking or having unexpected emotions—this left Robison, for example, with a painful mark (Robison, 2007, p. 201). In addition, he and Tim Page want neurotypicals to understand that, “The fact that [autistic people’s] understanding of affection, comradeship, and human empathy has been hard-won rather than hardwired from the start does not make those feelings less genuine” (Page, 2009, p. 182).

Using several folk-references to the brain, throughout Be Different Robison (2011) hypothesizes why his emotions may appear or work slightly differently from those of neurotypicals. This is perhaps an effort to reconcile adults and peers admonishing him for what they perceived as inappropriate facial expressions or reactions to emotional situations (Robison 2007, 2011). Robison suggests that autistic people may even have deeper emotions than neurotypicals. To illustrate this, he describes a discrepancy in how he and his friend Brya responded to news of a tragic bike crash. Robison “furrowed [his] brow and said, ‘Woof. That sucks,’” while Brya expressed sympathy, made a sad facial impression, and then became encouraging. Robison (2011) linked the circumstances to himself and considered what it would feel like if he, or someone to whom he was close, had been hurt. He
stated that he ended this exchange feeling badly and analyzed the situation utilizing neurological discourse:

And why did Brya feel ok at the end [of this situation], while I ended up feeling so bad?

I’ll lay that one at the feet of those mirror neurons. They seem to have operated very differently in the two of us. Brya mirrored Charley [the person telling the story], saw a response, and made a happy face to cheer him up. Her happy face cheered her up, too, allowing her to recover from mirroring his worry over the accident. So in the space of an instant she mirrored his distress, countered it with a smile, and felt better herself. That’s a successful and powerful system. I wish I had access to it.

My mirror neurons moved slower, and maybe deeper and stronger… I frowned as I acknowledged Charley’s sad story… All the while, my mirror neurons were assimilating Charley’s news. The more they took it in, the more I mirrored his feelings, and the worse I felt…

It’s also possible that autism makes my sense of self weaker than Brya’s. Recent neuroscience studies support that idea. The distinction between the concepts of ‘me’ and ‘you’ maybe a little more blurred for me at times. As often as I’ve been criticized for lacking empathy, exchanges like this leave me feeling like I have more empathy than typicals [neurotypicals]. My feelings of empathy move a lot slower than Brya’s, but once they get going, look out! They’re very real.” (pp. 112-113)

In this explanation, Robison reverses medical discourse that describes autistic people as having deficient emotions. Rather than asserting that he is equal to neurotypicals in terms of emotional processing, or that scientific notions of deficiency are irrelevant to lived experience, his hypothesis acknowledges that “more is greater,” and even uses what he perceives as one of his challenges (self-concept) to explain the production of “more,” in another area (empathy). Therefore, Robison points to differences (speed of emotion-development) not as equivalent to the norm, but as enhanced. This reminds me of his proud title “Be Different” and is representative of the message of this book that acknowledges the challenges of Aspergian experience,
yet emphasizes how autistic difference confers strengths. Furthermore, Robison inverts the valuation of speed by suggesting that despite the slowness of his emotional feelings, they are still intact, if not stronger. The assertion of a slow system or response as stronger than a quick one is contrary to cultural beliefs about efficiency.

Robison (2011) feels that prior to his diagnosis, the negative feedback regarding his atypical emotional expression was a major cause of his self-perception as a “sociopath,” a “fraud,” and a “misfit.” Therefore, I do not find it surprising that he views atypical mirror neurons/neuronal organization as one of the downsides of autism. This is perhaps why he states of mirror neurons, “That’s a successful and powerful system. I wish I had access to it” (p. 112). Alternatively, attributing his different emotional responses to his brain could also be a way that Robison reconciles his experiences and reconstructs his neurological weaknesses as strengths. This is an example of how internalization and promotion of naturalizing (scientific) explanations of difference enables individuals to deflect personal responsibility and to assert the “realness” of their different experiences that may not be visible to neurotypicals. In his explanation of his reaction to the bike accident, Robison uses science to prove that although neurotypicals may not observe his emotions, they certainly exist.

The assertion of emotional capacity is important in light of the painful childhoods discussed by many of the adult authors. These first-person accounts (described at length below) make it clear that the divisions drawn between autistic people and neurotypicals on the basis of emotional cognition and experience is inaccurate. Unfortunately, scientific research suggesting that autistic people lack self-
consciousness, typical inner experiences, and self-understandings, and the subsequent constructed autistic prototype may contribute to and justify neurotypicals’ poor treatment of autistic people. For example, adult neurotypicals may overlook bullying directed at autistic kids on the basis that it will not bother the autistic individuals, given research suggesting that autistic people can not be embarrassed, compare themselves to others, or be self-conscious (Dawson & McKissick, 1984; Frith & Happé, 1999; Hurlburt & Happé, 1994; Lombardo, 20070.)

Robison, Tammet, Prince-Hughes, Page, Stefanski, and McElwain, who grew up in Massachusetts, England, Connecticut, Illinois, Indiana, and upstate New York, respectively, all write about being teased and bullied. For Prince-Hughes, Page, and Robison, the misunderstandings they received from teachers and peers most likely influenced their negative associations with school.

Some descriptions of bullying include:

• Some of the boys in the playground would come up to me and tease me by mimicking my hand flapping and calling me names (Tammet, 2006, p. 77).
• I stood out as a freak in school: my tics, my monologues, my sensitivities, [and many other traits] all led to total ostracism and active aggression. People would corner me in the bathroom and force my head into the toilet, slam me into my locker, and throw trash at me in the hall. They hit me in the head with books and spat on me. They defaced my locker. They took my food away. Once some senior students made a sign with a derogatory word on it and hung it around my neck. (Prince-Hughes, 2004, pp. 60-61)
• Once, some kids from my school were at the driving range at the same time I was. They called me names and laughed at me, and I could tell they thought I would fail. I FELT TERRIBLE! (Stefanski, 2011, p. 33)
• All of these experiences support Robison’s (2011) statement: Don’t worry, he doesn’t even notice’ was a common refrain when people talked behind my back. Well, let me assure you, I may not have been able to read from people’s subtle clues their thoughts and feelings, or their expectations of me, but I absolutely noticed when they rejected or disregarded me, and I still do. I may seem robotic and mechanical sometimes, but there is nothing mechanical or cold about my internal feelings. I am just as sensitive
as anyone to snide remarks and criticisms. I cried inside fifty years ago, and I still do today. (p. 86)

To add to the hostile school environments students create, many felt that teachers and staff contributed to the problem of teasing, as Robison, Tammet, Grandin, and Page all describe instances in which school officials, teachers, and staff mistook their eccentricities for misbehavior or disciplined them for responding to a bully (Grandin & Johnson, 2005, p. 2; Page, 2009, pp. 52, 56; Robison, 2007, 2011; Tammet, 2006). Looking back on their childhoods, these adults relate teasing to the development of low self-esteem, and feeling as if activities normally associated with adolescence, such as dating, forming friendships, and even participating in class were inaccessible to them:

- All throughout my teens my confidence was always very low because of the teasing I received and my inability to talk and interact comfortably with my peers, so dating was never a possibility for me. (Tammet, 2006, p. 109)
- Determined to last out my high school career, I tried to find new ways to get through the day. I imagined that no one else existed in the school, so thoroughly that people literally disappeared from my sight. With my eyes fixed ahead and focused on nothing, I would wander the halls, seeing them empty, quiet, hallowed. I became unable to hear my teachers and would be speechless when they called on me. (Prince-Hughes, 2004, p. 60)

Bullying is still an issue for autistic children as it is estimated that 90% of children with a diagnosis of Asperger’s Syndrome are bullied (Shepard, 2010, p. 143). This was addressed in three of the four children’s books that I read:

- Stefanski describes a time that he was bullied at a driving range, and says, “Being a good friend means showing me respect,” and thus implies that although, “Sometimes, kids who are stronger or smarter might want to show off by hurting or teasing an autistic kid,” doing so is not an acceptable way to “show off” (Stefanski, 33).
- The picture book, All Cats have Asperger Syndrome explains that autistic kids (who are depicted as male) may be bullied or left out of social gatherings: “He isn’t interested in the things other kids his age do and when he’s forced to mix,
he doesn’t know how. Other kids make friends…but don’t invite him to play, and he may be bullied (Hoopmann, 2006).

• *Autism and Me: Sibling Stories*, follows its introduction of autism with, “You can help kids with autism by not teasing them or letting other kids tease them. They deserve respect” (Shapiro, 2009).

In addition to feeling the scars of being bullied, many autistic authors described their Childhoods as lonely and filled with longing for friendships, but without an understanding of how to form them and a sense that there was something they were doing “wrong” in social situations. These feelings were often associated with depression and anxiety, the two most common psychiatric comorbidities in autism (Ghaziuddin, 2005). In addition, many autistic people experience prolonged stress and associated physiological and psychological stress (Abbott, ongoing personal communication, December 2011-January 2012). The observation that diagnoses such as bipolar disorder frequently precede that of autism points to the psychiatric needs of this population, which ironically, often go unrecognized in individuals with autism diagnoses (Page, 2009; Prince-Hughes, 2004). This anxiety and depression may persist throughout adulthood (Page, 2009; Robison, 2011). Robison explicitly attributes his depression and anxiety to being misunderstood as a child and to constant social rejections: “The sting of those early failures followed me long into adulthood, even after I learned about Asperger’s” (2007, p. 201; 2011 p. 47, 89). Page’s “lifelong unease” (Page, 2009, p. 4) also does not seem alleviated by his knowledge of Asperger’s Syndrome:

I wouldn’t wish the condition on anybody—I’ve spent too much of my life isolated, unhappy, and conflicted—yet I am also convinced that many of the things I’ve done were accomplished not despite my Aspergers’ but *because* of it. I’m sure that it’s responsible, at least in part, for my powers of concentration. (p. 178)
It seems that despite Page’s acknowledgement of the strengths that he derives from autism, he does not feel that they compensate for the innate human need for this has left both him and Robison feeling as if they are missing something, despite their gifts. In addition to demonstrating the need for allies, researchers, clinicians, and disability community members to focus on ways in which to experience fulfilling social relationships, I believe that this sense of loss also points to the importance of supporting and encouraging a broad range of interests in strengths that autistic (and all) people have.

**Celebration**

Initially, I asked individuals about their strengths and interests with the intention of coding for neurological discourse. Although the strengths and interests identified were largely cognitive in nature, what I found much more compelling was the apparent difficulty of identifying strengths and activities of enjoyment, especially outside of those viewed as intellectual or cognitive. Today, it is accepted that high functioning autistic individuals are capable of learning and recall, however, many psychologists would attribute participants’ difficulty in identifying strengths and activities they enjoyed as reflecting the lack of self-understanding associated with autism. Contrary to this conclusion is the ease with which many of these same individuals talked about what it was like to be autistic and their recollection of and reflection upon research experiences. So, under the assumption that autistic youth do have the ability to describe that of which they are aware, the difficulty of describing their strengths could be taken as evidence that they do not have ample opportunities to learn about their strengths, and that the people around them fail to sufficiently
celebrate and support their interests, or those beyond their “special interests.” This lack of engagement with autistic youth about their strengths could stem from the perception that autistic children lack self-concepts and would therefore not even be able to benefit from these conversations. The writings of Grandin, Robison, Page, Prince-Hughes, and Tammet, along with my interview data, demonstrate that autistic people do have knowledge of themselves and that they crave indications that they are successful, likable, and talented, as so many of the messages that they receive from their peers, schools, and even homes, suggest otherwise. Perhaps most importantly, even if autistic people were to lack self-concepts, it is imperative to recognize that there is only risk involved in not telling someone something nice about themselves or failing to encourage an interest.

I interviewed one individual (Interviewee 012) with whom I had had a relationship for many years as his soccer coach and whom I had recently begun babysitting for. Although he was one of the participants who used less verbal communication than others, he provided verbal and written consent, and seemed enthusiastic about participating. The interview, during which we were seated on separate couches in the participant’s living room (where we spent most of our time while I babysat), proceeded as follows:

Interviewer (I): Do you know what autism is?
Participant (P): I don’t know.
I: What would you tell someone about yourself?
P: Tentatively said, Like to play games, and turned away.
I: Do you want to continue the questions?
P: Yes!
I: What are three things you are good at?
P: Being alone.
I: Anything else?
P: No response.
I: I know there are lots of things you like.
P: No verbal response, puts head in nearby pillow and looks upset.
I: We don’t have to keep doing questions if you don’t want to.
P: It’s ok. Picks head up.
I: Ok, what is something you like about yourself?
P: No verbal response. Frowns and puts head back in pillow.

At this point, I decided to revert back to being a familiar friend. In this role I told him several true things about himself: “You’re kind, have a great sense of humor, know a lot about movies, and are a lot of fun to be around.” In response, he lifted up his head and smiled at me. He continued to smile and I asked, “Did you know those things about yourself?” He frowned and promptly buried his head back into the pillow, and we agreed to stop the interview.

This individual has a caring and loving family. His parents and younger brothers openly express their affection for him and an appreciation of his personality and talents. As far as I am aware, this is not a case of an individual constantly receiving negative messages about himself and I imagine that he is often told about his strengths—perhaps though, not often enough. It is possible, his teachers and others around him provide more positive reinforcement for following directions and asking conversationally appropriate questions than praise for his caring and humorous personality. It is possible that the latter go unnoticed under the “accomplishment” of normalized daily function. However, knowing his family, and seeing his mother’s description of non-academic strengths in the survey, such as “determination to share what is interesting to him with others” and “his determination to accomplish tasks that are difficult without becoming discouraged” (Parent 012), I am hesitant to jump to the conclusion that he does not get enough positive feedback at home. His mother commented that he has started to notice differences between the activities in which he
and his brothers participate, and perhaps this in combination with a lack of positive input from environments outside of the home contribute to his apparent lack of confidence. Regardless, asking people what they like about themselves should not provoke them to bury their heads in a pillow. And it should not be the hardest question, or the one met with the most hesitation, during an interview that asks individuals to describe what it is like to be autistic and research experience that may be a distant memory. I am unwilling to believe that the reason this question went unanswered is due to a lack of self-awareness. There must be something more going on.

Regardless of self-concept, being able to answer from either a genuine place of self-understanding or from recall “What do you like about yourself?” “What are three of your strengths?” and “What do you like to do?” should not be upsetting for anyone. These are things that parents, educators, and others should discuss constantly with people, autistic, and neurotypical. In light of the high prevalence of depression and anxiety and the bullying that autistic people experience, perhaps something as simple as working on understanding strengths and weaknesses could help alleviate some of this pain, as it seems to have for the authors whose work I have cited.

How can we support autistic individuals in recognizing and developing their strengths other than “school smarts?” This extends beyond athletics and the arts, but also to helping autistic people see their sense of humor, their kindness, and other personality traits that occur just as they would in the neurotypical population. It seems that parents acknowledged cognitive strengths, but were also able to describe
their kids’ strengths outside of cognition, as they described their children with a variety of characteristics, as seen in Table 5.

### Mothers’ Descriptions of Strengths

<table>
<thead>
<tr>
<th>Strength</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring, tries to help others</td>
<td>001</td>
</tr>
<tr>
<td>Loving</td>
<td>002</td>
</tr>
<tr>
<td>Kind</td>
<td>002, 009</td>
</tr>
<tr>
<td>Happy</td>
<td>004</td>
</tr>
<tr>
<td>Cooperative</td>
<td>004</td>
</tr>
<tr>
<td>Sports</td>
<td>005, 010, 011</td>
</tr>
<tr>
<td>Sense of humor</td>
<td>006</td>
</tr>
<tr>
<td>Determination</td>
<td>009, 011</td>
</tr>
<tr>
<td>Musically/artistically talented</td>
<td>009, 010</td>
</tr>
<tr>
<td>Reliable and honest</td>
<td>010, 011</td>
</tr>
<tr>
<td>Affectionate</td>
<td>011</td>
</tr>
<tr>
<td>Participation in Scouts</td>
<td>011</td>
</tr>
<tr>
<td>Desire to be and share with others</td>
<td>012</td>
</tr>
<tr>
<td>Perseverance</td>
<td>012</td>
</tr>
</tbody>
</table>

Table 5. Mothers described their children as having a variety of strengths and interests other than intelligence.

In this world of mothers, autistic individuals are not only valued for intellectual talents, but are also recognized as people who are part of a complex social world that should include them.

Although at a young age McElwain understands his disability as situated in self (McElwain, 2008), many people’s understanding of autism (as a disability) as situated does not stick as early. Robison (2011) says:

I sure wish I could have seen my future when people called me names as a kid. And it wasn’t just the other kids—even teachers made fun of my focus and interests…Even today, psychologists say special interests and extreme focus are abnormal in a teenager. But if the person is twenty-five, the same shrinks call him an expert. That’s what happened to me. The world really does get better for Aspergerians, and indeed for all sorts of geeks and misfits, as we grow up. (p. 238)
Here it seems that in adulthood Robison recognizes the contradictions in how children are viewed compared to how adults are viewed, and how context determines whether or not an individual has a disability. As a child, Robison’s “special interests” were a cause of social rejection and an unpleasant childhood, but that suddenly changed in adulthood and enabled him to feel as if he had skills that others appreciated, which imbued him with a sense of “social value.” Robison gained this understanding from his career, whereas, Ne’eman explained that, from an early age, he “knew at some level to be true that I was an equal human being,” but that it took learning about neurodiversity (in which the social model of disability is prominent) to “[feel] more comfortable believing these things.” Therefore, as disability and autism stand for self in some cases (take for instance “It [autism] is an integral part of who I am” (Interviewee 003) and “It’s just how I am” (McElwain, 2008), it is imperative for everyone that we openly critique the societal conditions that produce both “healthy” bodies and our sense of bodies standing in for self.

The case of Jason McElwain (2008) of Greece, New York provides an interesting corollary to the autistic subject who is celebrated for intellectual skills and achievements. McElwain and those who know him describe him as funny, hardworking, and good at sports. McElwain, in his early twenties, is working towards earning his GED. He and his parents seem aware and accepting of the fact that he did not “truly” graduate from high school, but his interest in sports, particularly basketball (see Chapter 1), was fostered by his family and community.

It seems that McElwain’s love of basketball, his eagerness to help, and his upbeat and encouraging personality are what he and those around him celebrate. Is
this because he was unsuccessful in school or lacked intellectual strengths? His parents believed in hard work, not allowing his older (neurotypical) brother to ever use a calculator, and encouraging both children to complete their homework without assistance, lest they use their parents as a “crutch.” It seems that the many hours he spent focused on sports were his own choice, and although accompanied by his brother in their driveway or at the gym, his parents seemed far more concerned with his ability to live independently and succeed in school. The fostering of Jason’s interest in basketball perhaps led him to see himself “like one of the regular kids,” (McElwain, 2008), because an interest in sports is part of the cultural biography of teenage boys.

It seems that in the absence of intellectual talents, McElwain was able to flourish as a “regular kid” (or using Rose’s language, “normal kid”). Did Jason’s town, popular media, educators, and sports aficionados accept him because he was “defying” or “overcoming” his autism through sports that are socially nuanced and require coordination—both areas in which autistic people are supposed to struggle? Or was he accepted because in his basketball ability he represented a good American citizen, who, like a “regular kid,” can redeem his lack of academic success through athletics? Does the fostering of Jason’s athletic ability and his perhaps related self-understanding as “like a regular kid” provide an example of a well-supported autistic individual? Or is McElwain’s story just another example of an autistic person who gained acceptance on the basis of achieved neurotypicality? Do we perceive him as different only because he accomplished this through athletics rather than intellect?
We have seen that like anyone, autistic people respond and react to their social environments and develop self-perceptions based on the ways in which people perceive and treat them. Therefore, whose responsibility is it to communicate the message to disabled youth that the social suffering they endure is not their fault, but that of society? One might say that disability communities are invested in self-sufficiency and defining their own needs and rights. However, as an ally, I feel that it is my responsibility to open this door and admit how the world of the majority has failed so many people. Although messages from within disability communities are perhaps those that are most important (Crocker & Major, 1989), disabled people still live in a world designed for able-bodied neurotypical people, and derive their self-worth, at least in part, from that world. Therefore, I assert that making space for all people is imperative. This must be accomplished through individuals and institutions adopting the view of the body and health as situated.

In addition to the need of celebrating strengths and achievements beyond the classroom, communication, and daily functioning, narratives of emotion implore us to see autistic people as individuals who have emotional capacity. Despite research asserting that autistic people have impaired self-understanding and may not experience emotions, it seems that qualitative research and personal narratives demonstrate that not only do autistic people have emotions, but they also are able to identify them within themselves.

The ramifications of describing an entire population of people as emotionless cannot be underestimated. Emotionality is deeply tied to notions of morality—this is something that Robison knows all too well, as he describes growing up with the label
of “sociopath” as a result of his “atypical” emotional expression. Furthermore, insofar as morality is tied to personhood, positing autistic people as emotionless implicates them as non-human. The same can be said of self-concept. Although passive in some situations, personhood to some degree is rooted in being an active agent—something that could not be accomplished without a sense of self. The observation that autistic people have deficits in ToM has led to beliefs about autistic people lacking self-concepts and self-understanding that therefore limits their ability to integrate into community. To continue, without a sense of self, it seems that people may not be able to develop an understanding of others, which poses significant challenges to developing a sense of morality. Both of these challenges pose barriers to developing morality and community membership, and subsequently personhood. Clearly, then, the need to recognize autistic people as experiencing emotions and having the capacity for self-understanding is important from a theoretical perspective.

Practically, however, this recognition is perhaps even more imperative. In general, the autobiographic authors and my interviewees displayed emotions and self-understanding. Several adults commented on the difficulties they experienced growing up due to anxiety and being misunderstood. Aside from these experiences, these authors’ emphasis on how these experiences and specific misunderstandings related to emotionality demonstrate that autistic people feel that neurotypicals fail to acknowledge their very real emotions and concepts of self. In addition to recognizing emotionality as a part of being human, it is also important to establish in autistic people, because as previously discussed, the perception of autistic people as un-emotional paves the way for autistic people to be constructed as immoral and non-
human and to be bullied and physically harmed—all justified by the hypothesis that autistic people will neither understand their words nor actions, and if they do, they certainly will not be emotionally impacted. Thus, it seems that changing perceptions about autism in regard to these fundamental markers of personhood could play a significant role in facilitating the development of empowered autistic identification. Finally, the assertion of emotionality respatializes autistic people. Autistic people have been formally understood as a singular population whose (uniform) members exist in their own worlds. However, by asserting their emotionality, the autistic population becomes autistic people who participate in and share the world from which they have so long been theoretically and politically estranged.
CHAPTER 5
Re/presenting Autistic Individuality

People Making Engines

In his paper, “Making People Up,” Hacking (2006) proposes and categorizes ten “engines for making up people”:

<table>
<thead>
<tr>
<th>Engine’s Action</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Count</td>
<td>Discovery</td>
</tr>
<tr>
<td>2. Quantify</td>
<td>Discovery</td>
</tr>
<tr>
<td>3. Create Norms</td>
<td>Discovery</td>
</tr>
<tr>
<td>4. Correlate</td>
<td>Discovery</td>
</tr>
<tr>
<td>5. Medicalize</td>
<td>Discovery</td>
</tr>
<tr>
<td>6. Biologize</td>
<td>Discovery</td>
</tr>
<tr>
<td>7. Genticisze</td>
<td>Discovery</td>
</tr>
<tr>
<td>8. Normalize</td>
<td>Practice</td>
</tr>
<tr>
<td>9. Bureaucratize</td>
<td>Administration</td>
</tr>
<tr>
<td>10. Reclaim our identity</td>
<td>Resistance to Knowers</td>
</tr>
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</table>

He suggests that these engines, or machines, operate in the pattern that “our sciences create kinds of people that in a certain sense did not exist before.” Or in other words, these engines “produce what was classified” (Shepard, 2010, p. 16) and defined. Perhaps with the exception of the engine of resistance, these engines are self-sustaining and driven by (compulsory) categorization—Lennard Davis, a scholar of Disability Studies, explains:

If more time was spent on describing the variety of human experience and less in trying to categorize into forms (literary and visual) that proscribe anomalous states of physical identity, we would be able to explore the ways that society, narrative, and politics work to oppress bodies of difference. (Yergeau, 2010, quoting Davis)

Therefore, the very actions of these engines preclude us from stepping outside of their (naturalized) processes and discerning their oppressive nature.
In thinking about the construction of autism, this project has covered all of Hacking’s engines. Below, I will to review this project by describing how I have accounted for all of these machines. Although Hacking identifies the working of several of these machines in autism (noting that they operate differently in different diagnoses and, in particular, uses obesity as an example), at several times, I depart from Hacking’s view of these machines.

The counting machine was employed in many ways by psychological definitions of autism. Although not referring specifically to prevalence studies as Hacking does, the assessment of all types of cases and bodies by the clinician’s gaze led to the tallying of different types of humans. Eventually this resulted in the marking of some children as pathological, and more specifically, schizophrenic. Those children were then “counted” by Kanner and Asperger due to their distinctiveness from others in their category, and eventually identified as belonging in the created category of “autistic.”

Once autism was first proposed as a distinct category, researchers sought to derive diagnostic criteria that could distinguish the non/autistic. This is the machine of quantifying. Hacking suggests that “autism resists quantity. There are many diagnostic questionnaires, but it’s hard to quantify deficits.” However, I disagree. I believe that operationalization of ToM and verbal intelligence are just two of many examples in which autism is quantified. Although diagnostic criteria do not include a particular “score” on any assessment, all of the diagnostic criteria can be measured both when making diagnoses and when researching autism. Of course, identification and measurement of “abnormality” perform work on both itself and the norm. This
leads to the third engine: creating norms. I have discussed norms as relating to autism, and norms and can be seen at work in the previous two engines. In agreement with Hacking, I have reviewed how the establishment of norms has led to the identification of autism and its societal figuring as problematic.

Hacking (2006) describes correlation as “the fundamental engine of the social sciences.” I view this engine as the most powerful in terms of reducing autistic people to a particular (inhuman) prototype. This is because the engine of correlation looks at relationships such as the majority of autistic people being male or interested in math, and writes all autistic people as male mathematicians. Additionally, this engine looks to find causes for autism anywhere it can (Hacking cites the seemingly preposterous example of a study examining the length of mothers’ fingers), and when correlations are found, it has the potential to assert harmful theories and reductive etiology, pathology, and ends.

Today, correlations of autistic characteristics with particular brain differences led to the last three engines of discovery: medicalization, biologization, and geneticization. Initially, medicalization operated when autism was first identified as pathological. Thus, it becomes a state of being that requires a diagnosis and proper treatment. In modern times, this engine operates in concert with the sixth and seventh engines of biology and genetics. Here, medicalization has led to further research in which we have focused on the autistic body instead of the autistic person. Correlational studies have led to the construction (and subsequent “discovery” of) the autistic brain, which genetics may or may not cause. However, these three engines work with the previous engines of discovery to rein the pathological autistic person.
into biomedical spaces and dissect it in order to find units that can be scientifically counted and quantified relative to a scientifically determined norm. Here, we see how the autistic puzzle emerges.

In addition, the ability to construct coherent and visible biomedical understandings of the complex and “mysterious” autistic person has led to hope discourse, as this biomedical spatialization also suggests the possibility of normalization—the eighth engine, which is an engine of practice. Here, the norm, constructed in opposition to autism, can be attained through management of aberrant parts and their functions. This is the purpose of special education, behavioral therapies, special diets, medication, and other forms of management that parents and individuals may practice. This engine, ironically, works both to construct and erase the type of person it establishes. Although normalization is a process that continuously acts upon and re-constructs autistic people by changing the boundaries of autism (Hacking, 2006), this machine opens up the possibility of erasure, because the goal of normalization is homogeneity. I would like to note that this process becomes the responsibility of the mother, as she is often figured to have a role in the emergence of autism and is also expected to strive for its dissolution. My interviews confirmed this.

The ways in which normalization plays into understandings of citizenship is how I believe the engine of administration, or bureaucratization, applies to autism. Society is set up such that particular bodies are more productive than others and views those bodies that do not fit into this environment as irresponsible members, and are generally treats them as such. For example, despite legislation such as the
Americans with Disabilities Act (and its recent amendment in 2008), disabled people are one and a half times more likely to be unemployed than TABs ("Persons with a disability: labor force characteristics news release," 2011). However, the state is organized such that, for many, federal paychecks exceed the value of any potential salary they may receive. Thus, the political landscape maintains the distinction of disabled people as unproductive through its inability to mandate (universal) environmental redesign that could enable a wide variety of people to become employed and independent and fulfill its ethical duty to provide for its citizens. However, Hacking offers an alternative view, stating that the identification of children in schools (presumably through mandated testing) and the subsequent desire for an autism assessment demonstrates how the engine of bureaucratization is active in autism.

The final engine is “reclaiming our identity” or “resistance to knowers” (where I take “knowers” as the previous machines and those machines subsumed in their tropes) that can be observed in the flourishing neurodiversity movements. Here, autistic individuals “take back control from the experts and institutions” (Hacking, 2006) that frame their neurological differences as pathological and disabling. Although Hacking does not explicitly identify the neurodiversity movement as such, this is clear in Ortega’s (2009) description of cerebral citizenship and is a theme that has emerged throughout this thesis. Autistic people who mobilize neurodiversity discourse to assert personhood and social value reverse the actions of the previous engines. This reclaiming enables autistic individuals to rewrite their own narratives and live as autistic people, rejecting compulsory mimesis of the enabled world.
I hope that I demonstrated the new ways in which autistic individuals resist the reductivism and confinement of scientific and cultural discourses. In particular, we have seen how themes of emotion and self-understanding are emerging. This not only asserts the humanity of autistic individuals and refutes long-held beliefs about autism, but also helps to construct heterogeneous autistic individuals distinct from the singular autistic species that society makes up.

**Ally Work: Focusing on the Person**

Throughout this project, I have evaluated how scientific work and social environments impact autistic people. I believe that this project asserts the importance of qualitative research, as it demonstrated the ways in which engaging with autistic people as individuals yields humanizing data and contradicts data and conclusions drawn from quantitative methods. This does not mean that I think quantitative methods are inappropriate, but rather that I believe that these inconsistencies and the factors that produce them deserve to be studied. I most strongly believe that these inconsistencies point to the ways in which quantitative research, although it has its place, in some instances, flattens the individual. I realize now that my work as an advocate, activist, and ally over the past eleven years has been focused on the flattening of individuals on the basis of their disability. I take this moment to recount an experience I had this summer, as I believe that it speaks to the urgency of recognizing disabled people as individuals.

* For three days this summer, I am a substitute at a sheltered workshop that outputs mailing and plastic gift boxes filled with dried flowers. The first day,
there is an older woman in a wheelchair, and based on her movements and
the way her body hangs, I suspect she has cerebral palsy. We chat and it is
clear to me that she is intellectually capable of more complex and stimulating
work than filling boxes with dried flowers—something that she has been
doing for the past thirty years in this workshop. I notice that she has great
difficulty with her task, and kick myself for not feeling that it is my place to
suggest they simply lower the table so she can have a better angle (Why has no
one noticed this?! I am aghast by this oversight). While I try to help bring
materials and look for leisure activities in the room, she helps me locate the
materials. I acknowledge her assistance and tell her that she should be in
charge, and her response speaks volumes: “I’m too disabled. They don’t like
to have people with disabilities be in charge.” I tell her that things are
changing, but she doesn’t buy it.

It is so upsetting to me that this is the message that she has heard and
internalized. She is clearly capable, and I wonder how many times she didn’t
bother advocating for herself because she believed that she wouldn’t be
listened to, or that she would be ignored or overlooked, or simply equated to
a wheelchair with unclear speech. Written off. How many times has she
simply been written off?

The next visit to the workshop, I am assigned to another room. There is no
work, and the clients practice some folding (“task training” for mailings) and
flip through magazines. All day. I have the job of completing the gift boxes. I
imagine that many of the steps I am going through client could complete, but
it is very important to the company that all of the lines are straight and that
this particular job get done quickly. I chat with the individuals around me,
but see no other staff doing so. I get little response to my conversing. How
can you know how to respond when you are used to being ignored?
Probably not just in your workplace, but possibly throughout your entire life?

The third, and final visit, I return to last week’s site, and again, there is no
work. Magazine flipping. Again. This is all the clients have to do. I try to
converse, but again, this proves difficult. There is no precedent. I find out
from the Behavior Specialist, who seems to have good and interactive
relationships with all of the clients, that there is a game room with two closets
of games. We toss a ball, read Trivial Pursuit questions and re-experience the
tactile joys of Play-Doh. I feel as if the staff is glaring at me the entire time. I
imagine they wonder, “Why is she doing this? It’s easier to let them flip
magazines and chat amongst ourselves. It’s not like they can even play those games
properly. It’s not like they mind flipping magazines. Why are these people worth our
time?”

I can’t help but feel that places like this exist, are able to continue to function,
because of our perception of intellectual disability as something which
distances some people from the category of “human.” People with
intellectual disabilities, who may have “atypical” verbal communication or be
difficult to understand, are foreign to “typical” people. We don’t think they
matter. They aren’t human. They can’t possibly have feelings and interests
as we do. Most importantly though, they are not viewed as *individuals*, which in settings like these, justify them being treated as machines.

This thesis strives to identify the ways in which autistic people have been *incorrectly* and *intolerably* constructed into singular not-quite human beings. Maija Holmer Nadesen, a Disability Studies scholar, gives a wonderful description of how society inherently defines and produces narratives and categories of disability:

> Although there is a biological aspect to this condition named autism, the social factors involved in its identification, representation, interpretation, remediation, and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society. (Shepard, 2010, p. 20, quoting Nadesen)

This results in people who “have been passively constructed into autism—by discourse” (Yergeau, 2010). However, there is hope, as the “reciprocity of offering one’s own story to help others as they construct their own stories is an attempt to ‘change one’s own life by affecting the lives of others’” (Gregory, 2009, p. 28).

Therefore, the control of autistic people over autistic narratives is perhaps the only avenue towards creating supportive environments. We have seen how autistic people are navigating their relationship to their brains and are asserting their emotionality and individuality. Their stories demonstrate that “the stories we [neurotypicals] tell ourselves about autism affect people’s lives” (Shepard, 2010, p. 151) and urge us to recognize that the best thing neurotypicals can do is to open up space for autistic people to start telling their stories and step back, and listen.

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46 Shepard refers to neurotypicals here, but I would argue that this statement should be expanded to included both neurotypicals and autistic individuals as storytellers whose stories impact autistic people.
APPENDICES

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I. RECRUITMENT LETTER

Dear _______ Families,

I am writing to introduce you to a study I am conducting to examine how people with Autism Spectrum Disorders think about their minds, brains, and selves, and how this is affected by involvement with biomedical research and neurodiversity movements. My hope is that this research will shed light upon characteristics of empowering environments for people with Autism Spectrum Disorders.

In order to complete my research, I am conducting interviews with children and young adults on the Autism Spectrum, and administering questionnaires to their parent(s)/guardian(s), regardless of their experience with biomedical research and/or neurodiversity. I am writing to see if you and/or your child might be interested in participating. I anticipate that both the interview and questionnaire will take no more than thirty minutes of your time. Interviews will be conducted in a location agreed upon by the researcher and participating families, and you will have the option to fill out the questionnaire on paper or online. Finally, I am prepared to interview children without mentioning Autism, if you would prefer your child to not know and/or discuss their diagnosis.

If you think that you and/or your child may be interested in participating and/or have any questions, please contact me at aeschwartz@wesleyan.edu or (703) 527-7472.

Sincerely,

Ariel Schwartz
II. INTERVIEW QUESTIONS

Hi, my name is Ariel, and I’m doing a project to learn about how people with Autism Spectrum Disorders think about themselves. I would like to ask you a few questions about yourself and your experiences. It is OK if you do not want to. If you say yes, you can stop at any time or refuse to answer any question. Your parent(s) know that I will ask you some questions. Would you like to answer them? Please sign this form.

Great! Thanks so much. You’re really helping me out a lot! The first question is:

• If you met someone who knew nothing about autism, how would you explain to them what it is like to have Asperger’s Syndrome/Autism?
• What are three things you really like about yourself or things you are good at?
• Have you ever participated in research on autism?
  o Tell me about the research. What sorts of things did you do?
  o What do you think the researchers are learning/learned from you?
  o Do/did you like participating in research?
  o Why or why not?
• Do you know what neurodiversity means?
  o (If so): What does neurodiversity mean to you? How did you learn about neurodiversity?
  o (If not): Neurodiversity is a word that people use to talk about differences people have in their brains. They say that having a brain that works differently from others’ is something to be proud of. What do you think about this idea?

Thank you so much for talking with me. You’ve helped me a lot. Do you have any questions for me? If you think of any questions, please feel free to ask me at any time during camp or afterwards. Your parents have my contact information. Thanks again!
III. PARENT QUESTIONNAIRE

Parent Survey

Thank you very much for agreeing to participate in this questionnaire.

I am doing research for a senior project at Wesleyan University, where I am exploring how people with Autism Spectrum Disorders think about their minds, brains, and selves, and how this may be affected by their participation in scientific research, awareness of or involvement with neurodiversity movements, and other factors.

My hope is that this project will shed light upon the characteristics of environments that lead to empowering self understandings in individuals with Autism Spectrum Disorders. Please remember that you may decline answering any questions which you are not comfortable answering. The results of my study will be accessible to you through Talisman Programs. If you have any questions, please contact me at aeschwartz@wesleyan.edu or 703/795-0459.

In what state does your child attend school?


Does your child attend public school?

○ Yes
○ No

How old is your child (in years)?


What is your child's sex?

○ Male
○ Female
○ No answer
○ Other: ___________________________

How old are you?


What is your sex?

○ Male
○ Female
○ No answer
○ Other: ___________________________
Please indicate your background in science, if any.

☐ Bachelor's degree
☐ Master's degree
☐ PhD.
☐ Work as a researcher
☐ Work as a clinician or other work in the field of health care
☐ High school education and/or a few classes in college

Has your child ever been a participant in an autism research study?

☐ Yes
☐ No. If your child has not participated in research, please skip the next three questions.

Please check any reasons you choose to have your child participate in research. Please provide comments or additional reasons in the box below.

☐ To help researchers learn more about autism
☐ I believe it is a positive way for my child to learn about current autism research
☐ To learn more about my child
☐ Financial compensation
☐ Other: __________________________

Please indicate the number of times your child has participated in research of each type described below.

<table>
<thead>
<tr>
<th>Research Type</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4 or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain imaging research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motor skills studies research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioral and social skills studies research</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational studies research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you indicated "other" in the question above, please briefly describe the type of research in which your child has participated.
How does you perceive your child's respond to going to research sites and their experience? Please check all that apply, and use the box for any additional comments.

☐ My child is excited about participating
☐ My child is disinterested in participating
☐ My child likes the researchers
☐ My child dislikes the researchers
☐ My child learned something new from participating
☐ At some point during the research, my child was upset
☐ My child has inconsistent responses to participating in research
☐ Other: ____________________________________

Please indicate the degree to which you've relied on the following sources for information about autism.

<table>
<thead>
<tr>
<th>Source</th>
<th>Among the most relied upon</th>
<th>A moderate amount</th>
<th>Among the least relied upon</th>
<th>I have not used this source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information from my child's school</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Online or printed popular media (ie. television, magazines, newspapers)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Scientific or academic literature</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Books written as a resource for parents with children with Autism Spectrum Disorders</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Autobiographies of individuals with autism and/or personal narratives of raising children with autism</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other parents at school or work</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Parent Groups</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Workshops</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Online communities and forums</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

If you indicated that a source that you relied upon the most or a moderate amount as
"other," please describe.

When you talk to your child about autism, how do you talk about it? Please check all that apply.

☐ As a part of their identity
☐ As source of pride
☐ As a source of difference
☐ As a neurological identity
☐ As a neurological disability
☐ As a social disability
☐ As a learning disability
☐ I have not talked with my child about autism
☐ Other: ____________________________

How have you talked with your child about autism? Please check all that apply. If you have not talking with your child about autism, please skip to question X.

☐ Through conversation
☐ Through reading books
☐ By going to conferences with your child
☐ With the help of his/her teacher
☐ With the help of a health professional
☐ Other: ____________________________

What are three of your child's strengths?

Neurodiversity is a word that people use to talk about neurological differences and how this differences may be a source of pride. Have you heard of neurodiversity?

☐ Yes
☐ No
☐ Yes, but in different terms (please describe in next question).
When you talk to your child about autism, how do you talk about it? Please check all that apply.

☐ As a part of their identity
☐ As source of pride
☐ As a source of difference
☐ As a neurological identity
☐ As a neurological disability
☐ As a social disability
☐ As a learning disability
☐ I have not talked with my child about autism
☐ Other: ____________________________

How have you talked with your child about autism? Please check all that apply. If you have not talking with your child about autism, please skip to question X.

☐ Through conversation
☐ Through reading books
☐ By going to conferences with your child
☐ With the help of his/her teacher
☐ With the help of a health professional
☐ Other: ____________________________

What are three of your child’s strengths?


Neurodiversity is a word that people use to talk about neurological differences and how this differences may be a source of pride. Have you heard of neurodiversity?

☐ Yes
☐ No
☐ Yes, but in different terms (please describe in next question).
If you have heard neurodiversity defined differently, please briefly describe below.

Briefly, describe how you think of neurological differences.
**IV. DATA**

**TEMPLATE**
ID#, Age, School type (public/private), School State

<table>
<thead>
<tr>
<th>Statements of Confidence:</th>
<th>Parent education:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strengths:</strong></td>
<td><strong>Research</strong></td>
</tr>
<tr>
<td></td>
<td>Brain</td>
</tr>
<tr>
<td><strong>Weakness:</strong></td>
<td>Help</td>
</tr>
<tr>
<td><strong>Statements of Loneliness:</strong></td>
<td>Exc</td>
</tr>
<tr>
<td><strong>Brain discourse:</strong></td>
<td>Info</td>
</tr>
<tr>
<td><strong>Source of information:</strong></td>
<td>Most</td>
</tr>
<tr>
<td><strong>Research:</strong></td>
<td>School</td>
</tr>
<tr>
<td><strong>Other:</strong></td>
<td>Pop</td>
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<tr>
<td></td>
<td>Sci</td>
</tr>
<tr>
<td></td>
<td>Resource Books</td>
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<tr>
<td></td>
<td>Autobios</td>
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<td></td>
<td>Other parents</td>
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<td></td>
<td>Parent Groups</td>
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<td></td>
<td>Workshops</td>
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<td></td>
<td>Online</td>
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<td></td>
<td></td>
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<tr>
<td><strong>Talk</strong></td>
<td>Iden</td>
</tr>
<tr>
<td></td>
<td>Convo</td>
</tr>
<tr>
<td><strong>Strengths:</strong></td>
<td>ND?</td>
</tr>
</tbody>
</table>
ID#, Age, School type (public/private), School State

KEY FOR DATA SHEET TEMPLATE

Parent education: Q: Please indicate your background in science, if any.

Research (3 questions)

<table>
<thead>
<tr>
<th>Q. Please indicate the number of times your child has participated in research of each type described below.</th>
<th>Brain imaging (Brain)</th>
<th>Motor skills (Motor)</th>
<th>Behavioral/Social (Behave/soci)</th>
<th>Educational (Edu)</th>
<th>Communication (Commu)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>To help researchers learn more about autism (Help)</td>
<td>I believe that it is a positive way for my child to learn about current autism research (Positive)</td>
<td>To learn more about my child (Learn)</td>
<td>Financial Compensation ($)</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q. Please check any reasons you choose to have your child participate in research.

<table>
<thead>
<tr>
<th>Q. Please check any reasons you choose to have your child participate in research.</th>
<th>My child is excited about participating (Exec)</th>
<th>My child is disinterested in participating (Dis)</th>
<th>My child likes the researchers (Likes R)</th>
<th>My child dislikes the researchers (Dis R)</th>
<th>My child learned something new from participating (Learn)</th>
<th>At some point during the research, my child was upset (Upset)</th>
<th>My child had inconsistent response to participating in research (Incon)</th>
<th>Other</th>
</tr>
</thead>
</table>

Q. How do you perceive your child’s response to going to research sites and their overall experience? Please check all that apply.

| Q. How do you perceive your child’s response to going to research sites and their overall experience? Please check all that apply. | Information Sources: Please indicate the degree to which you’ve used relied upon the following sources of information about autism. |
|---|---|---|---|---|
| Information from my child’s school (School) | Online printed or popular media (ie. television, magazines, newspapers) (Pop) | Scientific or academic literature (Sci) | Autobiographies of individuals with autism and/or personal narratives of raising children with autism (Autobios) | Other parents at school or work (Other parents) |
| Among the most relied upon (Most) | A moderate amount (Mod) | Among the least relied upon (Least) | I have not used this source (N) |
| Information from my child’s school (School) | Online printed or popular media (ie. television, magazines, newspapers) (Pop) | Scientific or academic literature (Sci) | Autobiographies of individuals with autism and/or personal narratives of raising children with autism (Autobios) | Other parents at school or work (Other parents) |
ID#, Age, School type (public/private), School State

<table>
<thead>
<tr>
<th>Parent Groups</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Workshops</td>
<td></td>
</tr>
<tr>
<td>Online communities and forums (Online)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

**Discussion with child (2 questions)**

Q. When you talk to your child about autism, how do you talk about it? Please check all that apply. As a…

<table>
<thead>
<tr>
<th>part of their identity (Iden)</th>
<th>source of pride (Pride)</th>
<th>source of different (Diff)</th>
<th>neurological identity (N. Ide)</th>
<th>neurological disability (N. D.)</th>
<th>social disability (S. D.)</th>
<th>learning disability (LD)</th>
<th>I have not talked with my child about autism (No T)</th>
<th>Other</th>
</tr>
</thead>
</table>

Q. How have you talked with your child about autism? Please check all that apply.

<table>
<thead>
<tr>
<th>Through conversation (Convo)</th>
<th>Through reading books (Books)</th>
<th>By going to conferences with your child (Confer)</th>
<th>With the help of his/her teacher (Teacher)</th>
<th>With the help of a health professional (Health)</th>
<th>Other</th>
</tr>
</thead>
</table>

**Strengths (1 question): What are three of your child’s strengths?**

**Neurodiversity (3 questions):**

- Neurodiversity is a word that people use to talk about neurological differences and how differences may be a source of pride. Have you heard of neurodiversity?
- If you have heard neurodiversity defined differently, please briefly describe below?
- Briefly, describe how you think of neurological differences.
ID#: 001, Age 11, School = Ivymount, Private (MD)

**Statements of Confidence:** as I recall from Be Diff, can be extremely focused, most people on the spectrum have hyperfocus concentration when interested and motivated, can do things quickly, learn quicker than NT, learned to languages, can save money really well, have lots of confidence most of the time

Once I’m a grown up, I’d probably like having this b/c it’ll help me make a lot of money b/c when I like what I’m doing I can focus really well.

Knowing just a diff and not a disability = gives you more confidence

Looking forward to growing up and having more strengths than weaknesses

**Strengths:** playing video games, saving money, learning-languages

b/c read a lot

**Weakness:** outrage when demanded to do something, mood changing, 1 year learning delay, understanding emotions

**Statements of Loneliness:**

**Brain discourse:**

Brain has different interconnections

My Asperger’s brain can learn a lot quicker if I want to, feels diff → brain is different

**Source of information:**

**Parent education:** Masters

**Research**

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To let my child have the pleasure of making a contribution; to help create more effective interventions/programs; unsure b/c at school

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**Research:**
Interested in science research, I think they don’t understand what it feels like to have it, don’t see the essence. It’s easier to do the brain research when you actually have the disability or disorder.

**Other:** “Asperger’s people”
“Asperger’s just feels different, it doesn’t really anything else, it just feels diff.”
“Asp = disorder, difference, not a disability” (kept saying disability and retracting)
In a millennium everyone will be on the spectrum

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**Strengths:**
intel, focused on preferred activities, caring—tries to help loved ones, friends, the disadvantaged

**ND?** Yes The term is typically used to describe people with autism versus without—though I suspect in truth there is a great range of diversity, not just a dichotomy.

Neurological differences can confer certain strengths, though they can also be very disabling; to say that people with autism are different, not disabled, is a gross oversimplification. Some very high functioning people may not be disabled, but many with autism are--especially in our society where social abilities are the best predictors of independence and success.
ID#002, Age: 19, School = Public (VA), Currently in public college

**Statements of Confidence:**

**Strengths:** keen focus on one thing at a time; think about many things by relating them to the original; can branch interests-find commonalities; Answer to q: adaptive to new situations; developed empathy recently, proud of this; absorbing info w/o pressure—fav hobby = info acquiring (but calls this knowledge “useless”)

Hobbies: reading, art—figure things out about artist/culture

**Weakness:** harder to understand others’ behaviors, once do understand, can adapt quickly

**Statements of Loneliness:**

**Brain discourse:** prob will participate in ND movements in future

**Source of information:**

**Research:** in favor, not of curing, integral part of self, how to help can be a blessing or a curse; “I’ve benefited a lot personally in form of med + therapy”

**Other:** best word is different; didn’t pay attention to diagnosis until 11, but diagnosed at 7/8; subconsciously understood as learned to live with it; didn’t think about others w/ ASD until when to Talisman (15); connected X-men –people w/ diff abilities to himself and ASDs and folks at camp → changed perception of Autism → “something of an empowering thought”

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**Parent education:**

**Research**

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**Statements of Confidence:** couldn’t have answered q 10 years ago—didn’t know about self until family and friends support, academic support and therapy; can now look back and say this feels good, I’m good at that; NT may take years to come up w/ therapy, know people on spectrum who can do this in 15 min; makes up for lack in social skills-> incredibly smart “Part of community I share and am quite proud of”; “phenomenal benefits, "sometimes hard, tremendous leaps in social ability and academic success w/ therapy and meds, so happy to see advancements; "even though we’re diff, we can still live life and enjoy it”

**Benefits:** cognitive-universal thinking; once subject, surpass knowledge of experts; describes friends; “it’s rather astounding”

**Strengths:** think on more expansive scale-math; photographic mem

Media-link to stages in human culture; see things diff’this kind of goes for all people w/ asp” -> go deep in though w/o getting caught up in what doing”; movies

**Weakness:** “social awareness is typically an inhibitor/obstacle to overcome”; hard with social cue interpretation

**Statements of Loneliness:** talked about meeting other people w/ Asp and seeing them a first potential real friends

**Brain discourse:** “I would start by saying incredibly diff living experience in terms of how I think”; see strength

**Source of information:**

**Research:** parents went to conferences post-diagnosis, so did questionnaire; “we need to learn more about this”; knew what was going on, but indifferent about it; didn’t really understanding it (says part of Asp) → realized that there were lots of studies “oh, this is bigger than I originally though”; scenarios: what would you do? ; products: stress toys, etc w/ relaxing effect, “they’re still a lot
of fun”; in retrospect knew part of something bigger, but indifferent; no big deal, just did, didn’t require study or practice; “condition that can no be cured to sci knowledge today and were comes from.”

**Other:** did research paper on Asp→ enjoy understanding and learning b/c relevant to self, how it came about, how can use this knowledge to give advise and help others; Diagnosed 2000, used word “condition”

**How knew:** parents explained it, so did psychiatrist; years later more self are and started thinking to broader world, bigger than the little one he’d be living in for years of his life; didn’t know others had it until years later, parents set up programs to help people in schools; indulged myself in being around these people; very scary that so similar; exciting to have people to relate to; a few potential real friends (third and fourth grade); then started to notice in others “these people are so like me” and started to pay more attention

**Of ND:** yeah that sounds about right (of description); good-confidence is helpful in life-don’t be a jerk, won’t get down
**Statements of Confidence:**

**Strengths:** playing games, strategies, Wii, remember things in books, history, science, good at school because pay attention, school's pretty good, it's a place to learn, it's easy

**Weakness:**

**Statements of Loneliness:** to three things q “that's a good question”

**Brain discourse:**

**Source of information:**

**Research:** people have asked things I do and like

**Other:**

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**Strengths:** visual memory, interested in a wide variety of topics, usually happy and cooperative

**ND?** No Diff ways individuals’ brains process information
ID#: 005, Age, 10, School = Public (VA)

**Parent education**: F, 43 years old, Masters

**Research** NONE

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**Strengths**: academics, individual (sensory friendly) sports, flexible

**ND?** Yes I have no firm opinion. That said, culture is requiring less and less face to face social interaction. Therefore it is possible that, as some have said, it is a result of adaptation. Not sure I really buy that. I believe all people are created just as God wants them to be and that if He creates neurodiversity then there must be some purpose in it.
ID#: 006, Age: 16, School = Public (VA), previously attended Ivymount (Private School, MD)

**Statements of Confidence/Strengths:** I view the world diff, absolute things, computer things, art (showed me art), funny person

“I’ve heard people w/ Asp have hyperfocus (focus really independent), I’ve got it for the fun things” problem solving that NTs can’t do, more creative than a lot of people, good at figuring out things, very proud to have taught self square roots, good at reverse engineering

**Weaknesses:** harder to make decisions (b/c how view the world), take longer to think part of autism, broad thinking

**Statements of Loneliness:**

**Brain discourse:**
I think differently, I think the world should be fair, used to get upset about the little things—why? “I guess my brain is wired differently,” of research: “how my brain works diff from ‘normal’”, see other

**Source of information:**
Ivymount, mom talks, camp; helpful when younger, so knew why I thought differently (could tell was diff)

**Research:** Important: people misunderstand what Asp is like, what having it is like, why they do what they do.

MRI when 14, described emotions on faces, it was long (sigh), compensated, I like doing it, people to get to know how I am, so people can find out more about people w/ Asp’s

**Other:**
Of ND. “That’s good, I guess. I haven’t heard it before, but people have different brains. I think it is something to be proud of b/c you’re unique if your own way”

Self education at camp

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**Strengths:** sense of humor

**ND?** Yes I think of neurological differences as an important contribution to society. Those with neurological differences often have great strength in a particular area, and may be responsible for progress in our human development and evolution. I hope that we can better understand these differences and how they manifest in various individuals, so that we may benefit from the great gifts that result.
ID#: 007, Age: 17, School = Public (VA)

**Statements of Confidence:**

**Strengths:** easier to perceive different things; “I think I analyze stuff in a more objective way, I feel like I’m less worried about what people think about something and more like ‘well does it make sense’ that’s useful, well sort of” Math, playing flute (like about self), thinking

**Weakness:** harder to perceive some things

**Statements of Loneliness:**

**Lacking Confidence:** “not always sure what people think about me; assume people think I’m annoying and smell bad; people looking at me like ‘huh, you’re weird’, loooong time to answer good at/strengths, couldn’t say why liked or good at “I don’t know”, see ND

**Brain discourse:** of research 2. tested people had had social skills training so performed like typical but used diff part of brain b/c not instinctual , see ND

**Source of information:**

**Research:** sometimes liked; got sick of driving and waiting 1. puzzle solving—liked, wanted parents to get him the same one; 2. fMRI while still

**Parent education:** HS and college classes

**Research**

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Relationship w/ researcher, wanted to help, son enjoyed getting paid
Younger = interested, older = not, learned could manage MRI

**Info:** raising kids books, help her and her inform others

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**Talk:** change as older, first relieved not to be “weird,” now wants to distance self from label

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developing, told that folks on spectrum do better on Stroop task, (ignoring facial cues); thinks were learning about differences from “normal, NT, whatever” but wasn’t quite sure; usually the researchers were nice, didn’t think about how perceived by researchers

**Other:** wanted it known that mental condition, not a disorder; like being treated like a “normal” person; asp is not a disability; varying levels of severity of people on spectrum = harder time socially; “now I sometimes think about how others think of me b/c other people tell me to think about it”

**Of ND:** hadn’t heard defined said “diff people think diff, having a wide assortment” ; shrug, think it’s fine, are you proud? shrug: “I don’t think it is necessarily a good or a bad thing, I think the good or bad thing is something humans made up. In science we don’t say something is good or bad, we say this happens or that happens.”

**Strengths:** academic, intel (math and sci), general love of learning

**ND?** Some people use it as a source of pride. Others say it’s just a "cop out" – a way of giving people an explanation that can be used as an excuse. It is not sufficiently precise so if you don’t have a real science background and/or it’s not used in a specific context, it can be meaningless. People generally use the same "parts" of their brains to get through life. Those with neurological differences use different parts of their brains. Frequently that results in severe problems, socially and physically. Sometimes it can result in someone having a real "skills" (such as an amazing musician or, like my son, mathematician.) I’ve learned that different parts of the brain are responsible for certain types of actions, but that other parts of the brain can be "re-trained."
**ID#: 008, Age: 30**

### Statements of Confidence:
- **Strengths:**
- **Weakness:**

### Statements of Loneliness:
- **Brain discourse:**
- **Source of information:**
- **Research:**
- **Other:**

### Parent education: HS

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**Strengths:** Bowling, horseback riding, an interesting ability to figure out things and solve certain problems others can not.

**ND?** *YES* Those w/ disabilities which differentiate a person w/ them from others and make the person stand out from the rest.
**ID #: 009C, Age: 13, School = Ivymount, Private (MD)**

**Statements of Confidence:** "sometimes I am proud of having a different brain."

**Strengths:** running, hockey, skateboarding tricks, good b/c practice, eyesight, math really fast.

**Weakness:** destructing room and running away when angry only way to express myself, no one else does that, that’s autism; "sometimes I have trouble understanding what people mean and trouble trying to join conversations."; LD, paying attention, spelling hard words; don’t understand what people are talking about/doing

**Statements of Loneliness:**

**Brain discourse:** "I have a different brain, I don't understand what people are talking about or doing", brain kinda weak— "but other times it is good to have a brain that is diff from others" —tells about jumping, others can’t do that. Look eyesight and can do math work really fast

**Source of information:**

**Research:** I’ve never been asked if anyone could learn more about autism I never knew anyone who wanted to learn about a.

**Other:** police was nice to me b/c knew I had a.

Couldn’t really come up w/ things like about self; came up with “great trooper at camp; I like to help” and “great biker”

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**Parent education:** PhD., work in field

**Research**

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**Strengths:** Kindness, determination, musical ability

**ND?** Yes. Everyone is unique in their neurological makeup. Neurological functioning for all of us changes over time depending on development, health, environment, interventions, education. I try to help instill the desire and motivation to make positive changes without the expectation of becoming "typical" or "curing" differences.
**ID#: 010, Age: 11, School = Public (VA)**

**Statements of Confidence:** “It’s fine, it isn’t like you’re different, you’re practically the same as anyone else. You can see a little diff from others. I think right/wrong, fundamentals, order, use all factors to answer a question.” Likes that he can understand adult conversations

**Strengths:** Math, science, history—likes new ideas; independent workers; never bored of any book

**Weakness:**

**Statements of Loneliness:** “I just want to integrate into society”

**Brain discourse:** “Neurological disorder”, of ND. “Yes, being unique.” “It doesn’t really matter if your brain is unique or not. It doesn’t matter how much grey matter you have → shouldn’t treat people different” “Everyone’s brain is the same size”

**Source of information:** Learned 2-3 years ago, mom tells things, don’t remember when first told about.

**Research:** “I think it is necessary to figure out how the human brain works. I will subject myself to be questioned. I am definitely fine with autism research” it’s very useful.

**Other:** Would only give two strengths b/c mom said not to brag (mom told me this later)

Class predicted he would win competition—won trip to space camp (mom pulled this out of him)

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**Strengths:** Extremely artistic, extremely reliable and honest, a strong athlete w/ boundless energy
ND? No. Our family has, and has had, a number of individuals w/ neurological diffs—from ADD to anxiety to muscular to Guilliane Barre. It is not something we fixate on.
ID#: 011, Age: 13, School = Private (VA); ID#: 012, Age 11, School = Public (VA)

**ID#011**

**Statements of Confidence:**
**Strengths:** really smart, really tall, seem to be really nice; likes dinosaurs (Asp plays a role), drawing (getting better), Nascar

**Weakness:** sometimes have trouble with sarcasm, obsessions, notice detail more than the main idea

**Statements of Loneliness:**
**Brain:** I”I think it is something to be proud of. You can do things others can’t” (prob solving, dinos, don’t seem to get as mad as others).

**Source of information:** learned about when 7 or 8, was told it is how is younger brother thinks differently; asp is like a. but not as severe.

**Research:** should keep doing it, people need help, people need help talking and moving

**Brother, ID#:012**

**Interview Responses:** Didn’t know what autism was, good at being alone (maybe wanted to be alone).

**Neurotypical Brother (9 years old, VA private school)**
Knew something was wrong b/c brother acting weird, asked mom and she said it was something w/ his brain; didn’t know what that meant until saw him having diff behavior

**Parent education:** 45, F

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**Info:** The Behaviorist, therapists, our advocate, developmental pediatrician, neuropsychologist and other professionals that we’ve worked with directly. = moderate source of information

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**Talk:** as an adj. that describes a specific collection of individual strengths and weaknesses

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“I don’t tell my friends, unless they ask what’s wrong with [brother]”; friends seem caring, they feel bad for me, that’s the way he’s made hard to be brother, do things with him; think he’d be lonely w/o two brothers; we teach him, feels good helping sometimes like helping, other times feels like I like of work, “I was chosen to do this” “he has pretty good functioning a. He should be proud. I don’t know if he knows he’s diff b/c I want him to feel good.”

**Strengths:**

**011:** 1- Affectionate; 2- Honest; 3- He is good at his activities and takes pride in his accomplishments but the down side is they are not team oriented so it is difficult to share with peers. Piano, Organ, Swim (IM), and Scouts. He apparently is an excellent marksman at scouts.

**012:** His desire to be with other people. His determination to share what is interesting to him with others.; His effort to accomplish tasks that are difficult without becoming discouraged.; That he looks ahead and desires things for himself with the imagination of any child, such as to grow up to be a fireman or astronaut.

**ND? No,** Everyone is an individual and should be appreciated for the person they are.
V. RESULTS OF PARENT SURVEYS

**Figure A1.** Parents responded to the question, “When you talk to your child about autism, how do you talk about it? Please check all that apply.”

**Figure A2.** Parents reported how they have described autism to their children in response to the prompt, “How have you talked with your child about autism? Please check all that apply.”
Figure A3. Mothers reported the reasons they have decided to enroll their children in research studies in response to the prompt: “Please check any reasons you choose to have your child participate in research. Please provide comments or additional reasons in the box below.” The mother who indicated “other,” reported having a friend who was a researcher and wanting to help her.

Figure A4. Mothers responded to the question “How do you perceive your child’s response to going to research sites and their experience? Please check all that apply, and use the box for any additional comments.” Responses of “other” noted participation that occurred via correspondence and at school; both experiences obscured the ability of mothers to assess their children’s response to the research experience and visiting the research “site.”
Table A1. This table reports the frequency with which mothers reporting using particular information sources in response to the prompt, "Please indicate the degree to which you've relied upon the following sources for information about autism." Those parents who indicated using an “other” source cited referring to various clinicians and professionals who have been involved with their child and clinics while living abroad.

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VI. IVYMOUNT

The three interviewees whom either attended (Interviewee 001 and 009), or had attended (Interviewee 006) Ivymount School had responses that seemed distinct from that of others. All of these individuals referred to their brain as the source of both their differences and strengths, and unlike many others, seemed very aware of having different thought processes, yet two out of the three, did not seem to feel disabled. In addition, the same two seemed to have an interest in autism research and seemed to valued research. Therefore, I became more interested in learning more about the school.

Ivymount School and Programs, Inc. is located in an affluent Maryland suburb of Washington D.C. Established in 1961, by members of Christ Lutheran Church in Bethesda with the goal of putting their educational building to use as a non-sectarian school for students whose needs could not be met by the publish school, today this school’s missions has become more elaborate, and is proudly stated as:

- to enable students to achieve their highest level of development; to support families in their efforts to make intelligent, thoughtful choices for their children; and to learn to be leaders in the community and in the broad field of special education so that the School’s expertise is widely accessible (The Ivymount School).

Although a private school, since its beginnings, student attendance has largely been supported by local counties (although some parents do choose to pay the $50,000 annual tuition), which today means that Ivymount students come from not just Maryland, but Washington D.C., and Northern Virginia. Although supplemented by private donors, Ivymount’s budget is largely funded by and influenced by local governments; therefore, as Washington Post columnist Rick Weintraub suggests,
“Ivymount was a charter school before we knew about charter schools” (Matthews, 2011)

Ivymount serves about two hundred students ages four through twenty-one with a variety of disabilities through their Multiple Learning Needs Program, the Maddux School, a pre-K to first grade program, the Autism Program, and the Model Asperger’s Program (MAP). Their outreach programs also serve teachers, families, and individuals through educational and therapeutic programs.

Although to many, Ivymount is known for its exceptional work with children and young adults on the Autism Spectrum, in the book No Other Place, which celebrates Ivymount’s illustrious fifty years, it is suggested that the Autism Program is somewhat recent, and the Model Asperger’s Program was recently created in 2006 after the school was approached by parents requesting such a service. As with all of Ivymount’s programs, those that serve students on the Autism Spectrum rely heavily on educational research and the most current educational practices. Both programs cite independence as their goal. Students in MAP have average to above average intelligence but struggle in mainstream settings “due to difficulties with social skills, executive functioning, flexible thinking and self‐regulation.” However, through MAP, these students can earn a high school diploma and are highly encouraged to identify careers of interest and work towards them.

When I visited Ivymount, I was immediately struck by the colorful artwork displayed throughout the school. In the office, I flipped through a thick binder of articles in which Ivymount had been mentioned. These ranged from the school newsletter, to Washington Post columns, reports of Autism research, to a front cover
story of a student in *Parade Magazine*. As I was lead upstairs to a classroom, it appeared like any other middle school with lockers lining the hallways. The MAP director’s office was on the second floor where the program’s classes were held, and in her interactions with students and quick side-conversations with parents and individuals on the phone, seemed to have genuine knowledge about each individual in the program.

Once inside a classroom of ninth and tenth graders, I listened as teachers created a quiz-show atmosphere as students guessed the meanings of “lexicons,” or made-up words and phrases laden with social meaning, such as “eat the cheese, don’t be the cheese,” meaning “don’t be too silly.” This morning warmup had students and teachers discussing behavior and social skills, which for many of the students, is most likely their greatest challenge. Activities such as “lexicons” were supported by a variety of posters discussing social skills and emotional regulation throughout the classroom. Most prominent, at the front of the room was a sign reminding students how they were expected to behave, during a “bomo,” or a “boring moment,” as it listed “expected” and “unexpected behaviors.” The usage of “un/expected” behaviors in MAP is a deliberate switch from describing behaviors as “in/appropriate” as is often done in both mainstream and special education. In addition to removing such a strong value judgment from language used to describe behavior, director Monica Adler Werner describes how social thinking expert Michele Garcia Winner prompts this shift and her idea of framing behavior as a cognitive puzzle (Publishing, 2008). In addition to their innovation practices, it seems that these small details may be an
important part of Ivymount’s success and ability to cultivate independent, thoughtful, and confident students.

The school works hard to cultivate a sense of independence and self-efficacy. Werner explains how as students get older they “have to be involved with their own interventions.” This means that they encourage students to identify how their behaviors and development of challenging skills, be them academic or social, impact their goals. With these older students, teachers lead “college level discussions” on theories of motivation, and in doing so, try to layer separately taught social skills and social cognition on top of an academic foundation. The school makes efforts to cultivate self-awareness and self-advocacy, which in Werner’s terms, means “knowing what is hard.” However, she strongly asserts that in MAP, they are upfront about autism, with the philosophy that “It’s not your [the students’] fault, but it is your responsibility,” and that the school is there to “teacher, support, and reinforce.” At Ivymount, Werner says, “‘That’s my autism’ is not an excuse,” and students are expected to work hard on their weaknesses, while recognizing the strengths they may enjoy due to their autism.

Such a recognition of the strengths that individuals with Autism may have occurs through the exploration of books such as Be Different by John Elder Robison (2011), The Outliers by Malcom Gladwell (2008), bringing in role models such as Robison and Autism Self-Advocacy (ASAN) leader Ari Ne’eman, and discussing historical figures presumed to have Asperger’s Syndrome such as Albert Einstein. In thinking about how the characteristics of successful people, such as those described
by Gladwell, and hearing from successful Aspergians, Ivymount maintains its focus on “the real world,” while also celebrating Asperger’s Syndrome.

Werner maintains that in an era of education where many are pushing for mainstream classrooms, this type of environment can be viewed like an affinity group that provides the opportunity for individuals to feel supported and engage in meaningful relationships based on common interests and challenges, and as long as the focus is on understanding nypicals and functioning in mainstream settings later in life, she sees nothing wrong with “segregation” of these students for the time being; she sees Ivymount as providing a safe haven, which for even typically developing adolescents and children is sometimes vital. Therefore to be situated in Ivymount, is to experience autism as the norm, and neurotypicallity as that which must be studied and dissected.

Perhaps it is the school’s straightforward and research-based approach to autism that leads to their students talking not only about their strengths, but also their challenges with confidence and references to their brains. Two (Interviewees 001 and 006) of the three individuals whom I interviewed who either attend or attended Ivymount in the MAP program seemed to embody Werner’s hope of celebrating their autism while acknowledging their strengths and weakness with an eye towards the neurotypical world. I was particularly struck eleven year old Interviewee 001 who referenced Be Different and described ways that his brain might be different from a neurotypical brain with words such as “plasticity” and “interconnections.” He and the other two boys with backgrounds at Ivymount seemed to think about their
strengths and thought processes as deriving from neurological differences and identified strengths related to autism and a distinct way of thinking.

The mothers whose children attend Ivymount, all reported discussing autism as a part of their children’s identity and a neurological identity, and two of the three, as a source of pride (Parents 006 and 009). In addition, all three of these mothers had heard of neurodiversity. It is unclear whether or not this is due to the way parents are encouraged to discuss autism by Ivymount, or if it these opinions that lead them to push for placement at Ivymount (a lengthy process that often requires significant financial resources such as lawyers and advocates). Interestingly, it is possible that these parents may not be as influenced by the school as one might anticipate, as only one parent cited school as among their most important sources of information about autism (Parent 001). So, although Ivymount is clearly a unique institution, it cannot be concluded that this educational program is the only factor that these individuals have in common, as it seems that the way mothers talk with their children about autism may also play a significant role in their identity.
VII. AUTOBIOGRAPHIES

The reasons for choosing each book, in addition to a very brief synopsis of each work are found below.


I decided to re-read it because of the wide acknowledgement of John Elder Robison as a public figure for Asperger’s Syndrome. In the autism community, however, John Elder Robison is criticized by many for his distancing from the rest of the autism spectrum (Abbott, 20110). In his autobiography, Robison relates nearly unbelievable stories from his childhood and early career as an engineer for various bands, including KISS. Both this and his later book (see below), definitively put Asperger’s Syndrome on a pedestal as providing particular skills and intellectual benefits in contrast not only to neurotypicality but also the broader spectrum.


This book was chosen for its availability at my public library. Prince-Hughes describes her childhood and young adult life. She places more emphasis on autism as an explanatory variable for many of her struggles and interactions she had with others than do Page and Tammet (below). As an anthropologist and primatologist, she describes how her interactions with gorillas while in graduate school enabled her to learn how to connect with humans.

• *Parallel Play: Growing Up with Undiagnosed Asperger’s*, by Tim Page (2009)

Tim Page, an academic, producer, and music critic, writes about his life and emphasizes childhood struggles and anecdotes. He does not spend time explaining
his childhood with autism, but rather reflects on how a diagnosis would have perhaps helped him understand his struggles earlier in life. This was another book chosen for its availability at my public library.


Temple Grandin is a famous autistic author and scientist. Although I had read excerpts of her first book, *Thinking in Pictures* (1995), this book jumped out at me while wandering through a bookstore. In this work, as suggested by the title, Grandin details particular animal behaviors and relates them to her work as a livestock engineer. However, she explains all of these behaviors, her self-understanding and her world-view, through neurology and by drawing parallels to autism. In addition, she contrasts autistic and animal brains and behavior with that of neurotypicals. I choose this book for its discussion of neurology and my sense that I could not do this project without citing Grandin due to her iconic status in autism discourse. She added an intensely scientific perspective and explicitly discussed the boundaries of personhood.

I should note that many autistic people abhor Grandin and her use of animal-analogies to describe autism; they assert that she is an animal-behaviorist, not an expert on autism. This work in particular, is criticized for the way in which she makes claims about autism when drawing a significant portion of her “data” from personal experience. For this reason, although she is a famous autistic figure, many autistic people do not feel like she participates in the broader autistic community (Abbott, 2011).
• *Be Different: Adventures of a Free-Range Aspergian with practical advice for Aspergians, Misfits, families and teachers*, by John Elder Robison (2011)

After my first interview, in which this book was cited repetitively, I decided it was a “must read.” Learning that it is part of the curriculum in the Model Asperger’s Program at Ivymount further enforced this. This book is semi-autobiographical and reads as if written for children and young adults with Asperger’s Syndrome. Robison explains autistic behavior and symptoms through neurological discourse with much more frequency than in his previous book (*Look Me in the Eye*), and he provides numerous assurances that in the long run, individuals with Asperger’s Syndrome will realize more benefits than detriments from Asperger’s Syndrome.


Ian hacking cited this book in his article, “Autistic Autobiography” (2009). Again, this is an autobiographical work, and although it does not focus on autism, it does suggest that Tammet views many of his experiences as shaped by autism. He does not rely heavily on neurological discourse, but rather focuses on specific adolescent and young adult milestones and experiences and others received and interacted with him. Similarly to McElwain, despite not having received a diagnosis until he was twenty-five, Tammet gives us insight into how a particular family navigated autism.


Jason McElwain was substituted into the senior night game of his upstate New York high’s school’s basketball team, even though he was the manager. He scored twenty points in less than four minutes, which made him an overnight sensation. In
fact, I remember being sent a video of this amazing feat shortly after it happened.

In McElwain’s autobiography, he discusses growing up, his love of basketball, the senior night game and the following media-frenzy. In addition, coaches, friends, and family members provide anecdotes and reflections about McElwain. This book is very much a celebration of McElwain’s athletic accomplishment and an insight into his family’s and community’s understanding of McElwain and autism.

I read this book after coding my interviews and sought it out because it was written by a young adult, rather than someone in mid-life. I also decided to read this book because I suspected that it might provide insight into ways in which individuals are engaged in conversation about their strengths and weaknesses. Unlike the other works, this books appears to be written mostly by the collaborating author, with McElwain dictating.
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