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## Stimming Expresses Empathy, not to be Masked or Persecuted: A Scoping Review and Case Study of the “Double-Empathy Problem” Solved by Recognizing the Autism Language

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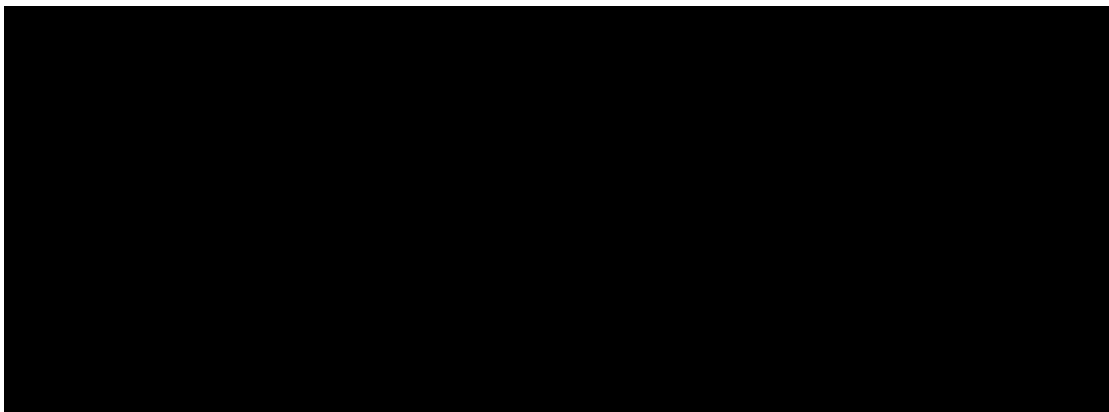
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ACCEPTED AND SIGNED:



From where did the albatross about my neck come? I know not, for mine eyes sting with the rotten stench of it. It is Assumption. It is Ostracism. It is Oppression. It is too heavy to unload with mine own hands. I flap and I hop, but it will not budge.

## **Stimming Expresses Empathy, not to be Masked or Persecuted: A Scoping Review and Case Study of the of the “Double-Empathy Problem” Solved by**

### **Recognizing the Autism Language**

#### **Introduction**

Person-first language has historically been practiced in the clinical literature (Centers for Disease Control, 2020b). However, many autistic individuals and autism advocacy groups prefer identity-first language (Brown, 2021). Now, scholarly writers are beginning to follow suit (Gernsbacher, 2017). This paper reflects the changes society is beginning to make by endorsing identity-first language.

The purpose of this scoping review and case analysis is to critically examine autism and autistic stimming through the lens of both the neurotypical and the autistic, evaluate the confines currently imposed upon autistics by neurotypical society, and synthesize what autistic leaders have expressed about their experiences striving for inclusion so co-empathy can be experienced (Gernsbacher, 2017; Milton, 2012). This paper highlights the form, structure, and predictability of stimming, like sign language is for the deaf. Moreover, the stimming language can even be taught to non-stimmers.

The following research questions guided the project:

1. What are the current and historical perspectives of the autistic population throughout the lifespan? How have past assumptions about autistics and stimming influenced neurotypical society’s perceptions of neurodiverse individuals today? How deeply have those perceptions been woven into interpersonal communications?
2. What is empathy? How to neurotypicals express and interpret empathy? What have autistic community leaders and researchers expressed about autistic empathy? Is

- stimming a component of the autistic's empathy dialogue? How does the neurotypical interpretation of an autistic's stimming reflect on the health and well-being of the autistic?
3. What types of interventions have been attempted with autistics to try to connect with them? What has been the effect of those interventions on autistic mental health?
  4. Is there a better way to connect the neurotypical and neurodiverse worlds in empathetic communication?

Questions 1-3 lend themselves to a scoping review. The following themes were identified using various methodologies: (a) prevalence of autism, (b) the interpretation and measurement of empathy, (c) discovery of genetic factors transformed autistics' identity, (d) publication of non-genetic factors such as vaccines undermined the legitimacy of the autism language, (e) the problem with the lack of social language legitimacy, (f) autistic empathy, (g) past and current interventions, (h) destructive interventions thwart connection and cause mental health decline, (i) neurotypical perceptions of the autistic; and (j) the responsibilities required in dual communication.

One important revelation of the scoping review was that maltreatment of autistics encouraged autistics themselves to dive deeply into autism research. These autistic-led studies, now at the forefront of the neurodiversity movement, are growing in fervor. These studies show there may exist an autism language that has not yet been defined or interpreted in a way the neurotypical community can comprehend. Moreover, it is this lack of understanding neurotypicals have of the autistic that causes a disconnect between the two groups (DeThorne, 2020; Kapp et al, 2019a; Milton, 2012).

Succeeding the scoping review is a retrospective case analysis in an attempt to answer the fourth research question. The case study exemplifies the immediate, familial connection a significantly autistic girl made with this researcher when I incorporated autistic social rules in my address of her. This retrospective case study represents the voice of one individual to be seen, heard, and known through the language of her stimming. Illustrations of other interactions will also be highlighted in several vignettes.

This scoping review and retrospective case study are warranted to provide a summary of the current literature, identify gaps for future study, and help justify the need to assess whether stimming is a language worthy of formal interpretation and reciprocity, so the choices made by the neurotypical majority for inclusion have a foundation in mutual understanding. It is this author's hope that the reader concludes that autistic empathy is physically manifested by the language of stimming; that it has form, structure, and predictability; and that it can be taught to neurotypicals.

## **Background**

### ***Definition and Prevalence of Autism***

An individual is categorized as autistic due solely to symptomology, specifically their stereotypical patterns of behavior or interests, by expert opinion and consensus (Pantazakos, 2019). Difficulties with communication, socialization, and learning within the neurotypical world are common (Rutherford & Johnson, 2019).

The prevalence of autism rose from only a few known worldwide in the 1800s (Bettelheim, 1959) to now being 1-2% of the population as of 2016, the most recent analysis to date (Chiarotti & Venerosi, 2020). As the population has become more autistic, people who identify as neurotypical are more likely to have met or known someone on the spectrum.

Whether judged from the neurotypical's standpoint or the autistic's, these interactions do not tend to go smoothly, and the autistic is usually the one held accountable for it (Alkhaldi, 2019; Baggs, 2007; Denome, 2018; DeThorne, 2020; Koehne et al., 2015; Milton, 2012; Sng et al., 2021).

### ***Definition of Empathy***

The Cambridge English Dictionary defines empathy as “the ability to share someone else's feelings or experiences by imagining what it would be like to be in that person's situation” (Cambridge.Dictionary.com, n.d., para. 1). Ample research is available about the process of how neurotypical people express and receive empathy (Batson et al., 2007; Benbassat & Baumal, 2007; Riess, 2017) as well as how empathy is measured (Côté et al., 2011; Fabes et al., 1993; Fabes et al., 1994; Kiersma et al., 2013; Stellar et al, 2015; Williams et al, 2016) so much that it now is part of the layperson's vocabulary. Even WikiHow has a tutorial on it (Rube, 2020).

## **Literature Review**

### **Frameworks**

Multiple frameworks and theories were considered for comparing autistic and neurotypical empathetic prosody (see Appendix A for a glossary of terms). Three models were most influential: Model of Human Occupation (MOHO) (O'Brien et al., 2010), Critical Disability Theory (Tremain, 2005), Critical Autism Studies (Sinclair, 1993).

MOHO is used primarily by occupational therapists to inform their practice. Volition, performance, habituation, and environment are all realized for the individual and the environment when MOHO is applied. Volition refers to a person's thoughts and feelings about their ability to perform what they want to do in life. Habituation is a person's daily



routines and expectations. Performance is influenced by neurophysiological abilities. Environment is the context, and the objects and people within it (O'Brien et al., 2010). Stimming and echolalia are neurophysiological functions that occur in all environments so the positive or negative perception that a neurotypical has of stimming and echolalia affects an autistic person's environment. Such a change impacts the expectations autistics have for themselves, their habits, and their thoughts and feelings about themselves, which ultimately shapes their social performance (Krieger et al., 2018).

According to Critical Disability Theory (Tremain, 2005), the neurotypical is in the social majority so controls who is included and excluded in society. Neurotypical assumptions about the autistic, in general, and stimming, in specific, continue to influence the neurotypicals' choices for inclusion. Critical Autism Studies (CAS) (Sinclair, 1993; Woods et al., 2019) is derived from both Critical Disability Theory and Autism Studies, the interdisciplinary study of autism. Its definition has been hotly debated in the research community. However, the following definition was recently adopted by autistic scholars (Woods et al., 2018):

The 'criticality' comes from investigating power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability.' (Waltz, 2014, p. 1337)

Critical Disability and Critical Autism Studies are centered in the neurodiversity movement, with autistics raising their voices in advocacy on all research platforms. MOHO, Critical Disability Theory, and Critical Autism Studies were essential frameworks for this project.

### **The Measurement and Interpretation of Autism**

### *Symptomology*

Autism is currently diagnosed based largely on expert opinion or consensus regarding the individual's symptoms. However, no behavior exists that is only manifested by autistics (Rutherford, 2019). *The Diagnostic and Statistical Manual for Mental Disorders*, 5<sup>th</sup> edition, (DSM-5) symptoms are (a) difficulties with social communication and (b) social interaction (c) across contexts (d) that are present during the early developmental period. Masking of symptoms may be learned and still qualify for the diagnosis. Severity is greater when repetitive behaviors or interests are present (Centers for Disease Control, 2020a). Six cognitive theories on autism are circulating in the research community: (a) autistics lack Theory of Mind to empathize; (b) autistics are impaired in executive function for ideation, motor planning, and continuation of a task (e.g. social interaction) to completion (Demetriou et al., 2019); (c) autistics have “weak central coherence” and so cannot see the big picture (Happe & Frith, 2006); (d) context blindness affects autistics because they cannot register sensory information adequately (Vermeulen, 2015); (e) autistics have a tendency toward monotropism which makes it hard for them to shift attention between multiple stimuli (Rutherford & Johnson, 2019); (f) a “double empathy problem” exists in which the blame for misunderstanding rests equally on the shoulders of the neurotypical and the autistic (Milton, 2012; Mitchell et al., 2019). This paper seeks to support the latter and take it one more step further, that autism is its own language like sign language is for the deaf. Moreover, it should be taught as such.

### *Discovery of Genetic Factors Transformed the Autistic Identity*

Both genetic and non-genetic factors contribute to the onset of autism spectrum disorder (ASD). As the population has become more autistic, a greater push has been made

by researchers to map the human genome (Little et al., 2003), do it cost effectively (Schloss et al., 2020), and find the autistic variant (Searles-Quick et al., 2021).

The genetic link was first identified in twins and then in extended family studies. At first, a much higher rate of ASD was found to be present in monozygotic/identical twins (92%) than in dizygotic/fraternal twins (10%) (Bailey et al., 1995; Folstein & Rutter, 1977). Later studies, however, showed this severe difference was likely inflated due to ascertainment bias (Ronald & Hoekstra, 2011). But that does not mean there is not a connection. Extended family studies found a 10-fold risk for sibling reoccurrence and 2-fold risk for cousins (Sandin et al., 2014) and identified rare genetic sequence variants that signified a high risk for ASD (Matsunami et al., 2014). Geneticists thus far have found 102 disruptive genetic variants, or mutations, 30 of which confer new or enhanced activity on proteins, associated with autism (Satterstrom et al., 2020). This discovery transformed the autistic identity (Anderson-Chavarria, 2021).

There is significant genetic overlap between ASD and other neuropsychiatric and neurodevelopmental disorders (Cukier et al., 2014). Co-morbid genetic disorders include epilepsy, schizophrenia, depression, intellectual disability, Tourette's (Cukier et al., 2014) as well as attention deficit disorder, sleep disorders (Richdale et al., 2009), and gastrointestinal problems (Valicenti-McDermott, 2006). Mutations occurring at more than one genetic site can cause the same observable characteristics, indicating that a single mutation can have wide-ranging effects (Cukier et al., 2014, Searles-Quick et al., 2021). Even though geneticists located many loci and genes related to autism etiology, no pathogenesis has yet been identified (Searles-Quick et al., 2020). Moreover, no "autism gene" has been located to

date that when mutated, causes autism without also causing intellectual impairment or neurodevelopmental disorders (Myers, 2020).

Autism is heterogenous and research in it often finds contradictory abnormalities (Levy, 2019). “ASD lacks biological and construct validity” (Levy, 2019, para. 8). Currently, there are multiple subgroups of autism, each vastly different than the other. This has made it difficult for scientists to even talk about autism without questioning which autist they are referring (Levy, 2019), for autistics are far from linear (Anderson-Chavarria, 2021).

The drive to find a genetic component of autism, the de-institutionalization of autistic people, and the birth of the neurodiversity movement all started in the early 1970s (Akerley 1979; Eyal, 2013; Folstein & Rutter, 1977). Communication issues were no longer attributed to psychosis or stubbornness on the part of the autistic, but instead due to hard wiring. It was during this time, in the 1970s, that communities of autistics started to teach the autistic language to neurotypicals (Eyal, 2013).

### ***Environmental Factors***

Scientists currently theorize that autism is caused by the interaction of both genetic and environmental factors (Gordon et al., 2012; Myers et al., 2020). Yet, how varied the etiological evidence is as well as the misinformation surrounding ASD have made autism research much more complex than the first twin studies surmised. In the 1980s researchers realized autism is inherited (Folstein & Rutter, 1977; Ritvo et al, 1985) with chromosomal links (Gillberg & Wahlstrom, 1985; Wahlstrom et al, 1986). This was evidenced first by locating discordant variations amongst monozygotic twins (Gordon et al., 2012; Kaminsky et al., 2009; Wong et al 2010) with considerable symptom severity differences (Ronald & Hoekstra, 2011). Environmental risk factors for autism that are widely accepted in the

scientific community are prenatal viral exposure during the first (Kamiri et al., 2017) or second (Atladottir et al., 2010) trimester of pregnancy as well as maternal age (Rubenstein et al., 2019; Sandin et al., 2021), paternal age at conception (Reichenberg et al., 2006, Yassin et al., 2019), and zinc deficiency (Pfaender et al., 2017; Yasunda et al., 2011). Controversies, however, remain. For example, many still believe that metal deficiencies and vaccines (Jang et al., 2017) also cause autism. Social media is the driving tool for autistic misinformation becoming mainstream news (Jang et al., 2017). Leading people to believe that autism is a side-effect of medical practice or disease, rather than an inherent characteristic of one's being, undermines the legitimacy of the autism language and gives credence to neurotypicals choosing to not explore co-empathy with them.

### **The Measurement and Interpretation of Empathy**

Biologists think neurotypical human empathy evolved from the mothering, caretaking, and resource sharing characteristics of mammals. Animal studies showed mammals interpret other's intentions to guide their social interactions (Panksepp & Panksepp, 2013). David Hume in 1739 said, "the minds of men are mirrors to one another," (p. 366) sparking a debate on the psychology therein. "Einfuhlung" or "feeling into" was first used by Robert Vischler to describe how a person understands an object or illusion (Vischler, 1873). It was later coined by Theodore Lipps (1903) while feeling his gut wrench watching a tight-rope walker, to measure how a person understands the mental states of other people. He called it "empathy" (Lipps, 1903). Empathy is required for all prosocial behavior (Eisenberg and Fabes, 1991).

There are multiple schools of thought on this topic, each discipline defining it slightly differently. They differ primarily on whether empathy is a contagion-like process of imitation

or if it incorporates higher level cognitive skills in perspective-taking that require Theory of Mind (Leiberg & Anders, 2006). Perspective taking is the process of using information from different sources to infer what someone is feeling, while inhibiting one's own feelings about it (Batson et al., 2003; Davis, 1996; Feshbach, 1978). Theory of Mind requires one to (a) attribute feelings and mental states to oneself and to others, (b) acknowledge that another's mental state may be different than one's own, and (c) understand that behavior is influenced by mental state (Premack & Woodruff, 1978). Simulation theorists think that we automatically understand other people's mental states and emotions by activating a representation of that state in our own minds (Goldman, 2005, 2006; Gordon, 1986) via mirror neurons (Gallese & Goldman, 1998; Gallese et al., 2004). Perspective-taking may either be self-focused or other-focused, but it always incorporates context. Self-focused perspective taking is imagining oneself in the other person's situation while other-focused is imagining what the other person is thinking or feeling (Batson et al., 1997; Davis et al., 2004). An even greater divide exists regarding the nuances of empathy. Social psychologists define empathy as a tenderness in response to seeing another's suffering (Batson et al., 1987). Developmentalists see it as an emotional response that is congruent with the emotional state of another (Hoffman, 1975). Personality researchers know it to be a trait while researchers in psychotherapy view it as a cognitive skill (Leiberg & Anders, 2006).

Empathy is thought by critical hermeneutic philosophers to be culturally mediated (see Appendix A). Judgement of whether an action or response is empathic is constrained by tradition, prejudice, and time (Kinsella, 2006).

Even how the term empathy is operationally delineated from sympathy and personal distress continues to be debated (Eisenberg et al., 1991, 2015). But the following three

components are shared across all disciplines: emotion sharing, cognitive perspective taking, and empathic concern for another's welfare (Decety & Meyer, 2008).

Currently empathy is measured across a multitude of facets. The first measurement of empathy was the Hogan Empathy Scale (Hogan, 1969). It was used exclusively until the early 1980s until psychometric analysis demonstrated it to have low test-retest reliability and low internal consistency (Roth & Altmann, 2021). The Interpersonal Reactivity Index (Davis, 1983) replaced it. However, it was deemed invalid as it was determined to not actually measure components of empathy (Baron-Cohen & Wheelwright, 2004). The Toronto Empathy Questionnaire (Spreng et al., 2009), Single Item Trait (Altmann & Roth, 2013), and others like them rely on the respondent's own personal definition of empathy rather than a definition based in research. These lack validity as measures of empathic emotion because the traits measured are susceptible to positive and negative self-biases and results do not correspond well to labels given by others (Roth & Altmann, 2021).

Expert analyses also lack validity because (a) relevant information about the person being assessed, such as their intention, is not known by the observer, (b) it is unclear if the results measure the target's empathy as each observer uses different information to base their ratings on, and (c) expert analyses do not correlate well to the target's actual emotion recognition ability (Roth & Altmann, 2021). Scholars are now calling to redesign and restructure autistic socio-emotional ability assessment and research (Olderbak & Geiger, 2019).

Recent attempts have been made to design more concrete, and therefore valid, measurements of empathy and autism. Physiological measures of empathy such as vagal tone (Palser et al., 2020; Porges, 2011; Stevanovic et al., 2021) and brain imaging (Castelhana et

al., 2017; Cote et al., 2011; Tso et al., 2018; Wada et al., 2021), as well as observation of pro-social behavior such as comforting someone in distress (Meng et al., 2017), offering eye contact (Lasagna et al., 2020), and walking in time with another person (Cheng et al., 2017) have been subjects of research. Other measures are assessment-based. These include tests of irony (Nuber et al., 2018) and social competence scales (Trevisan et al., 2018). However, they make up a minority of research topics and clinical assessments compared to less valid forms of measurement (Roth & Altmann, 2021).

Less valid forms of assessments show no difference between autistics and non-autistics, such as False Belief Tasks (Dufour et al., 2013), or have been found to be biased, such as questionnaires and assessments of communicative intent (Li & Koenig, 2019; Roth & Altmann, 2021). Some assessments are unreliable as well, because social prosody is different across cultures (Akechi et al., 2013). It is a wonder how autistic empathy can truly be quantified when there is so much debate about not only the way researchers think it should be measured, but also how to even define it.

### *Autistic Empathy*

Psychiatrists of the early and mid-20<sup>th</sup> century centered their framework on the psychoanalytic theories of Sigmund Freud. They defined autism as “morbid self-absorption,” (American Pocket Medical Dictionary, 1953, p. 68), with damaged Theory of Mind (Baron-Cohen, 1985), incapable of empathy (Koehler, 1927), and a response to frigid mothering (Bettelheim, 1967; Kanner, 1943). They postulated that Theory of Mind, or inferring what another person is thinking or feeling, is common to mankind, but absent in apes and autistics (Koehler, 1929; Premack, 1976; Premack & Woodruff, 1978), causing “mindblindness” (Baron-Cohen, 1985, p.4) and disordered kinesics and prosody (Baltaxe & Simone, 1985,



McCann & Peppé, 2003). Symptoms were disjointed verbal communication and social interaction with neurotypicals, along with stereotypic or “stimming” behaviors. Physicians and providers identified higher functioning, undiagnosed children as mere FLKs or “funny looking kids” (Grinker, 2008, p. 166; Myles & Simpson, 1994) and suggested they learn menial jobs that might bore others, are routine, and demand limited mental ability (United States, 1974). Children who also experienced “mental retardation” required more extensive support and, thus, were institutionalized for monitoring and treatment (Neimark & Neimark, 1977).

Kanner’s negative attribution of Theory of Mind to autistics was misinformation and consequentially debunked (Cohen-Rottenberg, 2009; Gallagher & Hutto, 2008; Leudar & Costall, 2009). Now, Theory of Mind is no longer used as a foundation in diagnosis (Rutherford et al., 2019) and the belief that autistics lack social motivation is inaccurate as well (d’Arc & Soulieres, 2019; Mundy, 2019; Olderbak & Geiger, 2019; Ujarevic et al., 2019). Social motivation as a theory of autism should be relocated to historical analyses, yet it unfortunately continues to be debated today (Gillespie-Lynch, 2019).

Recent literature argues that instead of poor social motivation, autistics have difficulty with social and environmental prediction (Kissine, 2019; Perrykkad, 2019; Riva et al., 2019;). Social prediction is the ability to predict one’s own and another person’s behaviors (Riva et al., 2019). Social prediction requires multisensory integration of environmental and interoceptive information, including social cues, to be successful (Riva et al., 2019).

### ***Autistic Social Rules***

Some researchers posit that autistics follow a different set of social rules (Milton, 2012) and that is why they cannot predict or be predicted by a neurotypical. Autistic communication may diverge from the typical, but the intention for connection is the same. It is not unusual for an autistic to hop, flap, fidget, and make noises that range from squealing to “digga-digga-digga” (personal communication, various autistic children, 1999-2021) or turn sideways and look down when meeting someone new. These autistic mannerisms, however, are often labeled “unnatural” by the neurotypical population, prompting neurotypical mindblindness (Edey et al., 2016) and unfavorable feelings about the autistic (Alkhaldi et al., 2019; Baggs, 2007; Denome, 2018; Grossman et al., 2018, Kapp et al., 2019a; Milton, 2012; Sng et al., 2021).

Researchers in both the neurodiversity movement and the medical community agree that autistics face difficulties with environmental prediction (Krieger et al., 2018; Legault et al. 2019; Milton, 2012; The National Autistic Society, 2016). Legault et al. (2019) stated emphatically, “‘cognitive deficits’ associated with autism are in fact mismatches between environmental resources and the particular form of neurological functioning of autistic people (neurodiversity), brought about by the fact that the cultural niches that set up the relevant fields of affordances are structured by and for neurotypicals” (Legault et al, 2019, p. 1). As a result of trying to fit autistics within neurotypical niches, autistics got forced to participate in various interventions designed to eradicate their mannerisms and, hence, their identity (DeThorne & Sears Smith, 2021; Kevles, 1985).

### ***Past and Current Interventions***

Until the landmark “Declaration on the Rights of the Mentally Handicapped” proclaimed by the United Nations on Dec. 20, 1971, people with identifiable autism did not

have the right to even be recognized as a person (Coleman, 1996). They were denied medical care, schooling, and the right to have a family (Gigli, 1996). Eugenics, the science of improving the quality of the human race through selective sterilization, was popular in Western countries such as England and the United States during the first and second World Wars and made infamous by Hitler's Germany. Autistics were among those forced to participate (Kevles, 1985).

As autistics became more and more human in the eyes of neurotypicals (Coleman, 1996), terror was replaced with pity and then a desire to reverse or improve symptoms. Interventions became focused on correcting the autistic. This medical model of disability empowered professionals and caregivers to treat the individual's deficits, thought unique to autistics (DeThorne & Searsmith, 2021).

The Education for All Handicapped Children Act of 1975 (1975) along with its amendments in 1990 and 2004, the Individuals with Disabilities Education Act (1997) and the Individuals with Disabilities Education Improvement Act (2004), supported early individualized education. Early intervention educational services are provided to children aged 0-3 in their homes. After a child turns 3 these services are picked up by their local school district (Souviron-Kehoe, 2019). School-based interventions are provided under first a multi-tiered system of support (MTSS) and then, if deemed eligible by a primary certifying discipline, under an Individualized Education Plan (IEP). A student on the spectrum may receive general education services under a 504 plan, but this is rare. The most common service providers are special education teachers, speech language pathologists, occupational therapists, and behavior aides. A student is reassessed for eligibility every 3 years (Boroson, 2020).

As of 2017 there are 28 non-medical evidence-based practices and 10 manualized interventions whose researchers have met the criteria of providing an acceptable level of research (Autism Focused Intervention Resources and Module [AFIRM], 2019). These include applied behavior analysis (ABA) techniques (AFIRM, 2019; Dixon et al., 2019; Novak, 2020): cognitive-behavioral interventions, antecedent-based intervention, differential-reinforcement, discrete trial training, extinction, reinforcement, response interruption, and functional behavior assessment (AFIRM, 2019). Researchers in ABA first introduced autistic infants and children to experiments in operant conditioning and social deprivation in the 1960s (Wolf et al., 1967). ABA therapy remains a key ingredient to both the educational and medical management of autistic people. However, more and more researchers are finding ABA to have abusive qualities and so are advocating for its abolishment from autism best practices (Kupferstein, 2018). In addition, the value of non-conforming behavior in education is on the rise (Young et al., 2018).

Many models of practice are used by autism specialists today. These include: the SPELL method, TEACCH, psychotherapy, Augmentative and Alternative Communication (AAC), Ayres Sensory Integration (ASI), the SCERTS Model, sensory processing, equine therapy, social skills groups, video modeling, early intervention, school-based, and pharmacology. The SPELL method is the framework endorsed by the National Autistic Society. It utilizes (S)tructure, (P)ositive approaches and (E)xpectations, (E)mpathy, (L)ow arousal, and (L)inks as a means for responding to the needs of autistic people (The National Autistic Society, 2016). Structure helps to make the world more predictable and therefore less frightening. Positive approaches and expectations based upon careful assessment builds on the autistic's strengths (Beadie-Brown & Mills, 2018). Empathy according to the SPELL

method is working to understand the autistic's motivations and sources of anxiety or preoccupation (The National Autistic Society, 2016). Low sensory arousal environments help autistics down-regulate and concentrate (Krieger et al., 2018; The National Autistic Society, 2016). Finally, links or support networks between autistics, their families, and community reduces misunderstanding and consolidates treatment approaches (Masiran, 2018; The National Autistic Society, 2016).

The TEACCH method compliments SPELL. It was developed in the 1960s by Eric Schopler as a way to maximize students' strengths and promote independence, while accounting for their deficits. The environment is arranged with visual barriers to reduce environmental distractions. Personal visual schedules are hung within reach. Stacked in one pile are work folders incorporating matching, coloring, writing, and other fine motor tasks. Each task has clear directions, structure, and time commitment. Folder tasks incorporate the students' interests so to make doing the task more palatable and functional. Once complete the folders are moved by the autistic to the "all done" pile. There is mixed consensus on the effectiveness of this strategy. Some randomized control trials indicated TEACCH promotes developmental progress and reduces teacher and parent stress (Sanz-Cervera et al., 2018; Zeng et al., 2021) while others showed there was no significant difference between control and experimental groups (Pellecchia et al., 2020). No autistic customer reviews of the TEACCH method were found.

Psychotherapy is also used to treat autism. The greatest success has been with Gestalt therapy life coaching, where the autistic is seen as fundamentally capable (Gregory, 2020). This approach is similar to the Therapeutic Use of Self (Taylor, 2020) found in occupational therapy (OT). Implicit social skills groups are used to teach autistics without intellectual

disabilities proper perception of neurotypical mannerisms in an effort to improve their empathy quotient (Guivarch et al., 2017). Social skills group leaders must emphasize the autistic's autonomy/identity and express respect for their expertise (Burkhart, 2019; Wilson, 2017). These groups are not only helpful for autistics, but also neurotypicals and other neurodivergent peoples alike (Barisnikov & Lejeune, 2018). Video modeling is most successful when used for explicit social skills training (Ra, 2018). Strengths-based social interventions demonstrate successful outcomes. However, deficit-based social interventions do not improve the connection between the autistic and the neurotypical. Instead, they dehumanize, pathologize, and reduce autists to a collection of deficits, thereby contributing to the autistic marginalization (Kapp, 2019; McGill & Robinson, 2020).

OT is based in the constructivist approach to learning. People learn by doing and derive meaning of our world by what is learned, reinforcing participation and social interaction. The construction of knowledge occurs within active and free discovery. ASI is a framework of OT practice based heavily in neuroscience literature and decades of clinical experience by its founder, A. Jean Ayres. Vestibular processing is the foundation for all learning (Ayres, 1968) and is often impacted by autism. If one does not process vestibular information adequately it will be hard for them to process other types of sensory input, which will drastically affect their abilities to master higher orders of movement, perception, and thought (Ayres, 1980). ASI utilizes projected action sequences, primarily targeting the vestibular system, to facilitate adaptive responses in all skill areas, including visual motor, fine motor, oral motor, and sensory processing (Ayres & Tickle, 1980). Since neuro-scanning has become more precise, researchers determined that a 1970s ASI occupational therapist's tendency to co-treat with speech pathology (Ayres, 1968; P. Haas, personal communication,

December 11, 2005) was not baseless (Bowers et al., 2013). Instead, EEGs during sensorimotor laden speech sessions demonstrated improvements in both speech and motor activity (Bowers et al., 2013). The relationship one has with their sensory environment, coined sensory affordances, can trigger sensory trauma (Fulton et al., 2020). Atypical sensory processing patterns are treated by occupational therapy providers using both top-down cognitive behavioral as well as bottom-up neurodevelopmental approaches (Tomchek et al., 2016). These are beneficial if compassionate and in collaboration with the autistic, but are degrading if not (Fulton et al., 2020).

The SCERTS Model stands for (SC) Social Communication, (ER) Emotional Regulation, and (TC) Transactional Support. SCERTS is a family-professional partnership designed to build upon strengths while addressing the most significant challenges toward “Authentic Progress”, which is the ability to spontaneously generalize new skills to various contexts. This model can be utilized throughout the life span and across a range of developmental abilities (Fiaz & Rehman, 2020; Prizer et al., 2006). Research shows this model has a positive influence on individual autistics and their communities (Fiaz & Rehman, 2020).

Many local community members and organizations now include people on the spectrum in their recreational programs, based in the philosophy of occupation as life-giving (Segerstrom Center for the Arts, 2021). These include martial arts (Phung, 2017), dance and music (Segerstrom Center for the Arts, 2021), swimming, surfing, theater (Shaughnessy, 2019), and horseback riding. At times they employ specialists such as occupational and physical therapists to assist in engagement (Phung, 2017; Segerstrom Center for the Arts, 2021).

Assisted horseback riding is known as equine therapy or hippotherapy. Equine therapy started near 600 B.C. but became a staple for treatment of disability in 1946. Autistics also use equine therapy to help “open up their world” (Malcolm et al., 2018, p. 220). It is the embodied sensorial experience of riding and interaction with the horse’s personality that help autistics feel freer to engage in other human interactions (Malcolm et al., 2018). Occupational therapists have the foundational skills to specialize in equine therapy and at times, do (Malcolm et al., 2018).

Speech pathologists and occupational therapists together assess autistics in the areas of AAC as well as assistive technologies. AAC technology is the transdisciplinary development of and training in technologies for non-speaking individuals. It is often used by people on the spectrum. AAC Technology has unequivocally changed the way non-speaking autistics are perceived by those around them by allowing autistics to “give expression to their rich inner lives in a neurotypically-accessible manner” (van Grunsven & Roeser, n.d, p. 2). In response, society made an “empathic turn,” a turn away from believing that autistics are “broken beings in need of repair” (Anderson, 2013, p. 126) and toward recognition as valuable members of society (van Grunsven & Roeser, n.d.). AAC is not only used by autistics to understand their world, but it is also deployed, albeit rarely, by medical settings to assess an autistic patient’s emotional state to facilitate care (Obe & Akinloye, 2017). However, AAC is also dangerous to the autistic, as it forces autistics to assimilate to neurotypical norms rather than allowing for genuine expression and reception, genuine empathy (Alper, 2017; van Grunsven & Roeser, n.d., p. 2). Assistive technologies range from low-tech pencil grips and line readers to high tech apps/software on mobile devices or computers to help autistics in their learning, home, or community environments (Hrvas et al.,



2019). Another type of assistive technology are social robots as replacement therapists in sensory environments utilized to detect and respond to autistic behavior. Many autistic leaders consider the use of therapist-replacement robots to be ethically suspect, devoid of empathy, and encouraging of the mis-categorization of autistics as akin to machines (Keyes, 2020; McBride, 2020). Designers, however, are beginning to coproduce with autistic end users for ethical design (Stark et al., 2021).

Pharmacological treatments range from preventing pre-morbid diseases, to ingesting dietary supplements (Coleman, 1996), and snorting hormone therapies (Strathearn et al, 2018), but none have been successful at preventing or reversing autism (Pantazakos, 2019). Pharmaceutical interventions including 3,4- methylenedioxymethamphetamine (MDMA)-assisted psychotherapy that have been successful in neurotypical populations to treat generalized anxiety were found to be beneficial to autistics too. Research in MDMA for autism is ongoing (Danforth et al., 2018). Some autistics take the naturopathic route. Herbs such as nervines are given to reduce sensory overwhelm, but these and other herbal agents need to be prescribed with caution due to the unpredictable responses autistics have with them (Donahue, 2016).

Some interventions have been applied to neurotypicals to attempt to reduce marginalization and stigmatization of autistics. A systemic review of pragmatic language interventions in 2017 showed the person the intervention focuses on is the greatest factor in how much improvement there is. The greatest improvement occurred when the focus of treatment was coaching caregivers and the autistic person together, not separately (Parsens et al., 2017).

Neurotypical awareness training under the constructivist framework has shown to have some benefit. Awareness training of neurotypicals in the presentation of high functioning autistic's oddities using virtual reality 3D avatars has been found to greatly improve participant knowledge and sensitization about high functioning autism. However, it did not improve measured empathy any more than those who received transcribed texts of the simulation (Hadjipanayi & Michael-Grigoriou, 2020).

Some interventions are autistic-driven, such as scholarly research (Brown & Foxley-Webb, 2019; Milton, 2012), blogging (Holt et al., 2020; Welch et al., n.d.), autobiography (Boldsen, 2018), public speaking (King, 2014; Lisi, 2020), and advocacy for sensory-inclusive accommodations (Davidson, 2010). Scholarly research has consistently dismantled the Theory of Mind and social motivation theories, yet they remain the dominant framing of autism in neurotypical discussions and writings (Welch et al, n.d.). Choosing assumption over hearing the autistic voice diminishes their humanity (Brown & Foxley-Webb, 2019; Holt et al., 2020; Milton, 2012; Welch et al., n.d), for much seminal research links social motivation with being human (Fletcher-Watson & Crompton, 2019). It is common for all people, neurotypicals and neurodiverse, to find social interactions unmotivating at times, but autistics should not be seen as “any less human” (Fletcher-Watson & Crompton, 2019, p. 1) for this.

### ***ABA and Attachment Therapy as Destructive Interventions that Thwart Connection and Cause Mental Health Decline***

Autistics are the greatest experts on autism. they work with various providers, including speech pathologists, occupational therapists, and also behaviorists, to learn to function more symbiotically in neurotypical society. Occupational and speech language

therapists have written within their evidence-based protocols for autism behavioral interventions strategies based off of ABA, but these are not the core of their therapies (American Speech-Language-Hearing Association, 2006; Tomchek et al., 2016). An ABA provider's mission is to "increase behaviors that are helpful and decrease behaviors that are harmful or affect learning" (AutismSpeaks.org, 2021, para. 1) via operant and classical conditioning, known as ABA services (AFIRM, 2019; Novac, 2019). Stimming and echolalia are often targets of ABA services (AFIRM, 2019). The literature shows that this service blocks the autistic from achieving occupational engagement and self-actualization (Williams, 2019). Occupational therapists must redefine their role in ABA and return to the occupational roots or they may become complicit in the autistic's persecution. Williams (2019) asked:

If we believe that autistic children are agential organismic beings with the right to connection, competence, autonomy, integrated self-regulation and self-determination; if we know that operant conditioning and contingent reinforcement erode autonomous motivation and interrupt the development of a competent embodiment and integrated true self – then why are we doing it [ABA services]? (p. 74)

Attachment theory underscores the importance of parenting style in a child's empathic development (Bowlby, 1969/1982, 1973, 1980). Insecure attachment occurs when there is an imbalance between exploratory behaviors and proximity seeking (Ainsworth et al., 1978) causing poorer empathetic skills, less relationship satisfaction, more profound irrational belief systems (Davis & Oathout, 1987; Franzoi et al., 1985), and a greater propensity toward autistic traits (Austin, 2005; Ingersoll, 2010; Turner, 2015). Theorists believe attachment behaviors shape our expectations of ourselves as well as our loved ones

and frame our understanding of events throughout our lifespan (Bowlby, 1980). However, there remains deep discordance within the clinical, scientific, and educational communities regarding the efficacy of “Attachment Disorder” and “Attachment Therapy” (Allen, 2016; Hanley, 2021). Hanley (2021) suggested it not only lacks scientific foundation, but is also abusive (Hanley, 2021). The coercive measures and holding techniques used in an attempt to facilitate parental sensitivity and reciprocity between parent and child have been detrimental (Bushman, 2002; Chaffin et al, 2006; Fowler, 2004; Prekpp, 1983; Welch, 1989). Attachment therapy remains, however, promoted to consumers (Hanley, 2021). Mental health therapies founded in attachment theory that are provided to families by a trained mental health practitioner in the home, with video feedback have been shown to be effective at training parents to be sensitive to their children’s needs (Bakermans-Kranenburg et al., 2005). Autistic stimming and stereotypic behaviors are still often assumed by neurotypicals to be devoid of connection and therefore attachment (Ameli et al., 2020; Baron-Cohen, 1985; Koehler, 1927). However, attachment is an interactive and reciprocal process (Harmsen, 2019). It rings true that when a communication partner’s language is foreign to us, even their intention for connection, or attachment behaviors, can appear foreign as well. Psychologists deemed autistics disorganized in attachment style and therapized them this way, to the detriment of the relationship (DeThorne & Searsmith, 2021) as well as to the detriment of the autistic’s health and well-being (Catala et al., 2021). Recent research indicates that autistic attachment is intact with one-half forming secure attachments with caregivers (Oppenheim et al., 2019). Epistemic injustices and discrimination are shrouded in unfair assumptions (Catala et al., 2021; Welch et al., n.d.).

Such assumptions are experienced by autistics in other contexts too. Researchers found multiple biases experienced by autistics during medical evaluations. Experience-based biases limit the listener to describing only conventional means of communication as intent. Prejudice against the credibility of the speaker, based on their appearance or behavior, invalidates the assessment (Li & Koenig, 2019).

### *Neurotypical Perceptions of the Autistic*

It is widely known in society that to speak and understand a new language one needs the aid of an interpreter who is fluent in both their language and the one they seek. The autistic community is making enormous attempts to incorporate the neurotypical language in their expressions and interpret the autistic language for the neurotypical audience so to give credence to the autistic's full inclusion within it. But neurotypicals continue to misunderstand because they try to fit the autistic language within the confines of the neurotypical framework of communication; yet it does not fit. Their misunderstanding of the autistic causes neurotypicals to perceive that autistics are incapable of communication and empathy, thereby further diminishing the autistic's role in society (Catala et al., 2021; Jaswal & Akhtar, 2018; Kapp, 2019; Milton, 2012).

Autistics are capable human beings but are still not perceived as such by many people who identify as neurotypical (Jaswal & Akhtar, 2018; Welch et al., n.d.). Even the "inclusive" cinema and television shows represent autistics and play musical scores that enforce the concept that autistics are incapable, unfeeling machines (Felepchuk, 2021; Jones, 2021; McMahon-Coleman & Weaver, 2020). As a result of the neurotypical perception, autistics have become victims of epistemic injustices: people who identify as neurotypical therapize autistics into forgetting their native autistic language (Pickles, 2016; Xu, 2016) and

cause post-traumatic stress disorders (PTSD) in the process (Kupferstein, 2018). This only further divides autistics from neurotypicals. At first impression, the neurotypical often perceives an autistic's stimming and echolalia to be socially awkward or unnatural, prompting unfavorable feelings about the autistic (Alkhaldi et al., 2019; Grossman, 2015; Grossman et al., 2018, Kapp et al., 2019a; Sasson, et al., 2016; Sng et al., 2021). This "thin slice judgement" (Sasson et al., 2016, p. 1) may be the first detachment during a communication attempt. Stimming is referred to by Webster Dictionary as a "repetitive action or movement of the body" (Merriam-Webster.com, n.d., para. 1). Echolalia is defined as "the often pathological repetition of what is said by other people as if echoing them" (Merriam-Webster.com, para. 1). The perception that stimming and echolalia are abnormal is demeaning (Kapp et al., 2019a) and inaccurate (Denome, 2018), and if it continues to be promoted, autistics will not gain social acceptance or opportunities for participation. "If being perceived unfavorably is a barrier to inclusion in the social world, where autistic people, who are in the population minority, instead are condemned to isolation" (Alkardi et al., 2019, p. 3981). It is the language barrier between the autistic and non-autistic, rather than a disability of the autistic, that keeps neurotypicals and autistics from understanding one another (DeThorne, 2020) and communicating empathy (Milton, 2012). Stimming and echolalia are not rooted in pathology, but are components of environmental coping (Kapp, 2019), social participation and communication (Koehne et al., 2015). They are important to the autistic identity (Arnold, 2019).

Stimming is a beautiful and expressive language. Just because the non-Autistic world doesn't derive meaning from it, doesn't mean there is none. (K. Rose, personal communication, June 10, 2021)

The attitudes autistic adolescents have about autism as neurodivergent (a normal variant of human neurology) predicts depressive symptoms. The more outside the norm the autistic considers themselves, the more depressed they often are (Ferenc et al., 2021). This indicates that neurotypical perceptions influence autistic self-esteem.

### **The Responsibility Required in Dual Communication**

When a person who identifies as neurotypical engages with an autistic in the autistic's story while partnering in their rhythmical movement, it is received the same as when a neurotypical gives another neurotypical warm eye contact, a smile, and a friendly handshake (Koehne et al., 2015; Livingstone & Russo, 2018; Robledo et al., 2021). Connection sparks because the autistic's rules of politeness were followed (Milton, 2012).

When autistics try to use neurotypical mannerisms, they find themselves feeling fake because they are camouflaging their autism to fit in (Hull et al., 2017; Lai et al., 2019; Mandy, 2019). Autistics are at least as expressive as neurotypicals in most situations; however, they are difficult for neurotypicals to understand, which causes them to be perceived unfavorably by them (Alkardi et al., 2019). However, the fact that autistics do attempt to camouflage their autism despite the mental health challenges it creates for them, indicates intact or even heightened social motivation (Livingston et al., 2019).

Today's researchers in 2021 are questioning what "typical" social interaction is and sharing the mental health consequences faced by autistics when forced to abide by neurotypical social rules (Mitchell et al., 2019). Neurotypicals greet others using the "rules that govern polite society" (Hill, 1873, p. 14), usually with eye contact, a square stance, and a handshake (Hill, 1873). Hill's rules of politeness continue to be followed and passed down to new generations (Chrisman, 2015). However, social behaviors achieve connection only when

both communication partners follow the same social rules (Hill, 1873; Milton, 2012), regardless of whether the rules followed are autistic or neurotypical. Interactions between autistics demonstrate enabling norms and exemplify the reason why neurotypical researchers need to take notice (Heasman & Gillespie, 2019). Damian Milton (2012), both a researcher and an autistic, dubbed the lack of understanding autistics and non-autistics have for one another the “double-empathy problem” (p. 884). Unfortunately, still, “it is the autistic’s responsibility to modify their behaviour and increase their self-efficacy in order to accommodate non-autistic people’s perception of how one should act” (Milton, 2021, slide 21). Optimistically, however, there is a “paradigm shift in motion but [it is] being held back by approaches based on radical behaviourism and other dated theories” (D. Milton, personal communication, June 9, 2021).

Themistoklis Pantazakos (2019) and Mary C. Lawlor (2017) argued for using the phenomenological framework to describe the autistic experience as being in a different “life-world” than neurotypicals (Pantazakos, 2019, p. 1). It is not pathological to be rhythmically off-beat in social interactions (Christenson, 2021). Some recent research has even shown that autism is “within normal behavioral variations exhibited by humans” (Masataka, 2017, p. 85) and that neurodiversity is as vital to the survival of humanity as biodiversity is for plants and animals (Masataka, 2017). Restricted interests and repetitive behaviors are purposeful, legitimately exploratory and learning associated (Mottron, 2019). The autistic and their loved ones are experts in understanding this (Lawlor, 2017).

Learning environments need to manifest from the autistic voice (Pantazakos, 2019), building on strengths rather than deficits (Masataka, 2017). Moreover, the focus of treatment



needs to be on training the neurotypical to communicate with the autistic and facilitating understanding of stimming.

### **Coproduction**

Research, medicine, and education until recently was controlled by specialists, done or given to individuals who had the “disease of autism” (Nelson, 2020, p. 50). Much research on autism is authored solely by neurotypicals with no scholarly input from autistics, while many autistic researchers have sought independence from neurotypical centrists so write autonomously (Milton, 2020). But things are starting to change. Coproduction is an emerging approach to research. With coproduction autistics and neurotypicals work together as equal researchers, writers, and participants (Kapp et al., 2019b; Milton, 2020; Stark et al., 2021).

Coproduction is starting to be incorporated into product design as well. A prototype musical instrument, Stim4Sound, was created for neurotypicals and autistics to redefine stimming collaboratively and freely between them (Nguyn, 2021). Responsive robots are coproduced with autistic designers (Stark et al., 2021) as well. The hope is that coproductions like these will train neurotypicals to communicate with autistics and facilitate understanding of stimming (Nguyn, 2021).

### **Methods**

A scoping review of the literature was conducted. A scoping review is a method of synthesizing a broad research question by investigating a variety of research study designs to summarize and synthesize known evidence in order to inform practice and prioritize future research (Colquhoun et al., 2014). Used for the review were electronic databases, select university libraries, raw primary source data, and professional journals relevant to the questions. Electronic databases that were searched were: (1) PubMed, (2) DynaMed, (3)

ESCO Host, (4) PLoS ONE, (5) CINHL, (9) PsychNet, (10) NCBI, (11) ProQuest, (12) Science Direct, (13) Directory of Open Access Journals (DOAJ), (14) Google Scholar, (15) University of St. Augustine Library, and (16) Colorado State University Library. Articles found that were not open access were entered into the (16) Sci-Hub database for full-text review. The keywords for inquiries related to the discussion topics of this paper contained the following main ideas: (a) autism [(*autism* OR *autistic* OR *autism spectrum disorder* OR *autistic disorder* OR *autistic disorders*)], (b) empathy OR double empathy, (c) stimming [(*stim*) OR (*self-stimulatory*) OR (*self-stimulation*)], and (d) perception OR prosody. Historical reviews were limited to seminal articles dating from 1710 to 1980 and secondary articles from 1980 to 2021. Research study reviews were primary articles limited in date from 2015 to 2021 (see Appendix B).

No population ages, sexes, genders, or ethnicities were excluded. No non-English articles were excluded due to language, but instead, a translated version was retrieved, or if none were available, I translated the article myself using Google Translate. All types of articles were included. Some article reviews triggered additional keywords, which became their own themes and paper headings (i.e., genetic and non-genetic etiology, past and current interventions). Articles were first reviewed by title and excluded if they did not fit did not add any different information other than what was already obtained. Duplicates were excluded. Autistic-led conferences were attended, advocacy groups contacted, and blogs and videos reviewed to understand the most current thinking on the autistic experience. A retrospective case was also analyzed, and vignettes highlighted to exemplify the themes in the scoping review. Consent was given by the participant's mother to include her child's case report in the manuscript (see Appendix C).

### **Results of Scoping Review**

Twelve scholarly databases were researched for the scoping review. Out of the twelve scholarly databases, only five produced any results, three of which produced fewer than 10 results. This revealed a gap in the literature, especially in literature that is inclusive of autistics. The following were the themes that emerged from the scoping review: (a) prevalence of autism, (b) the interpretation and measurement of empathy, (c) discovery of genetic factors transformed autistics' identity, (d) publication of non-genetic factors such as vaccines undermined the legitimacy of the autism language, (e) the problem with the lack of social language legitimacy, (f) autistic empathy, (g) past and current interventions, (h) destructive interventions thwart connection and cause mental health decline, (i) neurotypical perceptions of the autistic; and (j) the responsibilities required in dual communication.

### **Discussion**

#### **Case Study**

##### ***Background***

Students must be given the opportunity to learn in the least restrictive environment (LRE). When someone is unsuccessful in one environment, educational teams often recommend a transfer to another, often more restrictive one until that just-right environment with just-right supports is found. When a transfer outside the neighborhood school district is made, the student's local educational agency (LEA) remains responsible for assessing their eligibility for special education. A non-public school (NPS) is a LRE that provides students with no access to general education peers and, therefore, is one of the most restrictive that LEAs offer (Bolourian et al., 2018).

Adaliya [fictitious name] attended a special day class at a NPS located in California. The NPS was responsible for providing her with specialized academic instruction, occupational therapy, and speech language services. She participated in evaluations every 3 years to determine continued special education eligibility. These evaluations were conducted by her LEA and I was on her assessment team.

Her records indicated she was 8 years, 3 months old at the time of this triennial review. While she was in utero her mother experienced high blood pressure. She was born via cesarian section due to being in the breech position, but was discharged home within the typical timeline and with the typical follow up recommendations. Later on, in early childhood, Adaliya started showing signs of autism and so received early intervention services from the local Regional Center. Once she turned 3 years old, she was enrolled in her neighborhood school district's special education preschool. Her Individualized Education Plan special education services were provided under the primary eligibility category of Autism and secondarily Cognitive Impairment. And so began Adaliya's educational career.

In 2<sup>nd</sup> grade she was determined by her IEP team to require a more restrictive environment in order to access her school curriculum and make progress on her IEP goals. Her neighborhood school then transferred her to the NPS. Then, her special education goals focused on following directions for classroom compliance. The behavior the team practiced with her to attain this goal was teaching her to place her finger over her mouth to indicate understanding of "quiet mouth." Other focused behaviors were giving the teacher items and pointing to things. They also worked on requesting preferred items, responding to "wh-" questions, using joint attention, and acquiring functional hand skills for using classroom materials.

Her areas of focus remained the same from year to year: following directions, managing her behaviors so they did not impede the learning of herself or others, communicating her wants and needs, and improving in hand skills. When I received her records, these were still the areas of her special education focus. I noted, too, that previous triennial assessments deemed her untestable.

**Intervention.** I made an appointment with her NPS principal to conduct her OT assessment. When I arrived, the staff told me that I should come back, that she was having a very bad day. I told them if they would allow it, I would like to see what a very bad day looks like for her. The principal asked a teacher's assistant (TA) to bring Adaliya to her office, which was located in a corner of the building. The office was furnished with a desk and two couches with a coffee table between them. I turned down the lights and prepared our space. I could hear Adaliya's anxious vocalizations as they walked down the hall toward me. I met them outside the office. Adaliya hopped side to side, flapped her wrists, clicked her tongue, and had a very distressed expression on her face. Her eyes were wide, brow furrowed, and lips tight in a nervous smile. Her TA guided her toward the open door while she rocked, fidgeted, and made increasingly louder vocalizations. I stood with my body sideways to hers, intentionally avoiding eye contact. I introduced myself and reached my hand out a foot or so from my body, leaving it there hoping she would shake it. According to her TA, she looked at my face, and then I felt her sweaty fingertips briefly in mine. I motioned to Adaliya to sit on the couch across from me. She did; her stimming became more intense. Her TA went to sit too, but I asked her to leave so I could control all environmental stimuli during my assessment. As Adaliya rocked, so I rocked. As she clicked, so I clicked. We rocked forward so our heads almost touched then back and forward again. Our clicking

started out disjointed but ended up in unison, too. After a few minutes, I felt confident to look directly at her. And she was looking at me! We looked into each other's eyes. She gently touched the sides of my head with her hands, pulled me toward her, bent her chin, touched her forehead to mine, looked into my eyes, and smiled softly and deeply. Though she did not use any words, her "hello" was resounding.

I made Adaliya feel safe by "co-regulating with her" (G. Santucci, personal communication, November 10, 2021). She was in a physiological state of threat. What we built together was "more than rapport" (G. Santucci, personal communication, November 10, 2021).

After we said our hellos in this way, I presented her with an open Bruininks-Osteresky Test-2 (Bruininks & Osteresky, 1978) assessment kit and asked her to "pick one." She chose one subtest after another until she completed the BOT-2 in its entirety. I used the supplemental instructions with accompanying pictures to support her understanding.

While sharing my assessment report at her Triennial IEP team meeting, I told Adaliya's mother in detail about how Adaliya introduced herself to me. Her eyes teared, wetting her cheeks. She smiled, reached across the corner of the table, hugged me, and said, "She only touches foreheads to family members and she just met you." My eyes welled up, too, and we cried there together until the other IEP members at the table directed us back to business.

Adaliya had never before participated in a norm-referenced multi-step standardized assessment, let alone one as complex as the Bruininks-Osteresky 2. When compared to her neurotypical peers, Adaliya scored in the well below average range in all areas: Fine Motor Precision, Fine Motor Integration, Fine Manual Dexterity, and Upper Limb Coordination,

with Fine Motor Precision and Integration on the border with Below Average. However, when her scores were compared to the mean and standard deviation of others age 4-21 with cognitive impairments (Bruininks & Osteresky, 1978, p. 65), her descriptive categories were one to two categories higher.

Adaliya performed best with one handed skills that were similar to those she practiced in class. She did these quickly and efficiently with minimal need for supplemental instructions to understand the expectations. Her fine motor precision score was dampened most by her difficulties with the bilateral coordination required for cutting and folding. She showed more interest in the supplemental instructions for activities that were novel to her. She was less proficient in these, so she slowed down to improve her motor planning. This slowing down helped her score in some activities and reduced it in those that were timed.

She showed great interest in successfully completing all the activities I presented to her. This great interest in difficult and novel work was previously only seen at home, by her family. She showed me her true occupational profile only because we treated each other as kin.

**Discussion.** The case study of Adaliya exemplified that autistic empathy is physically manifested by the language of stimming. Adaliya taught me that autistic stimming has enough form, structure, and predictability to be perceived and interpreted by both autistics and neurotypicals alike. Her neighborhood school and NPS educators, however, subscribed to society's assumptions that autistic stimming has no social function. These assumptions derailed her access to status both in education and social living. Her stimming was interpreted by her educators to be without academic focus and, therefore, distracting to her peers. This was the primary reason for her transfer to a NPS where she was denied

access to general education peers and general education elective curriculum. Her stimming was how she socialized, yet only her family and I interpreted it as such. If her neighborhood school educators knew her stimming to be language, they likely would have understood her dialogue and she may have not been transferred out. The assumption that stimming has no social function runs deep in education, for many other children I assessed at NPSes were there because of their stimming. Moreover, many children I know or have known in neighborhood schools have been sent away to NPSes for their stimming.

Adaliya proved that stimming is indeed part of the autistic empathy dialogue. If stimming and echolalia are normalized through the neurodiversity movement (Kapp et al, 2019a) and language discovery, autistics and neurotypicals will finally join together for engagement in self-actualized occupations. However, dual responsibility in communication is needed, too. Dual responsibility will create a mutual understanding bound in co-empathy and elevate education and social access for all autistics. This is the map to solving the “double empathy problem” (Milton, 2012).

### **Vignettes**

My connection with Adaliya was not just “a beautiful accident.” Additional case vignettes give credence to reliability and validity. Even after ending services with Adaliya, I continued incorporating autistic social rules into all of my interactions with autistics. Regardless of the autistic’s age, I almost always (nearly 100% of the time) receive a clear empathetic response and an attempt to follow through with directions I propose in occupational therapy sessions.

### ***A Shy Hello***



A 3-year-old child came to the special education office for a multi-disciplinary team assessment for an initial preschool placement. I met the child and her mother in the front office. The child hid between her mother's legs and behind the corner of the counter while her mother signed in. I could barely see a small tuft of her hair peering through at me. After introducing myself to the mom she told me her daughter was extremely shy and will likely not participate in anything. I smiled, knowing she was only partly right. I squatted down, turned sideways, and tried to blend into the edge of the countertop like my new friend, peering just around the corner in her direction. When she looked toward me I giggled, flapped a little bit, and looked down. She giggled and flapped too. We played this game of shy hello for a few minutes. When her mother finished signing in and it was time to go to the assessment room, her shy little girl took my hand in one of hers and her mother's hand with the other and we walked together to the assessment room where she spent the next hour and a half completing each discipline's assessments in round-robin fashion.

Children imitate to get another's attention and sustain it (Asendorpf & Baudonnière, 1993; Eckerman & Didow, 1989; Kuczynski, ZahnWaxler & Radke-Yarrow, 1987; Nadel, 2002; Nadel & Baudonnière, 1982; Nielsen & Dissanayake, 2004). But children are not the only ones. Adults imitate to not only learn new skills, but also to demonstrate empathy, compassion, and understanding (Brewer, 2016; Koch, 2016; Koehne et al., 2016; van Berkhout et al., 2016; Williams, 2019). Body language imitation is the first step to achieving co-empathy.

### ***A Dancer's Ask for Help***

Autistic social rules are not just for academic settings. They work in community-settings too. I consult for a private community-based inclusive dance program that serves

people with disabilities from age 4 to adult. We have a certified dance instructor, a live musician, and a therapist in each dance and music class. Many of the children and young adults who come to classes are autistic. Some require significant, continuous support. We receive limited information about each dance student, usually medical diagnosis, likes, and dislikes. I follow the autistic social rules every time I meet or greet an autistic dance student. One such dance student is a tall teenage boy, Michael. He brought two ABA practitioners with him on the first day of class to control his violent tendencies. These ABA practitioners worked directly with Michael 28 hours per week. One of them had known him for 3 years while the other only for 1 year. They sat on the floor on either side of him, both talking at him, touching, grabbing at him. I noticed his soft neurological signs of overstimulation rising, though class had not even started yet. His body writhed and rolled, trying to get away. He struck one of them. I intervened, asking one of the ABA therapists to leave. I sat beside Michael, gently holding his hand, keeping my hand steady in pressure. His soft neuro signs decreased, but his other ABA practitioner started talking at him again, making him deals for good behavior. This was obviously not what he needed; his soft neuro signs increased again. So, I took him by the hand, asked him to stand up, and we walked. This was when I had my first opportunity to greet him properly. After a couple of laps we joined the group again, where I asked his other ABA practitioner to sit on the side of the studio. Michael and I sat on the floor with his peers. He faced me, I him. He and I participated in class together. I used a few neurodevelopmental techniques on his hand to guide his dance. I rarely spoke. When I spoke, it was only in one- and two-word phrases. Toward the end of class, he was participating without my touch. In a subsequent class this boy came in wearing a standard paper mask instead of his regular cotton. He looked right into my eyes and pulled at his

mask, then scratched his chin, pulled it again, leaning in toward me. It was obvious to me what he was asking for. So, I asked his ABA practitioner for a softer mask. She told me he was having a rough day and she did not think it would help him, but she got one anyway. Once it was on him, he stopped tugging at it. He stopped scratching himself. He even kept it up over his mouth and nose for the rest of the class. The few times it fell all I had to do was touch my mask, point to his, and he pulled it right back up into place. I wondered why his ABA practitioners did not notice he was irritated by his paper mask. Or maybe this boy only communicated it to me because he knew I would listen.

On average, children receive 20 hours per week of ABA services from a single provider, supervised monthly by a behavior analyst (Johnson & Hyman, 2020). Juxtaposed to this, children receive on average 0.96 hours per week of occupational therapy services (Watt et al., 2021). One could conclude based upon the empathy literature (Batson et al., 2007) and practice theories (Newell & Rosenbloom, 1981) that the ABA providers would be better able to understand Michael's needs because they spend more time with him. Instead, Michael's ABA practitioners experienced a "double-empathy problem" (Milton, 2012). But I did not. I had just met Michael, yet he communicated to me on a deeper level than to those who had known him for 4 collective years. My manner of relating maps for us a sustainable way to connect the neurotypical and neurodiverse worlds in empathetic communication.

### ***The Dog Park Theater***

Autistic social rules engage not only students but the whole community. I met one such community member, Emily [fictitious name], at my neighborhood dog park. She was there with her mother, sister, sister's friend, and their family dog. She appeared to be in her late teen years, walking around the dog park, holding her iPad and talking, but no one was

next to her. As I got closer I could hear her scripting Harry Potter. I asked her, “Harry Potter? Do you like Harry Potter?” That was the beginning of our 2 hour long Harry Potter performance, she as Harry and me as Ron. She pointed to various people and pets in the park and gave them their parts too. We laughed, we hopped, we talked, and we walked. The next time I saw Emily was 3 months later. The moment I walked through the gate I could see her on the other side of the dog park point at me and start running toward me. This time she grasped my elbow in hers and led me around the park like we were schoolgirls. She even tried to entice another dog owner, into our story by greeting her with a deep bow, “Hi I am Harry Potter!” But rather than responding with a similar overture, the other dog owner just looked at me, questioningly. I repeated my friend’s introduction, “She is Harry Potter!” It was to no avail, though, as the other dog owner looked again at Emily and just walked away. Emily grasped my arm again in hers, as if this kind of rejection was the norm. Although the story of Harry Potter was what our friendship’s foundation was built on, the emotional connection we developed was lasting.

This experience highlights the lasting emotional effects of a single empathetic connection after chronic rejection. Rejection occurs when one avoids another’s attempt at social engagement. A person’s mindblindness can cause others to feel deep feelings of rejection. According to Edey et al. (2016), “typical adults exhibit mindblindness towards those with autism spectrum disorder” (p. 1) because it is easiest to interpret people’s body language when they move similarly to us, and autistics and neurotypicals move in quantifiably different ways. The other dog owner demonstrated mindblindness when she withdrew from Emily, rejecting her introduction, yet it is not unusual for neurotypicals to withdraw or even become violent when they, themselves, experience chronic rejection (Gao

et al., 2021; Porcelli et al., 2019). Conversely, when autistics withdraw after chronic rejection they are given ABA Behavior Intervention Plans, social stories, and star charts (Autism Focused Intervention Resources and Module Team, 2019; Autism Speaks, 2021). This is just one more example of the many neurotypical characteristics for which autistics are stigmatized.

Autistics and neurotypicals alike relate best to people in their same grouping and withdraw from those who are not (Edey, 2016; Heasman & Gillespie, 2019). Neurotypicals should be encouraged to learn the language of autism just as hearing people are encouraged to learn sign language. Until the language of autism is recognized, it must be deemed unreasonable to expect autistics to continue attempting social connection with neurotypicals who lack understanding and chronically reject them by denying their “native language” (Baggs, 2007). This expectation is unfair and borders on abuse (Kupferstein, 2018).

### *A Contrast*

In contrast, Applied Behavior Analysis strategies do not equate with being emotionally present for a child on the spectrum. A 2 <sup>3</sup>/<sub>4</sub> year old boy was seated on the carpet with assessors in speech pathology, school psychology, physical therapy, and specialized academic instruction circled around him. I was late to the scene because I was at an IEP meeting. According to the other assessors, Carlos did not participate in any of the tasks presented to him. Instead, he compulsively placed various blocks and cars into a shape sorter box. If one of the assessors tried to play with the sorter alongside him or touched any part of it, he merely took it and moved away. They said they attempted 3 step guided compliance procedure (Tarbox et al., 2020; Wilder et al., 2020) They introduced a highly preferred contingency item and attempted differential reinforcement with it using variable time

delivery (Lomas et al., 2010). Carlos disregarded all of it and only attended to his compulsion.

The team was considering canceling the assessment, but our waiting list was months long. So, I decided to try as well. I attempted first to engage with Carlos by sitting next to him. He said, “via” and moved away. Then I offered him behavior strategies. I started by using visual supports and first/then strategies (AFIRM, 2019; Autism Speaks, 2021). He whined and continued to push away the test item, instead grabbing more at the shape sorter. Next, I tried touching the shape sorter too, hoping he would play alongside. But instead, he tried to take it away from me. I felt I could not reinforce his behavior of taking tangibles away from others so I held onto the sorter. I thought I had to extinguish it. I worked to extinguish his trying to take the sorter out of my hands by not giving any attention to him or his actions, a form of tactical ignoring (Katz & Lattal, 2021). I placed the shape sorter between my knees so I had a stronger grip on it, still within Carlos’s reach, but did not allow him to take it away, staying like a statue, not engaging with him in any way. I even kept my eyes down, fixed on the sorter. This holding on, without allowing the sorter to move when he tried to pull on it, elicited a violence I had never experienced before or since in my 22 years as an occupational therapist. He hit, kicked, bit, slammed his head into my body, jumped up and attempted to slam his head into the ground, stood on the shape sorter, and tried to pull it away with both hands and feet. This went on for 17 minutes. My colleague, a physical therapist, remained beside me to cushion his head when he struck with it, but did not intervene in any other way. I used the National Crisis Prevention techniques of “supported stance” and protecting my skin by pushing into his jaw when he bit (1993). He calmed slightly but continued to try to pry the sorter away. On the 19-minute mark he was able to

dislodge the shape sorter from a few of my fingers so that it moved slightly toward him. This triggered an extinction burst of violence (Katz & Lattal, 2021). He stripped off all of his clothes along with his diaper and attacked even more ferociously for another 5 minutes. Then, dripping with sweat, he calmly walked over to his mother and she and our staff redressed him. After receiving a hug from his mother, he came back over to me and attacked me more. He went back and forth three times between hugging his mother and striking me. On the fourth round, he remained near his mother and did not return to attack me again. Instead, he sat in the speech therapist's lap and received hugs and arm rubs which were calming to him. Hits, kicks, and head slams were too numerous to count. He attempted to bite 12 times. The entire behavioral episode lasted 24 minutes. Once his aggression stopped it was easy to elicit task completion, but it was obvious that he was fatigued. First/then strategies were used again and this time he complied. Carlos participated and complied with each assessor for the next hour and a half. His compliance, however, with assessments was not, however, the same as the kind of participation other autistic children and young adults engage in when I am empathetic to their needs, when I follow autistic social rules. His engagement was stiff and appeared resigned. There was no laughter, no child's play. He acted almost adult-like in his exchanges.

Compliance was the end-result of these techniques, but there was no empathetic interaction. This memory is several years old and until now I remembered it with feelings of success. We got an out-of-control child to comply. However, after completing the literature review for this paper, it became clear to me the strategies I used that day to gain this child's compliance, though seeming innocuous at the time and done before the first research paper

on ABA and PTSD was published, were instead traumatic to him. I wonder if this boy, too, will one day publish his own research on empathy and education.

### **Results of Case Study and Vignettes**

Each of these cases exemplifies the literature. Defining autistic stimming as communication and an expression of empathy is not just theoretical, but practical too. When a person “reads the room”, they must consider not only the age, gender, ethnicity, and attire, but also the autistic traits of each person in the room to inform them on appropriate interaction and predict others’ responses. Co-empathy is highly likely when one unmask stimming and echolalia for all of society to cherish rather than ostracize. Stimming and compulsion should be incorporated into all empathetic communication, regardless of what spectrum the communication partner is on.

### **Conclusion**

The purpose of this scoping review was to critically examine autism and autistic stimming through the lens of both the neurotypical and the autistic, evaluate the confines currently imposed upon autistics by neurotypical society, and synthesize what autistic community leaders have expressed about their experiences striving for inclusion (Gernsbacher, 2017; Milton, 2012). The case analysis and vignettes exemplify the scoping research and provide a road map to solving Milton’s “double empathy problem” (Milton, 2012). Autistic narratives were utilized in large blocks to enunciate the power of the oppressed.

Co-empathy can be experienced. The planned communication, contact, and connectedness, (Lindberg-Repo & Grönroos, 2004) is vital for the autistic to be understood within their social organization to attain a positive reputation within it. Perceiving the



linguistic intent within stimming and compulsion will allow neurotypicals to recognize an autistic's inner emotional state (Bascom, 2012; Lindsmith, 2014; Schaber, 2014) and respond with empathy instead of ostracism or oppression. Autistics have been ostracized by the assumptions neurotypicals have made of them. This oppression has caused a cyclic action and reaction dyad between the autistic and the neurotypical for decades, causing a "double-empathy problem" (Milton, 2012). Moreover, the autistic behaviors that the neurotypical community oppresses are similar behaviors neurotypicals themselves exhibit (Gao et al., 2021; Porcelli et al., 2019), just less frequently or intensely, causing many autistics to feel unfairly criticized. This problem can be solved, however, with community participation and support.

The first step is for autistics to celebrate. Be visible. Be heard. Be unapologetically autistic. Mel Baggs was a non-speaking autistic writer and advocate at the forefront of the neurodiversity movement until their premature death in 2020. Baggs' video, "In My Language" (2007), remains one of the most transformative pieces on neurodiversity in existence today. It realizes the autistic experience as greater than what neurotypicals generally are able to perceive. Baggs recorded and then translated her stimming into the following neurotypical verbiage:

The way I naturally think and respond to things looks and feels so different from standard concepts, or even visualization, that some people do not consider it thought at all, but it is a way of thinking in its own right.

However the thinking of people like me is only taken seriously if we learn your language, no matter how we previously thought or interacted. As you heard, I can sing along with what is around me. It is only when I type

something in your language that you refer to me as having communication. I smell things. I listen to things. I feel things. I taste things. I look at things. It is not enough to look and listen and taste and smell and feel, I have to do those to the right things such as look at books, and fail to do them to the wrong things, or else people doubt that I am a thinking being. And since their definition of thought defines their definition of personhood so ridiculously much they doubt that I am a real person as well... We are even viewed as non-communicative if we don't speak the standard language but other people are not considered non-communicative if they are so oblivious to our own languages as to believe they don't exist... And in a world in what those determine whether you have any rights there are people being tortured, people dying because they are considered non-persons because their kind of thought is so unusual as to not be considered thought at all. Only when the many shapes of personhood are recognized will justice and human rights be possible (Baggs, 2017, 4:36)

Stimming is the autistic language. To extinguish stimming is to extinguish the autistic (DeThorne & Sears Smith, 2021; Kevles, 1985). Should that occur, hope for legal personhood and agency may disappear with it (Higgins, 2020).

Like with the cultural and gender diversity movement in television (Ellithorpe & Bleakley, 2016), when other autistics watch and listen to Baggs they feel empowered to be themselves without judgement, without limitations. Identity develops when one is exposed to other people with similar characteristics (Ellithorpe & Bleakley, 2016). Eleanore Walsh, an autistic podcaster, commented on Baggs' work:

In AM Baggs' work *In My Language*, when sie hums, I know the note, can feel it rise in my throat. Sie rotates hir fingers around the knob on the chest of drawers and I gasp - that looks fun! I haven't let myself do that in years. Mel [Baggs] rocks, forward and back, and I realise I'm rocking with hir in my chair... So, even though it seemed to change on me every day, I learnt the confusing language of the majority around me. My own language and song lay dormant... I watch *In My Language* today, and tomorrow I can walk outside, flick my fingers, hum to myself behind my face mask, let my arms swing by my sides, let my body move like it wants. Mel's dance goes on (Higgins, 2020, p. 2-4)

The second step is for parents to take back their primary caregiver role from ABA providers. Spending 20+ hours per week with children causes the relationship to morph into that of primary caregiver (G. Santucci, personal communication, November 10, 2021). Parents need to feel empowered to manage their children's behavior without ABA help. Parents know their child's inner truth, while co-regulation and empathy gives that truth a voice.

### **Limitations**

Vast gaps in autistic-led research and literature inclusive of the autistic perspective permeate our databases. Though these gaps limited my scoping review, the autistic voice was cohesive, which allowed strong conclusions to be drawn. The case study participant provided permission to utilize papered assessments in this study but declined further interviews. This may have limited the breadth of case study, but it did not limit its depth because the papered assessments were rigorous and thorough.

### Implications for Future Research

Formal research studies are needed to quantify current anecdotal evidence on the perceptions autistics have of therapy after receiving OT, speech therapy, and/or ABA (G. Santucci, personal communication, November 10, 2021). Autistics need to be involved in and, moreover, leaders in developing the evidence-based practices service providers rely on. Autistics are speaking. Autistics are writing. It is time they are heard.

If the neurodiversity movement continues to permeate the neurotypical culture, the Autistic Language may eventually be taught in public schools, by YouTube, and other computer applications like German, Spanish, and American Sign Language are currently. Then, autistics, occupational therapists, and speech language pathologists will be needed to take on leadership roles in the design, distribution, and instruction of the curriculum so the sensory processing and integration components of stimming and echolalic prosody are accurately described and interpreted. It cannot be overemphasized that Autistics must be more involved, spear-heading this effort. This re-educating neurotypicals about autistic social language would diversify the neurotypical's understanding of social behavior. Autistics would finally be free from ostracism. Future autistic-led research would test the curriculum's fidelity.

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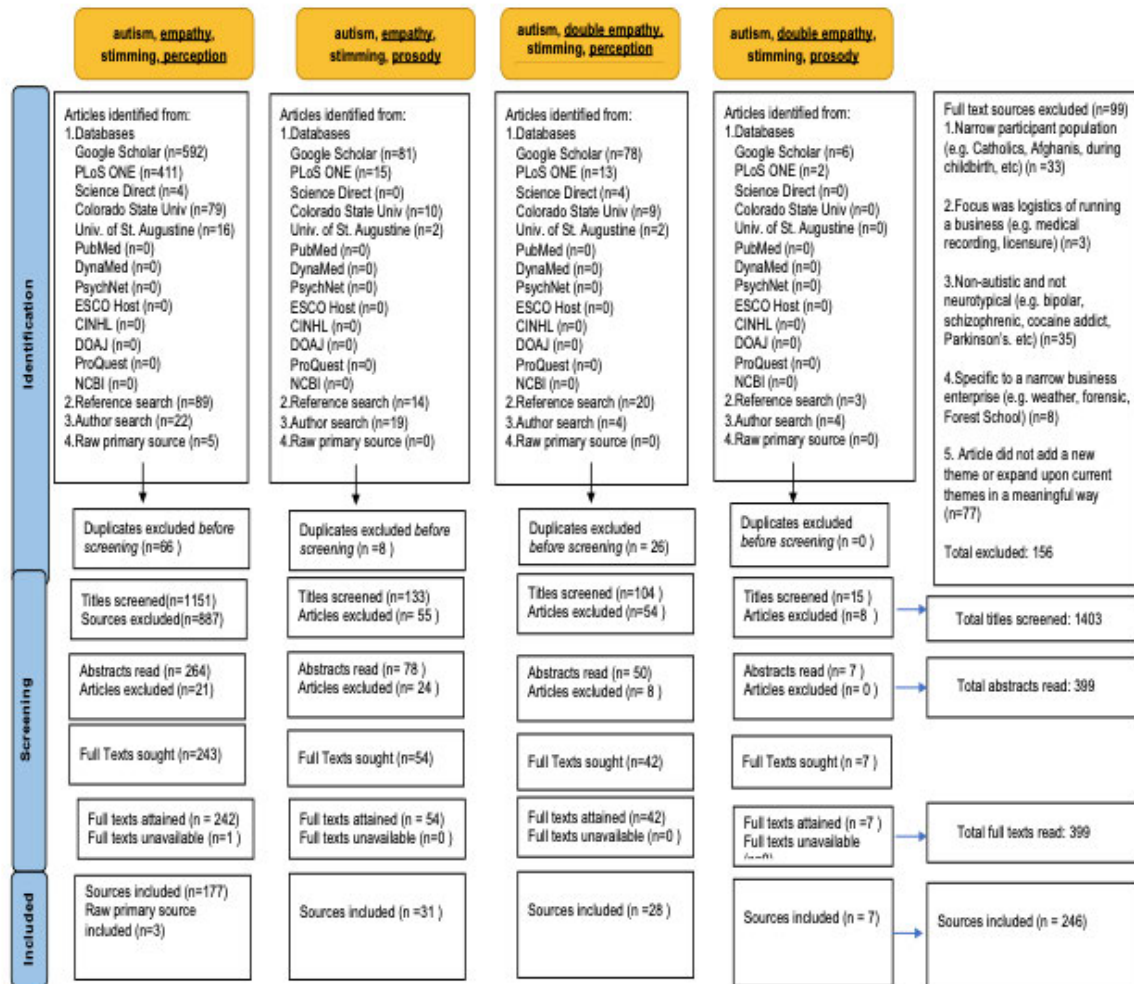
## Appendix A

### Glossary of Terms

1. Prosody - intonation
2. Monotropism – restricted interests
3. Stimming – coined for the autistic community but also present in neurotypicals, repetitive self-stimulatory muscle movements
4. Echolalia – repeating words and phrases
5. Neurotypical – people who define themselves as having typical development, neuromuscular, and cognitive skills

6. Neurodiverse – people who define themselves as other than neurotypical
7. Hermeneutics - the interpretive study of historical texts and languages in the context of the writer’s culture. The hermeneutic approach to research (a) seeks to understand rather than explain; (b) highlights the context, (c) acknowledges that interpretation is influenced by history and language, (d) perceives constructive questioning as conversation, and (e) is open to more than one interpretation (Kinsella, 2006).

Appendix B



Note. Adapted from “PRISMA Flow Diagram,” by PRISMA, 2021, *PRISMA Transparent Reporting of Systematic Reviews and Meta-Analyses*. (<http://www.prisma-statement.org/PRISMAStatement/FlowDiagram>). Copyright 2021 by PRISMA.

Appendix C  
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