

**Interrogating Normal**  
**Autism Social Skills Training at the Margins of a Social Fiction**

by

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## **Interrogating Normal**

### **Autism Social Skills Training at the Margins of a Social Fiction**

Thesis by Karla R. McLaren

#### **ABSTRACT**

Social skills training programs for autistic youths and adults exist in nearly every school district and community; these programs focus on bringing autistic people into synchronization with developmental, linguistic, and social norms. However, these norms have not been critically evaluated, and autistic people themselves have not been surveyed about their experiences of, responses to, or opinions about these programs. This study sought direct input from autistic people about these programs.

Nothing About Us Without Us (NAUWU), an anonymous cross-sectional survey study, was posted online from 18 February, 2014 to 4 April, 2014, and was open to adults (18 years or older) who were formally diagnosed or self-diagnosed on the Autism Spectrum.

Major findings from the NAUWU study are that most of the 91 autism-specific social skills programs studied are not focused on individuals or their unique sensory and communicative needs, do not recognize participants' existing social abilities and accomplishments, do not provide age-appropriate or gender-inclusive instruction, and do not consider or support autistic ways of learning and being social.

In response to these reported shortcomings, NAUWU participants shared what they would have included, changed, or kept in the social skills training programs they attended, and what sorts of programs they would create now, looking back. These suggestions and ideas are presented in eight categories in order of prevalence and stated importance, and curriculum design suggestions are included.

**Key words:** Autism, social skills, medicalization, social construction, deficit narratives, neurodiversity, gender diversity.

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And for all the neurodivergent people who have struggled mightily and continue to struggle to pretend to be merely normal, this work is for you.

# Interrogating Normal

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## Chapter 1 - Introduction

### Interrogating Normal

#### Background and Context

In 2006, in preparation for a job as an academic liaison and support person to 22 college bound autistic<sup>1</sup> students, I read everything I could find on autism. The books I read prepared me to meet an alien and unempathic type of people who had no theory of mind (Grandin, 1995; Attwood, 1997; Baron-Cohen, 1997). What I found instead were a group of often overwhelmingly sensitive people who were experiencing what was soon to be called an “intense world” (Markram, Rinaldi, & Markram, 2007), to the extent that they would often shut down or retreat to the comfort of silence, soliloquies, isolation, scripted language, or repetitive movements to manage overwhelming sensory, environmental, and social input.

As I worked to create an ecosphere of support around these students, I witnessed them being subjected to persistent dehumanization, and I watched as uncritically interpreted views of “normal” behavior were taught to them, lobbed at them as accusations, and used as social control tactics. I have worked since that time to understand autism, empathy, neurodiversity,<sup>2</sup> the social construction of normality, stigma, the disability rights movement, the complex multitude of issues facing autistic people, and the autism community as a whole.

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<sup>1</sup> This study intentionally uses *identity-first* language. See page 7 for an explanation of this semantic choice.

<sup>2</sup> The word *neurodiversity* was coined by Australian social scientist and autistic advocate Judy Singer in the late 1990s (Blume, 1998; Bumiller, 2008; Jaarsma & Welin, 2011; Silberman, 2013). The concept of neurodiversity frames autism as an expression of human diversity: “Echoing positive terms like *biodiversity* and *cultural diversity*, her neologism called attention to the fact that many atypical forms of brain wiring also convey unusual skills and aptitudes” (Silberman, 2013, para 1).



In my undergraduate degree in the social sciences, and in my sociological concentration in particular, I studied normality as a rule-bound communal construction that privileges the majority, the typical, and the unremarkable. Normality is commonly experienced as a steady state that is essentially invisible; it feels as if it is simply the way things are and should be, and its often concealed (yet very specific) rules and expectations can provide comforting stability.

Normality tends to be performed unconsciously and accepted uncritically as true reality – that is, until its hidden rules are breached, most often by people who cannot or will not enact normality properly, such as the very young or the very old, foreigners, gender-diverse people, or disabled people (and other minorities). These breaches can be disorienting, comical, or shocking (depending on the situation), but they are always noticed and often reacted to with dismay, censure, or anger. As I observed and worked with those 22 autistic students – and as I have deepened and extended my relationships in the autism community since that time – I have come to see autistic bodies and autistic ways of being as unintentional breaches that tend to trigger reactivity and a reduction in empathy in people who do not understand normality as a social construction.

In 2012, I entered the education program at Sonoma State University in order to search through the literature in education and the social sciences, and I hoped to bring together research on the enforcement of normality that would describe and illuminate the everyday dehumanization autistic people face. This dehumanization is not restricted to the exclusion and bullying that is a reliable feature of the social lives of autistic people; it is also a regular feature in clinical settings, in academic research, in seemingly authoritative books about autistic people, in media reports, in education, in social

services, in fundraising narratives, and in social skills training for autistic youths and adults. This dehumanization is so widespread that it seems to be an intrinsic aspect of normality – an accepted and acceptable way to view the bodies, minds, and lives of autistic people, or of any people who consistently breach the unwritten rules of normality.

In my studies, I have been able to delve into the literature and gather research from across disciplines and across the world that challenges deficit narratives about autism and autistic people. I have engaged with linguistic anthropology, disability studies, sociology, psychology, neurology, the neurodiversity movement, and the new and delightful “neuroqueer” movement, and I have been welcomed into the international online autism community. I have also developed deep friendships with many autistic people and parents of autistic children. My position as a long-term participant observer (Bernard, 2006) in the autism community has also allowed me to understand the issues well enough to create an online survey study (Nothing About Us Without Us<sup>3</sup>) about autistic adults’ experiences of social skills training. This survey went viral, and its surprising and voluminous data will form the basis of many studies to come. I look forward to combining the diverse threads of my research into this thesis.

### **Problem Statement and Research Question**

A tremendous amount of time, energy, and effort is spent on helping autistic children achieve social, behavioral, developmental, and linguistic norms. For instance, intensive early childhood behavioral therapies – many approaching 40 hours per week for children as young as 13 months – work to (among other things) inhibit autism-typical

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<sup>3</sup> “Nothing about us without us” is a well-known rallying phrase in the disability rights community; it is also the motto for the Autistic Self Advocacy Network (n.d.), an American non-profit policy and advocacy organization for the autistic community.

vocalizations, rocking, eye gaze preferences, communication preferences, and rhythmic hand and body movements that are negatively framed as “autistic stereotypes<sup>4</sup>” or “self-stimulating behaviors” (and have been reclaimed by the autistic community as *stimming*). These autism-typical behaviors are inhibited (or *extinguished*, to use a preferred term in the behaviorist community) so that the children will be able to perform stim-free “quiet hands” (Bascom, 2011) and be still, compliant, and “table ready” (Freeman & Dake, 1997).

However, there is very little scholarship within the autism social skills training industry about the social construction of normality and how it impacts people who fall outside the bounds of what is uncritically considered correct and normal. Anthropologist Karen Gainer Sirota (2004) notes that disability itself is a social construction “involving culturally and historically contingent meaning construction and value attributions regarding normality and deviance, competence and incompetence, personhood, moral agency, and so on” (p. 247). In this thesis project, I bring together multi-disciplinary research that interrogates the social construction of normality and its connection to autism social skills training programs, plus original survey research that – for the first time – asks autistic adults for their opinions about these programs. My research questions are: How does normalization training affect autistic students? Is it supportive? Is it effective? And if not, what would be supportive and effective?

### **Purpose and Significance of Interrogating Normal**

Autism and autistic people are the focus of enormous amounts of multidisciplinary research worldwide (Nicolaidis et al., 2013, report that in 2012, \$400 million was spent

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<sup>4</sup> *Stereotypies* are repetitive or routinized motor behaviors. See Appendix C, section B1 for examples from the *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition* (DSM-5).

on autism research in the United States alone); however, this research tends not to foreground autistic voices nor explore autistic experiences, opinions, or expertise. Similarly, an uncounted variety of social skills training programs for autistic youths and adults exist in nearly every school district and community. These programs focus on bringing autistic students into synchronization with the developmental, linguistic, social, and age-related norms of neurologically typically-developing (or *neurotypical*<sup>5</sup>) people. However, this vast consumer base of autistic students has never been surveyed about their own experiences of, responses to, or opinions about these programs. In my time as a participant observer in the international online autistic community, I have continually wondered, as researcher Mary Lawlor (2010) asks, what we could learn if autistic expertise “were foregrounded or privileged over other sources of knowledge” (p. 169).

**The Autism Industry.** The autism social skills training industry is a wide-ranging and essentially unregulated pastiche of community-based, school-based, and stand-alone programs focused on helping autistic people achieve normality. As of yet, the nearly universal focus of these social and behavioral programs for autistic people, which is to entrain and enforce neurotypical norms, has not been fully scrutinized through ethnographic and disability rights approaches to the social constructions of normality and disability. As educators Ray McDermott and Hervé Varenne (1995) state, “For every disability and difference that is brought to the fore, there is a cultural, and invisible, order that is the background” (p. 343). My research and thesis contribute an understanding of the omnipresent mechanisms of normality enforcement in social skills training programs for autistic people.

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<sup>5</sup> Autistic advocate Jim Sinclair (1998) is credited with coining the word *neurotypical* in the early 1990s. This word was originally used to denote people with non-autistic brains, but has morphed in usage to denote a neurologically typically-developing person or the culture that is built around such persons.

This thesis focuses on an original survey study completed in April of 2014. Nothing About Us Without Us (NAUWU), an international online survey, gathered the responses of hundreds of autistic adults (age 18 and over) who shared their experiences of and opinions about these social skills training programs. Some of these programs were developed specifically for autistic people, others were intended for different populations, and yet others were created by NAUWU participants for their own use.

This thesis concentrates on the cohort of 71 NAUWU participants who experienced, in total, 91 different, autism-focused social skills training programs. The responses from this cohort suggest that most social skills training programs intended for autistic people do not include their voices or preferences in curriculum design and tend not to consider their needs, opinions, autonomy, or agency in curriculum implementation. NAUWU participants described a pervasive atmosphere in these programs – of inappropriate design and insensitive application of curriculum. The participants also noted that they were unable to request accommodations or to suggest modifications to the curriculum. The findings of the NAUWU study strongly suggest that these autism-focused social skills training programs are simply not meeting the needs of their target population.

In response to these shortcomings, NAUWU participants shared what they would have included, kept, or changed in the social skills programs they attended, and what they would create now, looking back. These suggestions and ideas are organized in Chapter 5 into eight categories in order of prevalence and stated importance, and curriculum-design suggestions are included.

## Definition of Terms

**Functioning Labels:** This study does not utilize functioning labels due to their inherent bias. The much-used terms “high-functioning” (Ochs & Solomon, 2010; Sirota, 2004) and “low-functioning” (Gernsbacher et al., 2007; Yergeau, 2010) actually have no universally agree-upon definitions except, tellingly, that an allegedly high-functioning autistic person will display neurotypical behaviors (whether he or she is passing or not), use spoken language,<sup>6</sup> test well on verbal IQ tests, and require less physical care or support in day-to-day affairs – while an allegedly low-functioning person will display seemingly abnormal bodily movements and social behaviors, be nonspeaking (or partially verbal, see Carter, Williams, Minshew, & Lehman, 2012), test poorly on verbal IQ tests, and require more physical care and daily support. Hidden beneath these seemingly unremarkable normal/abnormal and high/low divisions are the complex yet mostly invisible networks of extensive and continuous support structures that exist to help apparently normal people successfully enact normality (Davis, 2010; Goffman, 1963; McDermott & Varenne, 1995).

**Identify-First Language versus Person-First Language:** This study intentionally avoids person-first language, which is an approach to disability that attempts to foreground the person first, and add the disability as an incidental to personhood, i.e., “person with learning disabilities” rather than “learning-disabled person.” Though often well meaning, person-first language is a tactic that actually tends to underscore rather than sanitize problematic conditions. For instance, we would not say “man with

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<sup>6</sup>Joshua Reno (2012) notes that intense focus on developing speech in autistic children can lead parents to avoid the use of other semiotic channels such as picture-based or written communication on tablets, letter boards, or other devices. In many cases, Reno notes, this speech-only focus interferes with the children’s ability to develop any language beyond “home signs.”

handsomeness,” “woman with French ancestry,” or “person who is funny.” Person-first language tends to be used only when the condition referred to is temporary, feared, or undesirable. Identity-first language challenges the idea that disabilities are something to sidestep, fear, or be ashamed of.

Ellen Brantlinger (2009) notes that person-first language “is meant to convey respect for those labeled; however, harmful naming and sorting practices continue regardless of new and improved classifications” (p. 407).

Person-first language has also been very controversial in disability rights circles, and is not the accepted terminology for many disabled people themselves, especially for many members of the blind, deaf, and autistic communities. In these communities, disability-positive and identity-first language is often preferred, i.e. blind person, deaf person, and autistic person, or simply, autistic (for autism community discussions of the importance of identity-first language, see Bagatell, 2010; Brown, 2011; Cohen-Rottenberg, 2012a; and Sinclair, 2013. In each case, these authors suggest that the preferences of disabled individuals should take precedence over any naming conventions).

**Nonspeaking versus Nonverbal:** In describing autistic people who do not utilize speech in communication, this study uses the term *nonspeaking* rather than nonverbal, because a lack of speech does not connote a lack of words, awareness, or intelligence.

### **Limitations of the NAUWU study**

The NAUWU study was limited to adults 18 years and older, and as such, the information gathered may not be representative of current social skills training programs being taught to younger children. This study was also limited to online participants so

that anonymity, ease of use (including use of assistive support and no scheduling limitations), and international access could be assured. This means that the NAUWU participants had access to computers, could read and understand English, and had facility with computers and online survey formats. This of course does not represent the entirety of the adult autism community; as such, these results may not be representative of all students of autism-focused social skills training programs.

It is important to note, however, that this online format was chosen deliberately. Since the late 1990s, the Internet has become a central unifying social network for the international autism community (Bagatell, 2010; Blume, 1997; Grinker, 2010; Nicolaidis et al., 2012). Anthropologist Roy Richard Grinker (2010) compares the rise of the online autistic community to the rise of deaf culture, and notes that Internet technology has provided opportunities for autistic people “to construct a cultural niche, communicate, work, and lead meaningful professional lives” (p. 174). “Ben,” a young autistic man interviewed by researcher Nancy Bagatell, adds that: “The computer is kind of like what sign language is for the Deaf. It’s the autistic way of communicating” (as cited in Bagatell, 2010, p. 37). Autism researchers Jennifer Stevenson and Morton Ann Gernsbacher (2013) also note that “Internet-based research platforms minimize the social and communication barriers often present in more traditional laboratory settings” (p. 7).

Another possible limitation of this study is that, due to extensive diagnostic biases and access issues for medically underserved populations (to be discussed in Chapter 2), this study accepted self-diagnoses of autism (and the related Asperger’s Syndrome and Pervasive Developmental Disorder, Not Otherwise Specified) and did not confirm or



contradict these diagnoses, which could mean that non-autistic participants were included.

A serious limitation of any study of the autism community, however, is its fragmentation into numerous and sometimes mutually exclusive camps. The director of the American National Institute for Mental Health (NIMH), Dr. Thomas Insel (2013a), published an essay on the NIMH website about these conflicts, “The Four Kingdoms of Autism.” Though Dr. Insel allows that he may not have fully identified all of the factions within the autism community, he describes the four kingdoms of *Illness* (autism as an epidemic and disorder that can and must be cured); *Injury* (autism as a direct consequence of environmental factors such as food, vaccinations, or as-yet-unidentified toxins); *Identity* (autism as a naturally-occurring form of neurodiversity requiring support, education, and disability rights awareness); and *Insight* (autism as a complex, multifactorial condition involving genetic, environmental, and social factors that can be understood through research). Dr. Insel points to a deep polarization within the autism community and between the kingdoms he identifies.

Language is one of the ways people in these kingdoms can identify in-group and out-group members. For instance, identity-first language (*autistic person*) is a sign of alignment with or membership in the Identity/neurodiversity and sometimes (but not always) the Insight kingdom, while person-first language (*person with autism*) is a sign of alignment with the Illness and/or Injury (and sometimes the Insight) kingdoms. Culturally speaking, I had to frame the NAUWU language in such a way that members of all four kingdoms would feel welcome in the study. I chose the somewhat ponderous “people on the Autism Spectrum” term, because it bows to person-first language while still placing

autistic people firmly *on* the spectrum. This semantic choice seems to have been acceptable to many Identity/neurodiversity and disability rights advocates, and the NAUWU study is enriched by their presence.

## Chapter 2

### Social Skills Training and the Gold Standard of Normality

*I would have included information. As it was, they just stuck a bunch of awkward kids in a room and tried to make us play games. The games were the sort that young children play on the schoolyard. Most of us had played those games at one time, but we had outgrown them. We found it condescending, but most of us were schooled enough in the ways of compliance-as-the-route-of-least-resistance to keep our mouths shut about that. I recall that there were occasionally skits. I think these were supposed to make us memorize hypothetical social situations by rote. Unfortunately, neurotypicals with their ostensibly good social skills often fail to understand that social interaction does not actually work that way. — NAUWU participant*

#### The Focus of Social Skills Training Programs

Social skills training programs for autistic children and adults primarily focus on bringing them into synchronization with the developmental, linguistic, social, and age-related norms of neurotypical people. Autism is almost universally framed as an unwanted deviation from normality, and is described with heavily medicalized language of disorder, loss, and lack (of social interaction, of eye contact, of connection to others, and of spoken language) in relation to neurotypical development and norms. Researchers Olga Solomon and Nancy Bagatell (2010) have noted that descriptions of autism are overwhelmingly focused on “the dominant biomedical discourse that casts symptoms of autism and their consequences for individuals and families in a categorically deficit-based framework” (p.1). This focus on deficits (and the failure of many autistic people to enact neurotypical forms of normality) can and does become, as Olga Solomon (2010) warns, “dangerously entangled in practices of othering, in social constructions implying that autistic people are less human” (Solomon, p. 252).

This othering does not merely occur on the playground or at school, where autistic children reliably experience exclusion and often bullying; this othering pervades media depictions and nearly every form of communication about autistic people, including academic research. Canadian cognitive psychologist and linguist Steven Pinker wrote in his 2002 book *The Blank Slate* that “Together with robots and chimpanzees, people with autism remind us that cultural learning is possible only because neurologically normal people have innate equipment to accomplish it” (p. 62). Regrettably, Pinker’s representation of autistic people as abnormal and cultureless scientific curiosities is not unusual; in fact, it is an accepted norm.

Olga Solomon and Nancy Bagatell (2010) write that this dehumanizing view of autism “has profoundly negative consequences for persons with autism and their families, and for the designs of educational programs and therapeutic interventions” (p. 2). This dehumanization is omnipresent and goes essentially unchallenged, such that the focus in much of autism research is to catalog and expound upon the ways that autistic people deviate from social, behavioral, and neurological norms – while the focus in many behavioral interventions and social skills training programs for autistic children, teens, and adults is to modify, mask, or extinguish signs of these deviations.

In the predominant form of early childhood autism treatment, known variously as Applied Behavior Analysis (ABA) or Intensive Behavioral Intervention (IBI), the openly stated goal is to produce children who are “indistinguishable from their peers” (Leaf, Taubman, McEachin, Leaf, & Tsuji, 2011, p. 259). As of yet, the nearly universal focus of these social and behavioral programs for autistic people, which is to entrain and

enforce neurotypical norms, has not been fully scrutinized through social constructionist and disability rights approaches to normality and disability.

### **Scrutinizing the Autism Prototype**

*[I would create a program that] models acceptance of self and strengths, and also acknowledges deficits. Also, one that seeks to guide a person towards their own goals for acceptance and/or improvement, without focusing on ameliorating others' difficulties with understanding disability. It is not a disabled person's responsibility to placate the abled, and all further premises would follow from that.*

— NAUWU participant

The diagnosis of autism exists in a continually shifting definitional landscape of medicalization (McGuire, 2012; Solomon & Bagatell, 2010; Yergeau, 2010) and social constructions of normality. Because there are currently no genetic or biological tests for autism, children and adults are diagnosed through “the subjective judgment of individual clinicians or interdisciplinary evaluation teams who negotiate a collective consensus of a diagnosis” (Solomon, 2012, p. 248). This diagnostic process focuses on individuals’ inability to achieve neurotypical developmental milestones and social norms that are not themselves fully explored, and reports abound about the pervasive inaccuracy of this diagnostic process (Hilton et al., 2010; Lord & Bishop, 2010; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell et al., 2009; University of Exeter, 2010).

For example, autism functioning labels use normality as a measuring stick, such that “high-functioning” essentially means more normal, more neurotypical, and more able, while “low-functioning” means the opposite. These functioning labels point not to the intrinsic capacity of autistic individuals, but to fundamentally ableist (Hehir, 2002) beliefs about the superiority and preferred status of the able-bodied, the neurotypical, and

the seemingly normal. This uncritical emphasis on normality and typicality has meant that autistic children who learn to pass go undiscovered (often until adolescence or early adulthood), while misdiagnoses (of ADHD, nonverbal learning disability, OCD, anxiety disorder, conduct disorder, adjustment disorder, oppositional defiant disorder, and other conditions) previous to the autism diagnosis are common. Many autistic people report that they were only finally diagnosed in late adulthood (some as late as their sixties or seventies).

Misdiagnosis, non-diagnosis, and late diagnosis are also fairly common for autistic girls and women, due to a gender bias in diagnosis; “even with the severity of autistic traits held constant, boys were still significantly more likely to receive an ASD diagnosis than girls” (University of Exeter, 2010). Children of color and poor children also experience misdiagnosis, non-diagnosis, and late diagnosis as members of medically underserved populations, with African American families facing the most marked “disparities in the age of their children’s diagnosis, in the number of visits required to receive a diagnosis, and the likelihood of a misdiagnosis” (Hilton et al., 2010; Lord & Bishop, 2010; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell et al., 2009: as cited in Solomon & Lawlor, 2013, p. 107).

Yet autism is discernible, and while it affects individuals differently, both receptive and expressive language skills and social interaction are impacted in most autistic people (Ingersoll et al., 2012; Kuhl, Coffey-Corina, Padden, Munson, Estes, & Dawson, 2013; Sterponi & Fasulo, 2010; Warren et al., 2010). Many, but not all autistic people also display atypical gaze behaviors (Doherty-Sneddon, Riby, & Whittle, 2012; Gernsbacher, Stevenson, Khandakar, & Goldsmith, 2008), a preference for sameness and repetition

(Carter, Williams, Minshew, & Lehman, 2012; Reno, 2012), and difficulties or delays in oral-motor and verbal skills (Gernsbacher, Sauer, Geye, Schweigert, & Goldsmith, 2007), sometimes involving hyperlexia (an early and precocious ability to read combined with difficulty in understanding or producing spoken language), echolalia, or the use of scripted language (Warren et al., 2010).

Autistic people (and their families) also report extensive sensory hypersensitivities that can affect their social interactions, as well as sensory integration issues and oral and manual-motor coordination difficulties called *dyspraxias* (Bumiller, 2008; Gernsbacher et al., 2007; Prince, 2010). However, these self-reported aspects of autism are marginalized or not mentioned at all in most formal medical definitions. This omission is not unusual; the voices of autistic people tend to be excluded from formal descriptions and media depictions of their condition and their lives. Anthropologist Dawn Eddings Prince (2010) writes that “rarely is the voice of the autistic heard as a source of understanding” (p. 56), while Olga Solomon (2010) reports that autistic children’s health and medical records describe them in authoritative and clinical terms, but that the descriptions and impressions of family, friends, teachers, and the children themselves “may never become entextualized to become a part of the child’s record” (p. 249.). This commonplace omission of autistic voices is most glaring in the highly controversial 2013 fifth edition update of the Diagnostic and Statistics Manual of Mental Disorders (DSM-5).

**Diagnosis and Dissent.** The 2013 update of the DSM has been much maligned by patient communities and medical professionals alike (Krans, 2013; Stout, 2013). For many people in the autism community, the changes appearing in the DSM-5 were especially troubling, as they involved folding previously separate diagnoses, including

autism, Asperger's Syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) into one large category. This series of changes were meant to simplify diagnostic criteria and bring cohesion to a chaotic diagnostic process that sometimes focused not on the presented symptoms, but on which diagnostic categories were accommodated by local school districts. However, this series of alterations to the DSM-5 initiated a backlash from parents worried about their children's continued access to supportive services; and from people with an Asperger's diagnosis (many of whom do not consider themselves to be autistic).

Strikingly, this backlash also includes the director of the American National Institutes of Mental Health (NIMH), Dr. Thomas Insel. Dr. Insel openly denounced the DSM-5 as a collection of scientifically non-validated symptom profiles. "Indeed, symptom-based diagnosis, once common in other areas of medicine, has been largely replaced in the past half century as we have understood that symptoms alone rarely indicate the best choice of treatment" (Insel, 2013b, para 2). The NIMH is now focusing on their new Research Domain Criteria project, and is funding autism (and other) research based on genetic and biological markers rather than DSM-5 symptom profiles.

Olga Solomon (2010) notes that the DSM "brings into focus the remarkable fluidity of psychiatric diagnoses and the complex interaction of sociocultural and sociohistorical forces that bring them into and out of being" (p. 250). However, this fluidity has not meant that autistic voices were incorporated into the 2013 update of the DSM. In the new DSM-5 criteria for autism (see Appendix C), sensory hypo- and hypersensitivities are included as a subcategory of restricted or repetitive activities or interests, but are not



connected to social impairments, while the sensory integration issues and dyspraxias commonly reported by autistic people and their families are not mentioned at all.

The denunciation of the DSM-5 from within NIMH seems positive, yet Olga Solomon (2010) warns that “When biomedical vision is thus extended by technology, some scientific narratives of autism become increasingly more authoritarian,” (p. 243). She questions why indicators of autism-typical versus neurotypical behaviors have not been examined “as a sociocultural rather than clinical phenomenon where an interpretation of atypical behavior is examined against sociocultural expectations of normative development under default socioeconomic circumstances” (p. 248). Sociologist Douglas Maynard (2005) adds that “social constructionism would investigate the community’s claims-making activities, their rhetorical procedures, [and] material interests that may lie behind such activities” (p. 500).

**An Epidemic of Sensationalism.** Since the mid-1990s, autism prevalence rates have been represented as progressively increasing worldwide, often through the claims of sensationalist reporting and manipulative fundraising appeals. The numerous, competing, and even absurd<sup>7</sup> explanations for this alleged increase are mired in breathless narratives of medicalization, alarm, blame, and moral panic. However, some public health officials, including Director Colleen Boyle at the American Centers for Disease Control, have proposed that this increase may only be in diagnosis, and not in prevalence: “It may be

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<sup>7</sup> Various research (Willingham, 2011) has linked autism to toxic chemicals, vaccinations, mercury, electronic devices, electromagnetic fields, industrialized foods, fluoridated water, asthma, low cholesterol, high cholesterol, paternal age >40, maternal age <25, maternal age >35, prenatal malnutrition, excess folic acid, folic acid deficiency, creased placentas, epidurals, induced labor, the use of Pitocin, maternal stress, maternal obesity, maternal diabetes, maternal antidepressant use, premature birth, post-term birth, high birth weight, low birth weight, birth order, birth month, Jewish ancestry, familial learning disabilities, familial IQ >140, computer use, exposure to pet shampoo, living near freeways, cellphone use, Internet use, exposure to plastics, television viewing, exposure to vinyl flooring, and as one disability scholar wryly notes, “being a carbon-based life form” (Cohen-Rottenberg, 2012b).

that we're getting better at identifying autism,” (Hamilton, 2014, para 3). A 2014 epidemiological study by researchers from Australia, England, and the United States (Baxter et al., 2014) supports Boyle’s hypothesis. Baxter et al. analyzed autism prevalence rates across the world from 1990 to 2010, and found no evidence of increase over that time, and very little regional variation; instead, these epidemiologists found that worldwide rates of autism in 1990 were calculated at 1 in 132 people – and again at 1 in 132 people in 2010. These findings support the assertions of the neurodiversity movement, which is that autism is a naturally-occurring aspect of human biodiversity that has been present throughout human history (though not identified as autism until the 20<sup>th</sup> century).

However, these findings are not being welcomed in many quarters. In response to the alleged increase in the prevalence of autism, autism research has become an intensely active, increasingly well-funded, and highly contentious international undertaking, with researchers from many disciplines focusing on autism as an alarming disorder to be eradicated rather than a natural circumstance to be understood. Autistic minds and bodies are measured, scanned, categorized, written about, worried about, manipulated, retrained, framed as tragedies, and used as scare tactics; however, autistic voices and autistic agency are not represented in most research, education, media, or formal communications about autism. Instead, autistic people are persistently depicted as the quintessential “other.”

### **Diagnosing Deviance**

In a 2010 study on intersubjectivity and autism, researchers Laura Sterponi and Alessandra Fasulo note that the autism prototype uncritically assumes that normal

development consists of objective facts rather than social constructions – and that through these unquestioned assumptions about normality, “the autistic condition comes to mark the boundaries of what we regard as human sociability and communication” (p.117). In sociological terms, autistic people can be seen as *deviants* (Goffman, 1963; Davis, 2010) who are identified by their seeming failure to understand, attend to, or perform ostensibly normal behaviors.

The word *autism* itself is a kind of slur which means “selfism:” a condition in which a person is assumed to be isolated inside himself or herself and unable (or unwilling) to relate to others. Olga Solomon (2010) warns that “Autism as a trope for withdrawal into an isolated and impenetrable world has proliferated at an alarming rate” (p. 242). This trope is everywhere, and it reliably leads to the everyday dehumanization of autistic people. For example, most media and fundraising narratives portray autism as a tragic condition, as an ominous, child-stealing calamity, or as an epidemic (though autism is not a disease, nor is it contagious), while autistic people tend to be presented as enigmatic and not-quite-human entities – and predominantly, as nonspeaking savants or as helpless children. Yet the most common autism image is not that of a child or even of a human being; it is “a jigsaw puzzle – with a piece missing” (Bagatell, 2010, p. 44), or a single puzzle piece detached from its puzzle, blue and lifeless, isolated and out of place.

**Robots, Chimpanzees, and Nonhuman Animals.** Certainly, media representations of puzzle pieces, otherworldly geeks, nerds, and nonspeaking savants identify autistic people as isolated and socially deviant outsiders. Sadly, much of the research literature does not rise above this dehumanization. Throughout the literature, autistic people have been equated not only with Steven Pinker’s “robots and chimpanzees” (2002, p. 62) , but

with great apes (Gernsbacher, 2007; Reno, 2012; Tomasello, Carpenter, Call, Behne, & Moll, 2005), “nonhuman animals” (Barnes & McCabe, 2011, p. 266), and wild and unreachable feral children (Bumiller, 2008; Grinker, 2010; Prince, 2010; Sirota, 2010; Sterponi & Fasulo, 2010). British child psychologist Tony Charman (2005) states confidently that autism is connected to “an inability to enter fully into human culture” (p. 696), while the concept of normality is consistently used to separate autistic people from the human race.

Hobson (2002) argues and presents evidence that in fact all of these problems may be traced back to problems with emotional relatedness, that is, a deficit in the normal human motivation to share emotions, experiences, and actions with other persons. The outcome is that, although there may be a few unusual individuals, the vast majority of children with autism do not participate in the cultural and symbolic activities around them in anything like the normal way (Tomasello, Carpenter, Call, Behne, & Moll, 2005, p. 686).

The lion’s share of research on autism tends to be grounded (openly or in nuance) in this dehumanizing approach to autistic functioning. Neuroscientist Laurent Mottron (2011) proposes that this dehumanization fundamentally biases the research, such that brain imaging researchers, for instance, reliably identify changes in autistic brain activation as deficits instead of alternative types of functioning. Mottron notes that “Similarly, variations in cortical volume have been ascribed to a deficit when they appear in autism, regardless of whether the cortex is thicker or thinner than expected” (p. 34).

This bias against autistic people and autistic functioning is widespread across the research disciplines (Gernsbacher & Pripas-Kapit, 2012). When superiorities in autistic functioning are observed, they are often treated as “islets of ability ... regarded as something of a myth or else as merely an interesting but theoretically unimportant fact” (Dawson, Soulières, Gernsbacher, & Mottron, 2007, p. 658). Similarly, autistic social or

cognitive peaks are treated not as innate gifts, but as somewhat magical – and not entirely human – savant abilities (Solomon, 2011), or strikingly, “as incompatible with genuine human intelligence” (Soulières, Dawson, Gernsbacher, & Mottron, 2011, p. 1).

In response to a neurological study in which there were no observed differences between autistic and neurotypical subjects’ capacity for irony comprehension (an assumed flaw in autistic understanding), American psychiatric researchers Ting Wang, Susan Lee, Marian Sigman, and Mirella Dapretto (2006) attributed this lack of difference not to the intrinsic skills and humanity of their autistic subjects, but to the “autistic participants having ‘normalized’ their ‘neurocircuitry’ ... or ‘hacked out’ a ‘compensatory’ neural circuitry” (as cited in Gernsbacher & Pripas-Kapit, 2012, p. 101). These dependably deficit-focused and ableist views of autistic people as “a special class of less than fully human persons” (Bumiller, 2008, p. 984) pervade the definition, diagnosis, and treatment of autism.

This ableism follows a long tradition of devaluation of disabled people in regard to their deviations from the norm. As educator Thomas Hehir (2002) writes, *ableism*

uncritically asserts that it is better for a child to walk than roll, speak than sign, read print than Braille, spell independently than use spell-check, and hang out with non-disabled kids as opposed to other disabled kids, etc. In short, in the eyes of many educators and society, it is preferable for disabled students to do things in the same manner as nondisabled kids (p. 3).

In nearly all media accounts, and throughout much of the research literature, autistic functioning is portrayed in thoroughly ableist terms as a medicalized deficit that requires extensive correction. For many autistic toddlers and young children, the requirement to do things in the same manner as non-autistic kids often means that months and years are spent in some form of intensive behavioral training meant specifically to make them

appear less autistic. Educator Lennard Davis (2010) calls the ableist enforcement of normality onto the bodies and minds of disabled people “the tyranny of the norm,” (p. 6) and states that “the ‘problem’ is not the person with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (p. 3).

This problem-focused and medicalized approach to autism, which is devoid of autistic voices and autistic agency, leads to treatments, therapies, and educational approaches that do not respect the humanity, autonomy, or dignity of autistic people – and this is especially true for many of the treatments that are focused on autistic toddlers and young children.

### **Making Children Indistinguishable**

*ABA therapy greatly improved my social skills because I was forced to interact with people. — NAUWU participant*

*I would not have included belittling and yelling at the child for not understanding what you are talking about. Nor would I have physically restrained the child till they co-operated and asked verbally to be let go. — NAUWU participant*

Applied Behavior Analysis (ABA) and Intensive Behavioral Intervention (IBI) are Skinnerian behavioral training programs that are promoted insistently, with “enormous pressure on parents to seek intensive behavioral training” (Bumiller, 2008, p. 977). The promise is that the best outcome (to be indistinguishable from one’s peers) follows laborious and protracted behavioral interventions – for children as young as 13 months – “defined as 25 to 40 hours a week of therapy over at least 2 years” (Autism Speaks, 2011, para 5). In the 2012 health plan coverage guidelines for the Behavior Analyst Certification Board, the procedures involved in ABA are described:

These procedures include different types of reinforcement and schedules of reinforcement, differential reinforcement of other behavior, differential reinforcement of alternative behavior, shaping, chaining, behavioral momentum, prompting and fading, behavioral skills training, functional communication training, discrete trial teaching, incidental teaching, self-management, preference assessments, activity schedules, generalization and maintenance procedures, among many others. The field of behavior analysis is constantly developing and evaluating applied behavior change procedures (p. 16).

The stated best outcome of the ABA training regimen, which involves positive reinforcement (often with tokens or candy such as M&Ms) and negative reinforcement (punishment), is achieved when children test at an IQ of 85 or higher on a verbal IQ test and perform “grade level work in a regular education class as of first grade with no support” (Leaf et al., p. 273). Children in the “‘poor outcome’ group had IQ scores in the severe to profound range, were placed in classrooms for children with autism, and continued to display strong characteristics of autism” (p. 260). It is illuminating to note that in the ABA/IBI framework, a central aspect of the poor outcome for an autistic child is that he or she remains identifiably *autistic*.

ABA and IBI are promoted insistently yet funded differentially – often wildly so – such that some families can expect to have the entire exhaustive treatment process funded by federal, state, and local agencies, while other families may have limited to no access. For instance, in 2012, the California Department of Developmental Services (DDS), which provides funding and support for disabled children, spent a yearly average of “\$1991 per child in the [predominantly black] inner city of Los Angeles to \$18,356 per child in [nearby and predominantly white] Orange County” (Solomon & Lawlor, 2013, p. 107). Access to therapies and services is preferentially provided to white over non-white autistic children, such that the chance to become indistinguishable from one’s peers (or to

be properly diagnosed in the first place) tends to be more readily available to white children, and to children from higher SES families and locales.

In a critique of the overwhelmingly non-consensual nature of ABA/IBI, Canadian neuroscience researcher Michelle Dawson (2004) writes that

Societies and scientists have historically made serious errors in determining which kinds of people are acceptable and which behaviours should aggressively be treated. People with differences have been ostracized then forced into mandatory treatments for their own good: left-handed people, and homosexuals, and many others. Societal and scientific assumptions about what constitutes freedom and integrity for disabled people have often been wrong. There exists no reason to believe that our society and its scientists are uniquely immune to these defects (section 13, para 4).

Canadian cognitive neuroscientist and autism researcher, Dr. Laurent Mottron (2011), adds that “Most educational programmes for autistic toddlers aim to suppress autistic behaviors, and to make children follow a typical developmental trajectory. None is grounded in the unique way autistics learn” (p. 34).

### **Challenging the Autism Prototype**

*Well. If you need help with emotional regulation, it is probably very useful. Entirely worthless if you expect your autistic kid to speak NT [neurotypical] afterwards.*

— NAUWU participant

*[I would have included] A much more respectful attitude towards people on the autism spectrum. — NAUWU participant*

There is a small but growing movement in the multidisciplinary autism research literature that challenges neuro-normativity and the consistently dehumanizing and deficit-based approach to autism. Mary Lawlor (2010) calls out the “striking paucity of ethnographic work” (p. 170) in autism research, while Olga Solomon and Nancy Bagatell (2010) note that the predominantly medicalized approach to autism means that there is far



less attention paid to “human experience, social interaction, and cross-cultural variation” (p. 2) than to deficit- and deviance-focused interpretations of autism. These calls for ethnographic, feminist, human rights, disability rights, and social constructionist scholarship on autism have been revelatory; when these approaches are incorporated into autism research, many of the medicalized certainties about autistic functioning tend to be disconfirmed.

**Nonspeaking Does Not Equal Low Functioning.** A prevalent assumption throughout the research literature is that autism is strongly linked with cognitive impairment. This is especially true for nonspeaking or minimally verbal autistic people, who “are considered the most cognitively impaired: it is commonplace to refer to such individuals as ‘low functioning’” (Dawson, Soulières, Gernsbacher, & Mottron, 2007, p. 657). British psychological researchers Anne Emerson and Jackie Dearden (2013) report continual underestimation of the cognitive abilities of nonspeaking and minimally verbal autistic children, and “the potentially dangerous assumption that ‘non-verbal’ equates to severe learning difficulties” (p. 242), such that some nonspeaking children are offered minimal education and minimal opportunities.

There are some data that support these reduced expectations; in standard verbal-based IQ testing such as the Wechsler Intelligence Scales for Children-III (WISC-III), as many as a third of autistic children test in the range of mental retardation, which is equated with low functioning. But neuroscientist Laurent Mottron (2011) questions why autistic children, whose diagnosis nearly always involves some language impairment, are tested with a primarily verbal instrument like the WISC-III: “In measuring the intelligence of a person with a hearing impairment, we wouldn’t hesitate to eliminate

components of the test that can't be explained using sign language; why shouldn't we do the same for autistics?" (p. 34).

This question is germane; when autistic children (speaking and nonspeaking) are tested with the nonverbal Raven's Progressive Matrices (RPM)<sup>8</sup> instrument, IQ scores change markedly. Instead of one third of the children being classified as low functioning according to the WISC-III "only 5% would be so judged according to the Raven's Matrices" (Dawson et al., 2007, p. 659). RPM scores tend to correlate directly with WISC-III scores in neurotypical children, but not in autistic children, whose RPM scores tend to be markedly higher.

Further studies (Barbeau, Soulières, Dawson, Zeffiro, & Mottron, 2013; Soulières, Dawson, Gernsbacher, & Mottron, 2011; Stevenson & Gernsbacher, 2013) note that the RPM is considered "the best marker for fluid intelligence" (Soulières et al., 2011, p. 1) in neurotypical children, that autistic children perform dramatically faster on the RPM than neurotypical children do, and that "autistic children are more accurate than non-autistic children" (Stevenson & Gernbacher, 2013, p. 3). As of 2014, however, most research mentioning IQ in autistic children still relies upon the Wechsler scales (especially in studies involving IQ-matched controls), which means that inappropriate test instruments are routinely given to autistic children – to their detriment. This unsuitable, ableist, and "crucial procedural decision" (Barbeau et al, 2011, p. 295) privileges neurotypical measures of intelligence and ignores autistic strengths.

**Dyspraxias May Underlie Both Linguistic and Social Delays.** One suggestion from the research is that it is actually early oral, visual, and manual dyspraxias – and not

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<sup>8</sup> In the RPM, a matrix (2x2, 3x3, 4x4, etc.) of figures containing discrete but interrelated geometric patterns is presented, with one figure missing. Subjects are asked to complete the matrix; this activity involves deduction, reasoning, visual-spatial skills, memory, and measures of general and fluid intelligence.

intrinsic social deficits – that may underlie the atypical linguistic and social interaction behaviors many autistic children and adults display: “Although autistics no doubt deploy atypical cognitive processes in performing tasks, we strongly caution against declaring these processes dysfunctional” (Dawson et al., 2007, p. 661). Researchers from the University of Madison (Gernsbacher et al., 2008) also challenged the idea that autistic people do not engage in joint attention (looking at something in concert with another person or animal) by questioning hidden assumptions about what attention and understanding of the intentions of others actually entail. Gernsbacher and her colleagues suggest that many of the ways typically developing babies signal and initiate joint attention is by turning their heads, pointing, following gaze, and reaching out – all of which are complex motor skills affected by the dyspraxias autistic people and their families report (but which are not mentioned at all in most biomedical descriptions of autism).

When Gernsbacher, Eve Sauer, Heather Geye, Emily Sweigert, and Hill Goldsmith (2007) studied oral motor and manual motor skills in autistic toddlers, both retroactively through home videos and in current-day studies, they found that these oral and manual dyspraxias were predictive of language delay, and also predictive of all measures of social interaction. They also found that the oral and manual skills of toddlers “are more predictive of their preschool speech fluency than are measures of social cognition, such as joint attention” (p. 44). This finding suggests that early oral- and manual-motor therapy and occupational therapy for these micro skills could be more supportive for autistic children’s later development than ABA/IBI, which focuses an enormous amount

of time and energy on the entrainment of neurotypical macro skills that some autistic children are not able to achieve.

**Linguistic Skills and Social Skills Are Interdependent.** In a study of receptive language skills in autistic toddlers, neurological researchers Patricia Kuhl and her colleagues (2013) observed a strong correlation between EEG responses to words in two-year-olds with autism and the children's receptive language skills, cognitive abilities, and developmental outcomes at ages four and six. Notably, Kuhl et al. found that this neurological response to words was the sole significant predictor of these developmental outcomes. This predictive relationship held no matter what form of treatment the children received in the intervening years (all of the children in this study received some form of intensive treatment, including ABA/IBI).

Kuhl and her colleagues propose a connection between linguistic skills and social skills, and suggest that linguistic development in both neurotypical and autistic children “is closely linked to social development” (p. 7). The researchers conclude by suggesting that developing an early language-based measure for autistic children “holds promise for novel early interventions that are tailored to individual children” (p. 12), rather than enrolling all autistic children in the same intensive behavioral retraining regimens. Linguistic anthropologist Elinor Ochs and her colleagues (2004) agree with this link between linguistic development and social development, and “argue against the distinction made in diagnostic accounts of autism between ‘social’ and ‘communicative’ domains” (p. 154).

As each seeming marker of autism is critically evaluated for bias, researchers are finding that we cannot neatly separate autistic sociability and communication from that of

other humans. For instance, in regard to autistic echolalia and scripting, *all* people use scripts and routines (Peters & Boggs, 1986) as they learn to use language. *All* people use gaze aversion (Doherty-Sneddon, Riby, & Whittle, 2012), and specifically avert their gaze from faces (Riby, Doherty-Sneddon, & Whittle, 2012) in order to strategically manage cognitive load. But not all people are identified, or *iconized*, as Judith Irvine and Susan Gal (2000) describe it, as pathologically disordered entities whose very place in humanity is in question – and whose innate social, linguistic, and bodily behaviors are negatively compared to unchallenged ideas about what constitutes normality.

### **Reclaiming the Autism Prototype**

*Rather than focusing on learning how to learn non-autistic social skills, I'd focus more on how to communicate feelings, wants, needs, and how to converse in a way that is comfortable to autistic people. — NAUWU participant*

*I would have taught that autism is a valid subculture rather than a disordered way of thinking. — NAUWU participant*

Autistic people all over the world have gathered together – online and off – to create community and to challenge the dehumanization they face. Jim Sinclair (who coined the word *neurotypical*) was a principal early organizer of the international online autism community and is also renowned for his seminal speech, *Don't Mourn for Us*, which he delivered at the 1993 International Conference on Autism in Toronto. This speech was directed at parents, many of whom considered their child's autism diagnosis as “the most traumatic thing that ever happened to them” (Sinclair, 1993, para 1). Sinclair (who reports that he himself did not speak until the age of 12) addressed the communal grief that parents felt by asking them to try to take the perspectives of autistic people:

Non-autistic people see autism as a great tragedy, and parents experience continuing disappointment and grief at all stages of the child's and family's life cycle.

But this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have....

There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person — and if it were possible, the person you'd have left would not be the same person you started with.

This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism (Sinclair, 1993, paras 1, 2, 5, and 6).

This speech was published online, and *Don't Mourn for Us* soon became a foundational civil rights touchstone for the growing neurodiversity community. The neurodiversity paradigm directly challenged the omnipresent deficit narratives – first in regard to the Autism Spectrum, but eventually in regard to other neurological conditions such as ADHD, learning disabilities, bipolar, schizophrenia, refractory depression, brain injury, and Tourette's Syndrome.

Neurodiversity advocates' intentional reframing of neurologically divergent people as valuable human beings overturns prevailing neuro-normative and medicalized views of autism. On a parody website created to confront this neuro-normative frame, Laura Tisoncik, an autistic woman writing under the name of Muskie (Institute for the Study of the Neurologically Typical [ISNT], n.d.) turns the tables by describing neurotypical people with medicalized language focused on their deficits:

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. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon 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.

NT is believed to be genetic in origin. Autopsies have shown the brain of the neurotypical is typically smaller than that of an autistic individual and may have overdeveloped areas related to social behavior (ISNT, n.d., paras 1-3).

Tisoncik's points are well taken, in that majority discourse about minorities nearly always paints the minority (be it racial, sexual, physical, linguistic, or neurological) as deficient and deviant until members of that minority group begin wresting the discourse away from the majority. In this vein, American neurodiversity scholar Nick Walker (2012) suggests referring to neurotypicals as the *neuromajority*, and referring to people in the autism, ADHD, learning-disabled, brain-injured, bipolar, and Tourette's communities (etc.) as the *neurominority*.

Internationally, autistic self-advocates<sup>9</sup> are working to reclaim their lives, their bodily integrity, and their unique ways of experiencing the world (Bagatell, 2007 & 2010; Blume, 1997; Bumiller, 2008). These self-advocates (some autistic people prefer the term *activist*) – are claiming their place as valuable members of the human race rather than as tragic, disordered, perpetually disabled, or “helpless, hopeless, nonfunctioning, and noncontributing members of society” (Barton, 2001). There is a flourishing and active online autism community that was first envisioned by Jim Sinclair and friends in the 1990s, and is now a full-fledged culture where autistic people have acknowledged themselves as a distinct neurominority with uniquely shared behaviors, communication styles, social skills, likes, dislikes, and bodily movement styles (such as toe-walking and

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<sup>9</sup> This *self*-label is a way to make explicit these activists' ability to speak (or communicate, in the case of nonspeaking people) for themselves. It is also a protest against the powerful deficit-focused organization Autism Speaks, which includes no autistic individuals in any functional capacity (Robison, 2013), and which persistently portrays autism as a tragedy and an alarming epidemic.

stimming) that are celebrated as markers of identity<sup>10</sup> rather than mourned as markers of deficit or disorder.

While this approach to autistic selfhood could be likened to a form of essentialism, it is also a response to the essentialism found in research and popular literature about the prototypical autistic (non) person, who is expected to exhibit specific deviations from the norm. As I have observed and engaged with the international online autistic community over the years, I have witnessed this essentialism and its impacts on the everyday lives of autistic people. For instance, it is normal and expected for autistic people to be called out as frauds (you *can't* be autistic!) because: they can make eye contact; they can speak and/or write; they have and can understand emotions; they have empathy; they can understand humor, sarcasm, and irony; they can understand analogy and metaphor; they have friends; they have careers; they have lovers and spouses; and because they have children. Autistic selfhood is essentialized, challenged, and stigmatized at every stage in an autistic person's lifespan, and as Erving Goffman (1963) points out, it is utterly normal for a group of people who experience stigmatization this extensive to reclaim their "stigma symbols" (p. 43), assert their identities, and reframe themselves as intentional agents.

### **Nothing About Us Without Us**

*[I would create] Maybe something by autistics for autistics? Definitely one that respects participants and enables them to grasp concepts with ease.*

— NAUWU participant

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<sup>10</sup> As it is with the d/Deaf cultural distinction (Senghas & Monaghan, 2002), a similar a/Autistic distinction has arisen within the culture, with the fascinating addition of the pride-moniker *Âû*, which is seen on the Facebook profiles of some Autistic people (i.e., John Doe *Âû*, Jane Doe *Âû*, etc.) and refers not just to autism, but also to the chemical symbol for gold.



*Autistic people do not need social skills classes. They need to be included in groups that have special interest type topics. There they are viewed as experts and respected versus just being included. — NAUWU participant*

Autistic-typical behaviors are routinely characterized as unwanted and disordered, and are a central focus of social skills training programs designed for autistic people. These behaviors, such as repetitive self-soothing movements (negatively framed as *autistic stereotypies*), echolalia and the use of scripted language (negatively framed as *scripting*), special interests (negatively framed as *perseverations*), biting, picking at, or hitting themselves (negatively framed as *self-injury*), walking away from classrooms or from school (negatively framed as *wandering* or *elopement*), and melt-downs (a negatively framed description of emotional or physical dysregulation) are explained in terms of pathology and are persistently corrected, punished, and subjected to extinguishment and *erasure* (Irvine & Gal, 2000).

However, when parents of autistic children reach out to ask autistic teens and adults about these seemingly confounding behaviors, wonderful conversations occur.<sup>11</sup> When autistic people are included in conversations about their own lives, autistic-typical behaviors can be understood in terms of their purpose rather than their pathology: We stim because it feels good, helps us stay regulated, and allows us to access cognitive resources. We script and repeat because we want to communicate, but can't get our own words from our brains to our mouths (or because repetition feels delightful). Our special interests are the center of our lives; we love them and we want to share them with you.

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<sup>11</sup> The neurodiversity community is very active online, and some U. S. sites where this autism-positive work is being done are the blogs *We Are Like Your Child*; *Neurocosmopolitanism*; *Emma's Hope Book*; and *Mama Be Good*; the Facebook pages *Parenting Autistic Children with Love & Acceptance*; *Karla's ASD Page*; *Autism Discussion Page*, and the websites *Autistikids*, *The Thinking Person's Guide to Autism* and *Olliebean*, among others.

We bite or hit or hurt ourselves because this self-caused pain (which sometimes doesn't actually hurt) deadens uncontrollable sensory input, and it actually soothes us. We leave and go on walkabouts because we're fascinated by the world, or because our current environment is boring, overwhelming, or abusive, and we need to get away. Our meltdowns are not tantrums; we're not angry – we're so overstimulated that we become emotionally and physically dysregulated. In each case, parents who have sought out autistic expertise have discovered that the autistic-typical behaviors of their children are not disordered, abnormal, or tragic; they are purposeful, meaningful, and practical.

When autistic expertise is recognized, requested, and privileged, the social, emotional, and practical knowledge of the dynamic autistic community is revealed. This expertise can humanize and revolutionize the education of autistic people – and this expertise is the central focus of the Nothing About Us Without Us study.

## Chapter 3

### Methodology for Nothing About Us Without Us

An uncounted variety of social skills training programs for autistic youths and adults exist in nearly every school district and community. These programs primarily focus on bringing autistic students into synchronization with the developmental, linguistic, social, and age-related norms of neurotypical people, yet to date, no one has ever surveyed a cross section of autistic people – a vast consumer base – about their experiences of, responses to, or opinions about these programs. The Nothing About Us Without Us (NAUWU) study was created to address this lack and to gather the opinions, responses, and expertise of autistic people.

#### Research Design

The international autistic community is highly active and highly connected online in places like Facebook and Twitter, on blogs by autistic people and their families (such as the blogs *Emma's Hope Book* and *We Are Like Your Child*), and on various autism-focused pages and websites such as *Autistikids*, *The Autism Women's Network*, and the *Autistic Self Advocacy Network*, among others. The NAUWU study utilized the online survey program Survey Monkey to create an accessible way for people in this widespread online community to share their opinions about social skills training programs.

NAUWU is an international, cross-sectional survey study that asked participants about their memories of and opinions about: (a) any of the formal, autism-focused social skills training classes or programs they attended; (b) any non-autism-focused social skills

programs or approaches that they discovered; and (c) any social skills approaches that they created on their own.

**Content Validity Assessment.** A pilot set of survey questions were previewed throughout January of 2014 by dozens of autistic teens and adults in numerous Facebook groups, and their input led to the addition, revision, and/or deletion of specific pilot questions. In the finalized and content-validated survey instrument, NAUWU participants were asked a series of open-ended questions about: how they learned of these programs; what they learned in them; whether the programs were clear, respectful, pertinent, and focused on their needs (these questions involved five-factor Likert scales); what they would include, change, or keep in these programs; and whether they would recommend these programs to others (this two-part question involved a Yes/No/It Depends portion and a text-based explanation of the chosen answer). Participants were also asked what kinds of programs they would create now, looking back.

**Human Subjects Review.** The finalized NAUWU questions were reviewed and approved for human subjects research by the Sonoma State University Institutional Review Board on 7 February, 2014 (IRB Application #2477). The NAUWU survey was posted online from 18 February, 2014 to 4 April, 2014. This thesis concentrates major data analysis on the cohort of 71 NAUWU participants who experienced, in total, 91 different, autism-focused social skills training programs.

### **Participant Description**

Anonymity was an important factor in ensuring candid and open responses about social skills training programs – as such, minors were excluded due to the requirement that their parents sign waivers for their participation. NAUWU was therefore focused on

adults (18 years of age or older) diagnosed with autism, Asperger's Syndrome, or Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). Due to extensive diagnostic biases and access issues for women and girls, minorities, and other medically under-served populations (see Chapter 2), this study accepted self-diagnoses of autism and did not confirm or contradict these diagnoses

Invitations to this survey were distributed to the international online autism community through social media channels such as Facebook, Twitter, and online autism community groups and websites in a snowball sample. Invitations to NAUWU went viral and eventually attracted 630 participants from 23 countries (see Chapter 4 for participant demographics).

### **Data Collection Methods**

NAUWU participants accessed the online survey through a link to a dedicated page on the Survey Monkey site; participants were able to take the survey at their own speed on their own computers, tablets, or cell phones. The data gathered were comprised of open-ended text responses and of check-marks on the Yes /No and Likert scale portions of the survey.

**Data Collection Issues.** NAUWU went viral almost immediately, and many participants reported having trouble with Survey Monkey in the first two days (from 18 February to 19 February, 2014). Participants reported being redirected to the start page, losing their answers, or making double and triple attempts to access the survey. Two participants had so many problems that they had to send their answers directly by email (to be hand-entered). These early crashes at Survey Monkey are likely responsible for many incomplete entries, and for the early attrition rate of 24.1% (overall, 643 attempts

to access the survey were made, while 488 participants continued past the first page). Early data collection involved supporting participants in their repeated attempts to access the survey, and identifying the double and triple entries that accrued as participants attempted to work around the Survey Monkey crashes. As a result, 13 compound entries (2.0% of the original 643 responses) were identified and deleted from the study, leaving 630 discrete participants. Software problems<sup>12</sup> notwithstanding, hundreds of complete entries and lengthy textual responses suggest that the software crashes in the first two days did not entirely hinder the data collection process.

### **Data Analysis Procedures**

**Quantitative Analyses.** The Survey Monkey program kept a running tally of responses, and performed cross sectional and individual calculations on Likert scales questions related to participant's opinions about the social skills programs they attended or created. Numerous statistical analyses of participant demographics were then performed in Excel, and these analyses are presented and explained in figures and tables in Chapter 4.

**Qualitative Analyses.** Text-based answers were analyzed through iterative hand-coding; this analysis eventually focused on eight central topic areas that arose from within the participant responses. These eight topics form the basis of a series of suggestions for improving and humanizing social skills training programs for autistic people, and will be discussed in detail in Chapter 5. especially

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<sup>12</sup> Future survey studies of the autism community should be carried out with more powerful social science survey software, and particularly with software that can handle multiple designations of gender identity (see Chapter 4).

## Chapter 4

### NAUWU Survey Results and Analysis of the Data

*While rote memorization works well for me, I really light up when someone gives me a reason. Having a discussion of precisely what psychological effects behaviors are likely to elicit gives me the power to write my own rules. Of course, most neurotypical people don't know the history of their own cultural artifacts, nor do they analyze the implications of them. However, whenever I am able to deconstruct a social convention from the point of view of its history and implications I become much more comfortable with using it or choosing to reject it with cause.*

— NAUWU participant

The Nothing About Us Without Us (NAUWU) survey study asked autistic adults about their memories of and opinions about any of the formal, autism-focused social skills classes or programs they attended, about any non-autism-focused social skills programs or approaches they discovered, and also about any social skills approaches they created on their own. The NAUWU survey was posted online from 18 February, 2014 to 4 April, 2014, and invitations were distributed through social media channels such as Facebook, Twitter, and online autism community groups in a snowball sample; the survey attracted 630 participants from 23 countries, and 488 participants (77.5%) completed all or part of the survey.

#### **Demographics of NAUWU Participants**

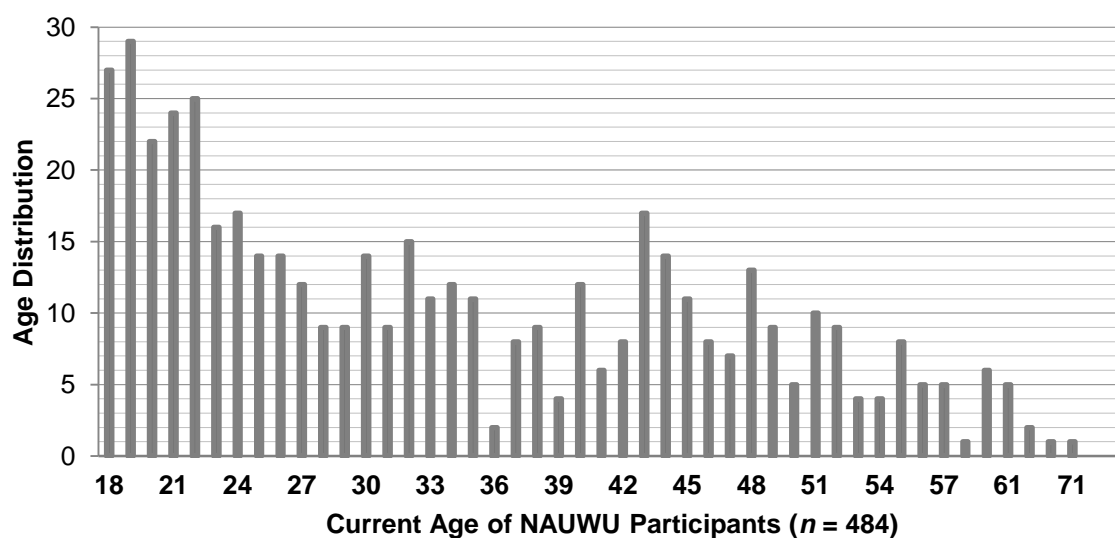
**Location.** Of the 486 participants who answered questions about their location, 351 (72.2%) were from the United States, 49 (10.1%) were from the countries of the United Kingdom, 42 (8.6%) were from Canada, 16 (3.3%) were from Australia, and the remaining 28 participants (5.8%) were from Northern Europe, the Middle East, Russia,

China, South Africa, New Zealand, and Trinidad and Tobago. All participants completed their surveys in English. Two participants (out of the total of 488) did not state their location.

**Age and Age Distribution.** The 484 NAUWU participants who gave their age ranged from 18 to 71 years old. Four participants (out of the total of 488) did not state their age.

**Figure 1**

*Age Distribution of NAUWU Participants*



*Figure 1:* The largest participant age group (232 people, or 47.9% of respondents) is in the 18 to 30 year-old group. The mean age for NAUWU participants is 33.8 years, with a median age of 32 years and a mode (of 29 participants) at 19 years.

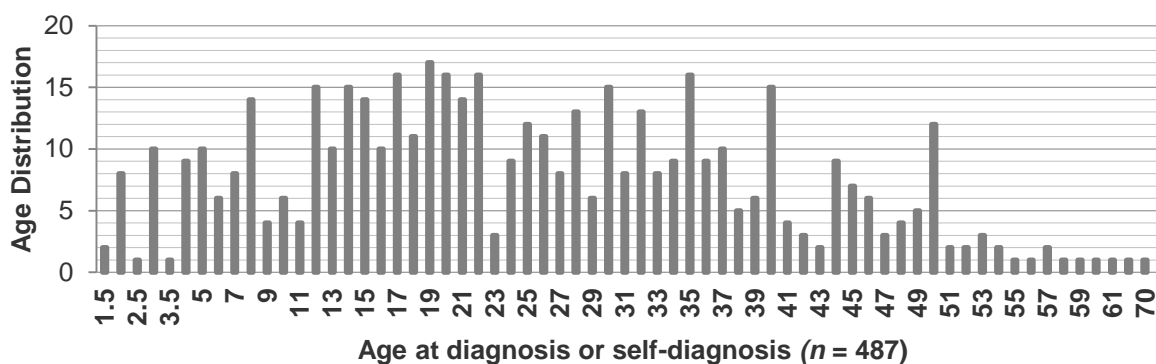
**Age at Diagnosis or Self-Diagnosis of Autism.** The 487 participants who gave their age at diagnosis (or self-diagnosis) were diagnosed (or identified) between the ages of 1.5 years and 70 years. In 27 cases (5.5% of the responding participants), two dates were given; these compound diagnosis dates either separated self-diagnosis from formal



diagnosis, or separated formal diagnosis from the time the diagnosis was divulged to the participant. In these 27 cases, the earlier date was entered into the calculation.

**Figure 2**

*Age Distribution at Diagnosis or Self-Diagnosis*



*Figure 2:* The mean age at diagnosis or self-diagnosis (whichever was earlier) for NAUWU participants was 25.3 years of age, with a median age of 24 years and a mode (of 17 participants) at 19 years. One participant (out of the total of 488) did not state an age at diagnosis; this participant answered with a question mark.

The largest cluster of diagnoses or self-diagnoses (134 participants, or 27.0%) occurred when participants were between 10 and 20 years of age. The second largest cluster of diagnoses (107 participants, or 22.0%) occurred when participants were between 21 and 30 years of age. However, the diagnoses continue throughout the life span of the NAUWU cohort, and tend to support CDC Director Colleen Boyle’s hypothesis that it is not autism prevalence rates that are increasing, but that there has been a steady increase in identification and diagnosis rates instead (Hamilton, 2014).

**Sex and Gender Identity.** Numerous conversations about gender diversity in the autism community led to the inclusion of an open-ended question about “Sex or Gender

Identity.” This question returned a wondrous and unanticipated array of 77 unique descriptions of gender identity (see Appendix B for the entire list), including 270 females (55.3%),<sup>13</sup> 105 males (21.5%), and 113 gender diverse people (23.2%) who identified in a variety of ways, i.e., as gender-fluid, nonbinary, complicated, genderqueer, Two-spirit, trans\*, cisgender, bigender, agender, androgynous, gender nonconforming, demifemale, masculine-presenting, AFAB, DFAB,<sup>14</sup> and the delightful “gray-agender demigirl/asexual/gynromantic,” and “Non-newtonian genderfluid (I round down to woman).” This varied abundance of descriptors suggests that there is currently no formalized gender identity terminology in the autistic community. It is also interesting to note that many participants included sexual orientation (such as *asexual* or *queer*, see Appendix B) in their descriptions of gender, seemingly as a way to further articulate their identities as distinct from merely binary gender roles and norms.

This wide-ranging array is eye-opening, particularly in contrast to the pervasive gender essentialism and gender conformity training that occurs in social skills programs for autistic people (especially for teens as they enter the realm of dating). Anthropologist Kristen Bumiller (2008) reports that many autistic children dis-identify with gender roles from an early age, and she suggests that this dis-identification and gender diversity may be a norm for many autistic people. However, as it is with other aspects of autism, this gender diversity is routinely medicalized and framed as a disorder.

Gender diversity in autistic people has been labeled as *gender-identity disorder* (Kraemer, Delsignore, Gudelfinger, Schnyder, & Hepp, 2005); as *gender dysphoria* (de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010); as *gender*

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<sup>13</sup> This seeming overrepresentation of females will be discussed below.

<sup>14</sup> *Assigned Female at Birth* and *Designated Female at Birth*.

*nonconformity* (Shumer, Roberts, Reisner, Lyall, & Austin, 2014); as a developmental disturbance (see Dawson, 2004); and as a psychiatric problem (Mukaddes, 2002) – rather than as a fundamental aspect of autistic identity. Kristen Bumiller (2008) notes that “The neurodiversity movement has raised vigorous objections to the scientific community’s pathological view of nonnormative gender behavior” (p. 978). NAUWU participants pointed out instances of gender essentialism in the programs they attended, and asked that gender diversity awareness be included in social skills training programs. This request is included in the eight recommendations listed in Chapter 5.

### **Spotlighting Formal, Autism-Focused Social Skills Training Programs**

Due to the sheer number of participants in the NAUWU survey – and with respect to the rich and detailed text responses they contributed – this thesis focuses deeper analysis on a specific cohort of participants. The larger NAUWU survey asked questions about formal, autism-focused social skills classes or programs, about any non-autism-focused social skills programs or approaches, and also about any social skills approaches that the participants created on their own. This analysis focuses on the 119 participants (24.4% of the 488 NAUWU participants) who attended formal, autism-focused social skills training programs. Survey questions related to these autism-focused programs are listed in Appendix A.

The NAUWU participants who attended social skills training programs designed specifically for autistic people answered questions based on how many of these programs they attended. This cohort of 119 participants reported attending one program (90 participants, or 75.6%), two programs (18 participants, or 15.1%), or three programs (11 participants, or 9.2%). The response rate for this cohort is displayed below in Table 1.

**Table 1**

*Autism-focused social skills programs described by NAUWU participants*

<b>Programs Attended</b>	<b>Number of Participants</b>	<b>Total Programs</b>
1 Program	56 participants	56 programs
2 Programs	10 participants	20 programs
3 programs	5 participants	15 programs
<b>Totals</b>	<b>71 participants</b>	<b>91 total programs</b>

*Table 1.* From the original cohort of 119 participants, 56 out of 90 (62.2%) completed questions about their one program, 10 out of 18 (55.5%) completed questions about their two programs, and 5 out of 11 (45.4%) completed questions about their three programs. All told, these 71 participants provided information about 91 different, autism-focused social skills training programs.

These 71 participants answered a series of open-ended questions about: how they learned of these programs; what they learned in them; whether the programs were clear, respectful, pertinent, and focused on their needs (these questions involved five-factor Likert scales); what they would include, change, or keep in these programs; and whether they would recommend these programs to others (this two-part question involved a Yes/No/It Depends portion and a text-based explanation of each participant's chosen option).

### **Data Analysis**

Data from NAUWU participants suggest that social skills training programs for autistic youths and adults are not standardized; they tend to be a pastiche of clinical,

school-based, group-based, or one-on-one training programs created by teachers, school districts, therapists, or private individuals.

**Program Types.** In the analysis of these programs, few specific titles, brands, or approaches were named, except for some form of the generic term “Social Skills.” This term was mentioned in regard to 33 programs (36.2% of the 91 programs), and included related terms such as Social Stories (3), Social Thinking (2), Social Group (1), Social Learning Group (1), Social Skills Special Olympics (1), and Socially Speaking (1). Four participants reported being enrolled in Cognitive Behavioral Therapy (CBT), while three reported that they had been enrolled in ABA. The remaining 51 programs involved emotion recognition (sometimes with flash cards or cartoon faces) and emotion regulation skills (including meditation), relationship and interaction skills in groups of autistic peers (sometimes with scripted responses, sometimes with an improvisational drama approach), story-telling and scripted communication exercises, speech therapy or occupational therapy, and life skills, dating, workplace, and/or school success courses.

**Referral Status.** Referrals to these programs were predominantly initiated by clinicians, teachers, or parents. Only 5 participants who took one program chose to do so of their own volition, while none of the participants who took two or three programs self-referred. All told, only 7.0% of participants self-referred, which would tend to support researcher Michele Dawson’s (2004) concern about the overwhelmingly non-consensual nature of these programs.

**Perceived Efficacy of These Programs.** Responses about the efficacy of these 91 programs in aggregate (see Figures 3-7) were not strongly positive. In regard to these programs’ clarity, respect for autonomy, pertinence, and focus on what Dr. Laurent

Mottron (2011) calls “the unique way autistics learn” (p. 34), NAUWU participant responses suggest that these formal social skills training programs for autistic people are by and large not meeting their needs.

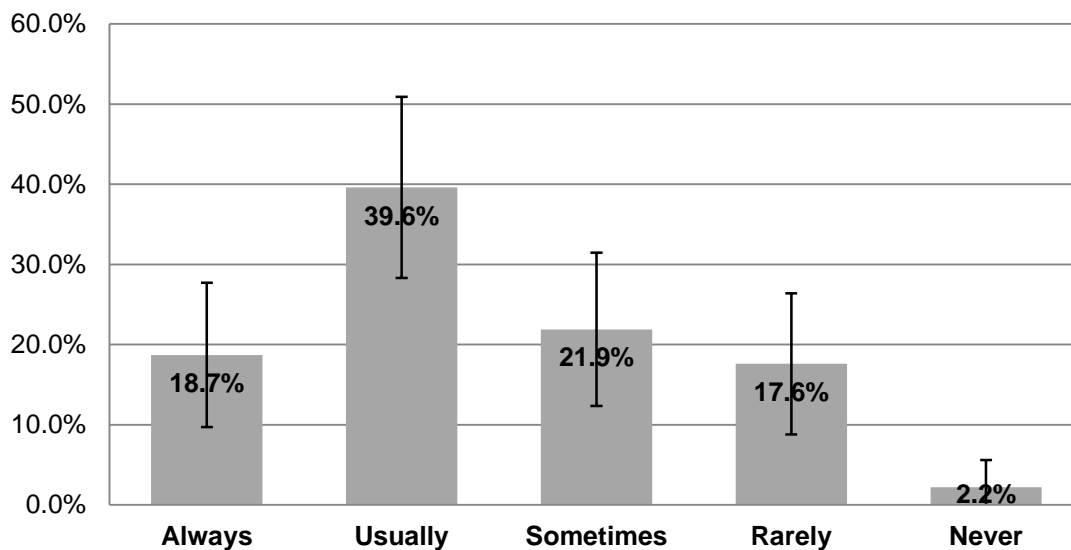
### NAUWU Participant Responses, Likert Scales

#### Did You Find This Program To Be Clear and Understandable?

- *It kind of seemed like they were babying us. I never felt like I was being treated like a high schooler. This was especially infuriating because the aides were all college students who were only a few years older than us.*
- *Too much information all at once and I don't always understand what it all means. How do I change ME?*
- *I can tell when you're using that voice reserved for children, even if some of the others on the spectrum can't.*

#### Figure 3

*Did You Find This Program to be Clear and Understandable?*



Note: 95% Confidence Intervals: Always [9.7%, 27.7%]; Usually [28.3%, 50.9%]; Sometimes [12.3%, 31.5%]; Rarely [8.8%, 26.4%]; Never [0.0%, 5.6%].

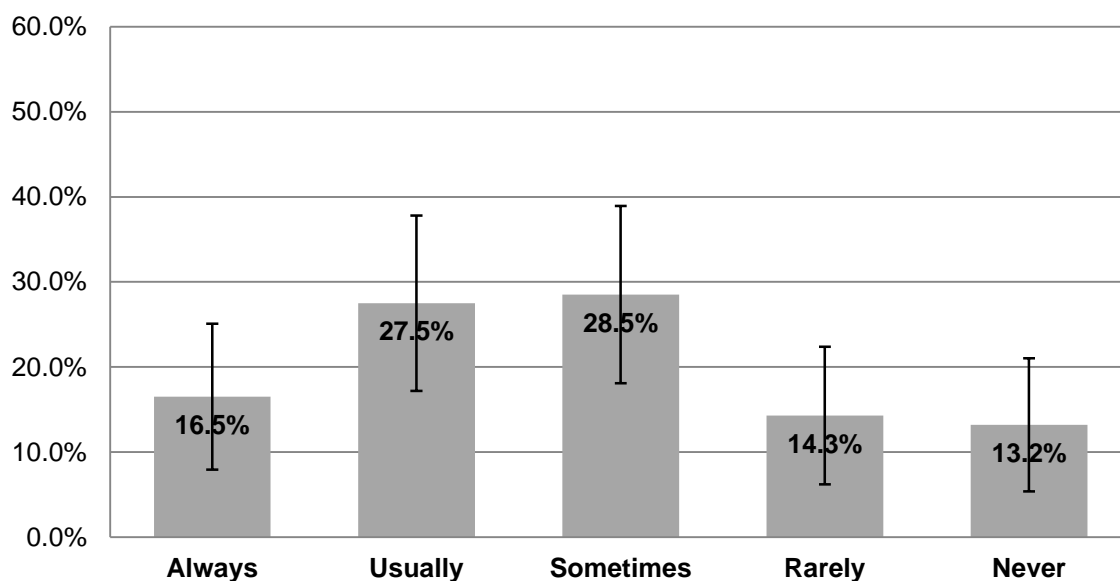
*Figure 3. Did You Find This Program to be Clear and Understandable: Participants on the whole found these autism-focused social skills programs to be fairly clear and understandable; however, many participants described their programs as simplistic, repetitive, and focused on the attention spans and sophistication levels of young children.*

### **Did You Find This Program to Be Respectful of Your Autonomy?**

- *I had zero input into what we worked on, and I often didn't even understand what we were working on because it was so badly explained.*
- *Cleared up some confusions I had, but overall tone was negative, which I tried to ignore.*
- *I liked that the instructor encouraged a disability rights perspective, even though some of the others in the group were less receptive due to attitudes about disability being a flaw their whole life.*

### **Figure 4**

*Did You Find This Program to be Respectful of Your Autonomy?*



*Note: 95% Confidence Intervals: Always [7.9%, 25.1%]; Usually [17.2%, 37.8%]; Sometimes [18.1%, 38.9%]; Rarely [6.2%, 22.4%]; Never [5.4%, 21.0%].*

*Figure 4. Did You Find This Program to be Respectful of Your Autonomy: Social skills programs for autistic children and adults tend to be provided non-consensually. These programs are prescribed by therapists, teachers, or school administrators, or sought out by parents for their children. Participants reported that their autonomy was Rarely or Never respected in 27.5% of these programs, and the non-consensual nature of these programs may be a central factor in these responses. Only 7.0% of NAUWU participants (5 out of 71) self-referred to these training programs; as such, it is a credit to some of the program providers that 44% of participants found their programs to be Usually or Always respectful of their autonomy.*

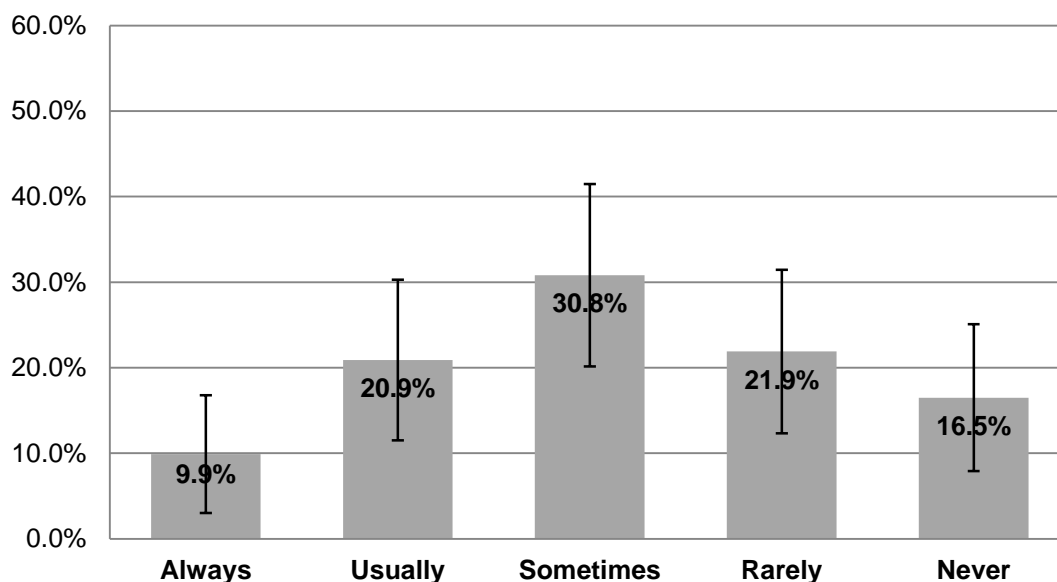
#### **Did You Find This Program to be Pertinent to Your Needs?**

- *The class was redundant (I know what a sad person looks like, I just don't necessarily know what to do about their sadness) and the teachers were patronizing.*
- *There was no practical application of anything to the real world, and no checking back to see if I'd had success with anything.*
- *I think I would just not have this class and instead have kids like me get involved in theatre or sports.*
- *It was just utterly useless. No client direction, no relevance to the real world, no advice on how to apply the stuff I was "learning" in real time or in practical situations, just being talked at by some jerk.*



**Figure 5**

*Did You Find This Program to be Pertinent to Your Needs?*



*Note:* 95% Confidence Intervals: Always [3.0%, 16.8%]; Usually [11.5%, 30.3%]; Sometimes [20.1%, 41.5%]; Rarely [12.3%, 31.5%]; Never [7.9%, 25.1%].

*Figure 5.* Did you Find This Program to be Pertinent to Your Needs: 38.4% of participants reported that their needs were Rarely or Never met, while 30.8% reported that their needs were only Sometimes met in these programs. Some participants described the programs as utter failures; however, many described their failed or less-than-ideal programs politely, and allowed that the programs might have been useful for other (usually much younger and/or less skilled) people.

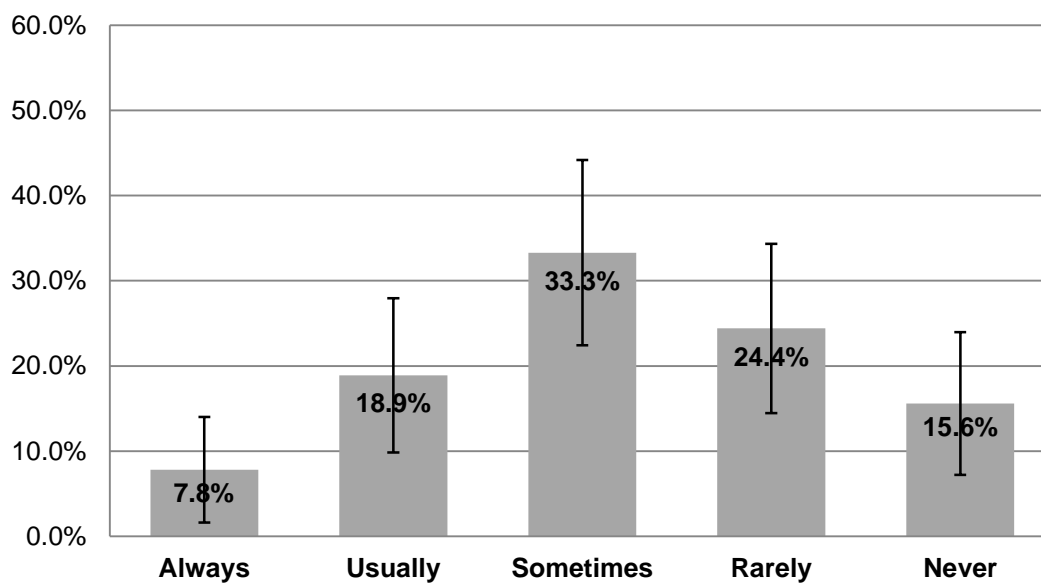
### **Did You Find This Program to be Focused on Your Way of Learning?**

- *I could type but wasn't given a chance*
- *I would have picked more sensory-friendly locations for some of our outings.*
- *I liked having a friendly, quiet teacher who doesn't yell. I can't learn anything in classes with teachers who yell because loud voices give me panic attacks.*

- *I'd incorporate the idea that eye contact isn't necessary and make it more about communicating effectively*

**Figure 6**

*Did You Find This Program to be Focused on Your Way of Learning?*



*Note:* 95% Confidence Intervals: Always [1.6%, 14.0%]; Usually [9.9%, 27.9%]; Sometimes [22.4%, 44.2%]; Rarely [14.5%, 34.3%]; Never [7.2%, 24.0%].

*Figure 6. Did You Find This Program to be Focused on Your Way of Learning:*

Most participants reported that these programs were not designed with autistic learning styles in mind; 40% reported that their learning styles were Rarely or Never a focus. In text-based answers throughout the survey, many participants suggested ways to create supportive, autism-positive curriculum and appropriate classroom environments. These suggestions are included in the eight recommendations listed in Chapter 5.

### **NAUWU Participant Responses, Open-Ended Text Answers**

**What skills did you develop in this class or program?**

- *More or less a bit of speaking skills but roundly nothing beside hiding my stims.*

- *It was structured as a hybrid of social skills learning and group therapy, so we also learned how to recognize when we were being taken advantage of or abused by others, and that it was okay to say “no.”*
- *None, really. I had by far the best social skills in the program, and so most of it was things I had already learned.*
- *I mostly developed low self-esteem.*
- *Self-advocacy; Focusing / Limiting distraction; Visual tracking of text on pages.*
- *I learned to cope well enough to grow up fairly well and wear other types of clothing and eat certain foods and not mind my foods touching. I also had learned how to cope with sound.*
- *None, other than how to hate humanity.*

When asked about the skills they developed in these programs, participants could remember no skills development in 31.9% of their programs (29 out of 91 programs). The participants who recalled having developed skills reported: conversational turn-taking and communication skills; stress-management; emotion recognition and emotion management; self-monitoring and self-soothing; money management; job skills; driving skills; basic social skills such as greeting and handshakes; some dating skills; and “Ways to fit in with regular kids.”

### **What approaches or ideas would you have included?**

- *Maybe a greater focus on advanced figurative language, such as sarcasm or irony (or perhaps some literary techniques like satire and parody; I'm sure that would have helped me in my English classes).*
- *More individualized interaction with group facilitators to help make participants feel comfortable.*
- *More emphasis on nonliteral language, reading body language, and how to better show empathy/happiness/etc.*
- *I needed to sit out on some things but wasn't given that option.*

- *Not being completely separated from my peers. If I had to learn that stuff, they should too.*

When asked about what they would have included in these programs, NAUWU participants wanted: more structure; more accountability; more focus on participants' individual needs; specific focus on advanced language skills and body language; disability rights awareness; more focus on adult needs; real social interactions rather than skits or cartoon faces; inclusion with neurotypical students; more focus on emotional skills and stress management; more respect for autistic people; GLBTIQ (Gay, Lesbian, Bisexual, Transgender, Intersex, Queer/Questioning) awareness; and more humility from program providers.

### **What would you change?**

- *I would have picked more sensory-friendly locations for some of our outings. It was mildly useful at first but became basically pointless and so I quit. I want it to be LGBTQ friendly and focused on my needs.*
- *Probably need to divide it into subgroups based on skills.*
- *I would have asked the kids about the social skills they felt they needed and tried to give them information about that. I would have dispensed with the skits. Memorizing hypotheticals is how people get that creepy, artificial, over-practiced vibe. I would have dispensed with the games. Most of us found them annoying. I would have tried to get the kids to share strategies they had discovered independently rather than [the teacher] acting as the sole locus of knowledge and authority.*
- *Just the pricing. Instead of \$100 per session it should \$20 per session.*

When asked what they would change about these programs, participants suggested making these programs: more appropriate for differing ability levels and age ranges; more focused on individuals and their stated needs; more focused on autism acceptance and autistic culture; more affordable and convenient; more organized; more accessible to

nonspeaking people (many of whom use keyboards or letter boards); more supportive of sensory sensitivities and learning preferences; more welcoming to women and girls; more aware of gender diversity and GLBTIQ people; less dependent on cartoons and flash cards; less focused on games and hypothetical skits; and less reliant on deficit-based views of autistic-typical behaviors (such as stimming).

### **What would you keep?**

- *Music and art therapy, group discussion, emotion charts (pictures for identification), and the retraining of thinking patterns to ease stress and anxiety.*
- *Relaxation techniques at the start of the class and focusing techniques.*
- *I really didn't derive any benefit from the program.*
- *The skills I've learned were useful in job and academic settings. They basically gave me a mental script of what to say.*
- *Nothing. I'd bin the lot and start again rather than trying to find some good in that pile of utter shite.*

When asked what they would keep in these programs, participants could find nothing to keep in 41.8% of their programs (38 out of 91 programs). The participants who answered in the affirmative mentioned: social interaction; the friends they made; group discussion and mutual support; individualized support; the emotion recognition and emotion regulation skills they developed; the specific communication techniques they learned about (such as how to work with tone, volume, and turn-taking); confidentiality in the sessions or classes; the relaxation and mindfulness skills they learned; the knowledge they gained about stress (in themselves and others); stress management techniques; and the self-advocacy skills they developed.

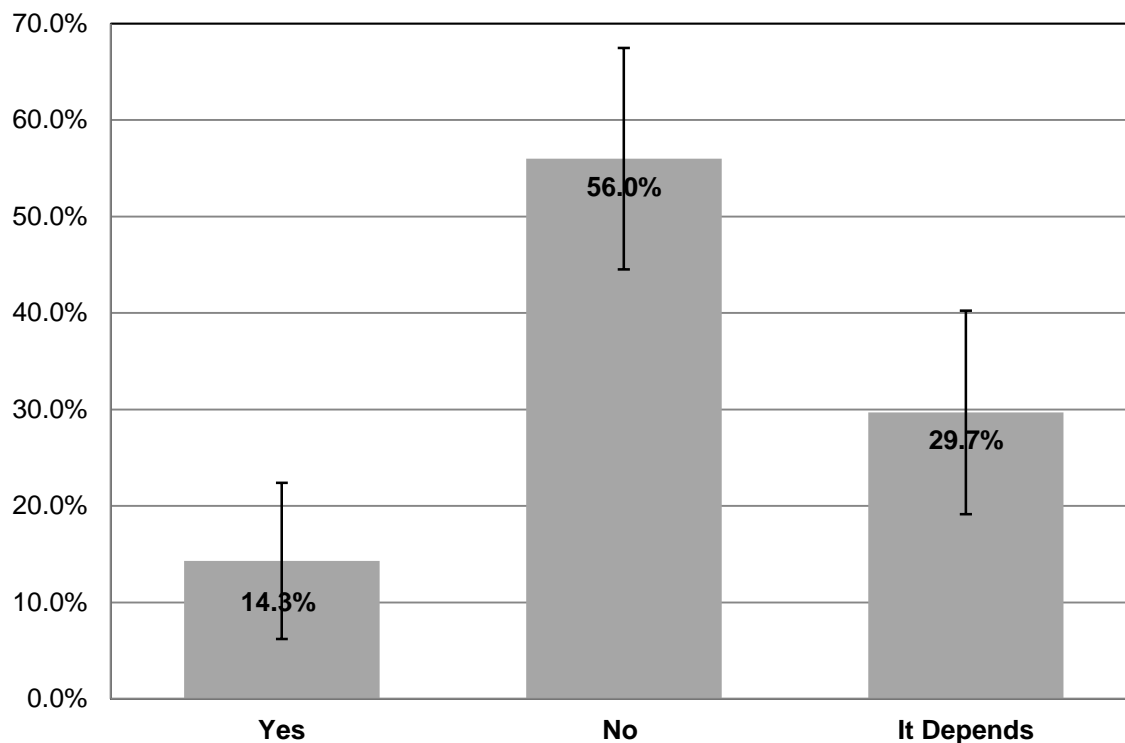
These responses – many of which request *more* social interaction, conversation, and interaction – stand in stark contrast to deficit narratives that equate autism with a lack of human sociability. As anthropologist Roy Richard Grinker (2010) notes, this presumed lack is not situated in autistic people “Instead, it is the rest of society that often lacks something – a theory of sociality that can encompass a wider range of human social differences” (p. 174).

**Would You Recommend This Program to Others? (Check Mark and Text Answers)**

- *I would recommend it for someone who is experiencing emotional trauma and is looking towards guidance for recovery. I would not recommend it for someone with an organic neurological condition who is experiencing trauma due to social-model disability impacts.*
- *I'm leaning towards saying no, but compared to the classes out there, this was very good. It's better suited for younger children definitely, but there aren't really any resources for those older.*
- *It was a waste of everyone's time and money.*
- *Very condescending, not remotely helpful, no respect or understanding for neurodiversity.*
- *Too much "YOU MUST DO THIS" "YOU MUST MAKE EYE CONTACT" and not respecting that we maybe didn't want to talk about those things or eye contact is not good.*

**Figure 7**

*Would You Recommend This Program to Others?*



*Note:* 95% Confidence Intervals: Yes [6.2%, 22.4%]; No [44.5%, 67.5%]; It Depends [19.1%, 40.3%].

*Figure 7.* Would You Recommend This Program to Others: The 14.3% percent of participants in aggregate who would recommend their programs found them to be helpful, meaningful, appropriate, supportive of developing friendships, and (in improv-based programs only) “fun.” The majority of participants (56.0%) would not recommend their programs; they found them to be confusing, condescending, frustrating, shaming, expensive, inconvenient, unprofessional, pointless, stressful, time-wasting, or physically and emotionally abusive and traumatizing. The 29.7% of participants who chose the It Depends option reported that their programs were not appropriate for their age, ability

level, sensory needs, situation, or interests, but that they might be useful for other (usually much younger and/or less skilled) people.

NAUWU participants also shared their ideas about what type of programs or approaches they themselves would create now, looking back. These responses and ideas, to be discussed in Chapter 5, are the foundation for a series of eight autism-positive recommendations to improve and humanize social skills programs for autistic people.

## **Discussion**

**Discussion of NAUWU Gender Percentages.** Females are seemingly overrepresented in NAUWU at 55.3% of participants. In keeping with the diverse spirit of the responses, 55.3% represents only those 270 women who answered “F,” “female,” “W,” or “woman.” However, if we include female participants with the modifiers *cisgender*, *genderqueer*, *agender*, *gender nonconforming*, or *nonbinary* (etc.), the percentage of women rises to 62.9% (307 out of 488) of NAUWU participants.

Autism is thought to affect males disproportionately in a 4:1 ratio, which would make the NAUWU participant proportions seem very irregular. Five considerations:

1. Greater female participation is a reported tendency in online survey studies (Rhodes, Bowie, & Hergenrather, 2003; Sax, Gilmartin, & Bryant, 2003).
2. The snowball sampling process may have occurred primarily in the extensive online social networks created by autistic women.
3. The gender bias against females in autism diagnosis, even when the presenting symptoms are the same as in males (see Chapter 2) could mean that there are far more autistic women and girls than have previously been counted.



4. The inclusion of self-identified (in addition to formally diagnosed) participants may have had the effect of uncovering a contingent of previously undocumented autistic women.
5. Some of the female-identifying NAUWU participants may have been designated male at birth, or some may be trans women who are not using the modifier *trans*.

Further studies that include autistic people as full partners in research about their lives may help to clarify the seeming overrepresentation of autistic women in this study.

**Major themes.** Major themes in the NAUWU responses are that a large percentage of the autism-focused social skills programs that participants attended are: not cognizant of individuals or their unique sensory and communicative needs; do not recognize participants' existing social abilities and accomplishments; do not provide age-appropriate or gender-inclusive instruction; do not include information that is directly pertinent to the needs and situations of participants; and do not support or consider autistic ways of learning and autistic ways of being social. Canadian neuroscientist Laurent Mottron (2011) notes that most autistic people “face the harsh consequences of living in a world that has not been constructed around their priorities and interests” (p. 33), yet these ostensibly autism-focused social skill programs seem to do little to soften such consequences.

The focus in much of autism research and treatment is to frame autistic people's deviations from neurotypical social, behavioral, linguistic, and developmental norms as medical and neurological pathologies. This deviation-as-pathology focus, and the authoritarian medicalization that it has spawned, has negatively affected the behavioral interventions and social skills training programs that autistic people receive. Many of the

NAUWU participants reported that the programs they attended focused on modifying, masking, or extinguishing signs of autistic-typical behaviors in favor of neurotypical social norms. However, these neurotypical social norms – and the very concept of normality itself – were only rarely explained as social constructions, while the social model of disability was mentioned in connection to only two of the 91 programs studied.

Autism is openly framed in many of these purportedly helpful programs as a deficit condition in need of intensive correction. Lost completely in this deficit framing are the voices of autistic people, their agency, their unique and valid social abilities, and the hard-won expertise they have gained as members of a socially and medically stigmatized population. Sociologist Douglas Maynard (2005) notes that “much has been said about what autism is not rather than what it is, a form of being in the world” (p. 500). The NAUWU study strongly suggests that this autistic form of being is not supported in the lion’s share of social skills training programs and behavioral interventions that are provided non-consensually to autistic children and adults.

In the next and final chapter, NAUWU participants share their ideas about what would have made these social skills training programs helpful, respectful, supportive, and effective.

## Chapter 5

### Eight Recommendations for Improving and Humanizing Social Skills Programs for Autistic People

*I have found that my biggest issues (as judged by what causes me to become ostracized from groups, or drive away individuals) are ones of calibration, that is: of intensity, not of content. I have picked up an extensive list of rules and algorithms, many from verbal corrections by people who were nice enough to take me aside and explain. But it is much harder to create a hard-and-fast rule about calibration. Learning what signals are indicative of incorrect calibration is a good start, but barely so. Understanding when you are going wrong, while better than nothing, is inferior to avoiding mistakes in the first place. — NAUWU participant*

NAUWU participant responses suggests that social skills training programs for autistic people tend to focus on normality, yet do not explore normality as a social construction that privileges the majority, the typical, and the unremarkable. NAUWU participants also noted that these programs tend not to request or include their preferences in curriculum design, and tend not to consider their needs, opinions, autonomy, or agency in curriculum implementation; as such, these programs are not meeting the needs of their intended population. In response to these shortcomings, NAUWU participants shared what they would have changed or included in the social skills programs they attended, and what they would create now, looking back.

- *A respect-based one-on-one session that taught based on what the client saw as important.*
- *One that would \*explicitly\* state there is no one "right" way to be sociable/interact with other people. Showing all kinds of different social situations like 9-5 work days, 3rd shift, people who talk on the phone for hours etc.*

- *It would be more of a mutual support group to share strategies to use as needed than a medicalized attempt to fundamentally change the patient. I just started a student organization at my college partly because I think this sort of thing will help students get by academically and socially. I think, if they helped each other, more autistic and otherwise disabled students would graduate.*
- *The class would have to be taught in parallel tracks: one for people like me who need in-person verbal instruction because we can't do text-based anything in real time; and another for people who learn best by text-based instruction and who can keep up with real-time chat-room like discussion. For the latter, there'd need to be laptops available for those who don't have their own, and a LAN so discussion could happen in text. Of course, this latter track could happen over the internet, which would be excellent for people who have mobility issues. There could be other tracks, too, depending on people's needs, and depending on the technology used.*
- *Nothing for toddlers!*

Throughout the NAUWU survey, autistic people's expertise in regard to program parameters and curriculum design was abundantly evident. Their suggestions and ideas for what they would create now, plus their responses to other NAUWU questions, are organized into eight categories in the order of prevalence and stated importance, and curriculum design suggestions are included.

### **Eight Recommendations for Improving Autism-Focused Social Skills Programs**

1. **Individualized curriculum:** Most participants (even those who enjoyed their programs) would have included individualized, one-on-one or small group instruction and a focus on their specific needs, concerns, and interests. Many participants expressed frustration about crowded, impersonal, and/or scripted programs with very little relevance to their actual lives.

*Curriculum design suggestions:* Intake questionnaires or interviews will help program providers prepare focused and relevant curriculum to better meet the individual needs of program participants.

2. **Age- and ability-appropriate curriculum:** Most participants asked for more appropriate curriculum for differing ages and ability levels. Many participants expressed frustration with cartoons, scripted skits, flash cards, and written materials aimed at young children. Others were overwhelmed by curriculum that required them to read, watch videos, speak, or interact quickly in communicative forms that were not comfortable for them. Many participants expressed frustration at being unable to type their responses, at being unable to engage with curriculum in text format, or at not being given the opportunity to learn at their own pace.

*Curriculum design suggestions:* Intake questionnaires or interviews will help program providers learn who their students are and how to provide suitable materials, appropriate learning accommodations, and focused curriculum.

3. **Acceptance-based approaches to autistic ways of learning and autistic ways of being social:** Many participants wished that their programs had been welcoming to them and aware of their unique learning styles and innate social skills. Many envisioned autistic-created and autistic-led programs focused on how to live, not as neurotypical-appearing people, but as happy, autistic-typical people who knew how to navigate in neurotypical culture rather than being “assimilated” by it. These proposed programs would include autistic peer mentoring, self-advocacy training, disability rights awareness, and ethnographic approaches to understanding neurotypical behaviors *as* behaviors, and not as the only blueprint for how to be human. This fully

autism-positive curriculum was not offered in any of the 91 social skills training programs NAUWU participants described.

*Curriculum design suggestions:* Program providers can invite autistic professionals (and autistic community members) with a neurodiversity background to support them in rebuilding curriculum to focus on acceptance and empowerment rather than on mere normalization enforcement.

4. **Sensory awareness about surroundings, groupings, and activities:** Many participants reported sensory issues in regard to classrooms that were too noisy, brightly lit, or crowded, and in regard to enforced social activities that were too frenetic. Many requested rest and recovery time during classes, and the freedom to step away from groups and activities at any time in order to self-regulate.

*Curriculum design suggestions:* Sensory sensitivities and social preference issues can be addressed by program providers as a part of designing and implementing individualized, suitable, and appropriate curriculum. Curriculum providers should also be properly trained (by autistic professionals with a neurodiversity background) and flexible enough to respond skillfully to any sensory, self-regulation, or social preference issues that may arise.

5. **Full inclusion:** Many participants would have welcomed “friendly neurotypicals” in their groups, especially during the social interaction, communication skills, and emotion recognition portions of their programs. In emotion recognition training in particular, many participants found flash cards or still photos of faces to be unhelpful or too simplistic, and would have preferred live demonstrations and discussions about how emotions are felt and displayed by a variety of autistic and neurotypical people.

School-age participants also requested that their neurotypical school peers be welcomed into these programs so that they wouldn't be pulled away from their actual social lives in order to learn scripted social skills in artificial environments.

*Curriculum design suggestions:* Program providers can work with students, their families, their peers, and autistic professionals and community members to create an open, inclusive, and neurodiverse atmosphere rather than artificially segregating students from their real social lives and their communities.

6. **Gender inclusion:** Many female participants felt left out in social skills programs that were primarily created for (and primarily attended by) men. None of the women in the NAUWU study asked for gender exclusive programs; instead, they wanted more gender balance in these programs.

*Curriculum design suggestions:* Program providers can survey autistic women about their needs and work to build curriculum that is gender inclusive. Providers can also welcome self-diagnosed people into these programs as a way to compensate for the extensive biases against formal diagnosis for women, people of color, and other medically under-served populations.

7. **Gender diversity awareness:** As reported in Chapter 4, gender diversity is a fairly prevalent feature of autistic identity that is currently being medicalized as a disorder or ignored altogether. Many participants would include gender diversity awareness, specific conversations about GLBTIQ (Gay, Lesbian, Bisexual, Transgender, Intersex, Queer/Questioning) issues, and an open and welcoming approach to diverse, nonbinary, and gender-fluid identities.

**Curriculum design suggestions:** Program providers can initiate and support open conversations about gender identity among participants, or invite members of the local GLBTIQ community to present information on gender diversity and community resources.

8. **Drama and improvisation:** As reported in Chapter 4, the word “fun” only appeared in relation to programs that included drama and improvisation. Some participants did not appreciate scripted skits, but their complaints related to having been required to act in scripted ways in hypothetical situations. Truly improvisational approaches were suggested as a way to practice social behaviors or re-enact real-life situations in order to gain clearer understanding of neurotypical social norms. Improv with “friendly neurotypicals” was also suggested as a way to explore emotion recognition and emotion displays in a variety of autistic and neurotypical people.

**Curriculum design suggestions:** Program providers can engage the expertise of local actors and drama departments, or, as one NAUWU participant suggested “everyone should just immediately run out and get a minor in theater from their local college, right away.”

### **Toward the Humanization of Social Skills Training Programs for Autistic People**

- *I think one-on-one social coaching would have suited me much better. This approach would have been much more targeted since I could have worked just on voice modulation and eye contact, not wasting my time learning about basic etiquette.*
- *The group I am helping develop has the larger social group where people interact at their own pace with various activities to pertain to multiple interests, but we are adding a mentoring component where people are paired with mentors to help them.*



- *I would create (and DO teach) that autism is its own, valid culture and that autistic people follow a different (but VALID) developmental trajectory.*
- *One that teaches social skills needed for special interests, to the fullest extent, and is taught by Autistics who currently work in those fields.*

Educator Thomas Hehir (2002) writes that “School time spent devoted to activities associated with changing disability may take away from the time needed to learn academic material” (pp. 3-4). For autistic children and adults, it is not merely school time that is impacted; for many autistic people, large chunks of home time, leisure time, school time, *and* work time are devoted to changing autistic-typical behaviors into neurotypical-appearing behaviors.

Social skills training programs for autistic people are, by and large, based on the biomedical view of autism as a deficit and disorder in need of intensive correction. As such, these programs tend to focus on enforced normalization training and the modification or erasure of autistic-typical behaviors, learning styles, communication preferences, and interests. All of these corrections and modifications require that enormous amounts of time and energy are taken away from regular life. Additionally, most social skills training programs for autistic people separate them from their social lives, from their school mates, from their families, and from their communities. This time-intensive segregation is counterproductive to the authentic acquisition of social skills and social awareness.

It is also very concerning that toddlers and young children enrolled in 25-40 hours of behavioral training per week may be missing out, not only on academic learning, but also on interpersonal and social learning about who they are as individuals and who they are within the social fabric of their families and neighborhoods. These intensively trained

children are essentially enrolled in nonpaying full-time jobs in which one of their central tasks is to modify or extinguish their autistic traits in order to appear to be indistinguishable from neurotypical children. In their task-filled early lives, how much time do these children have to play, to sleep in, to meander and goof off, to discover their special interests, to develop their own individual responses to stimuli, to think their own thoughts about the world, and to simply be children? And how do autistic teens and adults enrolled in an ongoing series of these social skills training programs maintain a healthy sense of self when their identities, preferences, communication styles, gender identities, and even their bodily movements are labeled as medicalized deficits and targeted for modification or erasure?

Sociologist Anne McGuire (2012) states that autism is “a social identity category and, as such, a viable and valuable way of being in the world” (p. 63). Medicalized narratives of loss, lack, and deficit have produced a pervasive view of autistic people as abnormal and socially incompetent beings who require extensive normalization and social skills training – yet the results of the NAUWU study suggest that these training programs are not providing supportive, effective, or truly educational approaches to normality and neurotypical social norms. Additionally, the 91 social skills training programs that NAUWU participants described did not respect (or in many cases even consider) autistic ways of being; as such, these programs are not meeting and cannot meet the true needs of this population.

It is important to note that some NAUWU participants questioned the idea that autistic people need social skills training programs at all, and neuroscientist Laurent Mottron (2011) writes that “in many instances, people with autism need opportunities and

support more than they need treatment” (p. 35). The Nothing About Us Without Us study suggests that a crucial facet of this support is to listen to autistic people and work with them *as* people, and not as deficit-framed members of an abnormal population.

When autistic expertise is requested and valued, program providers can develop autism-positive social skills approaches that respect the innate dignity, social intelligence, and autonomy of autistic people. This respect-based approach will help providers focus on their students’ stated needs, preferences, and autistic-typical ways of being social. This respectful approach is particularly important in regard to the non-consensual nature of these programs; with a humane and client-centered focus, these programs can move away from medicalized and authoritarian approaches that enforce normalization, and move toward providing humane, effective, appropriate, and meaningful support.

### **Recommendations for Further Research**

**Include autistic voices in all research studies.** Within the online autistic community, there are impromptu peer review committees that convene to evaluate studies of autism. These reviews are often top-notch and scathing critiques (Cohen-Rottenberg 2012b; Willingham, 2011; Yergeau, 2010) that challenge the dehumanizing and ableist foundations upon which many autism researchers build their hypotheses. Autism research would be improved immeasurably if researchers would engage with autistic individuals respectfully and ask about what certain behaviors or differences mean *before* describing them, problematizing them, or attempting to develop research questions about them.

**Seek content validity in all questionnaires and surveys for or about autistic people.** Many of the autistic people who previewed and approved the finalized NAUWU survey questions reported that most surveys they had seen or taken were inherently

ableist, and asked offensive and dehumanizing questions. Survey researchers can improve and humanize their work by intentionally seeking autistic people's input before their surveys are finalized.

**Focus research specifically on autistic girls and women.** Autistic girls and women are currently an under-diagnosed, under-recognized, and under-studied group. The decidedly female-centric nature of the NAUWU population may be explained by the five considerations listed in Chapter 4, or it may be a previously unrecognized feature of the autistic community. More studies that focus on autistic girls and women – and especially studies that welcome self-diagnosed people – are sorely needed.

**Approach autistic gender diversity as a fundamental aspect of identity.** Gender fluidity and gender diversity are intrinsic aspects of identity for many autistic people. The current approach in much of autism research is to problematize and pathologize autistic gender diversity as fundamentally disordered. Studies that rigorously interrogate gender essentialism and the commonplace dehumanization of autistic people are needed – as are critical studies that explore the intersection of disability rights-focused “crip theory” (McRuer, 2006) and human rights-focused “queer theory” (Sullivan, 2003).

## **Conclusion**

Autistic people are an exhaustively researched population – and yet as individuals and as human beings, they are essentially unheard. This silencing has meant that autistic people tend not to be portrayed as valid human beings with tangible social capacities and pertinent expertise about their own needs, their unique ways of learning, and their real lives. Instead, the dehumanizing portrayal of autistic minds and bodies has wide-ranging negative impacts on the clinical, medical, social services, and educational supports

offered to autistic people, and it especially impacts how autistic social lives and autistic social capacities are framed.

Social skills training programs for autistic people can begin to provide meaningful, humane, and worthwhile support when their program providers learn to interrogate normality, support autistic ways of learning and autistic ways of being social, and request, respect, and incorporate the stated needs of autistic people into the design and implementation of these programs.

## Appendix A

### Survey Questions

#### NOTHING ABOUT US WITHOUT US

A Survey for and About People on the Autism Spectrum

Approved by the Sonoma State Institutional Review Board on 7 February, 2014

#### Survey Questions Relating to Formal Autism-Focused Social Skills Programs

- Your Age
- Your Sex/Gender identity
- Current State or Country
- Age at realization, recognition, or diagnosis of autism, Asperger's Syndrome, or Pervasive Developmental Disorder, Not Otherwise Specified
- Number of siblings
- Have you taken any social skills, relationship skills, social interaction, or communication classes or programs intended for people on the Autism Spectrum?  
(Yes/No toggle and redirect [1])

#### YES [1] answers follow this flow

- How many of these classes or programs did you experience? (if more than one, all questions in this flow will be asked about each program)
- What kind?
- How did you learn about this class or program?
- Who referred you to this class or program?
- Did you find this class or program to be:
  - Clear and understandable? (Likert scale)
  - Respectful of your autonomy? (Likert scale)
  - Pertinent to you and your needs? (Likert scale)
  - Focused on your way of learning? (Likert scale)
- What skills did you develop in this class or program?

- What approaches or ideas would you have included?
- What would you change?
- What would keep?
- Would you recommend this class or program to others? (Yes/No)
- Why/Why not?
- What kind of class or program (if any) would you create now, looking back?

#### Final message

Thank you for your time! I appreciate your participation in this study. Please share this study with others who are on the Autism Spectrum; there is a wonderful depth of information within the autism community, and I would love to hear from as many people as possible.

## Appendix B

**Table 2**

*NAUWU Sex and Gender Identity Categories*

<b>Sex and Gender Identity as Reported by NAUWU Participants</b>	<b>Number</b>
AFAB [Assigned Female at Birth], genderfluid	1
agender	8
Agender, usually masculine-presenting but fluid	1
androgynous	3
androgynous	2
androgynous Female	1
Bigender	1
Bigender - Trans Female & Genderqueer	1
biological Female	1
Biologically Female by birth, two-spirit by identity (gender fluid)	1
Butch woman	1
cis <sup>15</sup> Female	9
Cis male	1
cisFemale	1
Cis-Female	2
Cisgender Female	3
cis-gender Female	1

<sup>15</sup> Cis and cisgender were coined in the 1990s (Blank, 2014) to denote a person whose biological sex agrees with his, her, or their gender identity. For instance, a biological female who identifies as a woman is cisgendered, and an intersex person who identifies as androgynous or bigender is also cisgendered.



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Cisgender woman	1
Cisgendered male	1
Cisgendered man	1
Cis-Male	1
Complicated	1
Currently unsure	1
DemiFemale	1
Female	270
Female (Cisgender)	2
Female body, agender	1
Female sex, queer identity	1
Female, androgyne	1
Female, androgynous	1
Female, gender fluid	1
Female, gender-neutral	1
Female, non-binary	1
Female/Female	1
Female/gender-nonconforming	1
Female/queer	1
Female-ish	1
Femme	1
femme cisgender lesbian	1
gender fluid (leaning Female)	1

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gender nonconforming woman	1
gender queer	1
Genderfluid	6
gender-fluid	1
Genderfluid (FAAB) [Female Assigned at Birth]	1
Genderfluid Asexual	1
Genderqueer	9
Genderqueer (Female/agender)	1
genderqueer (unfortunately perceived as Female, but that's not who I am)	1
Genderqueer/Female-toward-male transgender	1
gray-agender demigirl / asexual / gyneromantic	1
It's complicated. (Non-newtonian genderfluid) I round down to woman.	1
Male	105
Male, but prefer to be Female	1
male/gender fluid	1
Male; non-binary trans	1
Male-presenting	1
masculine-neutral	1
mostly Female, some neutrois <sup>16</sup>	1
non binary	1
nonbinary	1
Non-binary	3

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<sup>16</sup> Neutrois means genderless or agender.

non-binary (dfab) [Designated Female at Birth]	1
nonbinary femme	1
Non-binary trans*	1
nonbinary/genderqueer afab [Assigned Female at Birth]	1
non-binary/trans male	1
none/genderfluid	1
probably fluid or queer	1
sex = Female, gender identity = male	1
trans and genderqueer	1
(Trans) male	1
trans* woman	1
transfemme	1
Transgender male	1
Transmasculine	1
transsexual male (agender/genderless)	1
Two-spirit	1
<b>TOTAL: 77 Unique Descriptors</b>	<b>488</b>

*Note:* Participant responses were standardized to *Male* from Man, male, M, or m – and to *Female* from Woman, W, w, female, F, or f. However, in order to respect the rich diversity of the responses, all original word-pairings were treated as distinct answers (i.e., *cisFemale*, *cis Female*, and *Cis-Female*); hyphenations were treated as distinct answers (i.e., *Genderfluid* and *gender-fluid*); and unique modifiers were preserved as distinct answers (for instance, *Male-presenting* was not standardized to Male, and *Female/Female* was not standardized to Female).

## Appendix C

### Diagnostic and Statistics Manual of Mental Disorders, fifth edition (DSM-5)

#### Autism Spectrum Disorder: 299.00 (F84.0) Diagnostic Criteria

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

**Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table).**

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

**Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table).**

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum

disorder and intellectual disability, social communication should be below that expected for general developmental level.

**Note:** Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

**Specify if:**

**With or without accompanying intellectual impairment**

**With or without accompanying language impairment**

**Associated with a known medical or genetic condition or environmental factor**

(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

**Associated with another neurodevelopmental, mental, or behavioral disorder**

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

**With catatonia** (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition)

(**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

### DSM-5 Table: Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Retrieved from: <http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>

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