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Language of Disability, Language of Disorder: An Investigation of Lived Experiences and Perspectives of Individuals on the Autism Spectrum with Respect to Communicative Interventions

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LANGUAGE OF DISABILITY, LANGUAGE OF DISORDER: AN INVESTIGATION OF LIVED EXPERIENCES AND PERSPECTIVES OF INDIVIDUALS ON THE AUTISM SPECTRUM WITH RESPECT TO COMMUNICATIVE INTERVENTIONS

by
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ABSTRACT

The primary purpose of this study was to investigate the lived experiences and first-person perspectives of individuals with Autism Spectrum Disorder (ASD) with respect to interventions for communicative differences and/or deficits characteristic of autism. This study extends limited research into autistic experiences of interventions in the domain of communication. Furthermore, by extending prior research into neurodiverse values among speech-language pathologists (SLPs), this research contributes to the body of professional literature through exploration of autistic voices as in-group sources of expertise on ASD. The researcher recruited participants online, utilizing mixed methods in the form of quantitative surveys and qualitative interviews to collect and analyze data on the experiences and perspectives of autistic adults. Major conclusions of this research include the finding that participants' experiences with communicative interventions, though on average reported to be slightly more positive than neutral, vary widely. In addition, participants valued most highly aspects of intervention that emphasized autistic clients' autonomy and demonstrated respect for the individual expertise held by autistic people. One practical implication of this research is the need for SLPs to carefully consider intended and unintended effects of treatment on the lives of clients, in order to reduce bias and offer clients and families more comprehensive and accessible resources and perspectives to make more fully informed decisions.

Keywords: autism or autism spectrum disorder (ASD), speech-language pathologists (SLP), lived experience, models of disability, neurodiversity, self-advocacy

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CHAPTER I: INTRODUCTION

> Although knowledge is not yet power for many autistic people, identifying how autistic people think about autism is a first step toward developing research that is relevant to their interests and to the needs of the community whom the research is intended to serve. (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017, p. 11)

As Gillespie-Lynch and colleagues (2017) argued, the importance attributed to the voices and values of people with autism is a key factor that informs interactions with the autistic community that are sensitive and responsive to individuals' needs, opinions, experiences, and values. The significance of identifying and respecting these voices is applicable both within the context of research as well as in clinical practice as speech-language pathologists (SLPs) implement intervention for communicative deficits and/or differences characteristic of Autism Spectrum Disorder (ASD). "Client preferences and values," one of the pillars of evidence-based practice (EBP), become less accessible when service providers, such as SLPs, work with clients who present with communicative deficits or differences, for whom language may be less accessible or out of reach. If a client cannot effectively communicate experiences, concerns, or preferences, practitioners' ability to integrate client values into practice is dependent upon the family as a proxy for the client's voice; when a client experiences the world differently, as do individuals with autism, the validity of this assumption of the family as a proxy for the voice of a client comes into question.

From the standpoint of the neurodiversity movement and the conceptualization of autism as a difference that defines a community, identification of who speaks for the client's experiences, preferences, and values becomes more controversial. While minor children may not be capable of legal self-advocacy, children do have autonomous wishes and concerns, and these can and should be taken into consideration when making decisions about what is best for a child; even if adults are not legally obligated to listen, often, children do have a voice in the discussion. When a child is unable to express their thoughts in a manner that others understand, should parents be considered the sole proxy and represent the preferences of the family as a unit alone? What role, if any, should be played by adults with ASD, who may offer an insightful perspective into the experiences, differences, needs, values, and preferences of a child with ASD? These are important ethical questions with respect to intervention methods and therapeutic objectives. In this chapter, the researcher will present an overview of the purpose of this study, scholarly and practical rationales, definitions of key terms used in this research, background knowledge of foundational concepts addressed within, and a description of the methodology used to conduct this research.

Purpose Statement

This study will investigate the first-person perspectives of individuals with Autism Spectrum Disorder in the United States with respect to interventions addressing communicative differences and/or deficits related to ASD. In addition, the researcher will investigate perceptions within this population with respect to how individual values of people with ASD are integrated into the clinical services delivered by SLPs, and the perception of these voices as respected and valuable contributions to the broader conversation around autism.

Rationales

There are both scholarly and practical justifications for this research, with implications for clinicians, individuals with ASD, and families of individuals with autism. The first rationale for this research is to explore the viewpoints of people with ASD regarding interventions in the domain of communication; at present, a robust body of research into the viewpoints of people in the autistic community regarding communication therapies is lacking. Systematic explorations of the experiences and perceptions of people with autism with respect to interventions, specifically speech-language therapy, are extremely limited. When researchers have investigated autistic perspectives and lived experiences, areas of focus have trended toward areas such as the development and role of supports (Gillespie-Lynch et al., 2017, p. 5; Hurlbutt & Chalmers, 2002, p. 107); opinions of Applied Behavioral Analysis (ABA) therapy (Hurlbutt & Chalmers, 2002, p. 109; Kirkham, 2017, p. 115); transitions and transitional periods (Stevenson, Cornell, & Hinchcliffe, 2016, p. 230); experiences of stigmatization (Jones, Gallus, Viering, & Oseland, 2015, p. 1498); and the formation of cultural communities based on common discourse, interests, experiences, and values (Bagatell, 2010, p. 33). The emergence of an “autistic community” composed of people with ASD who both share common experiences and illustrate the rich spectrum of individual differences has offered new insights into how autism is defined, perceived, and experienced (Bagatell, 2010, p. 37; Giles, 2014, p. 180; Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013, p. 68; Sinclair, 2010, para. 5). Because research regarding these experiences is limited, in this study, the researcher will add to existing literature by investigating the experiences of individuals with ASD and their perspectives as in-group members of this community on the purpose, ethics, and value of interventions for characteristics of ASD, particularly communicative differences and/or deficits treated by SLPs.

Although self-advocacy by people with ASD is growing in visibility, the effects of the neurodiversity movement on accepted best clinical practices are variable and mixed at best. The rise of the neurodiversity movement is a relatively recent societal development; consequently, the current body of literature addressing these perspectives and opinions as well as the integration of these values into evidence-based practice by intervention specialists is quite limited in scope. The extant literature focuses more strongly on the paradigm of service providers such as speech-language pathologists as sources of expertise with respect to ASD and interventions for ASD; yet, as Hill (2014) reported, SLPs' self-reported awareness and integration into practice of values espoused by the neurodiversity movement are very limited in the United States (p. 83). Given that intervention approaches for ASD by nature target individuals with ASD, there is concerning lack of representation of these perspectives in the development of intervention programs or approaches (e.g., Gillespie-Lynch et al., 2017, p. 2). As McLaren (2014) reported, many autism-specific social skills training programs, as reported by participants, "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" (p. iv). These limited existent investigations of experiences with interventions in the domain of communication (e.g., McLaren, 2014), while valuable, are incomplete without further research into the perspectives of those whose differences and/or deficits are targeted. This study will contribute to the literature by extending prior research into neurodiverse values held by SLPs by exploring voices from the autistic community to deepen the conversation surrounding ASD.

From a clinical or practical standpoint, results of this research will be beneficial to clinicians as well as clients whom they serve. In practice, autistic perspectives on language-based interventions are not well understood and extant literature (e.g., McLaren, 2014) suggests that these perspectives do not significantly inform establishment of evidence-based practices in speech-language therapy for clients with autism. This study will offer insight into perspectives of individuals with ASD on their experiences with interventions that may inform SLPs who seek to provide services that are more sensitive and responsive to values and preferences of clients with ASD. In addition, the results of this study may provide valuable information for SLPs to incorporate in their counseling of parents of children with ASD, who may benefit from access to these first-person perspectives and experiences in contributing to decision-making for their child.

Definitions

Autism Spectrum Disorder, or ASD, refers to a neurodevelopmental condition that affects both how an individual experiences the world internally and interacts with the world externally, (e.g., through social communication and behavior). The etiology of ASD is uncertain; although research indicates a significant genetic component (Centers for Disease Control and Prevention [CDC], 2015b, para. 1), other contributing factors or influences may exist, and not all individuals with ASD may share the same etiology for the condition. The heterogeneity of ASD is also evident in how it manifests and affects individuals differently, with considerable variation among individuals in cognitive abilities, social/communicative differences and/or deficits, sensory experiences, and other domains of functioning (CDC, 2015b, para. 2 – 5).

The most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-V; American Psychiatric Association [APA], 2013) describes the diagnostic criteria for ASD. In summary,

> The essential features of autism spectrum disorder are persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criteria C and D). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment. Core diagnostic features are

> evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts. Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term *spectrum*. (p. 51)

Evidence-based practice (EBP) refers to a model of clinical practice supported by three pillars. The American Speech-Language-Hearing Association (ASHA) defined EBP as “an approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions” (ASHA, 2005, para. 1).

Background

Bloom and Lahey (1978) defined language as “a code whereby ideas about the world are represented through a conventional system of arbitrary signals for communication” (p. 4). According to the framework outlined by the researchers, language can be broken down into three fundamental components: form, content, and use (p. 11).

Form—comprised of phonology, morphology, and syntax—refers to the *how* of language; that is, the constituent units of language and the ways in which these units are produced and combined to encode meaningful messages (p. 16). Content, or semantics, is the *what* of language, the meaning of the message conveyed or received; the area of semantics refers to the speaker’s understanding of topics and the relationships among concepts as represented in language (p. 14). Use, or pragmatics, may be framed as the *why* of language. Pragmatics encompasses communicative functions and reasons for communication between speaker and listener as well as the influence of context on individuals’ use of alternative ways to convey a message (p. 19). These pragmatic rules govern ways in which individuals may modify the delivery of a message through changes in register or modification of non-verbal aspects of communication (for instance, eye contact, body language) according to the context in which language is used.

Communicative competence refers to the effective integration of the components of language that facilitates an individual’s ability to communicate with diverse listeners across varying contexts (Berko Gleason, 2017, pp. 3 – 4). Individuals with ASD may demonstrate reduced communicative competence in one or more areas with varying degrees of severity, such as expressive language, initiation of social interaction, and non-verbal communication (APA, 2013, p. 52).

In 2018, researchers Kogan and colleagues, based on data from the 2016 National Survey of Children’s Health (NSCH) estimated the prevalence of ASD in the United States among children between the ages of 3 and 17, per parent report, to be 1 in 40 children (Kogan et al., 2018, p. 1). As the researchers noted, differences and limitations of distinct methodologies used to calculate these estimated prevalence rates vary from study to study, limiting the viability of conclusions drawn from direct comparisons (p. 6). Kogan and colleagues also reported that “because there is no biological marker, ASD is a particularly challenging condition to track; thus, multiple systems with different case ascertainment strategies and supplemental data collection for children with ASD are useful in developing a full picture of ASD prevalence” (p. 8).

As of 2012, research from the Autism and Developmental Disabilities Monitoring (ADDM) Network estimated the prevalence rate of ASD in the United States to be 1 in 68 children; among males, the prevalence rate was estimated to be more than fourfold the prevalence in females of the same age. Within the data pooled from 11 ADDM Network sites in different states, Christensen and colleagues (2016) identified groups of children with ASD by earliest known diagnosis (by DSM-IV-TR), reporting 46% diagnosed with Autistic Disorder, 10% diagnosed with Asperger's Disorder, and 44% diagnosed with ASD-NOS/PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified). Estimated prevalence rates of ASD without intellectual disability were more than twice as high overall than estimated prevalence rates of ASD with intellectual disability. Researchers reported the median age at first diagnosis as 4 years, 2 months (pp. 6 – 8). Although these results are based on a sample of only 8-year-old children, it is important to note that autism is not only a disorder of childhood; although many or most individuals with ASD, particularly requiring higher levels of support, are diagnosed as children, ASD is a neurodevelopmental condition that persists throughout the lifespan (CDC, 2015b, para. 4).

Description of Method

This study utilized mixed methods in the form of quantitative surveys and qualitative interviews to collect and analyze data from adults on the autism spectrum with respect to their perspectives and lived experiences of autism, particularly with respect to communicative interventions. Questions addressed topics related to diagnosis, intervention methods, intervention outcomes, medical/social models of disability, neurodiverse values and opinions, perceptions of experiences and change over time, and general thoughts regarding communicative interventions for children with ASD.

Conclusion

In this chapter, the researcher discussed the premise of this study by presenting the purpose statement, rationales, definitions of key concepts and terms used in this paper, background knowledge of foundational concepts, and description of methodology. This study will contribute to existing literature by investigating the perspectives of in-group members of the autistic community with respect to the purpose, ethics, and value of interventions for communicative differences and/or deficits related to ASD. In the following chapter, the researcher will review the existing literature that contextualizes this study, including speech-language interventions for ASD, effects of ASD on communicative competency, and how the voices of individuals with ASD enter the conversation.

CHAPTER II: LITERATURE REVIEW

The following quote is taken from an editorial perspective in the *Journal of Child Psychology and Psychiatry* written by forerunning autism researcher Baron-Cohen (2017):

> These examples of cognitive talent are clearly incompatible with the notion of autism as a disorder. Aspects of social cognition reflect areas of disability in autism, and if a person is not showing any sign of disability, he or she would not warrant a diagnosis. But the language of disability is very different to the language of disorder. Disability requires societal support, acceptance of difference and diversity, and societal 'reasonable adjustment', while disorder is usually taken to require cure or treatment. These are very different frameworks. (p. 745)

The language employed by medical professionals, researchers, the general public, and autistic self-advocates surrounding the topic of autism can be polarizing, but the nuances of these linguistic conventions and the framing of which this language is indicative are less visible but no less significant. To understand the topic of this research, a deeper understanding of autism and the discourse surrounding it in today's society is critical in order to recognize and appreciate perspectives that do not, often, fit into the dominant paradigm.

This chapter provides a brief review of the literature relevant to this research. This includes explanations of the conceptualization of autism as a spectrum, intervention methods and practices for communicative deficits and/or differences related to autism, intended outcomes of language interventions for this population, and how these outcomes are determined. In addition, a review of the neurodiversity movement as it pertains to autism and the history and implications of autistic self-advocacy will be presented to facilitate an understanding of this research.

Autism as a Spectrum

The publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-V; American Psychiatric Association [APA], 2013) marked a departure from the system of classification of autism and related conditions utilized in the DSM-IV-TR (4th ed., text rev.; APA, 2000). Among the most notable changes in this revision was the rejection of the previously-used categorical model of classification in favor of a dimensional model; as Giles (2014) stated, “where appropriate, individuals [were] to receive a diagnosis along a continuum of ‘severity’ rather than being assigned to a discrete category” (p. 183). The condition now coded as Autism Spectrum Disorder (ASD) in the DSM-V subsumes three formerly distinct diagnostic categories in the DSM-IV: Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (Harker & Stone, 2014, p. 1).

The DSM-V codifies the spectrum nature of autism in concrete terms. An individual may be diagnosed with ASD based on criteria of impaired social communication, repetitive behaviors and/or restricted interests, presence of symptoms since early childhood, and the effects of these symptoms on everyday functioning (APA, 2013, pp. 50 – 59). Although the presentation of autism varies widely within the population, individuals with distinct diagnostic profiles may, according to the aforementioned criteria, receive the same diagnosis of ASD. An individual’s position on the spectrum is represented by the added “levels” described by the DSM-V, identifying the necessary degree of support indicated by an individual’s challenges in social/communicative and behavioral domains; the framework of three levels increases in severity, with Level 1 described as “requiring support” and Level 3 described as “requiring very substantial support” (APA, 2013, p. 52). These levels of support required may vary across contexts and over time for a single individual (American Speech-Language-Hearing Association [ASHA], n.d.-b, para. 7; APA, 2013, p. 51; Walker, 2012, p. 236).

Due to recent revision of the DSM, literature reviewed in this document may be published before or after publication of the DSM-V, leading to conflicting terminology that encompasses different definitions and subtypes of autism. Within this document, the researcher will use terminology consistent with the DSM-V (i.e., Autism Spectrum Disorder, ASD; Levels 1, 2, and 3). However, when referring to literature published prior to the DSM revision in 2013, terminology in use at the time of publication may be used with clarification as necessary. The terms ASD and autism may be used interchangeably in the interest of both conciseness and, as the researcher will discuss further in this chapter, sensitivity with respect to language. In addition, the term *neurotypical*, arising from the autistic-led Autism Network International, began as a neologism to refer to non-autistic people; over time, the term has spread and is widely used, including by the medical community, to describe individuals without noted neurological differences (Silberman, 2015, p. 441; Walker, 2012, p. 233). In the context of this research, the researcher will use the term in its original sense to distinguish between individuals with and without autism.

Within the range of the autism spectrum, a wide variety of communicative differences and/or deficits may be present. In the next section, the researcher will review commonly-implemented communication interventions to address these challenges.

Review of Speech-Language Interventions for ASD

Although in-depth examination of all existing approaches to communicative interventions for individuals with ASD is beyond the scope of this literature review—an interested reader may refer to Prelock and McCauley (2012)—within this section, the researcher will contrast between approaches rooted in medical versus social models of disability. In addition, the researcher will provide an overview of several approaches to communicative intervention for autism and modes of communication that are prevalent in the literature and clinical practice.

Models of Disability

A medical model of disability approaches autism as an inherent deficit—a condition causing impairment of a person's ability to function in the context of everyday activities. Within this model, approaches to treatment for characteristics of ASD aspire to make the individual less autistic and more "normal," or neurotypical (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013, p. 59). A medical model of disability compares the abilities of individuals with autism to those of people without autism and finds them lacking in comparison; oftentimes, approaches and perspectives on autism rooted in a medical model overlook individual strengths and advantageous aspects of conditions, focusing on "normalizing" the individual and diminishing or eliminating the visibility and/or state of being autistic (Kapp et al., 2013, p. 59).

By contrast, a social model of disability frames autism not as an intrinsic disability, per se, but as a more neutral *difference*; under a social model, "disability" is created by the societal demands imposed upon individuals whose abilities and needs diverge from expected norms. Changes in the environment facilitate changes in the nature—or presence—of disability as it impairs an individual's ability to function, interact, and perform daily tasks of living (Donaldson, Krejcha, & McMillin, 2017, p. 57). In the words of Donaldson and colleagues (2017), when physical or societal barriers are identified and eliminated, "disabled people can be independent and equal in society, with choice and control over their own lives. For those on the autism spectrum, [the social model of disability] specifically represents a neurodiversity perspective" (p. 57). The neurodiversity movement, often likened to a civil rights movement by and for individuals with disabilities (Baron-Cohen, 2017, p. 746; Jaarsma & Welin, 2012, p. 21), will be discussed later in this chapter. Approaches, methods, and models involved in communicative interventions for ASD may have roots in the medical model of disability, the social model, or some combination of the two.

Overview of Approaches to Treatment for ASD

Among the diagnostic criteria for ASD specified by the DSM-V (APA, 2013, p. 50) is onset of symptoms in the "early developmental period," but these characteristics may not be fully manifested until demands exceed capacities or may be masked by acquired strategies or behaviors; not all individuals with autism are diagnosed as children, and many may be diagnosed as adults (Bagatell, 2010, p. 35; Centers for Disease Control and Prevention [CDC], 2015a, para. 2). However, the focus of most interventions for ASD target children and adolescents (Howlin et al., 2015, p. 388; Prelock & McCauley, 2012, pp. 7 – 9). Deviation from expected developmental norms in domains such as language development may lead to referral for assessment and, for young children with a diagnosis of ASD, connection with Early Intervention (EI) services; early intervention to promote optimal developmental outcomes necessitates early identification (Boyd, Odom, Humphreys, & Sam, 2010, p. 75). In a recent international survey of speech-language pathologists (SLPs), researchers found that clinicians describing their caseload identified 3 – 4 years as the "typical" age at diagnosis of clients with autism (Gillon et al., 2017, p. 12).

According to Kasari and Smith (2016), rigorous research evidence to support particular instructional techniques, treatment modalities, or treatment models as best practices for individuals with autism is "paper-thin," at strong risk of bias, and in great need of further study in order to more effectively deliver evidence-based interventions that incorporate meaningful clinical expertise and go beyond what the authors refer to as a "cookbook approach" (pp. 261 –

263). For SLPs making clinical decisions as part of evidence-based practice to intervene for communicative deficits, two dimensions of intervention are most salient: theoretical foundations and associated instructional techniques, and communicative modality targeted for language function (LaRue et al., 2008, p. 27; Smith & Iadarola, 2015, p. 897).

As Smith and Iadarola (2015) explained, the most influential “theoretical principles” informing design of communicative intervention for ASD are applied behavioral analysis (ABA), developmental social-pragmatic (DSP), and combinations of the two (p. 897). Rogers and Vismara (2008) reviewed the extant literature examining efficacy of early intervention programs for young children with autism and found strong support for the model of “early intensive behavioral intervention,” or EIBI (pp. 23 – 25). This model is a rigorous ABA-based approach that relies upon one-to-one, time-intensive interventions to directly teach children to attend to an instructor and acquire “socially significant behaviors” that can be generalized to more naturalistic settings. Another intervention classified as “possibly efficacious” by the authors was Pivotal Response Treatment (PRT), a more naturalistic model that emphasizes incidental learning, or the acquisition of information through indirect and unplanned observation or interaction that is not the focus of teaching (Ledford, Gast, Luscre, & Ayres, 2008, p. 87). The goal of PRT is to “teach ‘pivotal’ responses that, when acquired, have the potential to improve performance across many other skill areas” (Rogers & Vismara, 2008, p. 28). All of these interventions may be applied to the domain of communication.

Communicative Intervention Methods and Models

Having established the breadth of intervention domains and theoretical approaches applied in treatment for characteristics of ASD, this literature review will focus on interventions that target differences and/or deficits associated with autism in the domain of communication. As the researcher has previously described, individuals with autism may present with communicative differences and/or deficits in many areas of language, including pragmatics and expressive language, particularly speech (APA, 2013, p. 52). For a more extensive analysis of evidence-based communicative interventions for ASD, see Prelock and McCauley (2012). Although review of all intervention methods and models for ASD is beyond the scope of this document, two types of communicative intervention are most relevant for the purposes of this research: augmentative and alternative communication (AAC) and social skills training.

Despite the efficacy of early intervention for communicative delays or deficits related to ASD, some individuals still do not fully develop spoken language (Tincani, 2004, p. 152). For individuals for whom the production of speech is challenging or unattainable, alternative modes of communication, such as AAC, may be introduced and utilized in speech-language therapy with the goal of providing the individual with a means of functional communication.

Augmentative and alternative communication. AAC may supplement or substitute for spoken language in order to facilitate functional and effective communication for individuals with complex communication needs (ASHA, n.d.-a, para. 1 – 2). Classification of AAC systems may refer to high-tech forms, using speech-generating devices (SGDs), or low-tech forms, either unaided “natural communication methods” (e.g., sign languages) or those requiring low-tech supports, such as the Picture Exchange Communication System, or PECS (Bedwani, Bruck, & Costley, 2015, p. 3).

Social skills training. Among the most common communicative deficits and/or differences associated with ASD are challenges in the areas of pragmatics, or social cognition (APA, 2013, p. 53; Müller, Cannon, Kornblum, Clark, & Powers, 2016, p. 192). Social communication interventions, as described by ASHA (n.d.-c), refer to intervention frameworks intended to teach and strengthen individuals' communicative competency by modeling, shaping, and reinforcing "appropriate behaviors and communication" with communicative partners, particularly peers (para. 48). Social skills training may often take place in groups facilitated by an SLP or other intervention specialist, in which "appropriate ways of interacting with typically-developing peers are taught through direct instruction, role-playing, and feedback" (ASHA, n.d.-c, para 52). As McLaren (2014) reported, these intervention programs "primarily focus on bringing [autistic people] into synchronization with the developmental, linguistic, social, and age-related norms of neurotypical people" (p. 12). Although the specific goals of communicative interventions differ among individuals, the desired outcomes may be comparable.

Factors in Determination of Desired Intervention Outcomes

The purpose and intent of interventions for characteristics of ASD warrant consideration. Under a medical model of disability, autism is pathologized, and treatment proceeds with end goals related to masking or eliminating that which makes a person autistic in order to bring the individual in line with societal norms (Donaldson et al., 2017, p. 57; McLaren, 2014, p. 13). By contrast, a social model of disability acknowledges challenges that individuals with autism may face, and treatment approaches rooted in this framework are oriented more toward capitalizing upon the strengths and skills of an individual and providing supports that enable an individual to more fully participate in society and engage in activities of daily living (Donaldson et al., 2017, p. 57). The number of proposed and practiced treatment models or frameworks for ASD is overwhelming; the researcher has reviewed several in this chapter, but for a more extensive review, an interested reader could explore Smith and Iadarola (2015).

Intended outcomes and goals of treatment are dependent on a number of factors, including the paradigm through which autism is approached in the context of intervention and the individual's age as well as unique profile of strengths, challenges, skills, and needs in the domain of communication. In examining the purpose and intent of interventions for characteristics of ASD, the desired end goal of treatment may speak to the value placed upon autism and individuals on the spectrum.

Target Population and Goals of Treatment

While communicative interventions for ASD may be implemented for or utilized by both children and adults, the majority of the extant research targets children (Smith & Iadarola, 2015, p. 899). The push for early detection and early intervention (EI) focuses on providing treatment to very young children, under 36 months of age. The mission of EI, as summarized by Zwaigenbaum and colleagues (2015), is to "provide the best opportunity for optimal development and outcomes" for children with developmental delays or disabilities, including children with autism (p. 61). Early intervention, according to Edwards and colleagues (2017), "has been found to significantly improve the outcomes for children with ASD" (p. 202). These desired outcomes are course-correction of the child's development to align with typically-developing peers. Explicit goals may vary from establishment of functional communication through speech or other modalities to the ABA gold standard of a child with autism who, after treatment, is "indistinguishable from their peers" (Leaf, Taubman, McEachin, Leaf, & Tsuji, 2011, p. 259). The stakeholders in the context of interventions for characteristics of ASD and their perspectives, experiences, and opinions are critical in the determination of treatment goals.

Stakeholders

Within the framework of evidence-based practice (EBP), input into the decisions made in treatment comes from the body of scientific evidence as well as stakeholders including the clinician, the client, and, particularly in pediatric practice, the parents or family (ASHA, 2005, para. 1). According to Prelock (2011), “Intervention decision-making for children with ASD … should not be limited by [clinicians’] preference or comfort with one approach over another. [Clinicians’] treatment decisions must consider the child’s goals, the family’s priorities and values, and the available evidence as it relates to the unique language and communication profiles of children with ASD” (p. 68). Given that extant research shows no single intervention approach or method to be most effective for all individuals with autism, clinicians and parents must work as a team to determine the course of action appropriate for each child (Auert, Trembath, Arciuli, & Thomas, 2012, p. 109). The stakeholder in this relationship who has the least input, under these constraints, is arguably the individual with autism.

Consideration of Autistic Voices

The question of who determines the intended and/or desirable outcomes of communicative and other interventions for ASD is contentious. While these treatment decisions are largely made by professionals and parents or families, the presence and significance of the voices of individuals with autism themselves are called into question, if not overlooked entirely. The need for a platform in which individuals with autism are visible and have a voice in society is evident in the development and current state of the neurodiversity movement.

State of the Neurodiversity Movement with Respect to ASD

A thorough examination of the neurodiversity movement is beyond the scope of this literature review. However, it is useful to briefly review the central ideas of the movement as well as its origins to better understand the context for this research.

History. The neurodiversity movement, as it exists today, arose in the 1990s from the combined voices of individuals with autism (Jaarsma & Welin, 2012, p. 21). Although the concept of neurodiversity encompasses many neurological differences, among them Attention-

Deficit/Hyperactivity Disorder (ADHD) and dyslexia, autism was the driving cause in its conception and early development; the movement focused on a paradigm shift to a conception of autism as a neurological difference, rather than an inherent disability.

A philosophy by which being autistic was equally as valid as any other way to be human contested the dominant discourse of "targeting" autism or focusing research into establishing etiology and a "cure" for autism (Donvan & Zucker, 2016, p. 516). This conflict between a medical model of autism as an inherent deficit and a social model of autism as a natural difference, with disability constructed by the demands and constraints of society, was critical to both the establishment of the neurodiversity movement and its opposition.

In 1993, Jim Sinclair, an autistic person, addressed an audience of primarily parents of autistic people at the International Conference on Autism with a provocative message: "Don't Mourn for Us." The outline of this presentation, published by the author online, acknowledged the grief of parents, then asked parents to consider autism and grief from the perspective of autistic people. "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" (Sinclair, 1993, para. 5). The direction of advocacy by parent groups and public awareness campaigns, Sinclair asserted, denied the humanity and dignity of autistic people (Donvan & Zucker, 2016, p. 514). As Sinclair (1993) explained at the International Conference on Autism,

> This is what I think autism societies should be about: not mourning for what never was, but exploration of what is. We need you. We need your help and your understanding. Your world is not very open to us, and we won't make it without your strong support. Yes, there is tragedy that comes with autism: not because of what we are, but because of the things that happen to us. Be sad about that, if you want to be sad about something.

> Better than being sad about it, though, get mad about it—and then do something about it. The tragedy is not that we're here, but that your world has no place for us to be. How can it be otherwise, as long as our own parents are still grieving over having brought us into the world? (para. 21)

In concluding their speech, Sinclair urged the audience to recognize and address both the challenges and strengths of individuals with autism as they existed, rather than seeking to pathologize autism as intrinsically negative and deny the value of autistic people. “Don’t Mourn for Us” was, and continues to be, widely regarded as a seminal moment in the rise of the neurodiversity movement.

Central premises and predominant themes. Jaarsma and Welin (2012) described the “neurodiversity claim” as consisting of two distinct but intertwined pieces. The first piece of the claim distinguishes between difference and disability, and asserts that autism is “not just natural and not pathological, but also valuable” (p. 23). The second piece pertains to conferment of value in the form of rights, recognition, and acceptance (p. 24). These two pieces of the neurodiversity claim are foundational to common driving threads with respect to neurodiversity, including: linguistic conventions; perception and value conferred upon treatment for characteristics of ASD; and societal perceptions, stereotypes, and stigmatization.

Person-first vs. identity-first language. In using language that describes and references people, it is a matter of both professionalism and ethics to respect the identities and experiences of the people to whom we refer, with whom we work, and about whom we speak (Dunn & Andrews, 2015, p. 256; Nicolaidis, 2012, p. 505). Accordingly, it is not just appropriate but essential to discuss the issue of language and linguistic conventions used to refer to people on the autism spectrum. In this literature review, the researcher has previously reviewed the medical and social models of disability with respect to both treatment of and interventions for characteristics with autism; these paradigms are also applicable to broader discourse about autism and the question of language used to refer to individuals and to communities.

As Gernsbacher (2017) defined, person-first language refers to the "structural form in which a noun referring to a person or persons…precedes a phrase referring to a disability" (e.g., *person with autism*, *individual with ASD*; p. 859). The use of person-first language is endorsed as a standard by professional associations including the American Medical Association (AMA), American Psychiatric Association (APA), American Psychological Association, and the American Speech-Language-Hearing Association (ASHA) as the prescribed form appropriate in both oral and written communication within their respective fields (American Journal of Speech-Language Pathology [AJSLP], 2018, p. 7; Gernsbacher, 2017, p. 859). Among the arguments for the use of person-first language, the most central might be the use of the convention as a linguistic equalizer: by recognizing an individual as a person first and foremost above the identifier of a disability or disorder, the convention recognizes all individuals as people with inherent value and humanity (Gernsbacher, 2017, p. 859; Tobin, 2011, para. 3).

However, as Gernsbacher (2017) explained, one objection to person-first language in the field of disability studies is the inconsistent application of this linguistic convention: "Not everyone is treated as a person first" (p. 859). An exhaustive search of extant literature across disciplines revealed that person-first labels are used far more frequently to refer to individuals with disabilities than those without disabilities, and most frequently of all to refer to individuals with disabilities that carry the most societal stigma. By contrast, terms that do not conform to person-first structure are predominantly used to describe people who are not disabled (e.g., *typically-developing child*, *gifted child*, *neurotypical person*; p. 860). This runs contrary to a fundamental argument for the use of person-first language in order to promote equal treatment, linguistically, of people with and without disabilities. Professional mandates for the use of person-first language, rather than acting as an equalizing force, may instead reinforce the biases they seek to eliminate by “call[ing] attention to some type of ‘marred identity’” (Vaughan, 2009, para. 5); by distancing the person from the disability, person-first language may be perceived as devaluing and reinforcing negative perceptions of disabilities such as autism (Dunn & Andrews, 2015, p. 256).

An alternative convention, commonly referred to as identity-first language, has become increasingly visible in the context of disability discourse. Identity-first language refers to linguistic convention in which the condition is a primary descriptor (e.g., *autistic person*; Gernsbacher, 2017, p. 859). The structure of identity-first language aligns with the English convention of placing positive or neutral descriptors before a noun (e.g., *gifted child*, *neurotypical person*; Kenny et al., 2016, p. 443). Identity-first language embodies the experiences and beliefs of many people on the autism spectrum. Among these shared values and beliefs are the significance of autism as a central component of identity rather than a peripheral aspect; the conceptualization of autism as a natural and neutral difference, rather than an inherently pathological deficit; and the permanency of autism as a condition that shapes a person’s experience of and interactions with others and the environment, not a condition that can be cured or, as the convention of person-first language may imply, separated from the individual (Donaldson, Krejcha, & McMillin, 2017, p. 58). As Sinclair (1999) wrote, “I am autistic because I accept and value myself the way that I am” (para. 4). Proponents of identity-first language within the autistic community perceive the shared but individual differences, challenges, and abilities associated with their lived experiences of being autistic as central to their identities as people (Bascom, 2011, para. 2 – 5; Ne'eman, 2010, para. 5; Sinclair, 1999, para. 2 – 3).

As both researchers and members of the autistic community have documented, there is not a consensus on which linguistic convention—person-first or identity-first language—is most appropriate (Bagatell, 2010, p. 39; Dunn & Andrews, 2015, p. 261). Neither is preferred or utilized by all people on the autism spectrum. However, growing trends among autistic self-advocates, activist groups, and, more broadly, in the literature and discourse of disability studies demonstrate stronger preference for the use of identity-first language over person-first language with respect to autism (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013, p. 60; Kenny et al., 2016, p. 457). Notably, Kapp and colleagues (2013) found that the preference for identity-first language was higher among autistic than neurotypical individuals (p. 64). Similarly, Kenny and colleagues (2016) found that in the United Kingdom, identity-first language was favored by the majority of autistic respondents as well as family and friends of people with autism, but preference for identity-first language was considerably lower among professionals associated with the autism community; conversely, support for person-first language was highest in the professional community, but espoused by only 28% of autistic people (p. 446).

The language that researchers and professionals use to describe something or someone speaks to the perceptions and beliefs that we hold about the subject; accordingly, the use of identity-first language demonstrates respect for and deference to the values and preferences of many autistic individuals, prioritizing their autonomy and identity over the beliefs of primarily neurotypical professionals and family members who might speak in their stead. While the preference for and use of identity-first language are not universally accepted by all members of the autistic community, the values for which the convention stands and the considerable segment of the population to whom this language refers deserve professional consideration. Officially, the use of identity-first language over person-first language stands in opposition to professional standards (American Psychological Association, 2010, p. 76; AJSLP, 2018, p. 7); however, it might be argued that this convention is consistent with the American Psychological Association's "focus on prioritizing language that respects individual preferences" (American Psychological Association, 2010, p. 72; DeThorne, 2018, para. 2). Accordingly, within this document, the researcher will use the preferred convention of individual subjects if known; otherwise, person-first and identity-first language with respect to autism will be used interchangeably, following the recommendations of prior researchers (Dunn & Andrews, 2015, p. 262; Gernsbacher, 2017, p. 861; Kenny et al., 2016, p. 459).

Perception of and value placed on treatment. Understanding the neurodiversity movement as a paradigm shift from conception of autism as disorder to one of autism as difference, the value and validity of existence as autistic is a central tenet; viewed through the lens of a neurodiverse paradigm, treatment for characteristics of autism is a polarizing subject. While a true consensus may not exist among all autistic people, perceptions of and the value placed upon treatment tend to differ from views expressed by neurotypical stakeholders such as parents or professionals (Bagatell, 2010, pp. 48 – 49). This disparity returns, in part, to the distinction between medical and social models of disability: autism as pathological and requiring intervention to "correct" course of development vs. autism as a different but equally valid way of experiencing and interacting with the world (Bagatell, 2010, p. 38; Kapp et al., 2013, p. 60).

The concepts of autism as a neutral difference and autism as a disability are not, however, incompatible; within the neurodiversity movement and autistic self-advocacy community, it is widely recognized that "disability," understood through a social model, speaks more to the societal norms and demands than to the inherent worth or competence of a person. Autism can be an identity of pride, but this ownership of identity coexists with challenges and needs for support (Bascom, 2011, para. 6 – 9; Brown, 2011, para. 11).

Individuals and organizations who speak as autistic self-advocates tend to find common ground, and shared identity, in asserting the inherent worth of their experiences and existences as autistic people; within the neurodiversity movement, the value placed on "treatment" for autism often depends on the intended outcomes as well as the means of intervention. As Kapp and colleagues (2013) described, advocates of the neurodiversity movement "promote subjective well-being and adaptive rather than typical functioning, such as reliable, but not necessarily spoken, communication" (p. 60). Strengths-based interventions that capitalize on the abilities of individuals, seeking to provide supports and tools to bridge gaps between demand and capacity, are most favorably viewed; these forms of intervention are *additive*, augmenting the abilities and compensating for challenges (Kapp et al., 2013, p. 60). By contrast, interventions that proceed with end goals that are *subtractive*—for instance, extinguishing behaviors related to autism that are seen as undesirable, such as echolalia or stimming—are overwhelmingly viewed as unnecessary and harmful (Bagatell, 2010, p. 48). ABA therapy is condemned particularly strongly by the neurodiversity movement and self-advocates, both for the desired outcome of "normalization" of autism and for common methods within this intervention framework, which autistic individuals have described in terms of trauma and abuse (Bascom, 2012b, pp. 177 – 182; Kapp et al., 2013, p. 60).

Societal perceptions. In a society in which autism is stigmatized as a disorder, a deficit that requires treatment and normalization, there are a number of popular stereotypes that selectively represent or misrepresent autism and autistic individuals. These stereotypes, transmitted and reinforced through popular culture and the media, can be not only offensive, but actively detrimental to the dignity, autonomy, and lived experiences of autistic people. Among the most common stereotypes that form the dominant discourse about autism are: selective representation as a particular “high-functioning” profile; autism as dehumanization (Winter, 2012, p. 118); and what Gross (2012a) refers to as the “catch-22 [of disability]” (p. 241).

One popular representation of autism in the public eye is autism as the idealized Asperger’s: a highly intelligent, but socially awkward, white male; this stereotypical person often does not understand or value humor, making him an easy target for jokes (Winter, 2012, p. 118). Although this stereotype, played out, is often argued to be positive—demonstrating the potential and strengths of a person with autism—it is problematic in several ways. By portraying the person as high-achieving, “high-functioning,” independent, and self-sufficient—just “socially awkward” in a way that conveniently sets up humor at their expense—this stereotype denies the valid difficulties faced by many individuals deemed “high-functioning” or diagnosed with Asperger’s Disorder (Nordahl-Hansen, Tøndevold, & Fletcher-Watson, 2018, p. 352). Furthermore, this stereotype creates division between what society perceives as acceptable, even valuable, difference in autism and what society deems unacceptable and lesser for its difference.

Popular culture’s effects on societal stigma surrounding autism may be mixed. Although “positive” portrayals of autistic individuals may be argued to increase representation and autism awareness, the portrayal of “autistic” characters in movies and on television can also reinforce existing stereotypes and distort the realities faced by autistic people (Nordahl-Hansen et al., 2018, p. 352). While Nordahl-Hansen and colleagues (2018) found that many “autistic” characters in a study of 26 movies and television series were depicted as demonstrating characteristics that mapped to DSM-V diagnostic criteria for ASD, the researchers also expressed several concerns about the value and potential ramifications of their findings. These concerns included the question of whether the writing and acting of a character "meeting all diagnostic criteria…can be described as 'accurate.' Instead, the characters portrayed onscreen might be described as 'archetypal' in relation to diagnostic criteria" (p. 352). This type of representation has the potential to reinforce existing stereotypes and stigma in relation to autism. Accuracy in diagnostic characteristics does not necessarily correlate with authentic representation of lived experiences, and flattening these narratives to best fit the context of the story erases opportunities to acknowledge both obstacles faced by and the human potential of autistic people (Nordahl-Hansen et al., 2018, p. 352).

A second dominant stereotype exists, by contrast, of autistic people as "not properly human": found lacking in some way so fundamental as to constitute an essential deficit in the humanity of a person. Perhaps one of the most widely-held beliefs relating to this stereotype is the conception that autistic people neither experience nor understand empathy (Winter, 2012, p. 118). Research concerning empathy in autistic individuals compared to neurotypical individuals has yielded inconsistent findings, with some studies finding deficits in both cognitive and affective components of empathy among individuals with autism (Mathersul, McDonald, & Rushby, 2013, p. 663) and other studies finding no difference in affective empathy between autistic individuals and neurotypical individuals (Dziobek et al., 2008, p. 471; Rogers, Dziobek, Hassenstab, Wolf, & Convit, 2007, p. 714). The empathy imbalance hypothesis (EIH), as Smith (2009) described, postulates that ASD is associated with deficits in cognitive empathy—"the ability to understand and predict the behavior of others in terms of attributed mental states"—but also comparatively greater affective empathy, "an emotional response in an individual that stems from and parallels the emotional state of another" (pp. 489 – 490). Autistic narratives tend to support the EIH (Brown, n.d., para. 22; Gillespie-Lynch et al., 2017, p. 7; Smith, 2009, p. 489).

Other societal perceptions related to the stereotype of autism as less human include devaluation and stigmatization of the behaviors, interests, self-stimulatory behaviors, and ways of socializing demonstrated by autistic people, assuming that the lives of people with autism—particularly "low-functioning" autism—are "empty," and that autistic ways of interacting with the world are "fundamentally wrong" (Bascom, 2012a, p. 202; Winter, 2012, p. 118). Taken to its most extreme, dehumanization of autistic people colors media coverage of the murders of autistic people, portraying caregivers and parents who kill autistic individuals as more sympathetic characters and characterizing their crimes as "acts of mercy" (Gross, 2012b, pp. 238 – 239; Winter, 2012, p. 119). The stereotype of autistic individuals as intrinsically alien, inherently less human than neurotypical people, not only denies the validity of autistic existences, but also erases the voices of autistic people that run counter to these stereotypes.

A third and particularly pernicious belief, referred to by Gross (2012a) as the "disability catch-22," relates to the validity of autistic voices (p. 241). If a person is capable of self-advocacy, then that person often is not perceived to be "autistic enough" to understand and speak on behalf of autistic people who are more visibly disabled, particularly individuals for whom communication is not in reach (Bascom, 2011, para. 17 – 22; E, 2012, p. 130; Gross, 2012a, p. 241; Winter, 2012, p. 119).

Within the paradigm of the medical model of disability, autism is an inherent deficit, a deviation from the norm that requires normalization. This emphasis on "overcoming" autism, on "treating" ASD, on pursuing a "cure," affects both societal stigma toward autistic people as well as the self-perceptions of autistic individuals. Internalization of negative ideas, perceptions, beliefs, and stereotypes in society, as self-advocates maintain, is detrimental to the wellbeing, autonomy, and empowerment of autistic people (Gross, 2012c, p. 269; Walker, 2012, p. 236; Winter, 2012, p. 118). With these concerns in mind, the goals of advocacy, and their relation to the identity of the advocates, warrant consideration.

Key Organizations and Advocacy Groups

Advocacy is not a phenomenon that occurs only on the level of the individual; within the sphere of autism discourse, a number of organizations and advocacy groups currently exist, with significant variation in the goals of their work. Language (person-first vs. identity-first) is an issue on which prevailing values and opinions differ between autistic people and neurotypical people (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013, p. 64); a similarly subtle difference is evident in the distinct intended outcomes of advocacy groups organized by autistic people and voices of autistic individuals, who lean toward acceptance, and organizations that speak for individuals with autism, who lean toward awareness. Acceptance, as a goal, does not seek to change autism or autistic individuals; awareness, as a goal, is tied to action and intervention.

In-group vs. out-group voices. While many self-advocacy groups organized by and for autistic people exist today and have contributed historically to the rise of the neurodiversity movement, for purposes of brevity, it may be useful in this literature review to discuss specifically one of the organizations at the forefront of the self-advocacy movement today. The Autistic Self Advocacy Network (ASAN), a 501(c)(3) nonprofit organization, was established in 2006 by autistic adults concerned about the prevailing discourse about autism in contemporary society and the need for means of empowering and supporting autistic people as they were rather than focusing on a cure agenda (ASAN, n.d.-b, para. 2). More than a decade after its establishment, ASAN has grown significantly in size, reach, and scope—extending now beyond advocacy into areas including “programming in leadership development, technical assistance, employment opportunities, publications, community based participatory research, public policy analysis and education and other efforts to help inform decision-makers and the public about the autism spectrum and the perspectives of those on it” (ASAN, n.d.-b, para. 3).

The disability rights slogan, which has been adopted by ASAN as their motto, speaks to ASAN’s overarching message: *Nothing about us, without us*. ASAN positions itself as a group that supports and empowers autistic individuals and the shared autistic community, primarily through the critical concern of making autistic voices heard and valued in spheres of the public as well as medical and research communities (ASAN, n.d.-a, para. 1). The goal of advocacy, then, through the lens of ASAN, is acceptance—including the acceptance of autistic and neurotypical people, autistic and neurotypical perspectives, as equally valid.

The neurodiversity movement, as the researcher previously discussed within this literature review, is a relatively recent development, with roots in the 1990s (Jaarsma & Welin, 2012, p. 21). A long history of discrimination against and unequal opportunities for people with autism, without the visibility of autistic self-advocates or an autistic community, has necessitated the engagement of other stakeholders to promote and preserve the rights of autistic individuals; historically, parents of children with autism have taken up this role (Silverman & Brosco, 2007, pp. 393 – 396). The significant role of parents as advocates in challenging the sole authority and power ascribed to medical professionals in declaring the value and determining the course of autistic people’s lives is not to be underplayed; indeed, it was through the efforts of parent advocates that many positive changes were effected, including the passage of the legislation that became the Individuals with Disabilities Education Act (IDEA) in 1990, which guaranteed the rights of children with disabilities to a free and appropriate public education in the least restrictive setting (Mead & Paige, 2008, p. 123). However, the transfer of power and authority from the medical community to “autism parents” and the empowerment that this paradigm shift brought runs parallel to the need, spoken by autistic self-advocates, for further progress: “That was a wonderful advance: celebrate it. But more and more disabled people are now challenging parental power and the image of disabled people as children” (Montgomery, 2012, p. 84).

Autism Speaks, among the largest and most visible non-autistic advocacy groups related to autism, was founded in 2005 by Robert and Suzanne Wright following the diagnosis of their grandson with autism (Autism Speaks, n.d., para. 3). In years since, the organization has merged with other leading autism-related groups, including the Autism Coalition for Research and Education, the National Alliance for Autism Research, and Cure Autism Now (Autism Speaks, n.d., para. 4). As currently represented on the organization’s website, the mission statement of Autism Speaks states that the organization

> …is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions. Autism Speaks enhances lives today and is accelerating a spectrum of solutions for tomorrow. (Autism Speaks, n.d., para. 1)

In the past, the self-described mission of Autism Speaks has explicitly included a cure-focused agenda; in the words of co-founder Suzanne Wright (2008), “We’re now trying to play catch-up as we try to stem the tide and ultimately *eradicate autism for the sake of future generations*” (emphasis added; para. 7). Itkonen and Ream (2013) noted that organizations such as Autism Speaks are typically founded upon, and operate under, an (often extreme) medical model of autism (p. 52); in the case of Autism Speaks, the narrative of pathology is further driven by emotional appeals that autistic people have referred to using descriptors such as "hate speech" (Sequenzia, 2014, para. 5) and "destructive to the psyches of autistic people" (Robison, 2013, para. 15). Historically, Autism Speaks has promoted a number of messages and theories that other stakeholders have found alarming; most central to this rhetoric, as Winter (2012) described, is the reductive conceptualization of "autism as tragedy" (p. 119). Within this narrative, autism is something that *happens* to families. Autism is a disruption. Autism is an entity unto itself, not an aspect of a person. Autism is to be pitied, hated, or even extinguished.

Perhaps among the most infamous fundraising campaigns launched by Autism Speaks, a 2009 video titled "I am Autism," featured a montage of images and video clips of autistic individuals with an ominous voiceover personifying autism as a threat (transcript retrieved from ASAN, 2009a). In response, ASAN published an open letter, stating not only that the provocative "awareness" campaign reinforced deeply harmful stereotypes and misconceptions about autistic people, but furthermore, that this bias was consistent with the broader political platform on which Autism Speaks operated, throughout which ran "a consistent and unfortunate theme of fear, pity and prejudice, presenting Autistic adults and children not as full human beings but as burdens on society that must be eliminated as soon as possible (ASAN, 2009b, para. 1 – 5). The video was subsequently retracted, with minimal acknowledgement of why its message was harmful (Saunders, 2018, p. 2); copies of "I am Autism," however, do still exist on the internet (see Find Yaser, 2016). Many of the position statements, public awareness campaigns, and other publications that have faced backlash from the autistic community have since been removed from the Autism Speaks website. For instance, the highly controversial statement by co-founder Suzanne Wright titled "Autism Speaks to Washington—A Call for

Action" has been preserved only by people who quoted it in order to respond (see Shane, 2013). At the time of this writing, the website of Autism Speaks has been sanitized of many of these prior campaigns and statements, external links to which no longer function.

Other concerns about the validity of Autism Speaks as an advocacy organization—including its allocation of funding; its lack of endorsement by the population for whom it claims to stand; implications of research directions; and the messages of fear and despair that it promotes through its "awareness" efforts—are well documented by autistic self-advocates beyond the scope of this literature review; for more in-depth examination of these concerns, see Brown (2013) and Sequenzia (2012, pp. 275 – 278). As Robison (2013) summarized,

> Autism Speaks says it's the advocacy group for people with autism and their families. It's not, despite having had many chances to become that voice. Autism Speaks is the only major medical or mental health nonprofit whose legitimacy is constantly challenged by a large percentage of the people affected by the condition they target. (para. 20)

Societal and clinical implication of autistic self-advocacy. In-group and out-group voices—that is, autistic people and people speaking in their stead—tend to differ in the values, perceptions, and ultimate goals of advocacy that they contribute to societal discourse surrounding autism. In-group voices, such as ASAN and individual autistic self-advocates cited previously within this document, tend to refer to the lives and lived experiences of existing autistic people—recognizing their wants, needs, and ways of existing as valid—and the prospect of directing research toward developing supports and eliminating barriers to access. By contrast, out-group voices often perpetuate stigmatization of autism and promote agendas focused on normalization or elimination of autism. In gathering best available evidence and contributing to decisions about treatment rooted in the model of EBP, Gillespie-Lynch and colleagues (2017) suggest that autistic people should be considered authoritative voices on autism, drawing from synthesized lived experiences and external information (p. 11). Although the medical model of disability may be deeply ingrained in speech-language pathology as a medical-adjacent profession, the clinical implications of autistic self-advocacy might include a responsibility to offer unbiased information to parents navigating diagnosis and intervention—including perspectives and paradigms that may differ but are no less valid and deserving of respect and consideration.

Conclusion

In this chapter, the researcher has reviewed the extant literature with respect to the spectrum nature of autism; contrasted approaches to communicative interventions for ASD rooted in medical vs. social models of disability; highlighted the use of two intervention methods or tools; and discussed the determination of desired outcomes by stakeholders in this process, including where and how voices of individuals with autism enter the conversation. In addition, the researcher has reviewed the history and common themes of the neurodiversity movement with respect to autism, including issues of language and identity. The researcher contrasted voices of autistic self-advocates and voices speaking for people with autism with regards to goals of advocacy, reception within the autistic community, and effects on societal perceptions of autism. This section concluded with a brief discussion of the implications of the perspectives and voices of autistic individuals for SLPs. In the next chapter in this document, the researcher will present the methodology used in this research study to investigate the experiences and perspectives of individuals with autism as they relate to communicative interventions.

CHAPTER III: METHOD

The purpose of this research is to investigate the first-person perspectives and lived experiences of individuals with autism with respect to communicative interventions, as well as autistic individuals' perceptions of their voices as valued and integrated into evidence-based practice by speech-language pathologists (SLPs). In order to investigate experiences and perspectives within this population, the researcher disseminated an online survey and conducted follow-up interviews by phone. In this chapter, the researcher will review justification for this methodology, information about the participants involved in this research, procedures for data collection, and the instruments by which data were collected.

Justification of Method

For the purposes of this study, online survey research and follow-up interviews by phone were optimal methods for collection of data from participants within the target population of individuals with Autism Spectrum Disorder (ASD). Survey research is an effective method of data collection that allows for the gathering of data about the habits, experiences, perspectives, opinions, or values held by a group of people; by analyzing the responses of many participants within a given sample of the population, researchers may identify patterns and correlations in order to make inferences with some degree of generalizability to a larger population of interest (Wrench, Thomas-Maddox, Richmond, & McCroskey, 2016, p. 216). Within this study, the researcher distributed the link to an online survey to potential participants within the target population of the autistic community.

The internet as a means of survey administration is particularly salient to this study. Online survey research allows researchers to contact geographically dispersed members of a population in a smaller time frame and at a lower cost, increasing the number and diversity of potential participants that may be contacted as well as the number of participants who can logistically volunteer to participate (Heiervang & Goodman, 2009, p. 69; Wrench et al., 2016, pp. 229 – 230). In addition, dissemination of the survey instrument online is well-suited to the nature of the population of interest. As Jaarsma and Welin (2012) noted, the autistic community is one that particularly thrives online (pp. 25 – 26); in this study, online survey research served as a means to contact individuals in this population through utilization of forums and social media groups that may be of common interest to many individuals with ASD.

Supplementing survey research with follow-up interviews conducted by phone allowed for more in-depth responses and elaborations upon topics that offered insight into participants' perspectives and experiences but that were less accessible through survey research. Interviewing participants by phone rather than in person was more feasible in terms of cost and ability to schedule or reschedule times at the convenience of both the researcher and participants, as in-person interviews with many respondents might require significant travel due to geographic distribution within the United States. Guiding questions were provided in advance of the scheduled interview to allow participants time to organize their thoughts.

Participants in this study were selected through purposive sampling, by posting to social media groups and online forums, and network sampling, by contacting program coordinators with a request to forward the email to students who meet the criteria for participation. While both methods yield nonprobability, or non-random, samples of the population of interest, these methods of sampling were selected for efficiency of time and cost in identifying and contacting eligible participants; network sampling, in particular, allows for the potential recruitment of additional participants by peers or other contacts and may increase the researcher's ability to recruit a larger sample size (Wrench et al., 2016, p. 319).

Participants

In the context of this research, the population of interest consisted of adults diagnosed with ASD or a corresponding pre-existing diagnosis (i.e., under the DSM-IV; 4th ed., text rev.; APA, 2000) within the United States. Individuals who consented to participate in the study completed the self-administered survey at the time and pace of their convenience.

A total of 64 individuals participated in completion of the online survey. Within this sample of the population, of the total 64 participants, 17.2% (*n* = 11) chose not to respond to the question regarding gender; 20.3% (*n* = 13) identified as male; 46.9% (*n* = 30) identified as female; 12.5% (*n* = 8) identified their gender as “other”; and 3.1% (*n* = 2) preferred not to say. Participants who completed the online survey were between the ages of 18 and 60 years (*M* = 28.59, *SD* = 10.47, *n* = 46); 28.1% (*n* = 18) chose not to respond to this question. Self-reported ages at diagnoses ranged between 2 and 59 years (*M* = 22.08, *SD* = 14.59, *n* = 49); 23.4% (*n* = 15) chose not to respond to this question. In addition, participants were asked to name the original diagnosis received; these data are depicted in Table 1.

Table 1

Original diagnosis received by participants

Diagnosis	*n*	%
Autism Spectrum Disorder (ASD)	24	37.5
Asperger’s Disorder	20	31.3
Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)	5	7.8
Autistic Disorder	2	3.1
No response	13	20.3

Complementary to participation in this research by completion of the online survey, two interested participants chose to complete a follow-up interview by phone with the researcher to elaborate on the themes and questions addressed within the survey. Of these interview participants, 100% (*n* = 2) identified as female.

Instrument

The primary instrument used to conduct this research was an electronic survey (see Appendix A). The survey was created using Qualtrics. Prefacing entry to the survey questions was an informed consent page displayed to all potential participants. By selecting the response choice “I agree,” participants indicated that they had read and understood the above information; were 18 years of age or older; and voluntarily consented to participate in the survey. Individuals who selected the response choice “I do NOT agree” were not shown any survey questions and redirected directly to the end-of-survey page.

The survey consisted of 110 items in total, including open-ended items providing space for respondents who wished to comment on or explain responses to closed-ended questions. Question types included multiple choice, select all that apply, Likert-type, and open-ended text entry. Blocks within the survey included basic demographic data; conceptions of autism; preferred means of communication; individual experiences with interventions in the domain of communication; values and beliefs with respect to the value of interventions for characteristics of autism; perceptions of value of autistic voices; and application of lived experiences and accrued knowledge in advising hypothetical individuals, families, and clinicians. Skip logic was used to determine participants to whom the block of questions regarding experiences with interventions was displayed, based on participant responses to a question asking about any experiences with interventions targeting communication skills. Interviews by phone were guided by a predetermined set of questions and topics also approved by the HSRC; see Appendix B for these interview questions.

Procedures

This research protocol was approved by the Human Subjects Research Committee (HSRC) at The College of Wooster on November 27, 2018 (see Appendix C). Following HSRC approval, the survey was disseminated through two primary means. First, potential subjects were contacted initially in December 2018 and January 2019 through staggered posts to several pertinent online forums, community pages, and groups on Reddit and Facebook. Second, on December 2, 2018, the researcher emailed coordinators of 33 programs specifically intended to support students on the autism spectrum at colleges and universities in the United States with a brief description of the research and a request to forward the recruitment text and survey link to eligible students. Of 33 programs initially contacted, four responded to the researcher's email; it is unclear how many additional programs may have forwarded the recruitment email to students without responding. See Appendix D for recruitment materials. The online survey was officially closed on January 22, 2018; subsequently, the researcher downloaded survey response data from Qualtrics for statistical analysis using SPSS.

In response to participant-initiated requests to schedule a follow-up interview, the researcher conducted two interviews by phone during the period in which the survey was active. Prior to each interview, a copy of the consent form was emailed directly to each participant, requesting an affirmative reply in order to schedule and conduct the interview. Interviews were completed by phone on December 8 and December 12, 2018; each interview was conducted using a landline in a private room, and audio was recorded with participant consent to facilitate complete and accurate transcription. In the following chapter, the researcher will present the findings of this research.

CHAPTER IV: RESULTS AND DISCUSSION

The purpose of this study was to investigate the first-person perspectives of autistic individuals with respect to interventions in the domain of communication. In addition, the researcher examined perceptions with respect to how the individual values of people with autism are integrated into clinical services delivered by speech-language pathologists (SLPs), and the perception of these voices as respected and valuable contributions to the broader conversation surrounding Autism Spectrum Disorder (ASD). To investigate these lived experiences, perceptions, and opinions, the researcher surveyed and interviewed autistic individuals regarding beliefs about autism, intervention methods and outcomes, models of disability, neurodiverse values and opinions, reflections on lived experiences, and general thoughts with respect to communicative interventions for individuals with ASD. In this chapter, the researcher will report the results of this study and discuss these results in the context of extant literature.

Results

Quantitative data obtained from the survey were analyzed using SPSS. The sample size of all individuals who participated by responding to the survey (i.e., *N*) is 64; unless otherwise indicated, the sample size for all analyses is 64. In addition to this survey data, the researcher conducted two follow-up interviews; Although complete transcripts of these interviews are not appended to this document to protect the privacy of participants, excerpted interview quotations and responses to open-ended survey questions will be presented along with scholarly research in the discussion in order to contextualize and interpret the results.

Conceptions of Autism

In this section, the researcher will present data from several sub-sections of the survey, all of which relate to conceptions of autism. These survey sub-sections include items asking about experiences of autism, communicative preferences and needs, beliefs and opinions relating to models of disability, neurodiverse values, and preferences for language. Responses to these survey items related to lived experiences of being autistic as well as perceptions and opinions related to autism. Additionally, participants described autism in their own words; for a complete list of responses (n = 54) to this question, see Appendix E.

Lived experiences. Participants indicated the means by which they communicated *in person* by selecting all choices that applied. Of participants who chose to respond to this question (n = 59), 58 (98.3%) indicated that they use spoken language to communicate with others face-to-face; 7 (11.9%) use sign language; 35 (59.3%) type or write; two (3.4%) use an AAC device; and five (8.5%) use an other means of communication in person. For a complete list of described "other" means of communication used in person, see Appendix F. Of the 59 participants who chose to respond to this question, 37 (62.7%) indicated that to communicate in person, they used two or more means (i.e., spoken language, typing or writing, sign language, AAC device, or other). Participants described their self-perceived communicative strengths (n = 55) and communicative challenges (n = 55) in response to two open-ended survey items; a complete list of responses to these questions can be found in Appendix G and Appendix H, respectively.

When asked about *preferences* for general means of communication with others, participants rated their preference for different means of communication using a 5-point Likert scale in which 2 = *strongly prefer*, 1 = *somewhat prefer*, 0 = *no preference*, -1 = *somewhat dislike*, and -2 = *strongly dislike*; the number of respondents, mean scores, and standard deviations for each of these items are reported in Table 2. Participants (n = 58) expressed a strongest preference for texting as a means of communication (M = 1.05, SD = 1.16, range = -2 – 2) and a strongest dislike for use of the phone to communicate with others (M = -1.22, SD = 1.06, range = -2 – 2). For a complete list of participant-described means of non-verbal communication in person, see Appendix I; for “other” participant-described means of general communication, see Appendix J.

Table 2

Levels of preference for different means of communication

Means	*n*	*M*	*SD*
Texting	58	1.05	1.16
Email	58	0.74	1.31
Other (please describe)	25	0.64	1.11
Verbally, in person	58	0.31	1.31
Non-verbally, in person (please describe)	51	0.00	1.13
Phone	58	-1.22	1.06

Note. These items were scored using a 5-point Likert scale in which 2 = *strongly prefer*, 1 = *somewhat prefer*, 0 = *no preference*, -1 = *somewhat dislike*, and -2 = *strongly dislike*. For all items in this table, responses ranged from -2 to 2.

Medical and social models of disability. Participants’ views of autism were measured in response to four statements about autism using a 5-point Likert scale in which 2 = *strongly agree,* 1 = *somewhat agree*, 0 = *neither agree nor disagree*, -1 = *somewhat disagree*, and -2 = *strongly disagree*. Values for Q4.4 (autism as “valuable difference”) were recoded to align with Q4.2 (autism as “deficit”) such that for these sub-items, a positive score corresponded to consistency with a medical model of disability and a negative score corresponded to consistency with a social model of disability; of the four statements presented to participants, scores for only these two sub-items directly reflected alignment with social and medical models of disability in relation to autism. For each of these four items, the number of respondents, mean score, and standard deviation are reported in Table 3.

Table 3

Levels of agreement with descriptions of autism

Statement	*n*	*M*	*SD*
“Autism is a disorder.”	64	-0.27	1.49
“Autism is a deficit.”	64	-0.89	1.31
“Autism is a neutral difference.”	63	0.70	1.13
“Autism is a valuable difference.”	63	-1.37	0.81

Note. These items were scored using a 5-point Likert scale in which 2 = *strongly agree*, 1 = *somewhat agree*, 0 = *neither agree nor disagree*, -1 = *somewhat disagree*, and -2 = *strongly disagree*. For all items in this table, responses ranged from -2 to 2. Participant responses to sub-items Q4.2 and Q4.4 only directly reflect alignment with a medical or social model of disability as it pertains to autism; sub-items Q4.1 and Q4.3 do not.

On two additional survey items, respondents provided their opinion regarding the level of importance they attributed to different statements using a 5-point Likert scale in which 5 = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *not at all important*. Participants attributed slight-to-no importance to finding a cure for autism (*M* = 1.33, *SD* = 0.84, range = 1 – 5). Similarly, respondents also placed slight-to-no importance on assimilation with neurotypical expectations and norms (*M* = 1.64, *SD* = 1.10, range = 1 – 5).

Neurodiversity. Given a brief definition of the term *neurodiversity* as it was to be used within the remainder of the survey, participants were asked to indicate the degree to which this definition was consistent with their understanding of the concept of neurodiversity. Participants responded using a 5-point Likert scale in which 5 = *extremely consistent*, 4 = *very consistent*, 3 = *moderately consistent*, 2 = *slightly consistent*, and 1 = *not at all consistent*. In response to a working definition of neurodiversity as *the idea that autism is a neurological difference characterized by both strengths and weaknesses, and that existing as autistic and existing as non-autistic are equally valid*, participants indicated that this definition was very-to-extremely consistent with their understanding of neurodiversity (*M* = 4.56, *SD* = 0.81, range = 1 – 5). For the text-entry response to a request to elaborate upon a response of “not at all consistent,” see Appendix K.

Using a 5-point Likert scale in which a score of 1 = *not at all familiar*, 2 = *slightly familiar*, 3 = *moderately familiar*, 4 = *very familiar*, and 5 = *extremely familiar*, participants indicated a high level of familiarity with the concept of neurodiversity (*M* = 4.41, *SD* = 0.81, range = 1 – 5). Participants also rated their level of agreement with the concept of neurodiversity as it pertains to autism using a 5-point Likert scale in which 2 = *strongly agree*, 1 = *somewhat agree*, 0 = *neither agree nor disagree*, -1 = *somewhat disagree*, and -2 = *strongly disagree*. Respondents indicated moderately strong agreement (*M* = 1.14, *SD* = 0.35, range = 1 – 2) with the concept of neurodiversity.

Language preferences. Participants indicated the language convention they preferred to use in reference to themselves; a majority of 53 (82.8%) of survey respondents preferred identity-first language. These data are depicted in Figure 1.

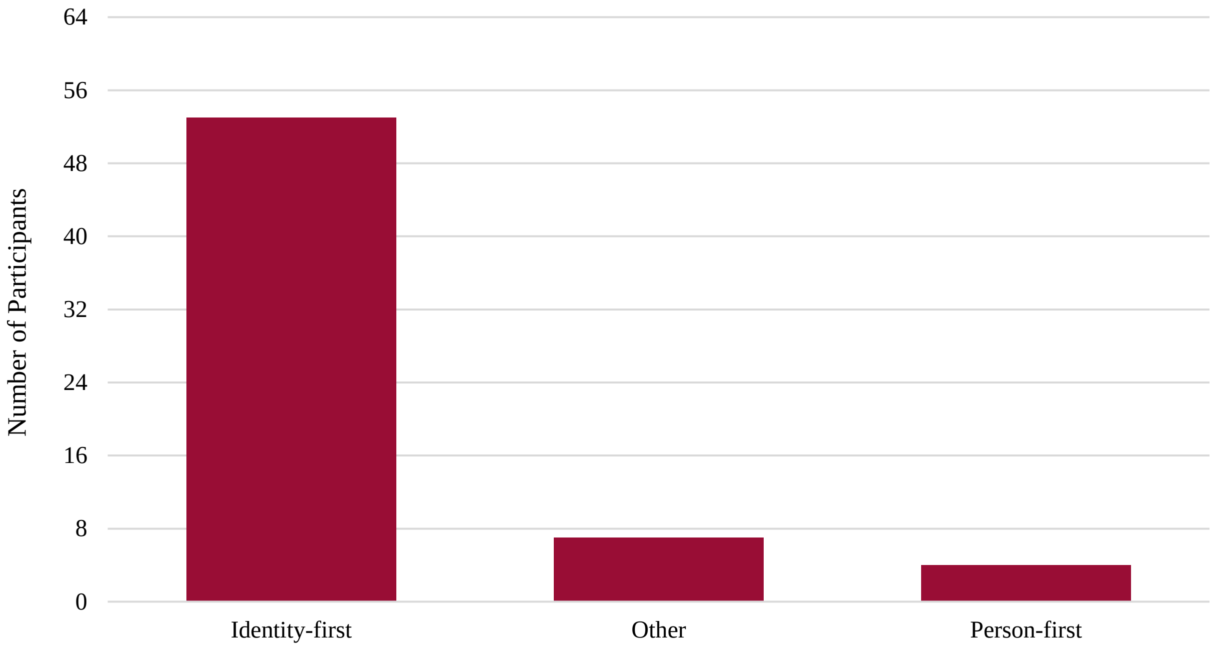

Figure 1. Participants' preferred linguistic convention in reference to autism (*n* = 64). All seven of the participants who selected the response choice "other" indicated no preference; see Appendix L.

Personal Experiences with Communicative Interventions

Participants indicated if, at any point in their lives, they had received intervention services targeting communication skills or participated in speech-language therapy. Aside from the initial informed consent to participate, this question was the only item in the survey to force response validation; that is, without selecting a response, participants would be unable to progress any further through the survey instrument. This forced response validation was applied to facilitate skip logic in Qualtrics such that the block of questions about experiences with communicative interventions was displayed *only* to participants who had experienced interventions in this domain. A total of 24 participants (37.5%) indicated that they had received intervention services for communicative differences and/or deficits; 34 (53.1%) selected "no"; and one participant (1.6%) was unable to recall. Five participants (7.8%) chose not to respond to this question and, unable to progress further without responding, exited the survey at this point.

Within this subsection of the results, unless otherwise noted, *n* = 24 for all analyses pertaining to participants' experiences with communicative interventions.

Demographics. Of survey respondents who indicated prior history with interventions in the domain of communication (*n* = 24), 12 (50.0%) identified as female, seven (29.2%) identified as male, four (16.7%) identified their gender as "other," and one (4.2%) preferred not to say. These participants were between the ages of 18 and 60 (*n* = 22, *M* = 26.73, *SD* = 10.09) and reported ages at diagnosis between 2 and 57 years (*n* = 22, *M* = 16.73, *SD* = 13.22). Of the 24 respondents with prior experiences with interventions in the domain of communication, eight (33.3%) reported an original diagnosis of ASD; one (4.2%) reported an original diagnosis of Autistic Disorder; 13 (54.2%) reported an original diagnosis of Asperger's Disorder; one (4.2%) reported an original diagnosis of PDD-NOS; and one (4.2%) participant to whom this survey block was displayed chose not to respond to this question.

Context. Participants who had prior experience with interventions in the domain of communication reported initiation of intervention services at ages between 2 and 24 years (*M* = 8.33, *SD* = 6.03). Eighteen participants (75%) began receiving intervention services at or before 10 years of age, while six (25%) reported initiation of services between 11 and 24 years of age. Participants reported, in years, the duration of intervention services targeting communication skills; these data are graphed in Figure 2. The most commonly reported setting in which participants received intervention services was school (*n* = 19); no participants reported receiving intervention services in the domain of communication in a postsecondary education setting. Service delivery settings by number of participants who reported receiving intervention services are shown in Figure 3. For a list of participant-reported "other" settings in which intervention services were received, see Appendix M.

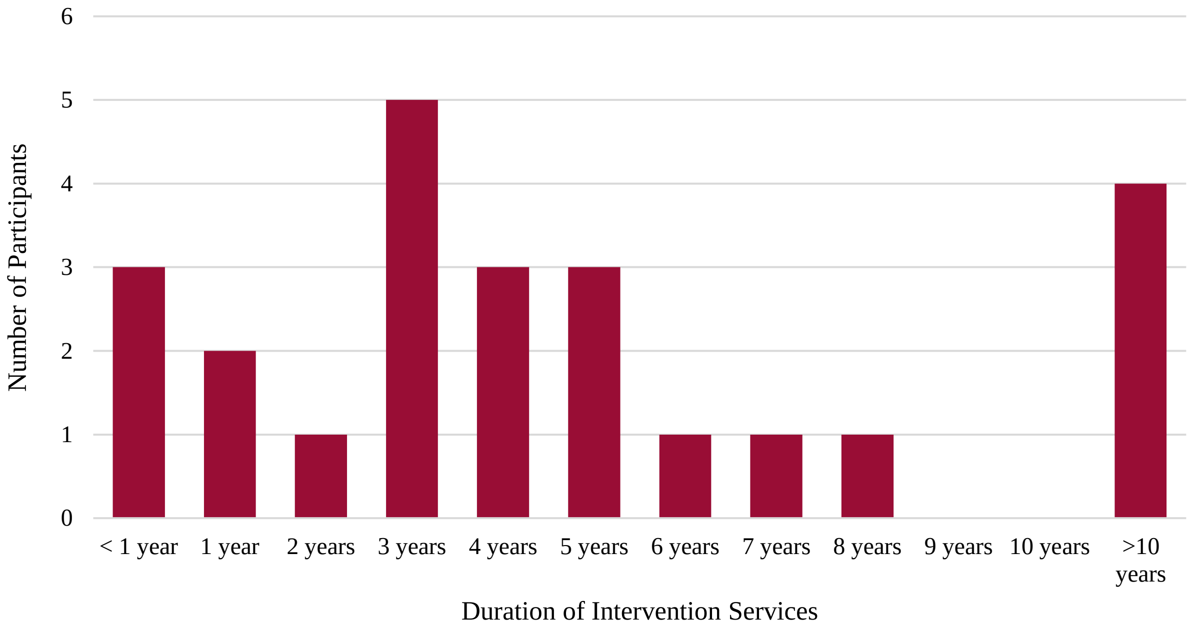

Figure 2. Length of time, in years, over which participants received intervention services in the domain of communication (*n* = 24).

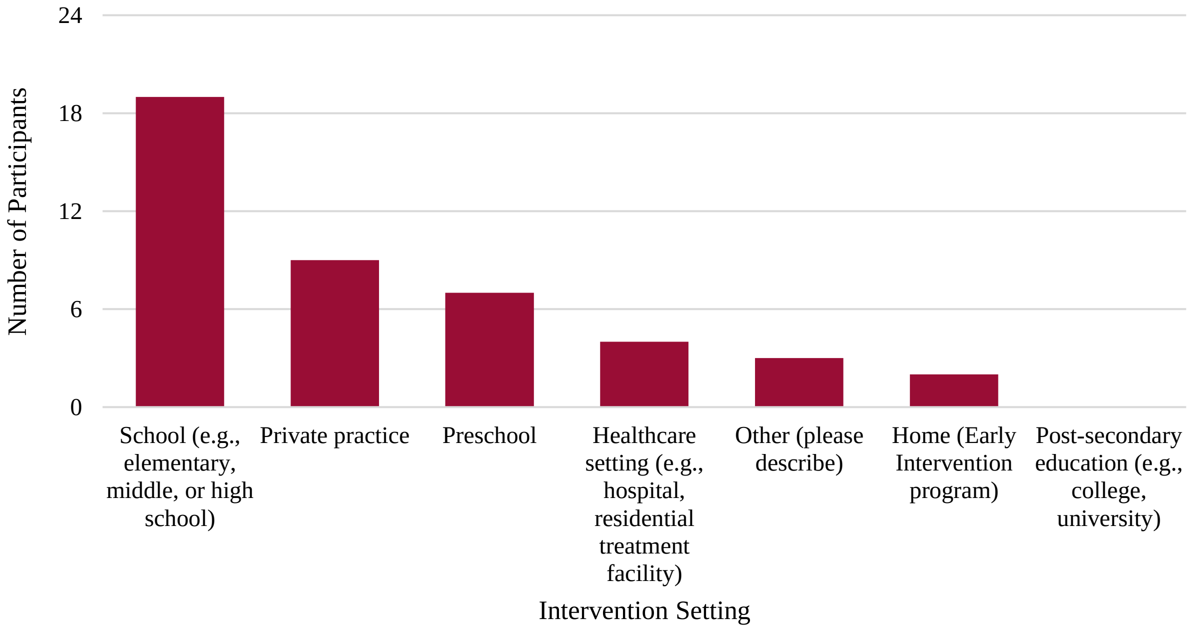

Figure 3. Settings in which participants received intervention services to target communicative skills (*n* = 24).

Focus of intervention. In response to two open-ended survey items, participants who had received speech-language therapy or other communicative interventions identified the focus of the intervention and, as they perceived it, the ultimate goal of the intervention. Complete inventories of participant responses to these two survey items can be found in Appendix N and Appendix O, respectively. In addition, participants indicated who determined the focuses and goals of intervention by selecting all choices that applied; these data are reported in Table 4.

Table 4

Determining figures in selecting focuses and goals of interventions

Determiner	*n*	%
Parents/guardians	19	79.2
Speech-language pathologist	14	58.3
Teacher(s)	9	37.5
You	5	20.8
Other (please describe)	5	20.8
Unsure	2	8.3

Feelings with respect to intervention. Using a 5-point Likert scale in which 2 = *extremely positive*, 1 = *somewhat positive*, 0 = *neither positive nor negative*, -1 = so*mewhat negative*, and -2 = *extremely negative*, participants described their feelings with respect to intervention methods, goals, experiences, or other aspects both at time of intervention and at present. When asked to recall and describe their feelings about intervention *at the time services were received*, on average, participants who recalled feelings at the time of intervention (*n* = 23) reported feelings between neutral and somewhat positive (*M* = 0.57, *SD* = 1.31, range = -2 – 2). When asked about their feelings regarding aspects of and experiences with these interventions *currently*, respondents (*n* = 24) reported, on average, feelings between neutral and somewhat positive (*M* = 0.21, *SD* = 1.38, range = -2 – 2). Comparative frequencies for each response for these two survey items are graphed in Figure 4.

Participants indicated their feelings about the *impact* of speech-language therapy, or other interventions in the domain of communication, on their lives using the same 5-point Likert scale. Based on their personal experiences, participants reported, on average, feelings between neutral and somewhat positive about the impact of these interventions (*M* = 0.71, *SD* = 1.04, range = -1 – 2). Six participants (25.0%) reported the impact as extremely positive; nine (37.5%) reported the impact as somewhat positive; five (20.8%) reported the impact as neutral; and four (16.7%) reported the impact as somewhat negative. No respondents reported the overall impact of interventions for communicative differences and/or deficits to be extremely negative. In response to two open-ended survey items, participants described outcomes and effects that they identified as a result of their personal experiences with speech-language therapy or other communicative interventions, both positive (*n* = 24) and negative (*n* = 23); for a complete inventory of responses, see Appendix Q and Appendix R, respectively.

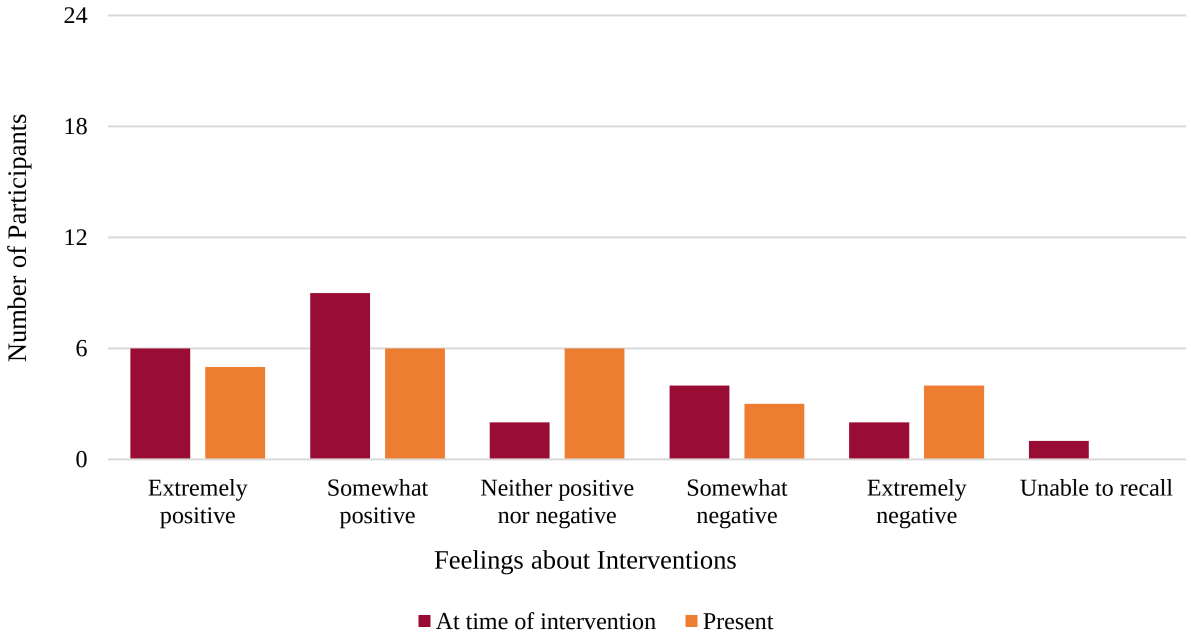

Figure 4. Participants’ feelings about aspects of and experiences with interventions in the domain of communication, both at the time of intervention and at present (*n* = 24).

Perceptions of How Their Values are Integrated into Practice by SLPs

The remaining survey items were displayed to all participants; unless otherwise indicated, the sample size is 64 for all analyses presented in the following sections of these results. To assess respondents' perceptions of how their individual voices, values, and preferences were integrated into clinical practice, the survey included questions about the validity of stakeholders who might contribute to decision-making about intervention approaches and goals as well as the perceived authority of different figures as sources of information in this process. Participants were asked to consider these questions within the frame of the process of selecting methods and desired outcomes of interventions for characteristics of autism.

When asked to indicate, by selecting all that apply, which stakeholders should be considered valid in the context of selecting intervention methods and desired outcomes for characteristics of autism, participants who chose to respond to this survey item (*n* = 55) indicated strong favor for the autistic individual in question, both as an adult (100%, *n* = 55) and as a minor (92.7%, *n* = 51). In addition, it should be acknowledged that in response to the final survey item, one respondent who had marked "other" in response to this survey item identified siblings as a valid stakeholder in this context. These data are illustrated in Figure 5.

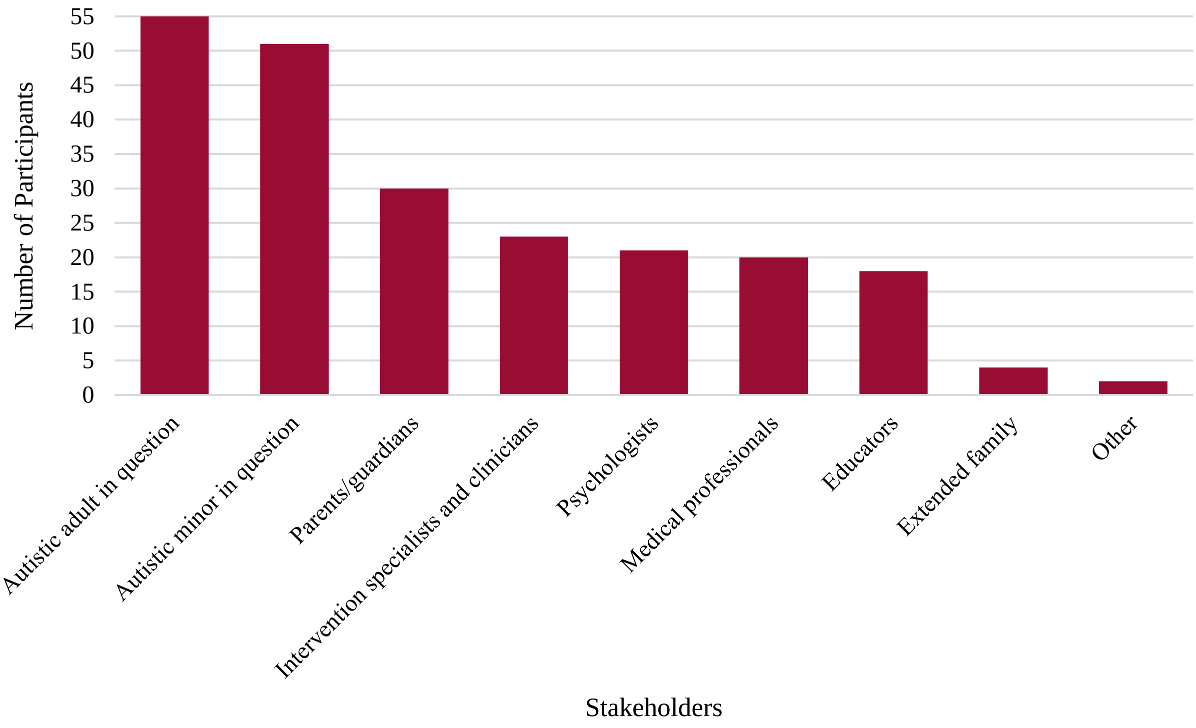

Figure 5. Validity of stakeholders in the context of selecting intervention methods and desired outcomes (*n* = 55).

Participants ranked the importance of potential contributors as authoritative sources of information using a 5-point Likert scale in which 5 = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *no importance at all*. Participants who chose to respond to these survey items attributed highest importance to autistic individuals in question, both adults and minors, and also considered other autistic adults to be important and authoritative sources of information in this context. Little to no importance was attributed to extended family of the autistic person. These data are reported in Table 5.

Table 5

Importance attributed to different authoritative sources of information in the context of clinical decision-making

Information source	*n*	*M*	*SD*
Autistic adult in question	56	4.96	0.19[d]
Autistic minor in question	56	4.73	0.52[c]
Other autistic adults	56	4.16	0.76
Researchers	56	3.13	1.08
Psychologists	56	3.09	1.13
Medical professionals	56	2.98	1.07
Parents	56	2.89	1.06
Intervention specialists and clinicians	56	2.89	1.20
Educators	56	2.61	1.00
Other (please describe)	18	2.06	1.26
Extended family	55	1.73	0.83[e]

Note. These items were scored using a 5-point Likert scale in which 5 = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *no importance at all*. For all items in this table with no superscript, responses ranged from 1 to 5. For all items in this table marked with a superscript to indicate range, [c] = 3 – 5; [d] = 4 – 5; [e] = 1 – 4.

Perceptions of Their Voices as Valued

Participants were asked to consider a variety of situations and, in each context, indicate the degree to which they felt their individual voice as an autistic person was valued when communicating with a professional (such as an SLP; if participants had no personal experiences in any of the contexts described, they were asked to imagine a hypothetical situation). Responses were indicated using a 5-point Likert scale in which 5 = *highly valued*, 4 = *moderately valued*, 3 = *somewhat valued*, 2 = *a little bit valued*, and 1 = *not at all valued*. Overall, participants who chose to respond to these survey items ($n = 58$) reported feeling that their perspectives and input were between a little bit and somewhat valued by professionals in all contexts represented in the survey. These data are reported in Table 6.

Table 6

Participants' perceptions of own voices as valued in various contexts

Context	*n*	*M*	*SD*
When communicating your experiences	58	2.79	1.35
As an autistic self-advocate or activist	58	2.69	1.30
With respect to consideration of your own goals, concerns, wishes, etc. in the context of intervention	58	2.64	1.22
When communicating your personal wants or needs	58	2.59	1.26
When speaking about autism to a general audience	58	2.57	1.17

Note. These items were scored using a 5-point Likert scale in which 5 = *highly valued*, 4 = *moderately valued*, 3 = *somewhat valued*, 2 = *a little bit valued*, and 1 = *not at all valued*. For all items in this table, responses ranged from 1 to 5.

Recommendations for Clinicians and Parents

Six survey items addressed participants' recommendations for clinicians and parents/families of clients with autism with respect to perceived importance of various subjects to be addressed in speech-language therapy (SLT), perceived importance of various themes to be addressed by SLPs in counseling parents/families of clients with autism, and recommendations regarding informational resources for parents of newly-diagnosed autistic children. Each of these survey items was paired with an open-ended follow-up question that asked if participants had anything else to say about the previous (close-ended) question.

Two survey items utilized a 5-point Likert scale in which 5 = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *not at all important*. When prompted to imagine an opportunity to address a group of speech-language pathologists on the value participants attributed to various subjects and themes to be addressed in the context of intervention with an autistic client, participants (*n* = 52) favored confidence in self-advocacy (*n* =

52, *M* = 4.81, *SD* = 0.56, range = 3 – 5) and compensatory strategies for communication differences (*n* = 50, *M* = 4.34, *SD* = 0.87, range = 1 – 5) as very to extremely important. Mean scores and standard deviations for all items are reported in Table 7; for participant responses to the open-ended follow-up question, see Appendix S.

In the context of SLPs' counseling of parents/families of autistic clients, respondents (*n* = 53), on average, rated every theme presented as at least moderately important. Particular emphasis was given to topics of neurodiversity (*M* = 4.77, *SD* = 0.58, range = 2 – 5), advocacy (*M* = 4.58, *SD* = 0.87, range = 1 – 5), and multiple means of communication (*M* = 4.57, *SD* = 0.69, range = 2 – 5), as reported in Table 8. See Appendix T for participant responses to an invitation to elaborate or comment on the topic of this survey item.

Table 7

Perceived importance of subjects to be addressed by SLPs in SLT for autistic clients

Subject	*n*	*M*	*SD*
Confidence in advocating for oneself and one's needs	52	4.81	0.56[c]
Compensatory strategies for communication differences	50	4.34	0.87
Scripts for social situations	52	3.75	1.08
Augmentative and alternative communication (AAC)	51	3.57	1.06
Use of spoken language to communicate	52	3.37	1.14
Nonverbal communication (e.g., body language, facial expressions, eye contact)	52	3.29	1.39
Echolalia	51	2.43	1.27

Note. These items were scored using a 5-point Likert scale in which = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *not at all important*. For all items in this table with no superscript, responses ranged from 1 to 5. For all items in this table marked with a superscript to indicate range, [c] = 3 – 5.

Table 8

Perceived importance of themes to be addressed by SLPs in counseling of parents/families

Theme	*n*	*M*	*SD*
Neurodiversity	53	4.77	0.58[b]
Advocacy	53	4.58	0.89
Multiple means of communication	53	4.57	0.69[b]
Education	53	4.30	0.87[b]
Support groups	52	3.67	1.15
Social groups	52	3.54	1.18
Treatment resources	52	3.38	1.27

Note. These items were scored using a 5-point Likert scale in which 5 = *extremely important*, 4 = *very important*, 3 = *moderately important*, 2 = *slightly important*, and 1 = *not at all important*. For all items in this table with no superscript, responses ranged from 1 to 5. For all items in this table marked with a superscript to indicate range, [b] = 2 – 5.

Respondents indicated, by selecting all that applied, which resources they would suggest as sources of information to which parents of newly-diagnosed children might be referred; five organizations were named, with a sixth “other” choice including a text-entry field. Overall, participants who chose to respond to this question (*n* = 51) showed strongest preference for the Autistic Self Advocacy Network (ASAN), as selected by 45 respondents (88.2%), and least preference for Autism Speaks, selected by only one participant (1.9%). Nearly one-third of participants who responded to this survey item (31.4%, *n* = 16) selected “other” as a choice; for a list of these fill-in responses, see Appendix U. These data are reported in Figure 6. All participant responses to the subsequent open-ended question asking for any additional comments on the subject can be found in Appendix V.

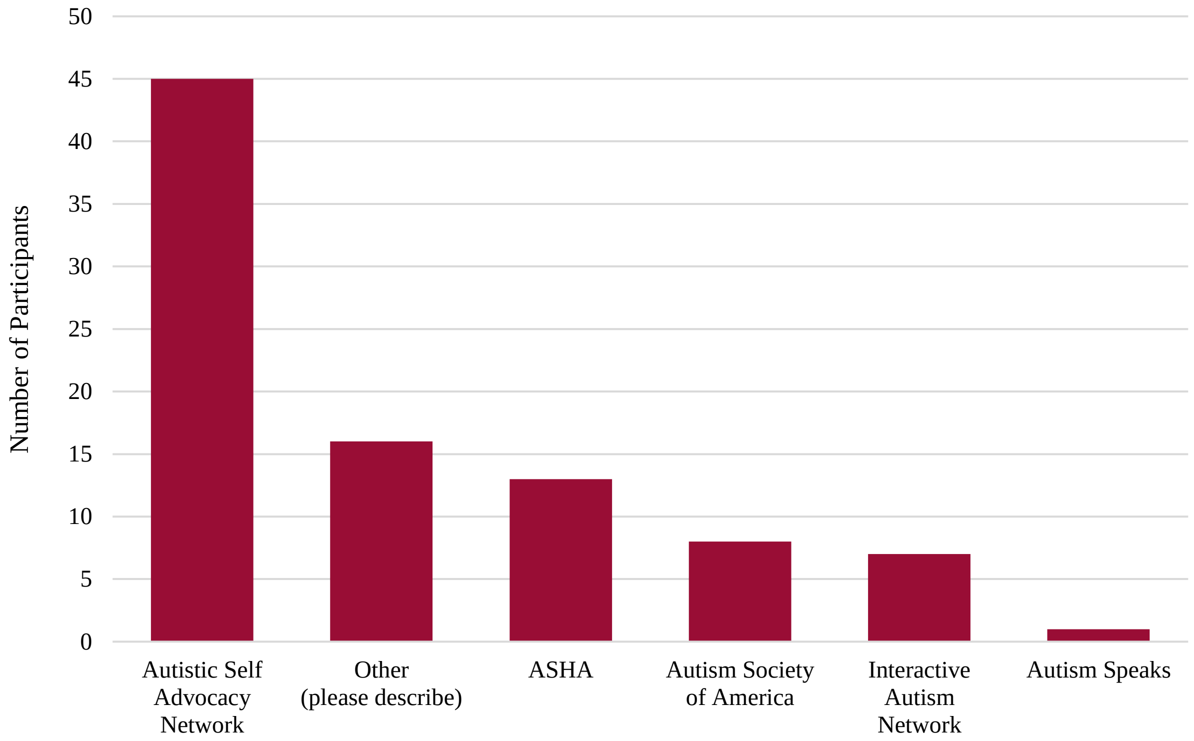

Figure 6. Resources to which participants would suggest referring parents/families of newly-diagnosed autistic children for information, as indicated by number of participants who selected each choice (n = 51). The resource represented in this figure as “ASHA” was decoded within the survey as the American Speech-Language-Hearing Association.

At the conclusion of the survey, an open-ended question asked participants if there was anything else not previously addressed in the survey instrument that they would like to share. A total of 23 participants (35.9%) chose to respond to this question. See Appendix W for a complete inventory of participant responses to this survey item.

Discussion

In the previous section of this chapter, the researcher presented the quantitative results obtained through survey research. In this section, these results will be interpreted and discussed in the context of extant literature on autism, lived experiences of autistic people, and interventions for communicative differences and/or deficits related to ASD. Qualitative data from follow-up interviews and participant responses to open-ended survey questions will be integrated to provide a more complete understanding of autistic individuals’ voices, values, preferences, and experiences. All participant responses presented in this chapter are reproduced as entered, without correction of grammatical or spelling errors, unless otherwise indicated for clarity or protection of privacy.

Demographics

The gender ratio reported by 64 survey participants reflected disproportionate representation of women (46.9%, *n* = 30) over men (20.3%, *n* = 13). Eight participants (12.5%) identified their gender as "other," and two participants (3.1%) chose not to respond to this question. While the survey item asked participants to report gender, rather than sex, a ratio in which women or females are more than twice the number of men or males in the sample is a significant deviation from estimated prevalence ratios comparing diagnosis of ASD in boys and girls; based on data collected in 2016, Baio and colleagues (2018) reported a prevalence ratio of 4:1 in favor of boys. While this research was conducted at Autism and Developmental Disabilities Monitoring Network (ADDM) sites and surveyed a population of 8-year-old children, not adults, the imbalance in favor of males has been well-documented (e.g., Ratto et al., 2018, p. 1698). Kapp, Gillespie-Lynch, Sherman, and Hutman (2013), finding similarly disproportionate representation of female participants compared to male participants in a self-selected sample of autistic people, theorized that potential contributing factors might include disproportionate representation of or engagement by females with autism in online communities for purposes of support, advocacy, and recognition that may be more difficult to obtain in person or through interactions with the professional community (p. 67). Furthermore, researchers such as Kreiser and White (2014) have explored sociocultural as well as biological factors that may affect the discrepancy in rates of ASD diagnosis between boys and girls, such that girls with autism are at higher risk of under-diagnosis or misdiagnosis (p. 78). Researchers have also found that many autistic females are diagnosed later than male peers (Begeer et al., 2013, pp. 1153 – 1154). For a more comprehensive review of the subject beyond the scope of this discussion, an interested reader might refer to the researchers named in this section as well as Dean, Harwood, and Kasari (2017) and Lai and colleagues (2017).

An additional demographic measure on which participants deviated markedly from norms that might be anticipated was age at initial diagnosis; participants reported ages at diagnosis ranging between 2 and 59 years (M = 22.08, SD = 14.59, n = 49). Given the high level of variance and existence of outliers in this data set, the *median* age at diagnosis was also calculated to be 18 years. In 2014, Christiansen and colleagues, based on data collection through the ADDM, reported median age at first diagnosis among a sample of 8-year-old children with autism spectrum disorders to be 4 years, 2 months (p. 8); Baio and colleagues (2018), within a similar cross-sectional sample, reported median age at first diagnosis of 4 years, 4 months (p. 11). However, given the range of presentation of ASD as a spectrum disorder as well as its persistence through the lifespan, individuals with ASD (or meeting diagnostic criteria for precursor conditions under DSM-IV-TR criteria) may very well reach adulthood without being formally identified as a child or adolescent (Brugha et al., 2011, pp. 463 – 465; Lehnhardt, Gawronski, Pfeiffer, Kockler, Schilbach, & Vogeley, 2013, p. 755). As Pilling, Baron-Cohen, Megnin-Viggars, Lee, and Taylor (2012) reported, “although some people’s autism is diagnosed in childhood, for every three known cases, there are two individuals without a diagnosis who might need assessment, support, and interventions for autism at some point in their lives” (p. 43). To further explore the phenomenon of autism diagnosis in adulthood and barriers to access of services, an interested reader may also refer to Lewis (2017).

Not only did participants self-report median age at first diagnosis to be higher than predicted in line with prior research, but the variability (*SD* = 14.59) and range (2 – 59 years) were considerable in size. This variability is consistent with extant research demonstrating that age at diagnosis of ASD may be influenced by demographic factors including gender (Rosenberg, Landa, Law, Stuart, & Law, 2011, p. 8; Russell, Steer, & Golding, 2011, p. 1291), race (Dababnah, Shaia, Campion, & Nichols, 2018, p. 322; Rosenberg et al., 2011, p. 8), socioeconomic status (SES; Mandell, Novak, & Zubritsky, 2005, p. 5), locational availability of resources (Rosenberg et al., 2011, p. 8), as well as presentation of specific symptoms or characteristics such as sensory processing differences (Chawarska, Paul, Klin, Hannigen, Dichtel, & Volkmar, 2007, p. 63), cognitive delays or disabilities (Chawarska et al., 2007, p. 63), and severity of language deficits or delays (Chawarska et al., 2007, p. 63; Mandell et al., 2005, p. 5). Access to, selection of, and participation in interventions for characteristics of autism may be similarly influenced by factors that facilitate or serve as barriers to families' access to information, resources, and intervention specialists.

Conceptions of Autism

When asked to describe autism/ASD in their own words, participants who chose to respond to this question (*n* = 54) reported a number of themes both consistent with DSM-V diagnostic criteria and beyond objective or clinical descriptions of autism. Among the most common themes in this sample of descriptions of autism by autistic individuals were differences in communication, cognition, experiences of sensory input, and executive functioning. With respect to the aspect of communicative differences and/or deficits associated with ASD, one participant described autism as "*a tri-fold disability in the area of communication; in how I* *communicate with others, in how other people communicate with me, and in how I communicate within myself*." Another participant, whose response spoke to the spectrum nature of ASD (APA, 2013, pp. 51 – 52; Giles, 2014, p. 183), described autism as

> *A neurotype in contrast to allistic, with common traits (which may present in varying ways in different autistic individuals, and which may not all exist in every autistic individual) such as literal and direct thinking, need for repetition and routine, intense and often specific passions/interests, sensory differences, stimming, communication and social differences (not deficits), executive dysfunction / inertia, alternative forms of communication (besides speech) and being partially or entirely non-verbal, difficulty understanding arbitrary and non-literal social norms and social cues.*

These responses also revealed variations in how autism was perceived and experienced by individual autistic people. Participants reported both positive perceptions and experiences of autism (e.g., "…*Autism provides an experience of the world that is rich with beauty and incredible strengths…*") and negative experiences of being autistic (e.g., "*Its* [*sic*] *a struggle and its* [*sic*] *something you deal with alone because no one else understands*"). In the words of another respondent describing his experience of autism,

> *You are essentially an alien born into a human world trying to convince everyone else you're human, too... when you're not. Your entire life becomes studying and attempting to understand humans, learning what their expressions, tones, and behaviors mean as well as what are the appropriate responses to them. Sometimes they're (humans) so incomprehensible nothing makes sense at all, like saying one thing and meaning the other, acting completely opposite of their interests, etc. It is really f***ing weird.*

By diagnostic guidelines and criteria established in the DSM-V, the "severity" of ASD is indicated by the level of support that a person requires, specifying a diagnosis as Level 1 ("requiring support"), Level 2 ("requiring substantial support"), or Level 3 ("requiring very substantial support"; APA, 2013, p. 52). Broad "functioning" labels, by contrast, are not and were not clinical diagnostic terms; the descriptors "high-functioning" and "low-functioning" are often applied to qualify a description of a person with autism, based on apparent or assumed cognitive capacity, social and verbal communication, and capability to engage in functions of everyday living (Kenny et al., 2016, p. 458). These "functioning labels" are controversial among autistic people (Nicolaidis, 2012, p. 507). In response to the final open-ended survey item providing space for participants to offer comments or explain anything that was not adequately addressed elsewhere in the survey instrument, one participant summarized their objection to functioning labels:

> *I appreciate that people like to use labels to define and understand the world better. That said I strongly dislike grading autism as high functioning and mild. My fate is intertwined with autistics who would have been or are institutionalized. If our society cannot respect them and keep them safe, they will not respect or protect me*.

Concerns about the implications of applying "functioning" labels to autistic people, or categorizing autistic people by the clinical designation of support level, have also been expressed by autistic self-advocates in extant literature. Montgomery (2012), writing on experiences of institutionalization and establishment of identity, described this dichotomization of the autistic community as "being asked to choose between two stereotypes, not two realities" (p. 75).

Another theme consistent with extant literature was concern about the accuracy of these categories, such as reflected in one participant's report that "*for me at least* [autism] *is very uneven. I have incredible ablilties* [*sic*] *in some areas and incredible challenges in others*."

One respondent, quoted by researchers Kenny and colleagues (2016), explained,

> [High-functioning autism] and [low-functioning autism] are often inadequate descriptors. I can see how they may be useful in a health/social care setting, but in my opinion they're overused. In my experience if you're viewed as high functioning then your needs are often dismissed. If you're viewed as low functioning then your strengths are often dismissed. Also, 'functioning' is something that can vary between tasks and on different days according to stress levels, for example. (p. 452)

Professionals may recognize that levels of support required by autistic individuals are not truly reflective of the variability of an individual's needs across contexts and over time (APA, 2013, p. 51; ASHA, n.d.-b, para 7). However, the flattening of an individual's unique profile of strengths, challenges, and specific support needs is a concern described by many autistic self-advocates, such as Becker (2011, n.p.) and Walker (2012, p. 236), and echoed in extant professional literature (e.g., Nicolaidis, 2012, p. 505).

Lived experiences. Participants described their individual communicative strengths and challenges; the themes of these responses varied among individuals, but some themes were shared by many participants. Commonly-reported *strengths* in communication included honesty/directness, vocabulary breadth, precision in word choice, and attention to detail. Many individuals reported that written communication was an easier or more natural means of communication than expressive speech. Among the more frequently reported communicative *challenges* described by participants were processing time required to formulate thoughts to express oneself, high cognitive demand of verbal communication, conciseness, and interpretation of intent behind others' words, or "*read*[ing] *between the lines*." As one participant explained, "*It's the spaces between the words* [that] *I struggle with.*"

Not all participants reported similar experiences of communicative differences associated with ASD. For instance, some participants highlighted faculty in wordplay, as per one participant's report—"*I'm great with language. I love puns/plays on words, riddles. I have a different perspective and that can be a really useful tool for communicating*." By contrast, others described difficulty with non-literal language, such as one participant's report that "*My language is hyper mechanistic and therefore literal.* […] *When people break the rules in speaking, I fail to understand them*." Another theme on which responses were divided was an understanding of and self-perceived skill in navigating pragmatics aspects of communication. One participant reported that "*Although I generally don't struggle with verbal communication I feel bad at social communication, what I think and what I say never seem to match well*." By contrast, another respondent explained that "*I believe my strengths are that I am direct, honest, and try to use my understanding of human behaviors to speak in ways they find most comfortable*."

Participants' reports of the means used to communicate in person, selecting all that applied from a list of multiple modalities, indicated that while a majority of participants used spoken language to communicate with others in person (98.3%, $n = 58$), the second most selected means was typing or writing (59.3%, $n = 35$). In addition, of the 59 participants who chose to respond to this question, 37 (62.7%) indicated that to communicate in person, they used two or more means (i.e., spoken language, typing or writing, sign language, AAC device, or other). Elements characteristic of participant-reported "other" means of communication used face-to-face ($n = 4$) include non-sign gestures and "graphics."

As Brignell, Chenausky, Song, Zhu, Suo, and Morgan (2018) reported, 25 – 30% of autistic children “fail to develop any functional spoken language or remain minimally verbal” (p. 6). In a review of communicative intervention approaches for language deficits associated with ASD, Brignell and colleagues (2018) discussed approaches to intervention to support development of communicative skills in “minimally verbal” children with ASD. The authors categorized these interventions as based on verbal speech, AAC-based, combined (verbal and AAC), and “comprehensive interventions with a communication focus”; the ultimate goal of language-focused interventions of each of these types was improvement of “spoken communication” (p. 9). While participants’ reports of the means of communication used face-to-face are consistent with the trend toward prioritization of speech and spoken language evident in extant literature (e.g., Brignell et al., 2018), the multiple modalities identified by participants as important and effective means of communication are representative of a more inclusive image of what effective social communication may comprise for autistic individuals.

Participants expressed the strongest preference for texting as a means of communication, and the lowest preference by phone; when rating their levels of preference for different means of communication, the item with the highest standard deviation was communicating “verbally, in person” (n = 58, M = 0.31, SD = 1.31, range = -2 – 2). Higher frequencies of preferences for written forms of communication were also expressed by participants who described their strengths and challenges in communication; per one participant report,

> *I am a very good writer, performer, artist, public speaker, and journalist. If I had to hypothesize why, I would say this is because there's less give-and-take with these forms of communication than there are in a meeting or a phone call. You're generally in control of the situation and can plan out what you need to say, and there's usually a formula to*

> *follow in order to be effective at that essay/speech/article/et cetera.* […] *Basically, I excel at communication when I can assume what will happen in a situation and/or I have a clear idea of what makes something good or bad (or effective or ineffective, if you will).*

Another participant explained their preference for communicating in text over speech as, in large part, difficulty translating thought into verbal expression:

> *Putting my thoughts into actual words is exhausting. There is a disconnect between what my brain says and how I am able to say it. Often, comes out of my mouth is an extremely processed, watered-down version of what I'm really trying to convey. Inside my head is a miasma of thought, thunderclouds all over of various processes going on. It makes sense in my head (usually) but channeling that into a consumable format for others is exceedingly difficult. Everything I say, the way my face moves (or does not move) has to be calculated so as not to offend or confuse others. I prefer text / typing / online communication for this reason.*

These findings are consistent with the spectrum nature of ASD itself as well as the many forms in which the diagnostic characteristic of "persistent impairment in reciprocal social communication and social interaction" may manifest in communicative differences and/or deficits in areas of language, including pragmatics and expressive language, particularly speech (APA, 2013, pp. 51 – 52).

Medical and social models of disability. In response to Likert-type survey items intended to assess participants' views of autism through different models of disability, respondents expressed, on average, moderate to strong alignment with social models of disability. That is, participants' average level of agreement with the statement of autism as "valuable difference" exceeded average level of agreement with the statement of autism as "deficit." Participants expressed the most variation in opinion with respect to the statement that "autism is a disorder"; mean scores were between neutral and slight disagreement.

In response to an open-ended question asking participants to describe autism in their own words, autistic individuals used many different words to refer to autism, including variations upon *disability, disorder, condition, variation, neurodivergence, neurotype, identity,* and, as one participant described it, "*a way to be human*." Participants attributed minimal levels of importance of both helping autistic individuals to appear more like neurotypical people as well as finding a "cure" for autism. Overall, opinions expressed by participants were more closely aligned with a social model of disability; this is consistent with extant literature such as the findings of Gillespie-Lynch and colleagues (2017, p. 3) and Kenny and colleagues (2016, p. 457).

Neurodiversity. Respondents' self-reported high levels of familiarity and agreement with the concept of neurodiversity, as it pertains to autism, were echoed in responses to open-ended survey questions; for instance, one participant described autism as

> *…not a disease or a tragedy, simply a different neurotype, a different way of being human (much like being gay is neither superior nor inferior to being straight; it is simply different). Autistic people are a marginalised group who face interpersonal and systemic, often as well as internalised, ableism.*

Within this survey, the term *neurodiversity* was explicitly defined as the idea that autism is a neurological difference characterized by both strengths and weaknesses, and that existing as autistic and non-autistic are equally valid. Overall, participants reported that this definition was highly consistent with their own understanding of the concept of neurodiversity. The single participant who indicated that the two were "not at all consistent" elaborated that "*I use* *neurodiversity as a concept to describe those persons who are autistic, have ADD/ADHD, OCD, etc. I use Neurotypical in reference to those who are not autistic, do not have ADD/ADHD, OCD, etc.*" As language and linguistic conventions have evolved with time, the term *neurotypical*, which began as a neologism to describe non-autistic people, has not only become popularized in use beyond the original autistic population, but has also come to be used both in the original sense (non-autistic) as well as to describe individuals without noted neurological differences, which include but are not limited to autism (Silberman, 2015, p. 441; Walker, 2012, p. 233). As noted in Chapter II, within the context of this research, the word is used in its original sense. Survey and interview participants used both the terms *neurotypical* and *allistic* to describe non-autistic people; the latter term was first used by an autistic individual in a satirical article as a complement to *autistic*, and while the term has gained some degree of popularity, its use is not universal or without controversy (Logsdon-Breakstone, 2013, n.p.; Main, 2003, n.p.; personal communication, February 1, 2019).

Language preferences. A marked majority of respondents indicated a preference for identity-first language—that is, "autistic" as adjective. Survey data found no true consensus on preference for one linguistic convention over another; that is to say, while the majority of respondents expressed preference for identity-first language, some respondents did indicate preference for person-first language. In addition, the seven participants who selected "other" and elaborated upon their opinion expressed no preference between the two conventions; as one participant stated, "*I don't care as long as you mean well*." These findings are consistent with prior research within this area, such as Bagatell (2010, p. 40) and Kenny et al. (2016, p. 459).

Personal Experiences with Communicative Interventions

Of 64 total survey participants, 24 (37.5%) reported receiving speech-language therapy (SLT) and/or other interventions in the domain of communication at some point in their lives. Given that communicative differences and/or deficits are a core diagnostic feature of ASD (APA, 2013, p. 52), the researcher anticipated that some participants would have experience with interventions in the domain of communication. However, the finding that participants who reported prior history of SLT or other communicative intervention experiences were a minority of the total sample was not surprising, given variability of presentation of autism among individuals as well as the many factors that may influence access to and utilization of resources, including interventions and supports, for characteristics of autism.

Context. The age at which participants reported initiation of services varied widely, ranging from 2 to 24 years; a majority of participants began receiving intervention services at or before 10 years of age, while one-quarter reported initiation of services between 11 and 24 years of age. While not all individuals with ASD are diagnosed as children and communicative interventions may be implemented in adolescence or adulthood, the majority of interventions for characteristics of ASD focus on children in the early developmental period as well as, to a lesser extent, adolescents (Prelock & McCauley, 2012, pp. 7 – 9; Smith & Iadarola, 2015, p. 899). The greatest number of participants received services in a school setting (K – 12), with the second most frequently reported setting of service delivery being private practice. These findings of rates at which intervention services are received in different settings are consistent with prior reports, such as the findings of Mire, Gealy, Kubiszyn, Burridge, and Goin-Kochel (2017), who found that school-based services were most frequently utilized by parents of children with ASD, followed by SLT in private practice clinical settings (p. 310).

Other settings in which participants reported receiving intervention services targeting communication differences and/or deficits included counseling/therapy. In addition, one participant described their experiences receiving rehabilitative SLT following a severe traumatic brain injury (TBI) in a healthcare and unspecified other setting; while this participant specified that the SLT received was not autism-*focused*, their experiences with SLT *as an autistic person* were included in this analysis of autistic experiences of intervention in the domain of communication.

Focus of intervention. Participants who had experienced interventions in the domain of communication reported that the focuses of these interventions often fell into categories of social skills and pragmatics of communication as well as spoken language and use of speech to communicate effectively with others. Other focuses of speech-language therapy and interventions for communicative differences related to ASD, as reported by participants, also included emotional regulation. Elements of social communication that participants described as focuses of interventions included eye contact, prosody, inflection, tonality, pacing, conversational turn-taking, "*and varying all of the above*." In an interview, one participant described a focus of communicative interventions as "*how to speak and what to say*." No participants identified augmentative and alternative communication (AAC) as a focus of speech-language therapy or other interventions in the domain of communication.

In response to a survey item asking participants to describe what they perceived to be the ultimate goal of intervention, responses highlighted common themes of normalizing social and communicative skills with typically-developing peers, effective communication with others, and increased independence. Normalization, or making the individual appear less autistic and more neurotypical, was highlighted by several participants; one reported that the ultimate goal of intervention, as they understood it at the time, was to "*learn 'The Rules' of social engagement so that I can be perceived as normal*"; in the words of another participant, "*it was kind of pointless, trying to teach me to be what I'm not*." These variations upon shared themes are reflective primarily of a medical model of disability, framing autism and communicative differences characteristic of ASD as less valid compared to neurotypical social and communicative norms and values (Kapp et al, 2013, p. 59). Ultimate goals relating to effective communication with neurotypical peers, described without further contextualization, may further "other" the autistic individual by emphasizing obligation on their part to adapt or conform to neurotypical expectations, rather than asking that neurotypical people accommodate for differences among individuals. These common threads of normalization and of placing the burden of bridging such a gap overwhelmingly upon the autistic individual is echoed in literature by autistic self-advocates; for example, as Bascom (2012b) wrote,

> I need to put more effort into controlling and deadening and reducing and removing myself second-by-second than you could ever even conceive, I need to have quiet hands, because until I move 97% of the way in your direction, you can't even see that's there's a 3% for you to move towards me. (p. 182)

Feelings with respect to intervention. Participants described their feelings with respect to intervention methods, goals, experiences, or other aspects as, on average, neutral to slightly positive, both at the time of intervention and in retrospect. The range of responses for each of these survey items ranged from extremely negative to extremely positive, with higher representation of neutral and negative feelings in retrospect.

Researchers such as Kirkham (2017, pp. 114 – 118) have documented both vehement denouncement of interventions for characteristics of autism, particularly Applied Behavioral

Analysis (ABA) therapy, as well as more nuanced positions and dispositions of people with ASD toward treatment or a theoretical cure (Bagatell, 2010, pp. 47 – 48). Feelings of conflict with respect to the purpose and ethics of interventions for characteristics of autism, such as the perspectives of autistic individuals documented by Bagatell (2010), highlight the tension between conceptions of autism as characterized by differences rather than inherent deficits in contrast with oftentimes overwhelming or unpleasant experiences of being markedly different in a societal context that does not accommodate for—or is hostile to—neurodiversity.

Respondents reported the overall impact of interventions for communicative differences and/or deficits on their lives to be, on average, neutral to somewhat positive; responses to this item ranged from extremely positive to somewhat negative. Participants reported positive outcomes including a "*greater understanding of social norms*" and improved ability to communicate with others, particularly neurotypical people, and be understood. Describing the positive effects of speech-language therapy in their life, one participant stated that

> *I have a bigger set of tools I can use to enhance my self-presentation when I choose to/need to. Passing is still exhausting, but it's somewhat less so if you have tried-and-true solutions and scripts within easy reach in your head. To the extent that these experiences enhanced that, it was useful.*

Participants also identified negative effects on their lives attributed to interventions in the domain of communication. Common themes included unrealistic or unfair expectations placed upon the autistic person, pathologization of autism, and anxiety related to communication; example responses representative of each of these themes are presented in Table 9.

Table 9

Negative outcomes of communicative interventions identified by autistic adults

Theme	Example quotes
Expectations are unrealistic or unfair	*Because I can physically communicate verbally, I am expected to all the time, and it hurts me. Therapy didn't do anything except set me up to be pressured and then punished when I cant live up to expectations* *This isn't natural and is extremely difficult for me, it doesn't benefit me it just befits others who don't communicate like me because they have difficulty understanding how I communicate.* *About the only one is that it makes it more tempting to try to pass -- which always wipes me out.*
Pathologization of autism	*There was nothing wrong with the way I communicated. My autistic child brain was beautiful and people could understand me just fine if they took even more than 1 second to pay attention. I felt like there was something wrong with me for the way I was, and other kids just knowing I was in therapy during school contributed more to bullying than the way I communicated.* *I learned to see my way of being as "wrong."* *As grateful as I am to be able to communicate and have people rarely be able to tell that something about my communication is abnormal, it feels like my parents/my teachers/my occupational and speech therapists were trying harder to make me "normal" than to help me adapt while acknowledging who I am, resulting in a lot of confusion about why I found certain things (like talking on the phone or participating in a class discussion) were so difficult for many years.*
Anxiety	*I felt a lot of shame about my perceived inability to be social and follow "The Rules" of social engagement, and saw social failures (such as the lapse of a friendship) as signs that I had personally failed and was not trying hard enough. Unlearning this shame is an ongoing process.* *I am currently seeing a speech therapist for my stutter. My parents and I believe that the stutter was the direct result of the childhood speech therapy.*

Table 9 (continued)

Theme	Example quotes
Anxiety	*I have developed severe anxiety surrounding the very process of communication, caused, presumably, by strict negative reinforcement (primarily by parents, though guided by the opinions of professionals) toward most every method of communication which feels remotely natural to me. The very experience of communicating in-person has become something so negative, I genuinely wish to entirely withdraw from society and never speak to another human being again. It was not always this way.*

Note. Quotes presented within this table are attributable to distinct participants. The researcher recognizes that errors in grammar and/or spelling may be present, but chose to preserve the original responses as they were entered by participants.

Participants' experiences of effortful and taxing control of outward presentation, even to the extent of passing as neurotypical, comprise a well-documented phenomenon (e.g., Hull et al., 2017; Lai et al., 2017). Also referred to as *masking* or *camouflaging*, the development of coping mechanisms to disguise or compensate for characteristics of autism, thereby reducing the appearance and stigmatization of being autistic, potentially opens doors and encourages acceptance by one's peers—but the price can be steep. As Lai and colleagues (2017) reported,

> Autobiographical descriptions and clinician observations often suggest that camouflaging unfortunately comes at a cost: it often requires substantial cognitive effort, can be exhausting and may lead to increased stress responses, meltdown due to social overload, anxiety and depression, and even a negative impact on the development of one's identity. (p. 691).

These negative outcomes resulting from interventions for communicative differences and/or deficits related to autism illustrate another side of normalization. These experiences and perspectives represent valuable insight into unforeseen consequences and ethical considerations of intervention.

Perceptions of How Their Values are Integrated into Practice by SLPs

The researcher assessed respondents’ perceptions of how their individual voices, values, and preferences were integrated into clinical practice. Participants were asked to consider two survey items within the frame of the process of selecting methods and desired outcomes of interventions for characteristics of autism. In response to a question about the validity of stakeholders as contributors to decision-making, participants indicated very strong favor for the autistic individual in question, both as an adult and as a minor. Parents/guardians and intervention specialists or clinicians were favored less strongly. This data stands in contrast to the reports of participants with prior history of SLT or other interventions in the domain of communication, who reported that the focuses and goals of the interventions they had experienced were determined most significantly by parents/guardians and SLPs; fewer than one-quarter of participants reported that *they* had a voice in selecting the focus and desired outcomes of interventions.

In the context of clinical decision-making, participants also attributed considerably higher levels of authority as sources of information to autistic people—both autistic adults and minors in question as well as uninvolved autistic adults—than to other figures such as researchers, medical professionals, parents/guardians, or clinicians. These findings are consistent with prior research that diverges from the paradigm of clinicians and parents as the “experts” on autism, lending more weight and consideration to the voices of autistic individuals themselves as important contributors in understanding autism (Gillespie-Lynch et al., 2017, p. 10; Milton, 2014, p. 798), supporting the needs of autistic individuals (Kapp et al., 2013, p. 66), and developing future research in directions that effectively support and include the autistic community (Gillespie-Lynch et al., 2017, p. 11; Nicolaidis, 2012, p. 507).

Perceptions of Their Voices as Valued

Participants’ perceptions of their voices as valued and respected when communicating with a professional, such as an SLP, were, on average, between a little bit valued and somewhat valued in each of the five contexts described in the survey. Notably, for each of these contexts, responses ranged from 1, or not at all valued, to 5, or highly valued.

One interview participant, who had experienced integrated speech-language therapy services for years as a child, expanded upon their feelings about how their voice was received and how respected they felt in the context of communicating one’s own experiences:

> *…I know there were things that helped, but I know there were things that didn’t. And yet they think that everything was good. Everyone around me reports everything being positive about therapy, but they didn’t have to experience it themselves. …And they say I’m the one who thinks in black and white.*

A participant who ascribed a score of 2, *a little bit valued*, to their perception of their voice by professionals in the context of consideration of their own goals, concerns, or wishes for intervention, elaborated further in response to the final open-ended survey item:

> *I would suggest that SLPs and other professionals working with autistic clients learn from autistic adults about what therapies and interventions worked for them, and put high value on what the client wants to get out of the treatment - even if the client is a minor or is an adult with a guardian. I felt my opinions on my treatments were not being heard or validated when I was a kid, and felt like adults would always invalidate my opinion with theirs, just because they were adults and I wasn't. I cannot stress the importance of listening to what clients say, especially if their goals differ from those of their parents and teachers.*

Recommendations for Clinicians and Parents

Participants indicated that themes of importance for SLPs to address in the context of intervention with an autistic client included confidence in advocating for oneself and one's needs and compensatory strategies for communication differences. The ability and confidence to self-advocate was the only item not ranked below *moderately important* by any participant; per one respondent's answer to a follow-up question,

> *I need to learn to navigate a world as ME and learning how to tell people 'I'm listening, I just don't do eye contact' is a much more useful skill than encouraging wasting 75% mental CPU usage faking eye contact thus not leaving enough CPU to actuLl engage in conversation.* […] *why is the burden always on us, especially often as children?*

In response to an open-ended follow-up question, many participants expressed agreement that the importance of distinct themes and subjects to be addressed in the context of intervention was specific to the individual client; variability of wants and needs within the population was more strongly emphasized than wants or needs perceived as shared by members of the community, and the broadest overarching goal was the empowerment to make choices and speak on one's own behalf. As another participant explained,

> *The primary goal should always be that autistic person is capable of communicating to their own satisfaction. If they want to use spoken language or AAC, then they should be aided as needed in doing so. If not, it shouldn't be foisted upon them. In cases where a person is unable to meet their goals because of a discrepancy between their communication style and the world at large (e.g. struggling to make friends), then the SLP should provide strategies for dealing with that discrepancy while clearly emphasizing that the autistic person's communication style is not inherently inferior, but*

> *rather is ineffective in that situation due to personal differences in communication style. The ability to self-advocate as needed without shame far outweighs any other goal.*

This theme of prioritizing the agency of the autistic person was echoed in participants' perceived importance of themes to be addressed by SLPs in counseling of parents/families of autistic clients. The theme of advocacy was, on average, indicated to be very to extremely important, second only to the topic of neurodiversity. Participants elaborated upon the nuances of this question in response to a follow-up survey item, and some expressed reservations or concerns about the meaning of "advocacy" in the context of parents or families. One participant interpreted this item as self-advocacy, stating, "*Yes. We need to be taught how to advocate for our needs as children.*" Another participant expressed more reservations, asking, "*Does 'advocacy' refer to the parents / families becoming advocates themselves (I'm very cautious of this, due to the huge numbers of ableist parent / family advocates out there) or to them listening to autistic self-advocates (which I consider to be very important)?*" This division in actions and values between autistic self-advocacy and parent advocacy on behalf of autistic individuals is recurring in the literature, both in the work of autistic activists (e.g., Bascom, 2011; Gross, 2012c) as well as by researchers such as Itkonen and Ream (2013, pp. 55 – 56), Kapp et al. (2013, pp. 59 – 60), Milton (2014, p. 796), and Nicolaidis (2012, pp. 503 – 504).

This sensitivity to distinctions between autistic self-advocacy, at the individual as well as organizational level, and advocacy on behalf of autistic people—listening to autistic voices, or speaking in their stead—was also evident in participant-chosen resources to which they would recommend referring parents or families of a child newly diagnosed for more information or support with respect to autism. A considerable majority of participants selected the Autistic Self Advocacy Network (ASAN), an autistic-led organization; fewer than half that number selected any other given choice. Low levels of support for parent-founded Autism Society of America and a research organization, the Interactive Autism Network, founded by Autism Speaks, were slightly exceeded by levels of support for the American Speech-Language-Hearing Association (ASHA) as an organizational resource for families. Participant-entered “other” resources included local organizations, online groups, books, and input from other autistic adults.

Only a single participant, of 51 total participants who chose to respond to this question, indicated that Autism Speaks was a resource to which they would refer families. Low support for—and considerable hostility toward—Autism Speaks, a high-profile non-advocacy group with a well-documented history of promotion of a strongly medicalized model of autism, was echoed in many text-entry responses to a follow-up question in which respondents criticized the organization’s history, actions, and mission. As one participant pointed out, “[Autism Speaks] *does have some useful resources but any health professional who would* [*sic*] *like to refer it should also objectively address the associated controversy*.” Another participant explained,

> *Autism Speaks doesn't speak for me. They see us as monsters and burdens on society that need to be eradicated. They are scum. I am not a parasite. I am not a monster. I am an intelligent human being who is worthy of respect and has an unique perspective on the world and much wisdom to offer if you would only listen. This is the message of neurodiversity that these resources need to be spreading.*

CHAPTER V: CONCLUSION

This research focused on the lived experiences and first-person perspectives of autistic individuals with respect to interventions in the domain of communication and interactions with the professional community. In this final chapter, the researcher will present the major conclusions of this study and discuss the implications of these findings. In addition, the researcher will review limitations of this research and provide recommendations for future research as well as offer final thoughts on this independent study.

Major Conclusions

This study investigated the first-person perspectives of individuals with Autism Spectrum Disorder (ASD) with respect to interventions for communicative differences and/or deficits related to ASD. In addition, the researcher investigated perceptions within this population with respect to the integration of individuals' values into services delivered by clinicians and the perception of these voices as respected contributions to the broader conversation surrounding autism. Three major conclusions emerge from the findings of this research.

The first major conclusion is that individuals' lived experiences of autism and being autistic—particularly with respect to communication—are extremely diverse. Participants' descriptions of their communicative strengths, challenges, and needs varied widely among individuals. Some common themes were identified—for example, commonly-reported strengths in communication included precision in word choice, attention to detail, breadth of vocabulary, and honesty, while commonly-reported challenges in communication included conciseness, interpretation of others' words and intentions, processing time, and high cognitive demand associated with verbal communication—but every experience was distinct. For most, if not all, participant-reported strengths or challenges, another participant described a contrasting experience. A predominant shared theme mentioned by many participants was a preference for textual over verbal forms of communication, or, more broadly, more predictable and controlled forms of communication over means of communication perceived to be less structured or rule-governed.

A second major conclusion pertains to participant-reported experiences with interventions in the domain of communication. Overall, participants generally reported experiences as slightly more positive than neutral, both at the time of intervention and in retrospect; similarly, participants described the overall impact of interventions for communicative differences and/or deficits on their lives as neutral to somewhat positive. Despite these average ratings, the ranges of participant responses for each of these questions spanned from extreme positivity to extreme negativity. Participants' descriptions of the impact of treatment on their lives, both positive and negative, represented a broad spectrum of outcomes, both intended as well as unintentional.

The third major conclusion is that participants placed high value upon aspects of intervention that centered around the voices, needs, and preferences of the autistic individual, both as an adult and as a minor. These intervention aspects of concern included the stakeholders considered to be valid in determining approaches and intended outcomes of intervention as well as topics to be addressed in speech-language therapy (SLT) with an autistic client and themes to be addressed in counseling provided to families by speech-language pathologists (SLPs).

Implications of the Research Findings

Based upon these major conclusions, several implications of the research findings can be identified as relevant and applicable to SLPs. A primary implication of the first major conclusion is the impetus not only to consider the voices and values of individuals with ASD with respect to issues that pertain to their lives, but to *actively seek out* these voices and to reach out to the autistic community. Scholarly literature and research on aspects of autism or approaches to interventions for characteristics of autism are incomplete and decontextualized without the lived experiences of autistic people themselves.

Given the diversity of experiences and perspectives within this community, the importance of seeking to identify and learn from these experts about their own experiences is critical in developing supports and approaching interventions in a way that is sensitive and responsive to the needs, strengths, challenges, values, and preferences of clients with ASD. No one person may be able to authoritatively speak to the internal experiences of a client, particularly a minor, who is not able to clearly communicate these experiences for themselves. To this conversation, families bring their relationship with and knowledge of their child as an individual; clinicians bring clinical education and expertise in assessing and providing treatment for characteristics of autism; and the missing component, in the case of clients who are less able to self-advocate, of insight into their lived experiences as autistic people may be most effectively provided by other autistic people. By developing a deeper appreciation for the knowledge and understandings unique to this population, clinicians may reduce bias in the framework of disability, better communicate the value attributed to the individual needs and values of the autistic individual, and offer clients and families resources and perspectives to make more fully informed decisions.

A second implication of these findings is the need for SLPs to be aware of and take into consideration the potential for treatment provided to have significant impact on clients' lives. These effects may relate to primary treatment goals and objectives with respect to communicative competence. It is also critical that SLPs consider secondary outcomes, both positive and negative, not only in the area of communication needs and skills, but also in relation to how clinicians and experiences of treatment may affect clients’ self-esteem, self-perception, or understandings of autism and disability. While determination of intervention approaches, methods, objectives, focuses, or modalities may appear more relevant to intended outcomes in the domain of communication, it is important not to lose sight of or disregard the potential ramifications of these experiences for autistic clients, and to be mindful of how interventions for communicative differences and/or deficits related to autism may be experienced, understood, and internalized by autistic individuals. By considering outcomes beyond the immediate therapeutic objectives and goals, clinicians may be able to more positively shape these experiences and outcomes such that all stakeholders stand to benefit most fully from intervention.

Limitations

The first limitation of this study was sampling bias due in part to the methods used in this research. As discussed earlier in this document, this sample exhibited overrepresentation of some groups and underrepresentation of others. The sample of the population who participated in this research was, by nature, self-selected, and many participants were recruited by posts to social media. Accordingly, an indeterminate proportion of the sample included individuals who were represented in online autistic communities and also willing to participate in research without any compensation or direct benefit. Similarly to studies such as Gillespie-Lynch and colleagues (2017), participants in this research may have been more “intrinsically interested” in the subject of this study (autistic lived experiences) and/or the question of a dominant paradigm (i.e., the empowerment of autistic people to tell their own experiences; p. 11); perspectives of individuals whose beliefs align more closely with the neurodiversity movement, as an example, may be overrepresented within this self-selecting sample compared to the population of autistic individuals.

Convenience sampling and online recruitment may also have selected against, and therefore limited generalizability to, autistic individuals who would meet eligibility criteria for participation in this research—that is, autistic adults in the United States with or without prior experience with interventions in the domain of communication—but whose access to this online survey, or the interview process, was more limited by its modality. For example, one participant contacted the researcher expressing interest in a follow-up interview, but making it clear that the phone was not a viable modality by which the interview could be completed; despite adaptation of the research protocol to include interview by email, several interested participants who initially inquired about interviews were lost to follow-up.

A second limitation of this research was that the survey did not distinguish between speech-language therapy and other integrated therapies that target communication. The researcher chose to address the broader scope of interventions in the domain of communication, rather than narrowing the focus to speech-language therapy provided by SLPs only, with recognition of the fact that interventions for communicative differences and/or deficits related to ASD do not always stand alone, and interventions may be integrated into a more comprehensive approach or program (Brignell et al., 2018, p. 9). As a result, participant responses to items concerning their experiences with interventions in the domain of communication did not distinguish between SLT provided by SLPs and intervention services within this domain that were provided by other professionals such as special education teachers, intervention specialists, or Applied Behavioral Analysis (ABA) therapists. Consequently, the findings from this part of the research cannot be identified as relating specifically to SLPs.

A third important limitation of this study was that because the survey instrument was disseminated online, there was no verification that participants had received a formal diagnosis of autism. It is possible that some participants may have self-identified as autistic, whether or not diagnostic criteria were met, but lacked a formal diagnosis. As researchers such as Geurts and Jansen (2011) documented, many adults who meet diagnostic criteria for ASD may be unidentified, or not formally diagnosed (pp. 299 – 300). In addition, as Lewis (2017) noted, even as the direction of research becomes more inclusive and aware of the prevalence of autism among older individuals who were not identified or diagnosed within early developmental periods, the barriers to formal evaluation that stand in the way of adults seeking to better understand themselves or to qualify for needed support are substantial (p. 2420; see also Gillespie-Lynch et al., 2017, p. 11). Therefore, the viewpoints represented in this research may not be representative of the viewpoints and experiences of all autistic adults.

Recommendations for Future Research

Although the conclusions and implications of this research are subject to limitations, the findings as well as boundaries of the present study indicate potential directions for future research to more fully explore the breadth and depth of these lived experiences of autism in relation to communication and interventions for communicative differences and/or deficits characteristic of ASD. The sample of participants in this research was both small in size and subject to biases; accordingly, a recommendation for future research is extension of this line of investigation with a sample larger in size and using methods of sampling and recruitment beyond the scope of this study. For example, contacting more programs and groups with less of a base in an online community may be viable ways to increase sample size and decrease some forms of sampling bias. Greater flexibility in offering text-based interview modalities, such as through the use of instant messaging programs and services, may also be beneficial in extending the reach of this research to individuals excluded by the research protocol followed in this study.

A second recommendation for future research is to examine if and how experiences of autistic individuals with interventions in the domain of communication differ across contexts. This research did not distinguish between participants who received SLT, delivered by SLPs, and participants who received communicative interventions integrated with other treatments for characteristics of autism. Identifying similarities among these groups as well as ways in which their experiences and perspectives on intervention diverge may offer greater insight into how these research findings are specifically relevant and salient to speech-language pathologists, who may provide services to a client independently or in collaboration with other providers or specialists such as educators or ABA therapists.

Finally, the researcher recommends that future researchers more closely investigate differences in the experiences of and perspectives on autism and interventions for associated characteristics among groups that differ by diagnostic pathway and/or age at diagnosis. Many individuals meeting diagnostic criteria for ASD may not receive a formal diagnosis until adolescence or adulthood, yet some may have qualified for and/or have had experience with interventions for communicative differences and/or deficits prior to diagnosis as autistic. In addition, some individuals self-identify as autistic without or prior to formal diagnosis; experiences of and viewpoints regarding interventions within this group may also contribute to a better understanding of autism and lived experiences of autistic people.

Final Thoughts

Over the past year and a half, it has been a privilege to conduct this Independent Study at the College of Wooster. Not only have I learned and grown in my skills as a researcher, thinker, and communicator, but I have also grown in my appreciation for and understanding of the depth and breadth of that which we do not yet know. Although scholarly research into the lived experiences and personal expertise of autistic people is still limited, this is a field growing both in breadth, as prevalence continues to rise, and scope, considering the increasing visibility of autistic self-advocacy at the individual and organizational levels. Through the lens of the paradigm of neurodiversity, these voices and perspectives are coming into sharper focus.

My pursuit in this line of research is both scholarly and personal. An awareness of and interest in autism has been a part of my life since early childhood. Experiences as a peer mentor, cadet teacher, and shadow to an SLP in a specialized setting sparked a deeper interest in interventions for characteristics of autism and, more specifically, the experiences and perspectives of autistic people with respect to these practices and influences upon their lives. Close relationships with autistic friends as well as deep connections to the topic of autism itself have further drawn me in the direction of my research undertaken through Independent Study.

This research may only serve as a small step toward greater awareness of and appreciation for these voices and values; nevertheless, I hope that it may serve as a stepping stone in the direction of a richer understanding of autism and respect for autistic people. I believe it is only through explicit efforts to highlight and bring to the forefront those voices not heard or understood that we may better understand and respect the autonomy of autistic people. As professionals who directly provide services and mediate delivery of interventions for communicative differences and/or deficits related to ASD, clinicians have both great power and, of course, great responsibility. By building upon individual strengths, acknowledging and respecting individual needs and values, and providing communicative supports, SLPs are uniquely positioned to empower autistic individuals to act as self-advocates, exercise their right to self-determination, and establish their place as authoritative figures within the broader societal conversation surrounding autism. I hope that my research may draw attention to the professional ethics and evolving discourse with respect to autism and autistic people.

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Appendix A: Survey Instrument

Start of Block: Consent

Q1

CONSENT TO PARTICIPATE IN A RESEARCH STUDY
THE COLLEGE OF WOOSTER

Experiences and Perspectives of People with Autism Regarding Communicative Interventions
Principal Investigator: Rebekah Burkhart

Purpose
You are invited to participate in a research study. I am investigating the lived experiences and first-person perspectives of people with ASD with respect to interventions in the domain of communication.

Procedures
If you choose to participate, you will be asked to answer questions about your personal experiences, opinions, and recommendations in an online survey. You will also be asked to provide some basic demographic information. The survey will take approximately 15 minutes to complete.

Risks
This survey asks you to reflect upon your own experiences. It is possible that recalling and discussing these memories may cause some distress. In the event that thinking about these topics causes distress, you may find it helpful to talk about these feelings with your primary care provider or someone else whom you trust. You may also choose not to respond to any questions that make you uncomfortable.

Benefits
There are no direct benefits to you for your participation. An indirect benefit is that through this study, speech-language pathologists will learn more about experiences, perspectives, and values within a population with whom we interact in an intervention/treatment capacity.

Compensation
There is no compensation associated with participation in this study.

Confidentiality
Any information that you provide in response to the survey will be anonymous; this survey does not ask for any identifying information. Any contact with the researcher following completion of this survey can only be initiated by you.

If you choose to contact the researcher and participate in a follow-up interview, your survey responses may no longer be anonymous to the researcher. However, your identity will always remain confidential, and no names or identifying information would be included in any publications or presentations associated with this study.

Costs

There is no cost to you beyond the time and effort required to complete the procedure described above.

Right to Refuse or Withdraw

Your participation in this study is completely voluntary. You may refuse to participate in this study. If you decide to participate by taking this survey, you may change your mind and withdraw at any point by exiting the survey in your browser window.

Questions

If you have any questions or concerns, you may contact me at rburkhart19@wooster.edu. You may also contact my advisor, Dr. Joan E. Furey, at jfurey@wooster.edu.

Consent

By selecting "I agree," you indicate that:

- You have chosen to volunteer as a research participant.
- You have read and understood the information provided above.
- You are at least 18 years of age.

○ I agree

○ I do NOT agree

Skip To: End of Survey If CONSENT TO PARTICIPATE IN A RESEARCH STUDY THE COLLEGE OF WOOSTER Experiences and Perspectives of... = I do NOT agree

End of Block: Consent

Start of Block: Conceptions of autism

Q2 *Some questions in this survey block have been adapted from Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman (2017).*

Q3 How would you describe autism/autism spectrum disorder(s), in your own words?

____

Q4 Please indicate your level of agreement or disagreement with each of the following statements.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Autism is a disorder.	○	○	○	○	○
Autism is a deficit.	○	○	○	○	○
Autism is a neutral difference.	○	○	○	○	○
Autism is a valuable difference.	○	○	○	○	○

Q5 Within this survey, I refer to *neurodiversity* as the idea that autism is a neurological difference characterized by both strengths and weaknesses, and that existing as autistic and existing as non-autistic are equally valid.

Is this consistent with your understanding of neurodiversity?

○ Extremely consistent

○ Very consistent

○ Moderately consistent

○ Slightly consistent

○ Not at all consistent (please elaborate)

____

Q6 Please indicate your level of <u>familiarity</u> with the concept of neurodiversity.

○ Extremely familiar

○ Very familiar

○ Moderately familiar

○ Slightly familiar

○ Not familiar at all

Q7 Please indicate your level of <u>agreement</u> with the concept of neurodiversity, as it pertains to autism.

○ Strongly agree

○ Somewhat agree

○ Neither agree nor disagree

○ Somewhat disagree

○ Strongly disagree

Q8 In your opinion, how important is it to find a cure for autism?

○ Extremely important

○ Very important

○ Moderately important

○ Slightly important

○ Not at all important

Q9 In your opinion, how important is it to help autistic people seem more like neurotypical, or non-autistic, people?

○ Extremely important

○ Very important

○ Moderately important

○ Slightly important

○ Not at all important

Q10 What language convention do you prefer to use in reference to yourself?

○ Person-first language (e.g., a person with autism)

○ Identity-first language (e.g., an autistic person)

○ Other (please describe) ____

Q11 *A note about language:*
In professional communities, person-first language is most often standard. As both researchers and members of the autistic community have documented, there is not a consensus on which convention--person-first or identity-first language--is most appropriate. With that in mind, within this survey, the researcher will use identity-first language out of respect to growing favor within the autistic community.

End of Block: Conceptions of autism

Start of Block: Preferred means of communication

Q12 Which of the following do you use to communicate in person? Please select all that apply.

- ☐ Spoken language
- ☐ Sign language
- ☐ Typing or writing
- ☐ Augmentative and alternative communication (AAC) device
- ☐ Other (please describe) ____

Q13 How would you describe your strengths in communication?

____

Q14 How would you describe your challenges in communication?

____

Q15 How do you prefer to communicate with others?

	Strongly prefer	Somewhat prefer	No preference	Somewhat dislike	Strongly dislike
Verbally, in person	○	○	○	○	○
Non-verbally, in person (please describe)	○	○	○	○	○
Email	○	○	○	○	○
Texting	○	○	○	○	○
Phone	○	○	○	○	○
Other (please describe)	○	○	○	○	○

End of Block: Preferred means of communication

Start of Block: Individual experiences with interventions

Q16 At any point in your life, have you received intervention services targeting communication skills or participated in speech-language therapy?

○ Yes

○ No

○ Unable to recall

Skip To: End of Block If At any point in your life, have you received intervention services targeting communication skills... != Yes

Page Break

Q17 In what settings did you receive intervention services? Please select all that apply.

☐ Home (early intervention program)

☐ Preschool

☐ School (e.g., elementary, middle, or high school)

☐ Post-secondary education (e.g., college, university)

☐ Healthcare setting (e.g., hospital, residential treatment facility)

☐ Private practice

☐ Other (please describe)

____

Q18 To the best of your recall, at what age (in years) did you begin to receive intervention services?

▼ 1 ... >30

Q19 For how long did you receive intervention services?

▼ < 1 year ... >10 years

Q20 To the best of your recall, what was the focus of the intervention? (Examples might include AAC, spoken language, or pragmatics/social skills.)

____

Q21 As you perceived it, what was the ultimate goal of the intervention?

____

Q22 Who determined these focuses and goals? Please select all that apply.

☐ Parents/guardians

☐ You

☐ Speech-language pathologist

☐ Teacher(s)

☐ Other (please describe)

____

☐ Unsure

Q23 To the best of your ability, please describe any feelings at the time of these interventions that you recall with respect to methods, goals, your experiences, or other aspects of these interventions.

○ Extremely positive

○ Somewhat positive

○ Neither positive nor negative

○ Somewhat negative

○ Extremely negative

○ Unable to recall

Q24 To the best of your ability, please describe your feelings now, in retrospect, with respect to your experiences and/or the methods, goals, or other aspects of these interventions.

○ Extremely positive

○ Somewhat positive

○ Neither positive nor negative

○ Somewhat negative

○ Extremely negative

○ Unable to recall

End of Block: Individual experiences with interventions

Start of Block: Values and beliefs w/r/t value of intervention for characteristics of autism

Display This Question:

If At any point in your life, have you received intervention services targeting communication skills... = Yes

Q25 Based on your personal experiences, please select the choice that best describes your feelings about the impact of speech-language therapy on your life.

○ Extremely positive

○ Somewhat positive

○ Neutral

○ Somewhat negative

○ Extremely negative

Display This Question:

If At any point in your life, have you received intervention services targeting communication skills... = Yes

Q26 Based on your personal experiences, what positive outcomes or effects do you identify as a result of speech-language therapy?

____

Display This Question:

If At any point in your life, have you received intervention services targeting communication skills... = Yes

Q27 Based on your personal experiences, what negative outcomes or effects do you identity as a result of speech-language therapy?

____

End of Block: Values and beliefs w/r/t value of intervention for characteristics of autism

Start of Block: Perception of value of autistic voices

Q28 In each of the following contexts, please indicate the degree to which you feel your voice as an autistic person is valued when communicating with a professional (such as a speech-language pathologist) or a professional community. (If you have no personal experience in any of these contexts, please imagine a hypothetical situation.)

	Highly valued	Moderately valued	Somewhat valued	A little bit valued	Not at all valued
When communicating your personal wants or needs	○	○	○	○	○
When communicating your experiences	○	○	○	○	○
With respect to consideration of your own goals, concerns, wishes, etc. in the context of intervention	○	○	○	○	○
When speaking about autism to a general audience	○	○	○	○	○
As an autistic self-advocate or activist	○	○	○	○	○

End of Block: Perception of value of autistic voices

Start of Block: Looking forward, through lens of lived experiences and accrued knowledge

Q29 **In the process of selecting methods and desired outcomes of interventions for characteristics of autism...**

Q30 Who should be considered <u>valid stakeholders</u>? Please select all choices that you believe apply.

☐ Parents/guardians

☐ Extended family

☐ Autistic minor in question

☐ Autistic adult in question

☐ Medical professionals (e.g., primary care physicians, pediatricians, psychiatrists)

☐ Intervention specialists and clinicians (e.g., speech-language pathologists)

☐ Psychologists

☐ Educators

☐ Other (please describe)

Q31 Who should be considered authoritative sources of information? Please rank each of these figures.

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Parents/guardians of autistic person	○	○	○	○	○
Extended family of autistic person	○	○	○	○	○
Autistic minor in question	○	○	○	○	○
Autistic adult in question	○	○	○	○	○
Other autistic adults	○	○	○	○	○
Medical professionals	○	○	○	○	○
Intervention specialists and clinicians	○	○	○	○	○
Psychologists	○	○	○	○	○
Educators	○	○	○	○	○
Researchers	○	○	○	○	○
Other (please describe)	○	○	○	○	○

Page Break

Q32 **These questions ask you to imagine that you have the opportunity to address a group of speech-language pathologists.**

Q33 Please indicate below how you would rank the importance of each of these subjects to be addressed <u>in speech-language therapy</u>.

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Use of spoken language to communicate	○	○	○	○	○
Augmentative and alternative communication (AAC)	○	○	○	○	○
Nonverbal communication (e.g., body language, facial expressions, eye contact)	○	○	○	○	○
Confidence in advocating for oneself and one's needs	○	○	○	○	○
Compensatory strategies for communication differences	○	○	○	○	○
Scripts for social situations	○	○	○	○	○
Echolalia	○	○	○	○	○

Q34 Do you have anything else to say about this question?

____

Q35 Please indicate how you would rank the importance of each of these themes to be addressed by speech-language pathologists <u>in counseling with parents/families</u>.

	Extremely important	Very important	Moderately important	Slightly important	Not at all important
Multiple means of communication	○	○	○	○	○
Support groups	○	○	○	○	○
Social groups	○	○	○	○	○
Treatment resources	○	○	○	○	○
Education	○	○	○	○	○
Neurodiversity	○	○	○	○	○
Advocacy	○	○	○	○	○

Q36 Do you have anything else to say about this question?

____

Q37 To which of the following resources would you suggest referring parents of newly-diagnosed children for information? Please select all that apply.

☐ American Speech-Language-Hearing Association (ASHA)
☐ Autistic Self Advocacy Network
☐ Autism Speaks
☐ Autism Society of America (ASA)
☐ Interactive Autism Network (IAN)
☐ Other (please describe)
____

Q38 Do you have anything else to say about this question?

____

End of Block: Looking forward, through lens of lived experiences and accrued knowledge

Start of Block: Demographics

Q39 Please enter your age in years.

▼ 18 ... 100+

Q40 Please select the choice that best describes your gender.

○ Male

○ Female

○ Other

○ Prefer not to say

Q41 Please indicate, in years, the age at which you were first diagnosed with ASD (or a prior diagnosis now included in ASD).

▼ 1 ... 100+

Q42 What original diagnosis did you receive?

○ Autism Spectrum Disorder

○ Autistic Disorder

○ Asperger's Disorder

○ Pervasive Developmental Disorder, Not Otherwise Specified

End of Block: Demographics

Start of Block: End of survey

Q43 Is there anything else not previously addressed in this survey that you would like to share?

____

Q44 Thank you for your time and consideration in contributing to this research.

Q45 As indicated earlier in this survey, several questions have been adapted from the following study: Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*, *8*(article 438), 1–14. https://doi.org/10.3389/fpsyg.2017.00438

Q46 Are you interested in participating in a follow-up interview by phone? This interview would provide you with the opportunity to elaborate on the topics and themes addressed in this survey.

○ Yes

○ No

Display This Question:

If Are you interested in participating in a follow-up interview by phone? This interview would provi... = Yes

Q47 You have indicated that you are interested in a follow-up interview by phone. Please contact the researcher at rburkhart19@wooster.edu for further information and to schedule a time.

End of Block: End of survey

Appendix B: Interview Questions

Follow-up interviews conducted will be organic to some extent, but structured around several open-ended questions and broader themes that are beyond the scope of survey research. Additionally, participants may wish to elaborate upon responses to questions within survey and/or talk about personal experiences that relate to survey questions and topics. Below is a short list of general and specific questions or topics that will guide follow-up interviews.

- How would you describe your communication needs?
- Is there anything that you would like to elaborate on about your personal experiences with SLT/communicative interventions? (Setting, duration, goals, methods, perceptions, experiences, anecdotes, etc.)
- When and why was intervention terminated?
- Based on your understanding of different models of disability, how would you describe the model under which the intervention you experienced was implemented? Do you think that either the medical model or social model of disability could be described as a bias in this context?
    - Are there any examples that come to mind in how this manifested in your personal experiences?
- If you, as an autistic adult, were to meet with parents of a newly-diagnosed child, what would you like them to know? How would you like that interaction to go?
- What role, if any, do you think that autistic adults or peers should have in supporting/guiding/mentoring families of children or adolescents who have been newly diagnosed with ASD?
- Based on own experiences in SLT, what might be lacking?
- Based on own experiences in SLT, what was positive and/or effective?
- How can clinicians more effectively meet the needs of clients on autism spectrum?
- How should clinicians be mindful and respect autistic adults when implementing interventions in the domain of communication for autistic children/adolescents?
- Any other topics, themes, opinions, experiences that have not been previously addressed in survey or interview that the participant wishes to address

Appendix C: Human Subjects Research Committee Approval

College of Wooster IRB *HUD Approval Notification*

To: Rebekah Burkhart
From: John Neuhoff, HSRC Chair
Subject: Protocol #2018/11/12
Date: 11/27/2018

The protocol **#2018/11/12, An investigation of lived experiences and perspectives of individuals on the autism spectrum with respect to communicative interventions** has been approved by the Human Subjects Research Committee Chair on **11/27/2018**.

The approval of your study is valid through 11/26/2019, by which time you must submit an annual report either closing the protocol or requesting permission to continue the protocol for another year. Please submit your report by **10/29/2019** so that the IRB has time to review and approve your report if you wish to continue it for another year.

If you have any questions, feel free to contact me.

John Neuhoff,
HSRC Chair

Appendix D: Recruitment Materials

Online Recruitment Text

My name is Rebekah Burkhart, and I am conducting research for my senior thesis at The College of Wooster. My study investigates the lived experiences and perspectives of people on the autism spectrum with respect to interventions in the domain of communication. This research protocol has been approved by the Human Subjects Research Committee at The College of Wooster.

A fundamental component of this research is the intent to investigate the perspectives of autistic people themselves, as a departure from the perception of parents/caregivers and professionals as the dominant voices on issues of interventions. If you are an adult living in the United States with a formal diagnosis of ASD or prior diagnostic labels that now fall under the umbrella of ASD—particularly if you have experience with communicative interventions/supports at some point at any age—I would appreciate it if you would consider participating in this research. (Interventions might include speech-language therapy, assistance obtaining and learning to use an AAC device, social skills training/groups, or any other form of intervention addressing communicative differences and/or deficits.)

The following is a link to my survey. All survey data are anonymous, and participants may choose to opt out at any time. [*Qualtrics link*]

If you have any questions, feel free to contact me at rburkhart19@wooster.edu. You can also contact my advisor, Dr. Joan E. Furey, at jfurey@wooster.edu. Thank you for your time and consideration.

Email Recruitment Text

To whom it may concern:

My name is Rebekah Burkhart, and I am conducting research for my senior thesis at The College of Wooster. My study investigates the lived experiences and perspectives of people on the autism spectrum with respect to interventions in the domain of communication. This research protocol has been approved by the Human Subjects Research Committee at The College of Wooster.

A fundamental component of this research is the intent to investigate the perspectives of autistic people themselves, as a supplement to the paradigm of parents/caregivers and professionals as the dominant voices on issues of interventions. I am contacting your program because of its focus on post-secondary students on the autism spectrum. I would greatly appreciate it if you would consider forwarding my survey link to students who have a formal diagnosis of ASD or prior diagnostic labels that now fall under the umbrella of ASD.

The following is a link to my survey. All survey data are anonymous, and participants may choose to opt out at any time. [*Qualtrics link*]

If you have any questions, feel free to contact me at rburkhart19@wooster.edu. You can also contact my advisor, Dr. Joan E. Furey, at jfurey@wooster.edu. Thank you for your time and consideration.

Appendix E: Open-Ended Responses to Item Q3

How would you describe autism/autism spectrum disorders, in your own words?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

A communication and sensory neurodivergence
A difference in communication that can be experienced by the autistic individual and those they communicate with
A different way of seeing the world, with a range of side effects and mannerisms depending on the person.
A different way of thinking. Behaviors oriented to the pre-industrial age.
A different wiring of the brain that amplifies senses and collects a lot of information about a few topics
A group of individuals whose experiences and perceptions interacting with their internal and external world differ from the accepted majority due to natural and normal neurological variences, who are disabled to varying degrees by a world culture that marginalizes them due to lack of acceptance or understanding of divergent expressions of pleasure and pain, and whose structures and conventions exclude autistic persons in its design.
A multi-dimensional disorder that isn't easy to categorize. It can include social impairments and sensory issues, but these are by no means the limits of what autism can screw up in your life. There are niche benefits though, like I have sensory issues with hearing but at the same time fantastic hearing In more blunt terms I'd call it a pain in the a**
A neurodevelopmental difference that affects sensory processing, social interaction, and preferences, resulting in a variety of characteristics.
a neurological difference
A neurological difference found in some human individuals
A neurological difference in the processing of stimuli and in thinking patterns
A neurological difference that spans a vast spectrum
A neurological difference.
a neurological disorder that occurs during prenatal development

A tri-fold disability in the area of communication. In how I communicate with others, in how other people communicate with me, and in how I communicate within myself.

A neurotype in contrast to allistic, with common traits (which may present in varying ways in different autistic individuals, and which may not all exist in every autistic individual) such as literal and direct thinking, need for repetition and routine, intense and often specific passions / interests, sensory differences, stimming, communication and social differences (not deficits), executive dysfunction / inertia, alternative forms of communication (besides speech) and being partially or entirely non-verbal, difficulty understanding arbitrary and non-literal social norms and social cues. It is not a disease or a tragedy, simply a different neurotype, a different way of being human (much like being gay is neither superior nor inferior to being straight; it is simply different). Autistic people are a marginalised group who face interpersonal and systemic, often as well as internalised, ableism.

A neurotype with different sensory experiences than allistics.

Alternate mapping of neurons in the brain

ASD is a neurological developmental disorder that may or may not inhibit or augment intellectual abilities, verbal skills, and social skills.

Autism is a condition that can make it difficult for people to communicate, interact socially, understand what others are thinking, make eye contact, and otherwise behave "normally." People with autism may find comfort in routines and repetition of all kinds, including repetitive movements or sounds.

Autism is a condition where certain thought processes and perception processes are increased and decreased in comparison to a neurotypical person.

Autism is a congenital condition characterized by an unusual cocktail of proficiency and deficiency in various functions.

Autism is a developmental disorder that affects a person's communication and socialization skills and sensory processing, executive functioning, and more.

Autism is a difference in the way your brain handles information, creating a unique set of strengths and disadvantages, that can sometimes make it difficult to function in an environment in which people don't understand and make incorrect assumptions about you.

Autism is a neurovariance characterized by a tendency towards hypers-and-hypos (sensitivities, focuses, socialization, ect).

Autism is a way to be a human. It is an identity, a way your brain works, a personality. In this way it is similar to other identity categories you are born with that are essential to who you are, like your gender, ethnicity, first language(s), etc. There are many different ways for people’s minds to work, many different ways to be a human, and autism is one of them.

Difficulty with expressive and receptive communication and executive functioning.

Autism is a natural form of neurodiversity which is primarily the result of genetic factors. Autistic people experience sensory stimulation differently than neurotypicals (NTs), and thus are likely to seek decreased exposure to loud noises, strong tastes, etc. and/or become overwhelmed/overstimulated by their environment. Autistics tend to have limited fine and gross motor skills, which is why I suck at sports. Autistics tend towards blunt, honest, and literal communication. Thus subtle nonverbal cues and arbitrary social norms imposed by NTs frequently lead the exclusion and frustration of autistics. Most autistics have at least one "special interest" (which I usually call a "focus"), which is a topic which we are deeply passionate about. These focuses range across an immense variety of topics, and allow us to become driven experts within narrow fields of study. Many autistics struggle to converse about topics not relating to a personal focus, which can fuel their social isolation. Despite popular stereotypes and high rates of isolation, autistic people generally have the *desire* to be social, but often struggle to make friends. The variance of intelligence across the autistic population is greater than that of the neurotypical population, which is a contributing factor in the categorization of autistics as "high-functioning" and "low-functioning". Many autistic children have speech delays, which can lead their to be mistakenly identified as less capable than they actually are. In my personal opinion, in a world where the population ratio of autistics and NTs was flipped, NTs would be considered disabled and autistics would be considered abled. For further discussion of this idea, see "The Neurotypical Wife" Facebook page (with which I am not affiliated).

Autism is an example of neurodivergence. Autistic brains work differently than allistic/non-autistic brains. Autism is associated with social difficulties, sensory sensitivities, and other characteristics that may make it difficult for an autistic person to live in an allistic society.

Autism is, essentially, a permanent state of altered functioning. The symptoms of this condition can vary wildly from person to person, though there are some symptoms that are more common, and these are things ones used generally as a diagnosis tool. The amount that someone is affected by their autism can vary widely as well, with some people able to function (or at least mask and appear to function) as well as Neurotypicals, while others may be unable to function better than the average toddler. Some folks even vary between these states and others, depending on factors that are unique to each person.

Autism Spectrum Disorder is a range of developmental disabilities characterized by some of the following: difficulty with social interaction, atypical attachment/aversion to certain sensory stimuli, atypical adherence and attachment to patterns

Being on a different wavelength from everyone else and that results in trouble communicating and overwhelming sensory experiences

Experiencing social and sensory reality in a nontypical way, which does not mesh with typical (allistic) experience.

For me at least it is very uneven. I have incredible ablilties in some areas and incredible challenges in others. My senses are height. I also require more movement in order to be calm.

I couldn't give a comprehensive description but I'd describe it as a different frame of reference
Having a brain that works differently in the way that it processes sensory input as well as information. Makes atypical connections and reactions. More sensitive and reactive to change and discomfort.
Having my brain wired differently to other people.
How would you describe allistic disorder in your own words?
I am autistic. Autism provides an experience of the world that is rich with beauty and incredible strengths. It also comes with deficits. Each autistic is unique just as each neurotypical person is an individual with their own unique differences.
I would describe it as a difference. It had pros and cons. I wouldn't classify it as a disorder or a disease or anything like that.
I would describe it as your brain being put together in a different way than neurotypicals meaning that an autistic person has different needs than a neurotypical person
It is a neurological difference that results in intense mental focus, which in turn creates a variety of social presentation issues.
It's kinda of like an ice cream bar. Only instead of ice cream, it's executive dysfunctions. And we're like "I'll have a little of that and a little of... Oh I just noticed that delicious stimming!! I'll also take five scoops of that!"
It’s akin to being gay in that it’s an innate way of being that is often discriminated against and seen as abnormal and something needing to be fixed. We are taught compliance above all else and pushed into ABA conversion therapies which result in many of us having comorbid PTSD.
It’s just a part of mind and some people’s lives. It has it’s ups and downs but ultimately I wouldn’t be without it.
Its a struggle and its something you deal with alone because no one else understands
Learning perspective in a dimension other than current social norms with extreme sensory sensitivities evolved for team complementum.
My own experience is that, subjectively, autism seems to be a condition caused by abnormal filtering of sensory input, leading to thought processes and a general view of the world which do not align with the expectations of a neurotyical-dominated society. The difficulties we face, thus, are more a matter of lack of accommodation by a society which neither understands nor accounts for our differences than an intrinsic lack of ability. This, of course, is only my own opinion, formed by mere introspection, but, given that empirical data on the outward manifestations of autism are readily available, I can only assume that this is the type of response such a question was intended to elicit.

Not a disorder. A different way of thinking.

It is a different manner of thinking, generally noticed by neurotypical people by differences in sensory and communication expression and perception. Many consider it a 'disorder' because only about one percent of the population experiences it internally (as opposed to knowing a person who has it). Some autistic people experience extreme differences and difficulties in communication, such as lacking verbal speech.

Self diagnosed at 53. I cried tears of relief upon reading a book about female aspergers. I was relieved because I always thought I was just a miserable asshole. There was a reason that made my whole life make sense.

The brain thinks different from everyone else's, that is where all the problems stem from

You are essentially an alien born into a human world trying to convince everyone else you're human, too... when you're not. Your entire life becomes studying and attempting to understand humans, learning what their expressions, tones, and behaviors mean as well as what are the appropriate responses to them. Sometimes they're (humans) so incomprehensible nothing makes sense at all, like saying one thing and meaning the other, acting completely opposite of their interests, etc. It is really f***ing weird.

Appendix F: Open-Ended Responses to Item Q12.5

Q12. Which of the following do you use to communicate in person?

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Gesturing (other than sign language)
Graphics
Some gesture-based. I was once described as having NVLD, tho, sometimes I miss other people’s meaning in gestures.
Sounds other than words, gestures.

Appendix G: Open-Ended Responses to Item Q13

Q13. How would you describe your strengths in communication?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Ability to perceive when people aren't understanding each other and facilitate communication When speaking online, without the pressure of in-person communication, can communicate extremely clearly Gift for languages - highly perceptive to patterns; once I understand a word or a rule, it's in my memory forever without any effort on my part
Detail oriented, clear, direct, honest
Excellent descriptive language. Earnest.
Extraordinary strength in writing, write professionally as an academic
Generally speaking, if I fully understand a concept and have the words to explain it, I can explain it pretty quickly.
Given that I learned to read before I could talk, my conception of the English language is based upon its written form rather than its spoken one. The result of this is that, despite near-complete lack of formal education, I am an above-average writer simply due to an intrinsic understanding of the structure and conventions of language.
Good
Great with visceral narrative and stream of consciousness fictional prose. Huge vocabulary and vocab is constantly adapting.
Honest, gentle [spelling corrected for clarity]
I am a very good writer, performer, artist, public speaker, and journalist. If I had to hypothesize why, I would say this is because there's less give-and-take with these forms of communication than there are in a meeting or a phone call. You're generally in control of the situation and can plan out what you need to say, and there's usually a formula to follow in order to be effective at that essay/speech/article/et cetera. (Of course the formula can be tweaked, but regardless I have a grip on what is being said.) Basically, I excel at communication when I can assume what will happen in a situation and/or I have a clear idea of what makes something good or bad (or effective or ineffective, if you will).
I am a very good writer.
I am almost always able to use spoken language. I have a large vocabulary and usually little trouble in figuring out how to phrase things

I am better speaking than I am writing.
I am fluent and verbal I have good speech
I am good at spelling and details, I would also say I'm good at being formal
I am good in writing when I can review and revise my words.
I am great at writing when given the time
I am highly verbal, like many with the diagnosis of Asperger's syndrome or ASD Level 1. Once I learned how to intepret sarcasm, I was quick to pick it up and use it myself.
I am honest, direct, and open with people. I have a fairly complex vocabulary. I am able to listen well to what people have to say, and I'm comfortable speaking in front of crowds.
I am hyperlexic and indistinguishable from neurotypical when communicating in writing. I am also really skilled at learning and speaking foreign languages (to the extent that I learned to speak an undocumented language for my PhD). I perform well in conversations when I am in "interviewer" or "listener" or "information delivery" mode.
I am often able to have more open and honest conversations than some allistic people might. Despite my slightly below-average oral communication skills, the quality of my written communication skills is well above-average.
I am very articulate in writing.
I am very good at writing. I am a talented creative writer, and I'm also very good at academic writing. I am also pretty good at expressing myself verbally, though I'm better in writing. I'm good at explaining things and I'm good at coming up with interesting dialogue. I am also decent at mimicking the way a word is pronounced when learning a secondary language.
I am very precise and to the point, which is advantageous in technical writing.
I can be short and to the point.
I can speak, yet I find writing easier because I can see what is being communicated
I can typically express myself clearly and concisely, especially with those I know. My strength is more in written communication but I do reasonably well in spoken communication as long as I have time to think and process.
I dont have many strengths in communication
I have a large vocabulary and an excellent command of grammar. I speak three languages. My writing is usually quite clear.
I have a large vocabulary and I am very honest and honest.

I have a PHD degree in communication
I have a vocabulary that is in the 99.6 percentile and a comprehension that is in the 95 percentile as measured on the WAIS-IV.
I have been told that I am very eloquent in speech and in writing (though more so in writing). I have also been told that I am polite. I think verbally and therefore find it very easy to convey my points using words. I also intake written information very quickly.
I have strong verbal skills, a large vocabulary, and the ability to clearly communicate my ideas and opinions. I am told that I'm witty. I am fluent in Spanish from studying it in school.
I tend to be straight forward and honest
I think that I can communicate very well when my presence or my voice isn't required. With text, writing, typing and such I have the time to focus on and process more truly what I'd like to say instead of the awkwardness of pausing a conversation every so often to puzzle-piece together my responses as accurately as possible. I can convey much given the time, and I believe my strengths are that I am direct, honest, and try to use my understanding of human behaviors to speak in ways they find most comfortable.
I'm good at formal, academic communication which I do for work. Although I generally don't struggle with verbal communication I feel bad at social communication, what I think and what I say never seem to match well.
I'm great with language. I love puns/plays on words, riddles. I have a different perspective and that can be a really useful tool for communicating.
I'm hyperlexic (started reading at three), and have made my living for 40 years as a professional writer.
I'm ok
I've been pretty good with communication most of my life...I got communication merit badge in Boy Scouts! 😆
I’m a charming wordsmith.
I’m good at typing my thoughts
Literal
My language is hyper mechanistic and therefore literal. I have difficulties understanding people who speak and/or write like the lazy sh*** they are. When people break the rules in speaking, I fail to understand them.

My verbal and writing skills are above average, but I have a hard time accurately conveying and intuiting certain concepts (mostly interpersonal matters).
Poor
Precision.
Specific; I recognise details and am unlikely to gloss over things, making me suited for deeper, more complex discussions. Honest with tact. I value listening to people who are often overlooked and not listened to. Because of difficulty recognising things like implications, I often recognise more potential meanings of things said, which can be helpful when recognising the impacts statements could have and the ways in which they could be misinterpreted; it gives me insights that other people often do not have due to them only recognising the implied meaning and not all other potential meanings. Can be very expressive, particularly in my eyes. Have become quite good at non-verbal communication (more so me communicating my thoughts to others than understanding what other people are communicating non-verbally) due to being non-verbal quite a lot of the time (note: not speaking is not an inherently bad thing, and other forms of communication are not inferior or less preferable). Quite good at expressing my emotions in an emotionally mature and open way. Good at speaking softly and validating and encouraging others in a gentle way. Pretty good handwriting. Good at spelling. Sometimes good at making my tone pleasant to listen to (not in an overly-polite, submissive way, but in a rhythmic, soft, almost melodic way).
Using and explaining precise meaning, where appropriate. Breadth of vocabulary. Preference for direct communication.
usually misunderstood or ignored
Very particular about word choice. An understanding of social/emotional implications behind word choice informs what kinds of language I use. I'm very aware of how I want to make people feel or avoid making them feel with word choice. This helps me navigate diplomatic social situations. Strong at generating communication.
Weak
When not in person (writing) or in person given time to think, being very capable of articulating ideas and feelings in an understandable way
Written communication is vastly easier for me. Words come to me with far fewer challenges as I am able to think mindfully about my responses.

Appendix H: Open-Ended Responses to Item Q14

Q14. How would you describe your challenges in communication?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Ambiguity and subtlety.

Aside from the issues I have with auditory processing getting in the way of clear communication I also have significant deficits in working memory as indicated by WMI scores that put me in the 30th percentile.

Communicating in person is difficult and I often fail to convey what I meant because I need extra time to translate from the picture in my brain to words; I also have auditory processing difficulties and it takes extra time for me to understand what I heard

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Eye contact, lack of processing time, word confusion, anxiety, bluntness

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Fatigue around spoken expression. Difficulty with conversational pattern in the moment.

Following and appropriately responding to verbal communication and nonverbal cues

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For the same reasons stated above, verbal communication, for me, is more difficult than average. Rather than a typical direct conversion from thought to spoken language, I have to convert thought into something analogous to written form before "reading" it aloud. If inflection is to be added, it must also be added consciously at this stage, as my natural communication method lacks this feature. As such, verbal communication, for me, is a feat of great concentration and is atypically given to becoming fragmented and dysfluent when focus is interrupted. Given my liability to become severely overstimulated in modern post-industrialized society, this often proves to be a grave problem.

Frustration with people who lie/say things sincerely that you can tell they don’t mean.

I am often unsure what other people are or thinking or feeling; I can’t tell when I’m being lied to, manipulated, or made fun of; I don’t know how to tell people I’m interested in establishing a relationship with them.

I am very very bad at being interviewed (to the extent that I've experienced years of unemployment). I can't lie without a lot of practice. When people surprise me with personal questions I'm supposed to have a diplomatic answer to, I freeze up or tell the truth undiplomatically. I have great difficulty making small talk and initiating a conversation is intimidating. I find it challenging to manipulate people's emotions through talking (like giving speeches or managing a classroom).

I babble like a f***ing moron when someone asks me for a simple explanation for hyper complex questions. My struggle to communicate is excessively hampered by my desire to *NOT* "talk down to" The Inferior Race (non-autistic people).

I can never verbally express myself... sometimes it feels like I can’t even communicate fully to myself- I don’t know what I’m feeling very often. But when I do, I still can’t express that verbally very well. I use a lot of one-word communication and noises more than full sentences. I can pretend to communicate well but it is EXTREMELY draining and more like playing a guessing game with everyone around me

I can sometimes have trouble carrying conversations because I often lack the conversational reflex to turn my internal curiosities into verbal questions. A friend or partner will make a leading statement that I won't recognize as being such, which can cause frustration that they sometimes take to indicate disinterest. Not so strong at responding to incoming communication.

I dont know what to say 3/4 of the time and when I do say something it comes out wrong and then people get mad at me

I go nonverbal sometimes and during those times also struggle communicating through written or typed word which are my only other options. I also struggle with properly forming my thoughts into a way to communicate them with others.

I have a near-inability to detect sarcasm and dry humor in in-person interaction (I am usually able to tell if something is sarcastic or humorous if I'm watching TV or a movie that I know is supposed to be funny) -- leading to confusion when I answer questions meant to be rhetorical or don't pick up on a joke, I have problems mingling (making networking, funerals, weddings, and other big occasions difficult), I had difficulty in college classes that involved discussions because the conversation would move too quickly for me to construct a thought so even if I were passionate about something I wouldn't be able to say what I was thinking (this is still a problem in work meetings and even informal group discussions), I have a tendency to dominate conversations with the things I'm interested in and alienate people (or so my friends have told me), being interrupted throws me completely for a loop and I am unable to remember what I was saying before, I struggle to voice things I need/want/feel, and I cannot process what is being said to me or what I am saying if music is playing/there's a lot of ambient noise/there's cross talk in a room. This all hinders my ability to both process and express information.

I have little social intuition. Also, if I am dysregulated or otherwise overwhelmed, I lose a good deal of my ability to verbalize. That’s frustrating, and my frustration can make the problem worse.

I have severe deficits with communicating with allistics. I cannot 'read between the lines'; the way allistics use semantics doesn't make sense to me.

I have some auditory processing difficulties that can sometimes make understanding others' speech difficult. I also find it more difficult to speak fluently when I am stressed or tired (I will slur my words / stammer / speak in fragments).

I have trouble reading microexpressions and intepreting emotions from facial expressions. As a child, I generally took everything literally, and had to be explicitly taught not to do that.

I have trouble verbally, especially under pressure.

I have trouble, at times, communicating with strangers or people I don’t know well, especially on challenging or complex topics. It can take some time to formulate what I want to say.

I occasionally go nonverbal when I'm very upset, or get stuck only able to phrase things in a hurtful way. (Writing is also affected but less than speech.) I'm also not great at noticing nonverbal cues while simultaneously using language, it's like it turns off the nonverbal when I use the verbal. This particular issue doesn't seem to be affected by modality of communication.

I often can't anticipate how something I say or do will make someone else feel. I say things that are hurtful without meaning to.

I often skip over the niceties, making people think I'm rude or inconsiderate or upset when I'm not. I also have a speech impediment and a stutter, which has caused cops to think I'm drunk when I'm not on multiple occasions.

I sometimes do not understand hidden meanings within spoken words, and have trouble reading emotions quickly and accurately.

I struggle to maintain communicative relationships with others

I struggle with speaking articulately. I forget the words I want, and I think I’m expressing myself clearly but then I go back and realize that I was very unclear and I articulate.

I struggle with writing

I suck at talking because I can have trouble keeping things coherent. I also go off on tangents/loose associations sometimes. If I talk at all. I often don't talk at all.

I take things literally, which is not inherently problematic, but occasionally leads to miscommunications. Sometimes I miss sarcasm and/or take longer than average to recognize that someone is being sarcastic. My vocabulary regarding emotions is somewhat limited, which has been an obstacle in some close relationships and group therapy setting (eg. Parent: "I'm not angry; I'm frustrated." Me: "What's the difference? That's like saying 'That's not red; it's scarlet.'"). Because this has been repeatedly targeted, it is much less apparent than in years past.
I worked on social communication skills with an SLP in middle school. My mom did a lot of role-play social conversations with me in elementary and middle school. My "default state" of social communications was challenging, but I've put in enough effort and training to be fairly well masked.

I think the biggest problem is people don't give me enough processing time. Groups are tiresome because each time I think up my answer someine else has already added more to the discussion.

In times of extreme stress I occasionally will become nonverbal for a short period and need to use writing or typing. I have auditory processing issues so understanding what other people are saying can be a little challenging. I tend to come off as "weird" in conversation and sometimes have trouble following the usual conversational rules

If communication is the act of expressing yourself and receiving input from the world, I have zero deficits except the rare event of not being able to understand verbal communication. My particular challenges come to interpretation. I can be too literal. I may become stuck in misunderstanding and need something rephrased with different words. I also lack typical responses to emotionally charged situations and may not know what the appropriate response should be.

If I don't fully understand a concept or have the words to explain it well, I tend to ramble a lot because I'm trying to explain something I don't know how to do or I don't have the words for.

In speaking I am less so, as my auditory processing takes a moment to "click" with both what I am hearing and what I am saying, although I am often well spoken when speaking about an area which I am passionate about or have had time to think about.

It's the spaces between the words I struggle with.

Judging others reactions and knowing what's appropriate or not is very difficult

Most of them are with verbal communication. I speak too fast -- mouth can't keep up with brain -- and can overwhelm people. Tend to monologue. I've worked VERY hard on non-verbal communication skills (it became a special interest for a long while), and can more or less pass as NT now, at least for a while. But it takes exhausting amounts of cognitive bandwidth to pull it off. If I'm not feeling 100%, I will tend to stay home rather than try to summon this act.

Never know when it's an infodump or how much to talk. Can't verbalize my own feelings sometimes as they feel amorphous and thoughts fire too fast to communicate.

Non verbal communication issues under standing sarcasm and I often talk about the same three things over and over

non-literal

Other people don't understand. I don't know how to make them understand. Online, people understand.

Putting my thoughts into actual words is exhausting. There is a disconnect between what my brain says and how I am able to say it. Often, comes out of my mouth is an extremely processed, watered-down version of what I'm really trying to convey. Inside my head is a miasma of thought, thunderclouds all over of various processes going on. It makes sense in my head (usually) but channeling that into a consumable format for others is exceedingly difficult. Everything I say, the way my face moves (or does not move) has to be calculated so as not to offend or confuse others. I prefer text / typing / online communication for this reason.

Reading the body language/tone/word choice of others to understand their feelings and disposition, communicating clearly without given time to think
Relative lack of social intuition, using obscure vocabulary/concepts, trained "people pleasing" instincts get in the way of assertiveness/self-advocacy.
Sometimes I don't know what to say, or get overwhelmed and can't think straight enough to properly participate.
Somewhat challenging
time consuming
Uh sometimes... I'll pick an example out. [SITUATION], I just had a really hard time emphasizing with her situation a lot. Because I'd sort of blocked myself from even thinking about it. It hurt too much.
usually misunderstood or ignored
Verbal communication as a whole is difficult for me. I prefer expressing myself as I understand how to do natural, which is visually and tactilely
Verbal communication is harder for two reasons: 1. My thoughts can get jumbled and so I end up either speaking too much or too little, and 2. It is hard for me to pick up on the facial expressions and cues of others.
When speaking, I am not always able to pick the right words

Appendix I: Open-Ended Responses to Item Q15.2

Q15. How do you prefer to communicate with others?

[Nonverbally, in person (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

AIM or FB Messenger

being present, connected

Body Language

Either sign or typed messages

Gestures and typed words while near the other person

If this is a traumatic situation or one that I have a lot of fear in, the kindest thing a person can do is agree to my request to write their comments to me.

nods, shrugs, pointing, etc.

Not unless paired with verbal. Body language is important to verbal communication.

Sign language or writing on a notepad

Sign language, and written in-person communication

Sometimes I like to write things out beforehand and give them to people, but I don't like how weird this option makes me seem.

Speaking via text in person

Text

Through typing or writing on phone or piece of paper

Typing in a word processing program and showing it to others

Visual and tactile communication

Writing, signing, gesturing.

Appendix J: Open-Ended Responses to Item Q15.6

Q15. How do you prefer to communicate with others?

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Depends who

easier to talk in person or on phone with the few people who are understanding of my communication difficulties, otherwise, somewhat prefer written correspondence through texting, email

I mean there's a lot of other text-based instant messaging things and that's really what I've used as much as I could most of my life

I prefer to *NOT* communicate at all.

Instant message

instant messaging

Instant messaging/social media

letter writing

online generally

Online messaging

Snap chat

Social media

Tapping code. Yes/ No responses to questions.

written so that I acan refer to

Appendix K: Open-Ended Responses to Item Q5

Q5. Within this survey, I refer to neurodiversity as the idea that autism is a neurological difference characterized by both strengths and weaknesses, and that existing as autistic and existing as non-autistic are equally valid. Is this consistent with your understanding of neurodiversity?

[Not at all consistent (please elaborate)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

I use neurodiversity as a concept to describe those persons who are autistic, have ADD/ADHD, OCD, etc. I use Neurotypical in reference to those who are not autistic, do not have ADD/ADHD, OCD, etc.

Appendix L: Open-Ended Responses to Item Q10

Q10. What language convention do you prefer to use in reference to yourself?

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Doesn't matter
don't care
Don't really care.
I don't care as long as you mean well
I don't really care either way.
No preference; I use both
they mean the same thing

Appendix M: Open-Ended Responses to Item Q17.7

Q17. In what settings did you receive intervention services? Please select all that apply.

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

After my 2014 brain injury I had SLT during recovery, mostly due to my being a total monotone
And therapy
Counseling. I’ve spent years in episodic counseling starting as a young teen. In hindsight much of what we worked on was communication and relationship skill building.

Appendix N: Open-Ended Responses to Item Q20

Q20. To the best of your recall, what was the focus of the intervention? (Examples might include AAC, spoken language, or pragmatics/social skills.)

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

drilling remedial skills

I was unfortunately so young when I had speech/language therapy that I only remember playing UNO and drawing rainbows. I can assume based on an IEP I read from when I was three that pragmatics/social skills was the focus of my therapy (but can clarify with my parents if necessary).

I’m sorry i don’t remember I know had a speech and language delay

Pragmatic language, social skills, had to complete readings/assignments outside of appointment which psychologist would discuss and make me practice skills learned

Pragmatic social skills

Pragmatics/social skills, speech therapy. I also took acting lessons with a speech coach as an adult to perfect my diction.

pronunciation, such as 'r's and 'sh's, as well as things like eye contact and tonality.

Prosody. Inflection. Tone. Pacing. And varying all the above.

Social skills

Social skills & pragmatic communication

Social skills and dealing with being anxious in public and also I am still receiving services and will continue to do so for the rest of my life. Adult Community Autism Program or ACAP through Keystone Autism Services

Social skills, dealing with speech impediments (lisp from tongue thrust, cluttering)

Social skills, mainly eye contact and conversation carrying

Social skills, reading emotion and expressing emotions conventionally. There was more related to speech, but I can't really recall the details.

Speech therapy when in grade school; social skills as a teenager

What to say, approite laungage, confidence in speaking, having a conversation, tone of voice

Speech therapy - couldn't say Ls correctly (this lasted the year I was in first grade, before any autism/learning disorder diagnosis) Social skills - learning to interpret figures of speech and tones of voice, in both spoken and written language. I loved to read before this, but could not decipher a text's hidden meaning that wasn't explicitly stated within the text.
Spoken language
Spoken language, social skills
Spoken language, social skills, controlling emotions, controlling special interests
Spoken language. I spoke some unusual, made-up way that no one was able to understand clearly. Speech therapy completely changed my life and gave me the opportunity to communicate better.
The focus was to teach me to speak in such a manner that others could understand me (I did not enunciate / articulate words well when I was younger). I also had some invention in emotional regulation, though this was only partially due to autism (which wasn't diagnosed as such until I was 17, though I was diagnosed with "developmental delays" at 3 years old) and more so due to [SITUATION] and the subsequent trauma.
When I was younger, to figure out why I had “behavioral issues.” Nobody knew why I acted the way I did. When I was older, it was to build social skills

Appendix O: Open-Ended Responses to Item Q21

Q21. As you perceived it, what was the ultimate goal of the intervention?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Ability to communicate with my peers and adults.
Family harmony
For my speech to be understandable to others.
Generic learning.
Getting me back to society after six weeks of coma.
Getting me out of the classroom so they didn't have to deal with me anymore. (That sounds bitter. Am I bitter? I may be bitter.)
Getting me to learn how to have spontaneous conversations, so I wouldn't talk like a script
Getting rid of a sibilant S. Learning to slow down and enunciate. Managing energy while speaking.
Help me communicate more effectively so I could attend college independently, form relationships with others
I actually didn't know this until this fall, but apparently the goal was to improve the pragmatics of my language and possibly some syntax issues. According to the aforementioned IEP, I would answer open-ended questions inappropriately (i.e. "With the reindeer" in response to "What is Santa going to bring you") and often just repeat what had been asked of me. For the past eighteen years I believed I was seeing a speech therapist because of a lingual frenectomy I had had.
It was kind of pointless, trying to teach me to be what I’m not
Learn "The Rules" of social engagement so that I can be perceived as "normal." This, in turn, will make it so that people will want to be friends with me and employers/etc. will be willing to hire me. Note: My current view is more nuanced than this, but this is an approximation of what I would've told you until at least early college.
Look and function as neurotypicals
My perception was, and still is, that it was a means of social control, intended to force me to conform to communication and social standards prescribed by others.

To be able to communicate more clearly.
To channel my speech into comprehensible structures, sounds, and give me the ability to communicate with others effectively.
To get me to be more independent
To help me better be able to communicate
To improve social skills and help me seem more like a NT kid.
To make me better at making friends by teaching me to act in "socially expected" ways
To make me fit in with my neurotypical peers
To make my social skills match what was appropriate for my age
To teach me how to talk and express myself just like all the other kids do.

Appendix P: Open-Ended Responses to Item Q22

Q22. Who determined these focuses and goals? Please select all that apply.

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

educational psychologist

My doctor in the hospital.

SENco and Tas

Social worker

Therapists

Appendix Q: Open-Ended Responses to Item Q26

Q26. Based on your personal experiences, what positive outcomes or effects do you identify as a result of speech-language therapy?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Ability to communicate with (most) others, code-switching abilities to work well with allistics.

able to express my needs more effectively than before, less resulting problems and conflicts. Have a somewhat of a better understanding of why people do what they do. Better understanding of how autism affects me, now able to forgive myself and try to prevent things from becoming issues

Based on the IEP, I apparently would have continued to struggle with language and communicating if it weren't for speech-language therapy. Now I definitely am able to answer "Wh" questions, and I generally don't repeat things people say to me.

Confidence in having conversations

I am able to speak to my friends and family

I am better with eye contact, tonality, and some pronunciation.

I am indeed better able to communicate like neurotypical people.

I can communicate better but ocupation therapy was of far greater help because my sensory and motor issues were far more severe

I can hold a conversation now

I can now speak in such a way that others can understand me; this helps me to communicate my wants and needs.

I can verbally communicate, when needed, to a degree that is effective enough for others although I find it myself an inefficient method of truly communicating.

I did not have speech or language therapy

I did not receive speech-language therapy that I recall.

I didn’t have traditional speech-language therapy. I attended counseling. The positive impact is that I’m passable. I can negotiate the world with less trouble than other autistics. I also have a great grasp of who I am, my boundaries and my gifts.

I gained a greater understanding of social norms. I learned how to interpret and display facial cues. This ultimately helped me build social relationships and fit in better.
I have a bigger set of tools I can use to enhance my self-presentation when I choose to/need to. Passing is still exhausting, but it's somewhat less so if you have tried-and-true solutions and scripts within easy reach in your head. To the extent that these experiences enhanced that, it was useful.
I learned social and academic skills that I now consider useful in different settings. My social skills were adequate enough by middle school that people stopped teasing me for them. For many years my verbal skills were much better than my written skills, due to a writing disability. This has changed since attending college.
I no longer clutter as much and my tongue thrust is better so I can swallow pills and better pronounce my "s"s.
Made me way less likely to say things that hurt people’s feelings
My speech is indisquishable from most people's... Four years out it's doing about the same it did three months after my collision.
Neurotypical people can understand what I have to say, otherwise they have a hard time understanding
None
None whatsoever
The therapy I received was not speech-lanaguage therapy. Did I misinterpret the rest of the survey? I thought it was about autism therapies in general. Later, as a special education teacher, I was taught some speech therapy stuff and I found it personally very helpful.I received training in Linda-Mood Bell reading/writing and for the first time, I understood some things about the english langague because feeling it in my mouth helped me hear it.

Appendix R: Open-Ended Responses to Item Q27

Q27. Based on your personal experiences, what <u>negative</u> outcomes or effects do you identify as a result of speech-language therapy?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

About the only one is that it makes it more tempting to try to pass -- which always wipes me out.
Again, sorry, but I didn't get SLT
Because I can physically communicate verbally, I am expected to all the time, and it hurts me. Therapy didn’t do anything except set me up to be pressured and then punished when I cant live up to expectations
I am currently seeing a speech therapist for my stutter. My parents and I believe that the stutter was the direct result of the childhood speech therapy.
I constantly overthink every social scenario I’m in
I did not have speech or language therapy
I got very frustrated because I understood the concepts quickly but still was not getting better at making friends. I became ashamed of my infodumping and assumed that any time I did so I would be annoying people
I hated being singled out, and being the only girl in school who had to see the SLP. Nobody ever explained to me why they were teaching me these skills, or why I couldn't naturally learn them like the NT kids I was in school with. I only figured that out years later by myself.
I have developed severe anxiety surrounding the very process of communication, caused, presumably, by strict negative reinforcement (primarily by parents, though guided by the opinions of professionals) toward most every method of communication which feels remotely natural to me. The very experience of communicating in-person has become something so negative, I genuinely wish to entirely withdraw from society and never speak to another human being again. It was not always this way.
I suppose there aren't any negative outcomes of the therapy itself, but I'm upset that I never knew what I was going to therapy for until I requested the IEP in October (which my parents would not show me while I was in school). As grateful as I am to be able to communicate and have people rarely be able to tell that something about my communication is abnormal, it feels like my parents/my teachers/my occupational and speech therapists were trying harder to make me "normal" than to help me adapt while acknowledging who I am, resulting in a lot of confusion about why I found certain things (like talking on the phone or participating in a class discussion) were so difficult for many years.

I learned to see my way of being as "wrong." I felt a lot of shame about my perceived inability to be social and follow "The Rules" of social engagement, and saw social failures (such as the lapse of a friendship) as signs that I had personally failed and was not trying hard enough. Unlearning this shame is an ongoing process. After internalizing so many rules about how to interact with people, I would become very frustrated with myself when I had broken them, and angry when other people broke them, especially if a popular person broke a rule and was still well-regarded by peers. For example, one of the rules was that if someone asked you a question about yourself in conversation, after answering it, it was required that you follow up with a related question for them. If I saw a well-liked person break this rule, I would internally rant to myself that they didn't deserve to be popular while I was not, and that these rules were created by society to police me while neurotypicals remained "above the law." Because I became so attached to an image of how I thought I "should" be, I still have a hard time parsing whether I want something to happen a certain way or if I feel obliged for it to happen that way.
I wasn't offered alternatives of communication, most likely because they were not as readily available at the time.
None actually
None, although I had a really RUDE person working with me once. She was quickly replaced. From there it was good.
None.
None. My SLPs were solely there to help me and did exceptionally well with it. However I've had no autism-related SLT.
Not every counselor is a good fit. Some spout trendy noise. Even though I had lots of counseling and a psych evaluation as a teen my autism wasn’t diagnosed until I was in my late twenties. Diagnosis didn’t come with any explanation, support or even a resource sheet.
Taught me social skills but I still am not sure when to use them so still having trouble forming relationships, and there are other issues that serve as barriers to communication (eg. sensory and attention issues) that were not entirely addressed.
There was nothing wrong with the way I communicated. My autistic child brain was beautiful and people could understand me just fine if they took even more than 1 second to pay attention. I felt like there was something wrong with me for the way I was, and other kids just knowing I was in therapy during school contributed more to bullying than the way I communicated.
There were times where the speech-language pathologist did not understand why I'd react negatively to certain stressors (some of the therapy was group-based, especially in elementary school, and we would play competitive games, which would cause me frustration). The pathologist would sometimes belittle me in front of my peers / the other students for this reason.
This isn't natural and is extremely difficult for me, it doesn't benefit me it just befits others who don't communicate like me because they have difficulty understanding how I communicate.

Viewing compliance and "normalcy" as virtues, internalizing pressure to achieve these.
When I was at secondary I found the ways things were done slightly patronising.

Appendix S: Open-Ended Responses to Item Q34

[Q33. Please indicate below how you would rank the importance of each of these subjects to be addressed <u>in speech-language therapy</u>.]

Q34. Do you have anything else to say about this question?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

Echolalia is a good thing and should be encouraged, not suppressed nor punished.

First find out what communication strategy is best for autistic person, then work on that first. Autistic person should then be able to communicate what other forms of communication they want

I assumed that echolalia referred to preventing it. As well, the only thing here that I think would be important to cover for every patient is self advocacy. The rest would depend on each patients needs and abilities

I assumed the question about the use of spoken language meant should spoken language be considered a more valuable and desired communication strategy than others. There’s a problem with this approach. It has zero concern or regard for the skills and preferences of the person seeking services.

I do not.

I feel speech therapy should be about learning to communicate effectively to express your needs and feelings.

I have no experience in this area.

I think that the energy level / "spoons" that an individual uses on different types of communication should be taken into account. A person who can use verbal speech well but who tires themselves doing so should be encouraged to use AAC / writing / sign language when need be as to not lead to burnout.

I'm not sure how echolalia is a problem.

If us autistics can interface with the world in an effectual manner, that's where we can best be helped. But almost every situation is going to be different. So what worked to help me may not help another...

invalid question

It depends on the person and their needs/preferences.

It would be helpful to have explanations for what each one means. For example, I'm not sure what 'compensatory strategies' means. Also, 'nonverbal communication' is a very broad umbrella, and I view different aspects of it to be of different importance - eye contact as completely unimportant, and things like gesturing as moderately important.

Methods should be focused on helping the autistic person in question interface with the world in a way they find comfortable. Help them discover adaptations & accommodations that work for them, confidence in themselves, etc. Don’t try to force them into a neurotypical mold or force them to take on neurotypical traits. Work with them and for them, not against or to “train” them.

No

Nonverbal communication question views it in a neurotypical light, and communication with neurotypicals nonverbally is not the samething as communication being autistic nonverbally

Please respect that doing ANY of this is taxing. You're teaching us to do something that doesn't come naturally, and which we may never be good at. It may always be hard. For that reason, we may not always use what we've learned. Whether or not we choose to use what you teach us must ALWAYS be left up to us. And when we do choose to perform, we deserve respect for the amount of focus and energy that performance sucks out of us.

Relative importance of treatment directions should be decided by the individual whenever possible; it is not my, nor anybody else's, place to prescribe what constituted "help." As such, the question has been answered based upon priorities I would have chosen solely with regard for my own situation.

That's impossible to answer as it will vary with each individual. The whole point, to me, is that we should be helping people reach their individual goals, not forcing them into our idea of perfect.

The ability to communicate is much more important than the manner by which it is achieved. I would argue that speech pathologists have an obligation first to enable autistic patients to communicate and as part of that inform their patients about different forma of communication and what they entail. I.e., choosing to use sign language oe AAC has a social consequence vs. Spoken word, but that consequencs may be less than forcing someone to speak because it is socially favorable. Weight options in the case of each individual.

The primary goal should always be that autistic person is capable of communicating to their own satisfaction. If they want to use spoken language or AAC, then they should be aided as needed in doing so. If not, it shouldn't be foisted upon them. In cases where a person is unable to meet their goals because of a discrepancy between their communication style and the world at large (e.g. struggling to make friends), then the SLP should provide strategies for dealing with that discrepancy while clearly emphasizing that the autistic person's communication style is not inherently inferior, but rather is ineffective in that situation due to personal differences in communication style. The ability to self-advocate as needed without shame far outweighs any other goal.

Regarding echolalia, I don't think you should ever be focused on reducing it. Harnessing it to build communicative speech, on the other hand, is very important.

This question makes no sense to me. Are you asking what should be 'treated'? Echolalia is a stim. We need to f***ing stim! I'm not going to look you in the eye or try f***ing guess what your body language means; I'd have better luck figuring out your intentions based on whether Mercury is in retrograde (that's my sarcasm font just to be Autistically obtuse). These aren't important things. I will never fit in and I will never be as fake allistic as these aims want. I need to learn to navigate a world as ME and learning how to tell people 'I'm listening, I just don't do eye contact' is a much more useful skill than encouraging wasting 75% mental CPU usage faking eye contact thus not leaving enough CPU to actuLl engage in conversation. F***ing hell. Autistic natural communication methods should be taught to everyone else; why is the burden always on us, especially often as children? What I'd like to say to abusive speechies: Stop trying to force us to assimilate and teach those who are supposed to love and respect us how WE communicate. We will speak of and when we are ready. We will not look you in the eye. We will not allow you to touch us. Our bodily autonomy is not worth less than your incessant and f***ing repulsive need for us to pretend to be allistic enough for you to get a paycheck. To the good speechies? Thank you for teaching us to be ourselves and to advocate for our autonomy and Autisticness. You're the best!

Appendix T: Open-Ended Responses to Item Q36

[Q35. Please indicate how you would rank the importance of each of these themes to be addressed by speech-language pathologists in counseling with parents/families.]

Q36. Do you have anything else to say about this question?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

advocates are usually so ignorant as to be dangerous

As above

Does 'advocacy' refer to the parents / families becoming advocates themselves (I'm very cautious of this, due to the huge numbers of ableist parent / family advocates out there) or to them listening to autistic self-advocates (which I consider to be very important)?

Forcing an autistic person to behave like the inferior race (non-autistic humans) is evil, unethical, immoral, and abusive and should be criminalized. ABA should be against the law, and its practitioners thrown into prison while they await death and Hell. F*** them people, in the eye, with a stick.

I do not.

I have no experience in this area.

Most important would be for families to listen to autistic adults and take them seriously. Get autistic mentors for autistic kids if at all possible.

No

No, I do not.

No.

Parents need to know that the goal should not be to "fix" their child. "Curing autism" should never be a goal.

Parents need to learn how their Autistic family member communicates. Support groups and social groups currently seem to only be eugenics groups so they can f*** off. Treatment resources/Education must be neurodivese and Autism positive. Any advocacy must be neurodiverse focused; parents do NOT have the right to silence Autistic voices. Parents do NOT have the right to post stories, pictures, or videos of their children for bullsh** sympathy fake internet points (upvotes on Reddit etc.); it is NOT their story to tell.

Support for parents is important. I like the idea of introducing them neurodiversity and self advocacy so they can seek advice from autistic adults who have been through what their kids have.
Support groups are only helpful if the leader understands autistic people, they are entirely voluntary, and they never use shame or peer pressure.
Yes. We need to be taught how to advocate for our needs as children.

Appendix U: Open-Ended Responses to Item Q37.6

Q37. To which of the following resources would you suggest referring parents of newly-diagnosed children for information? Please select all that apply.

[Other (please describe)]

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

ACAP, Adult Community Autism Program

Aspergirl is also an autistic-run group I'm a part of.

Autism Outreach

Autism Society of Minnesota, if applicable

autism speaks does have some useful resources but any health professional who woukd like to refer it should also objectively address the associated controversy

Autistic Women and Non-Binary Network, Autistic Inclusive Meets (AIM), Agony Autie, Neurodivergent Rebel, The Aspie World

Autistic Women and Nonbinary Network

Autistic Women and NonBinary Network (AWN)

I don't have specific names, but any groups / charities that are against things like cures and ABA therapy and that use primarily identify-first language. Those are usually good.

Local autism advocacy groups

Local community groups, especially with autistic leaders

Local resources

NAS only for children; adults are left to kill themselves [*continued in response to Q38*]

Read "Neurotribes"

Speak for Yourself and PrAACtical AAC

Things I hear of American ASC societies are terrible, they support ABA I wouldn't recommend any!

Appendix V: Open-Ended Responses to Item Q38

[Q37. To which of the following resources would you suggest referring parents of newly-diagnosed children for information? Please select all that apply.]

Q38. Do you have anything else to say about this question?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

"Autism Speaks" does *NOT* speak for me! F*** them people, also, in the eye with a stick. A big f***ing huge pointed stick. How f***ing dare they grow wealthy and politically powerful on the corpses of suffering, misery, and frustration autistic people live in like a fish in water.

“Nothing about us without us” should be the motto of the group. Autism Speaks for example is the antithesis of that theme.

NAS only for children; adults are left to kill themselves [*Continuation of response to Q37.6*]

Autism Speaks doesn't speak for me. They see us as monsters and burdens on society that need to be eradicated. They are scum. I am not a parasite. I am not a monster. I am an intelligent human being who is worthy of respect and has an unique perspective on the world and much wisdom to offer if you would only listen. This is the message of neurodiversity that these resources need to be spreading.

Autism Speaks is a plague and no serious study of autism should include them.

Autism Speaks is probably a horrible resource. It has been shown that they never spend money helping the people they represent, waste it all searching for a "cure" that even if possible, would amount to the death of my personality, so I and a lot of other people in the community would not go for it.

Autism Speaksis evil!

BURN AUTISM $PEAKS with the heat of a million suns!! I'm not even sure who most of the groups above are.

Don’t follow a disease model. Autistics are not horribly broken people inflicted with a disease that must be cured. They are humans who could use some compassionate coaching and education.

F*** AUTISM SPEAKS I don't know the others so I left them unchecked.

F*** Autism Speaks. They're a eugenics organization. I don't know anything about ASHA, ASA, or IAN.

I checked the ones I know about and would recommend. I very much do not recommend autism speaks. The rest I am not knowledgeable about
I do not know enough about organisations other than ASAN and Autism $peaks eugenics org to comment on the others so I won't. If I were in a position to recommend, I'd look into other Autistics' opinions and the Deaf/HoH community's comments.
I don’t know any of those
I'm not familiar with a few of these!
Like much of the autism community, I think Autism Speaks should be avoided whenever possible.
No
No.
Oh god! Your suggestions for organizations are horrible.
Parents should also be referred to local resources if those exist.
Rather than pointing toward organizations, I would suggest books and academic research, the particulars of which would, of course, depend upon the individual in question. I would also provide a warning about the agenda of Autism Speaks.
There are quite a variety of autistic adults with online presences. I would direct the parents to them.
Us autism society is incredible I went to their conference in Las Vegas amazing!

Appendix W: Open-Ended Responses to Item Q43

Q43. Is there anything else not previously addressed in this survey that you would like to share?

Note: Participant responses are represented as entered, without editing for grammar or spelling; the researcher recognizes that errors are present, but chose to preserve the original responses as they were entered.

“Nothing about us without us!”

All animals share a very similar brain that responds the same way to the same chemicals and neuro signals, in fact any animal can be treated with the same anxiety medication humans use because humans are animals too (we are part of the great ape family). All animals (including ourselves) have thoughts and feeling and in fact have the same emotions. Anyone how has had a pet can a simple demonstration. When your cat or dog come up to to be pet they are doing two things: 1. They are coming to you. Not your sofa, not the table, not anything else, to go to you. They have remembered that you pet them and when they want to be pet again they know to come to you. They are to distinguish between you and everything else. This demonstrates thought. 2. When your pet gets the pet they wanted they preform a response or pleasure, and when they get pet the wrong way they preform a response of discomfort. This demonstrates that they can feel. Using MRI scans we can see the areas of the brain light up where emotions are in the same areas of our brain when you account for size. The fact we treat other animals that appear to show signs of mental illness using the same medication that we use to treat that mental illness shows they not just feel but also have emotions and the same ones. Why can't we "listen" to what animals have to say when they communicate? Well, you can and you can't. All things communicate uses their senses, it what senses they use to communicate that can differ. When it comes to mammals the majority communicate using primarily visually and secondarily tactilely and tertiarily verbally. It is not to say that don't use their other senses to gather information, just they don't use those sense to express information. Perhaps you are thinking you have seen your dog sniff to gather information before. What they are doing if sniffing for pheromones, which humans do the same thing after shaking hands but this isn't the same thing as expressing information. It is not commo

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Consideration of research of adult and aging for females

Diagnosis’s with Sensory Processing disorder now included under the Autism spectrum.

Even people who present well (especially women, who mask) deserve communication support. We're ducks: we may look calm above the waterline, but underneath, we're paddling madly, and anything that reduces that effort is useful. But the most useful thing of all is permission not to paddle at all, unless we choose to.

Generally speaking, as a child I was fairly verbal.

Good luck! Sorry I don't have a phone

I think that it would be good to include people who don't have a formal diagnosis. Many people just know they are Autistic and struggle to get a diagnosis for many reasons.

I was originally diagnosed with Nonverbal Learning Disorder at age 7, and received interventions throughout elementary school (up to age 11). I would suggest that SLPs and other professionals working with autistic clients learn from autistic adults about what therapies and interventions worked for them, and put high value on what the client wants to get out of the treatment - even if the client is a minor or is an adult with a guardian. I felt my opinions on my treatments were not being heard or validated when I was a kid, and felt like adults would always invalidate my opinion with theirs, just because they were adults and I wasn't. I cannot stress the importance of listening to what clients say, especially if their goals differ from those of their parents and teachers.

I would like to address the question below, "Are you interested in participating in a follow-up interview by phone? This interview would provide you with the opportunity to elaborate on the topics and themes addressed in this survey." Using a telephone is all but an impossibility for me, for the very reasons this survey was meant to study. I would be interested in following up; however, it would have to be done through email or some other written format. I am not sure whether the following page will have a form accepting of an email address, so I will state here that mine is [REDACTED TO PROTECT PARTICIPANT IDENTITY]. Thank you.

I'm female-aligned nonbinary, but I chose female because I'd rather be seen as a woman than as neither a man nor a woman. I would recommend either allowing people to select multiple options or having a textbox attached to the other option.

last question invalid, had multiple diagnosis over years - all ignored

My official diagnosis is avoidant personality disorder and social anxiety if Aspergers could be ruled out. My child was diagnosed with ASD - high functioning. It’s very likely he will be a passable autistic too. I appreciate that people like to use labels to define and understand the world better. That said I strongly dislike grading autism as high functioning and mild. My fate is intertwined with autistics who would have been or are institutionalized. If our society cannot respect them and keep them safe, they will not respect or protect me.

No

No.

Not really

Please don't even talk about a "cure". We don't need a cure, the world needs to adapt to our neurodivergencies... Many are neurotypical and capable of doing that. It's not too much to ask I don't think.

Siblings. Your "others" box didn't work, so I didn't get to mention siblings in the stakeholders page.

Whether or not treatments most autistic people consider abusive (Shock therapy, aversion therapy, complete compliance training, etc.) were given to autistics in question. Note: I was not given any except a small amount of compliance therapy.

The first psychologist I ever saw accused my parents of bad parenting and didn't diagnose me with anything. My first real diagnosis at 8 was PDD-NOS. After doing some research, my mom informally diagnosed my with Asperger's syndrome, and I've used the label "Aspie" ever since. At 17 my high school guidance councilor sent me to a psychologist who formally diagnosed me with Asperger's syndrome. Although that diagnosis contains some erroneous input from my Dad, doesn't address my sensory processing disorder, and uses an outdated term, I see no need to get a new diagnosis.

The evil sh*** at GENERATION RESCUE should be set on fire. I am *NOT* diseased; I am *NOT* broken; I do *NOT* require being "cured." Robbing people in my name, under the pretense of helping me, is evil, and I resent the tens of thousands of criminals engaging in that behavior.

Thanks for making an effort to study the perspectives of autistic adults. I think this will be crucial in improving autism supports for the future. I would like to add that I was first professionally recommended for an autism diagnosis at 13 when I went to see a p psychiatrist about severe social anxiety. I was not evaluated until I was 17, realized I woukd need a dx to recieve accommodations in college. When I was very young, under 5, a family member who is an expert in early childhood osychology, specializing in developmental disorders suggested I be evaluated but my mom did not like that, did not want to thin there was anything wrong with me. Only agreed to seek diagnosis at 17 when she accepted I probably was autistic and whether or not I had a diagnosis would impact mymy ability to succeed in college. I would like to see society's perceptuon of ASD change so kids can start recieving supports early and will not have to suffer as I have.

Thanks for asking Autistics how they feel. You're awesome.