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FLIPPING THE SCRIPT: PRIORITIZING THE AUTISTIC VOICE IN THE UNDERSTANDING OF SCRIPING AS "KEY TO AUTISTIC IDENTITY"

A Dissertation Presented
To
The Faculty of the School of Education
Department of Learning & Instruction

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Education

By
Colleen D. Arnold
May 2019

ABSTRACT

Traditional research regarding communication differences for autistic individuals, including scripting ("delayed echolalia") is grounded in the pathology paradigm and thus emphasizes the elimination of scripting, without looking at the features and benefits it serves the individual utilizing it.

This study, by prioritizing the autistic voices as the resounding experts on the topic of scripting, attempts to identify the communicative features and benefits of scripting, as well as how the dynamics of the conversation partner impact the exchange, both positively and negatively. Further, the research looks at the features of scripting as described by autistic adults. It also addresses the pressures placed on families regarding how to react to communication differences.

Using qualitative methods, 21 autistic people completed an online, open-ended survey about their experiences with scripting. Further, two of the participants were part of a follow-up in depth interview, and a third participant was referred as a successful communication partner, or familiar listener. The results of the data support a variety of positive benefits of scripting in the realm of communication including; navigating small talk, communicating complex thoughts and emotions, and communicating during stressful situations. Further benefits include providing comfort and fun, as well as success in the workplace. Despite these benefits negative responses to scripting from communication partners have detrimental implications due to the isolation, embarrassment, and pressure to fit in that is put forth by society. This may have serious impacts on the mental health of the autistic community resulting in depression and

anxiety. Features of scripting include their evolution over time as they become more subtle and complex based on life and social experiences. Familiar listeners report benefits for engaging in scripting with autistic family members, but also recognize outside pressures placed upon them regarding how to respond in an effort to normalize behavior.

SIGNATURE PAGE

This dissertation, written under direction of the candidate's dissertation committee and approved by the members of the committee, has been presented to and accepted by the faculty of the School of Education in partial fulfillment of the requirements for the degree of Doctor of Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Colleen Arnold	4/30/19
Candidate	Date

Dissertation Committee

Dr. Emily Nusbaum	4/30/19
Chairperson	
Dr. Nicola McClung	4/30/19
Dr. Jane Bleasedale	4/30/19
Nick Walker	4/30/19

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CHAPTER I

INTRODUCTION

Autism and the Neurodiversity Movement

Understandings of autism, as a labeled category and a claimed identity, have shifted recently due to the efforts of the Autistic Self-Advocacy Movement and Autistic civil rights activists. Through the work and advocacy of the neurodiversity movement, the characteristics and identity of autism have been shifting from what once was a pathologizing standpoint, to reclamation of both the term and the identity. Judy Singer, an Autistic self-advocate, is often credited for coining the use of the term neurodiversity in the context of disability studies, based on her graduate thesis work (Arnold, 2017). This term describes the concept of human brain variation as a natural part of diversity, and thus should be accepted as a naturally occurring form of human variance (Walker, 2014). The neurodiversity movement pushes back on the deficit model of disability, instead encompassing a social model approach. The medical model views disability as something that needs to be cured and/or eradicated through medical intervention, and the focus lies on the alleviation of all characteristics that make individuals "different" and therefore in need of intervention, remediation, and "person fixing". The medical model places doctors and scientists as the cognitive authority, or the keepers of knowledge, and thus puts the medical profession in the forefront of defining and framing the conversation around areas such as disability. This framing of disability emphasizes the biological perspective, and thus focuses on limited functioning from a deficit lens, impairment of the body and mind,

and disability as a problem to be medically solved so the individual can function in society (Haegele & Hodge, 2016). These issues framed by the medical model of disability ignore the possibility that problems faced by the disabled community are in fact a result of societal issues impacted by society's social, physical, and political views and discourse (Brittain, 2004). It is from this perspective that the social model grew to contrast this old, traditional paradigm.

The social model is built upon the notion that it is not the disability that creates the barriers for the disabled, but society itself. Society's unwillingness to remove the barriers that impact the disabled population's participation in all forms of society result in discrimination, isolation and exclusion, which are the truly disabling factors (Haegele & Hodge, 2016). The emphasis of the social model is on political action and social change in order to impact the attitudes of society, and to shift the focus from fixing the person, to removing environmental barriers (Brittain, 2004). Through this lens disability is also seen as a form of diversity that should be celebrated, or is at least neutral, which supports the work of the neurodiversity movement.

The impact and gains that may be credited to the neurodiversity movement are evidenced through many facets; these include the shift in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) from viewing autism as a binary condition to a spectrum, as well as through the movement spurred by autism advocates to identity-first labeling as opposed to person first, as well as the movement of "Nothing about us without us" which focuses on the importance of voices of Autistic adults leading the charge in both research and best practice. This slogan was first used in the context of disability by Charlton (1998), to support the notion

that disability policy should not be decided upon without the direct input and representation of those being impacted by such policy. It then became the slogan used for the Autistic Self Advocacy Network, and encompasses their mission statement (ASAN, 2013). The neurodiversity movement has also led to a change in mentality regarding not only the perception of autism, but also the recognition of the positive attributes that are connected with autism (Baron-Cohen et al., 2009), as well as the competitive advantage that an individual on the spectrum may bring to the workforce (Austin & Pisano, 2017). The orientation of the presumption of competence of individuals with autism remains a cornerstone in this ideology (Biklen, 2005). Walker (2014) describes the impact of the neurodiversity movement:

> Autism is still widely regarded as a "disorder," but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past). Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact (pg. 3).

In an effort to convey a definition of autism that is not grounded in traditional pathological language and reliant on inaccurate stereotypes, Walker composed the following to be utilized as a replacement definition for that put forth by the DSM and other traditional documents. Walker describes autism as:

> Autism is a genetically-based human neurological variant. The complex set of interrelated characteristics that distinguish Autistic neurology from non-Autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that Autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the Autistic individual's subjective experience more intense and chaotic than that of non-Autistic individuals: on both the sensorimotor and cognitive levels, the Autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.

> Autism is a developmental phenomenon, meaning that it begins *in utero* and has a pervasive influence on development, on multiple levels, throughout the lifespan. Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. One analogy that has often been made is that Autistic individuals have a different neurological "operating system" than non-Autistic individuals.
>
> According to current estimates, somewhere between one percent and two percent of the world's population is Autistic. While the number of individuals diagnosed as Autistic has increased continually over the past few decades, evidence suggests that this increase in diagnosis is the result of increased public and professional awareness, rather than an actual increase in the prevalence of autism.
>
> Despite underlying neurological commonalities, Autistic individuals are vastly different from one another. Some Autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-Autistic individuals, Autistic individuals are almost always disabled to some degree – sometimes quite obviously, and sometimes more subtly.
>
> The realm of social interaction is one context in which Autistic individuals tend to consistently be disabled. An Autistic child's sensory experience of the world is more intense and chaotic than that of a non-Autistic child, and the ongoing task of navigating and integrating that experience thus occupies more of the Autistic child's attention and energy. This means the Autistic child has less attention and energy available to focus on the subtleties of social interaction. Difficulty meeting the social expectations of non-Autistics often results in social rejection, which further compounds social difficulties and impedes social development. For this reason, autism has been frequently misconstrued as being essentially a set of "social and communication deficits," by those who are unaware that the social challenges faced by Autistic individuals are just by-products of the intense and chaotic nature of Autistic sensory and cognitive experience. (Walker, 2014, pg. 3)

This shift of thinking and view of autism as a natural neurological difference is contested in traditional, positivist research, as well as within special education spaces and K-12 schools. The school systems are grounded in the deficit-based model, which are imbedded in the systems of eligibility which outline who receives support and who does not, guided by federal legislation. In these contexts autism continues to be viewed as an affliction to be treated, as evidenced by its mere definition, both through the Center for Disease Control (CDC) and through the Individuals with Disabilities Act (IDEA). The

CDC (CDC, 2015) defines Autism Spectrum Disorder (ASD) as a developmental disability that impacts social, communication, and emotional skills. ASD is cited as a "public health concern" and it is stated that, "there is currently no cure for ASD". There is also a list of deficits included on their website to describe the symptoms of autism, which include, "avoid eye contact and want to be alone", "have trouble relating to others or not have any interest in other people at all", and "repeat and echo words or phrases said to them, or repeat words or phrases in place of normal language" (pg. 1). As Yergeau (2018) describes, "…facets of autistic personhood (are transposed) into sterile symptom clusters, pathologizing character traits such as 'intense and fulfilling interests' with clinically ornate buzzwords such as 'perseveration of autistic psychopathy' (pg. 11). Through their definition and the language utilized to describe autism, it can be seen that the emphasis is placed solely on the perceived negative impact which autism has on an individual, and unlike Walker's description (2014) does not consider differences in cognitive and sensory experiences or processes. The Individuals with Disabilities Education Act (IDEA), the primary legislation that ensures that students with disabilities have access to a Free and Appropriate Public Education (FAPE), ensures both parents and student rights and protections under the law. IDEA also qualifies students diagnosed with ASD under the category of Autism for special education services. IDEA provides the federal definition of autism as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance." Also included in the definition are characteristics and traits including, "engaging in repetitive activities and stereotyped movement, resistance to environmental change or changes in daily routines,

and unusual responses to sensory experiences" (IDEA, 1990).

As evidenced above by more traditional definitions of Autistic characteristics, often in research and education deviation from "normal" is relied upon to define disability, instead of recognizing disability as a part of human neurodiversity. These laundry lists of symptoms are often described clinically, such as, "repeat and echo words or phrases said to them, or repeat words or phrases in place of normal language", as described by the CDC (2015, pg. 1).

Identity-First Language

As noted, part of the result of the neurodiversity movement has been a recognition of the disconnect of the terminology preferred by many Autistic self-advocates, versus the terms utilized by professionals, parents, and some Autistic individuals. As language often does have an impact on shaping societal views, the importance of this semantic debate is not lost. The debate is clearly outlined by Brown (2015), who describes the importance of using identify first language such as "Autistic person", "In the autism community, many self-advocates and their allies prefer terminology such as 'Autistic,' 'Autistic person,' or 'Autistic Individual,' because we understand autism as an inherent part of an individual's identity- the same way one refers to 'Muslims,' 'African-Americans,' or 'Jewish.'" (pg. 1). In contrast Brown describes the more traditional view of using the term "person with autism" because, "they (those who use the term) do not consider autism to be a part of an individual's identity and do not want their children to be identified or referred to as 'Autistic'. They want 'person-first language' that puts 'person' before any identifier such as 'autism,' in order to emphasize the humanity of their children." (pg. 1).

While Brown (2015) agrees that humanizing the Autistic population is the goal of both groups, she supports the use of identity-first language and describes her disagreement with the use of terms such as "person with autism" as, "it *does* have an attitudinal nuance. It suggests that the person can be *separated* from autism, which simply isn't true. It is impossible to separate the person from autism, just as it is impossible to separate a person from the color of his or her skin." (pg. 2). She goes on to describe that autism is, "an edifying and meaningful component of a person's identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all pervasive." (pg. 2)

To utilize identity-first language is to support and affirm the views of many Autistic self-advocates, it is to recognize the power of language and how it drives societal change. [1] As Brown describes (2015),

> …When we say 'Autistic person', we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person- that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual's potential to grow and mature, to overcome challenges and disability, and to live a meaningful life as an Autistic. Ultimately, we are accepting that the individual is different from non-Autistic people- and that that's not a tragedy, and we are showing that we are not afraid or ashamed to recognize the difference. (pg. 3)

More and more this debate is pushing allies and members of the community to closely consider their word choice, and the impact that the connotations of these different terms have on the way we view and think of Autistic individuals.

Scripting as a Feature of Autism

One feature of autism recognized by both Autistic adults and IDEA includes

[1] Identity-first language will be utilized throughout this work in an effort to respect the autism community based on the arguments presented by Brown, 2015.

differences in communication, specifically for some in the areas of expressive communication. The medical model uses language such as "stereotypic", "socially awkward" or "developmentally inappropriate" (Shawler & Miguel, p. 112) to describe the expressive language patterns associated with autism. Conversely, Sequenzia (2015), who identifies herself as a multiply disabled, non-speaking Autistic activist and writer discusses how every individual communicates, but, "We (Autistic individuals) are consider[ed] to be 'able to communicate' only if we speak, and act in accordance with, the language the majority chooses to know" (pg. 96). She identifies the outside attitude towards communication differences, as a huge stumbling block, which creates a lack of understanding regarding any communication that is not considered "normal".

Speech patterns for Autistic individuals are often pathologized, and are used as a diagnostic measure. One of these speech differences includes *scripting* or "delayed echolalia", which the CDC (2015) describes as when individuals, "repeat or echo words of phrases said to them, or repeat words or phrases in place of normal language" (p. 1), individuals may also, "repeat actions over and over again" (pg. 1). The use of the term echolalia is common among traditional researchers when discussing this type of conversing, but the term often used in a more practical sense by some Autistic individuals to refer to a similar phenomenon is "scripting". Researchers also may use the term "vocal scripting" (Silla-Zaleski & Vesloski, 2010), and tend to use the term synonymously with echolalia. Some Autistic authors have also differentiated between the term delayed echolalia versus scripting, treating them as separate communication mechanisms (Schaber, 2014).

Through definitions of scripting[2] present in the current, positivist literature, it is clear that the use of scripting as a communication strategy is labeled as socially unacceptable and as a behavior to eradicate, even though for some it may be their most comfortable communication approach. Research has typically focused on what is termed as non-contextual or nonfunctional vocalizations (Colón, Ahearn, Clark, & Masalsky, 2012; Liu-Gitz & Banda, 2009), "including repetitive babbling, grunts, squeals, and phrases unrelated to the present situation" (Colón, Ahearn, Clark, & Masalsky, p. 109). Prizant and Rydell (1984) were the first researchers to present a universally accepted definition in traditional, special education research, as previously "delayed echolalia" was loosely characterized as echoing after a delay, or lapse of time (Shapiro, 1977). Delayed echolalia is currently defined by traditional researchers as: a) an echo that occurs more than two conversation turns from the original utterance; b) and/or is classified as a learned phrase through familiar listeners; c) or is a higher level of conversation than the speaker could generate independently (Prizant & Rydell, 1984).

What continues to be missing in the research however, are definitions and understanding of the term and act of scripting from Autistic individuals who utilize it as a part of their communication. The emphasis is not on understanding scripting from the Autistic perspective, but from the perspective of the researchers and the professionals working with them. As recognized by Robledo, Donnellan, and Strandt-Conroy (2012), "Most often the description offered by the professionals pay little attention to the experience of people who live with autism" (pg. 1), and scripting is a prime example of

[2] The researcher will use the term "scripting" throughout the work in an effort to convey the commitment to relying on Autistic voices to shift traditional thinking and produce more humane responses to linguistic differences.

this being the case, and reflects the clear disconnect between traditional research and the autism community. Milton and Bracher (2013) discuss how the narrative that is framed around autism, comes from clinicians and researchers where, “Autistic people were the objects of inspection, rather than active participants in the creation of knowledge relating to their own experience” (pg. 63). This is where the emergent research style of auto-ethnographic essays, written by Autistic adults, fills a serious void in the research and shifts the focus (Dowley, 2016). This type of research is critical, as from the first reference of scripting (Kanner, 1943) in traditional research, the assumption of it as a meaningless behavior was put forth.

First Description of Scripting

Kanner originally discussed scripting, or as he referred to it “delayed echolalia”, in his first descriptions of children with autism, as he described their speech as: “parrot-like repetitions of heard word combinations. They are sometimes echoed immediately, but they are just as often ‘stored’ by the children and uttered at a later date. One may if one wishes, speak of *delayed echolalia*” (Kanner, 1943, p. 243). Kanner specifically described one of his patient’s language as, “Irrelevant utterances…were his ordinary mode of speech. He always seemed to be parroting what he had heard said to him at one time or another” (Kanner, 1943, p. 219). This demonstrates that, from the start of the earliest traditional research about autism researchers made dangerous assumptions about the use of scripting, and the lack of relevance linguistically speaking.

Scripting: An Ethical and Linguistic Debate

Traditional research is grounded in the medical model of disability, with an emphasis on behaviorism, and thus the results of such research focuses on the

normalization of the individual. To contrast, the social model of disability views the barriers that are presented to disabled people as an issue of society and access, not as an internal personal deficit. These belief systems and assumptions hugely impact research, as they create the platform upon which the research questions are based, and thus the type of methodologies that are employed to address those questions.

In terms of scripting, these highly contrasting belief systems have a tremendous impact on the way that the research is framed. In traditional research the voice of the Autistic participant is ignored through the investigative process, and the focus remains on providing interventions with a goal of alleviating the "Autistic symptoms" regardless of what scripting may be providing the individuals themselves. As scripting is viewed as a behavior that needs to be eradicated, the focus is on the intervention to decrease "delayed echolalia" (Ahrens, Lerman, Kodak, Worsdell, & Keegan, 2011; Colón et al., 2012; Conroy, Asmus, Sellers, & Ladwig, 2005; Nuzzolo-Gomez.et al., 2002; Scalzo et al., 2015; Valentino, Shillingsburg, Conine, & Powell, 2012; Vanderkerken, Heyvaert, Maes, & Onghena, 2013).

From the social model of disability, the often less accredited or recognized belief system, scripting is viewed as having a meaningful purpose for the individual using it, as well as is seen as a bridge to further communication development. This research highlights that scripting has implications for communication, and therefore looks to uncover these aspects of the communication style (Sterponi & Shankey, 2014; Stiegler, 2015; Stribling, Rae, & Dickerson, 2007).

Communication and Scripting

The communicative nature of scripting can be better understood through

Stiegler's (2015) analysis of the literature. Stiegler (2015) reviewed the current literature on scripting, looking at behavioral, linguistic, and speech-language disciplines. Stiegler discussed characteristics of scripting that are supported by current research, including, "a key communication adaptation, a cognitive tool, and a self-regulatory tool" (Stiegler, 2015, p. 750). Stiegler also identified the developmentally appropriate context of mimicking, as in the early stages of language development all individuals echo or "borrow speech" (Stiegler, 2015). Through the work of Ann Peters (1983) it can be noted that, "some children acquire language in a different, but equally valid way. Instead of single words, they capture longer units from the ongoing speech stream in the environment. Their units are sentence-length strings marked by intonational contours, and they are said to posses a gestalt processing style" (Stiegler, 2015, pg.751). From this perspective, this language development may in fact be a bridge to further development of language, also referred to as "mitigated echolalia", or evolving scripts.

Research on evolving scripts or "mitigated echolalia" has shown that scripting may change over time, with the original echo later being manipulated to convey meaning within a social context. In essence, instead of repeating a script verbatim, overtime the individual may alter the script to adapt the meaning that fits a specific circumstance (Gernsbacher, Morson, & Grace, 2016). Research has also articulated the use of scripting as a tool for communication for the Autistic individual, even if the expression and intention is not fully understood by the receiver, especially inexperienced listeners (Prizant & Rydell, 1984). It was also identified through this research that as Kanner noted (1946), some echoes may be characterized as *metaphoric language*, and thus had "private

meanings", which may only be privy to *familiar listeners*[3], and thus made them difficult to categorize. This research highlights the importance of the knowledge base and listening experience of the communication partner. Due to this, Stielger (2015) discusses the importance of understanding the primary source of scripts.

Positivism and "Delayed Echolalia"

The positivist paradigm and approach to scripting, or "delayed echolalia" as referred to in this paradigm of research, is reflected in a large body of intervention research, which attempts to show decreased use of "delayed echolalia", and in some cases, an increase in "functional communication" through the use of an outside intervention. In a systematic review conducted by Neely, Gerow, Rispoli, Lang, and Pullen, (2015) a total of 568 peer-reviewed articles were found which focused on the use of scripting and autism. Of the studies, 11 were included in the review based on specific inclusion criteria that included the use of an intervention for echolalia and reported an outcome, as well as utilized experimental design. All of the 11 studies included interventions that had behavioral components, some of which included a specific treatment package (e.g. Natural Language Paradigm, computer intervention, cues-pause-point), while others used a behavioral strategy (e.g. error correction, differential reinforcement, and modeling) (Neely et al., 2015). None of these studies attempted to

[3] *Familiar listener* is defined by this researcher as individuals who assist in understanding and conveying the meaning of a script (Prizant, 2015), who do not treat scripting as inappropriate behavior, and use scripting in an effort to connect, communicate, and gain the attention of their child (Barrow & Tarplee, 1999).

determine the function or they meaning behind the communication, and as the authors note, “Of particular concern is that echolalia may serve various social as well as non-social communicative functions for individuals with ASD…In addition, as there is divergence within the field regarding whether echolalia is nonfunctional, a necessary part of developing functional communication, or serves a social function, identifying the function of echolalia would help guide future research and practice” (Neely et al., 2015, pg. 89). The vast amount of research focused on the eradication of scripting is clear through this review, as is the notion of the lack of attention paid to what scripting does for the actual individual. Without understanding the purpose of scripting is it ethical to focus research solely on how to eradicate it?

An example of an often-utilized strategy with an emphasis on decreasing the use of “delayed echolalia” is Response Interruption Redirection (RIRD). RIRD has been described and implemented in different ways, with similar results. The overarching commonalities include that when the child engaged in “vocal stereotypic behavior”, the researcher or teacher immediately interrupted the child, by saying the child’s name in a neutral tone (Ahrens et al., 2011; Shawler & Miguel, 2015). Some studies also specified that eye contact be initiated along with the name of the child to gain attention during the intervention (Saini, Gregory, Uran, & Fantetti, 2015; Shawler & Miguel, 2015). Next, the student is asked questions. These questions may be general (‘What is the weather like?’), or more specific to the interests of the child (Who do you like in Toy Story?) (Liu-Gitz & Banda, 2009). Researchers also used some fill-in-in-the-blank statements (‘You sleep in a –‘) (Ahrens et al., 2011). Some researchers used both motor and vocal RIRD, and in those cases at times the question may have required a physical response (‘Touch your

nose') (Ahrens et al., 2011), or relied only on physical/motor demands (Saini et al., 2015). Saini et al. (2015) chose to use only motor demands, which allowed them to use physical prompting if the participant was not "compliant" during the RIRD sessions, a more invasive technique for the participants.

In other intervention studies, the vocal demands consisted of echo responses ('Say house') or labeling or echoing a vocal model of visual cards (Colón et al., 2012; Shawler & Miguel, 2015), dependent on the verbal abilities of the participant and their ability to fluently answer questions. The literature suggests that RIRD is an effective behavioral intervention for "vocal stereotypy" when implemented in a clinical, or highly structured setting such as an in home therapy room, without significant outside distractors or high task demands (Colón 2012;Ahrens 2011;Schumacher 2011;Saini 2015;Shawler 2015).

While RIRD is an intervention that has been addressed by a wide variety of studies, it is one that ignores the communicative nature of scripting. The emphasis on the response is that the individual is continuously interrupted when attempting to communicate, thus presenting an ethical issue, especially when scripting may be the primary or preferred mode of communication in some cases. The research does not consider that limiting scripting will actually limit the ability to communicate effectively. There is also very little research to support the notion that RIRD can be effective outside of the clinical setting, such as in a small special education classroom environment (Liu-Gitz & Banda, 2009), but there is no research to confirm the effectiveness in a larger special education setting, or in a general education setting. The difficulty with implementing this type of strategy in the classroom setting is that like much of behavioral research conducted, studies using RIRD were often in a clinical 1:1 setting; therefore the

environment is not typical to what the Autistic individual would experience in their daily lives. To implement an intervention to eradicate the use of scripting without a real understanding of the purposes it serves for the individual, as well as how it impacts and shapes their communication, is an ethical issue, and an issue this research attempts to uncover.

Disruption to Positivist Research

The pathology paradigm that drives positivist research frames the conversation of autism. As Walker describes, "At the root of the pathology paradigm is the assumption that there is one 'right' style of human neurocognitive functioning" (Walker, 2016, pg. 1). This paradigm emphasizes Autistics as damaged, and focuses solely on the deficits and negative impacts on the Autistic individual. Historically, similar frameworks have been used in an effort to suppress other minority groups including women, people of color, and the gay community (Walker, 2016). This paradigm leads an overwhelming emphasis in both research and practice fixated on making Autistic individuals less Autistic, and in turn "normalizing their behavior". This focus on normalization thus occurs "…at the expense of any significant focus on societal acceptance of autism, accommodation of Autistic needs, removal of systemic barriers to access and inclusion, or supporting Autistic persons in thriving *as* Autistic persons" (Walker, 2016, pg.1). The impact of this phenomenon is not lost in regards to Autistic communication and scripting.

Despite the fact that studies (Sterponi & Shankey, 2014; Stiegler, 2015; Stribling, Rae, & Dickerson, 2007) and Autistic self-published auto-ethnographic essays and blogs (Brown, 2015; Higashida, 2016; Kim, 2015; Shaber, 2014; Sutton, 2015; Walker, 2016; Zurcher, 2014) support scripting as a meaningful tool for Autistic individuals, including

for communication, the majority of the research base has emphasized the eradication of this type of communication and has relied on this deficit paradigm. By focusing energy solely on eliminating a form of communication by a group of individuals, in essence we are deeming what they have to say as unimportant, and in some cases are restricting their ability to communicate or self-regulate. As the neurodiversity movement advocates, autism is a naturally occurring phenomenon, and the emphasis on elimination of traits that are viewed as Autistic is grounded in positivist thinking, and are harmful to the community. The emphasis of our systems should not be to normalize all individuals, but to celebrate autism as a part of human diversity. As Walker states, "At this time, sadly, the pathologization of Autistic minds, bodies, and lives still has not been widely recognized – especially not within the academic and professional mainstream – as being yet another manifestation of this all-too-familiar form of institutionalized oppression and othering" (2016, pg. 1).

As researchers and advocates for the autism community, it is our responsibility to disrupt this positivist perspective and to shed light on how the pathology paradigm has been allowed to shape autism research as whole. To disrupt the current paradigm, this proposed research is grounded in the neurodiversity paradigm and will work to provide an in depth understanding of the use of scripting, in terms of what it provides the individuals themselves by prioritizing the perspective of the Autistic individuals who utilize this language in their daily lives and creating space among research to validate and support these individual perspectives.

Purpose of the Study

The perception of scripting is shaped by the paradigm that society emphasizes,

and in the United States the medical model of disability drives the way autism and Autistic characteristics are viewed. In order to support and encourage the communication and regulatory functions of scripting for Autistic individuals, it is important to increase our understanding, and to do so one must reframe their view of disability and emphasize both the social model of disability and the neurodiversity movement. Therefore, the purpose of this study is to frame the Autistic voice as the priority, to utilize their personal experiences and reflections upon the use of scripting to frame general understanding. The goal is to obtain the perspective of those who engage in it, in order to examine the relationship between scripting and communication, as well as to establish other benefits that the use of scripting provides Autistic adults. The study will also identify how *familiar listeners* impact the successful use scripting as a form of communication, and what outside influences are placed on listeners to react to scripting in a specific way. Through the insight uncovered by the proposed research, the conversation will shift and the Autistic adults will become the primary educators of their own experience in relation to scripting.

Methodology

To accomplish the above-described purpose qualitative methods will be utilized, including online survey data collected on a national sample of Autistic adults ages 18 and older. Autistic people, through a pilot study prior to dissemination, reviewed the survey. This was done in an effort to obtain input regarding the accessibility and clarity of the survey from the Autistic perspective. Through this input, a final draft was revised and will be distributed electronically to a wide audience, which will be recruited digitally, utilizing connections with the autism community, self-advocacy organizations,

professional list-serves, and the research community. The survey will include demographic information, as well as open-ended questions that ask Autistic adults to share their experiences of the use of scripting. Participants will then be given the option for a follow up semi-structured interview. Information about successful *familiar listeners* will also be solicited from survey participants who choose to share this information. These familiar listeners will be contacted to participate in a follow up interview regarding their experience communicating with Autistic individuals that utilize scripting.

Significance of the study

While Autistic voices are gaining power and momentum through a variety of forums, they continue to be ignored in the realm of traditional research, and are positioned as passive subjects of predetermined methodologies. The research questions and qualitative methods of this study will emphasize the Autistic voices in the forefront, prioritizing their expertise. The study will also address the importance of reactions of communication partners and how responses, both positive and negative, impact scripting, communication, and the Autistic individual. In addition, understanding how scripting evolves over time can assist in exploring the impact on communication, as the survey will look to uncover how scripting contributes to language development from the Autistic perspective. This study is also important to the disability community as a whole, as it emphasizes the importance of disabled voices in the world, in an effort to make participants active in the research process. The study also relies on the premise of assuming competence of the Autistic community. By assuming competence, the research attempts to prioritize the ability of the community to reflect on the usage, function, and success of their own communication strategies. The researcher's role will be purely as a

learner, and the emphasis will be placed on the Autistic people as the experts in their own experience and in the field of autism research.

Theoretical Rationale

When children are developing speech, it is a developmental milestone to engage in echoing, but as Autistic children continue this type of communication long after it is deemed “developmentally appropriate”, the echoing is classified and viewed as deviant. Gestalt language acquisition is a part of typical language development. In the first stage of development language phrases are learned and spoken in their entirety. As language develops the child moves onto the second stage, mitigation, where the language may be recombined and chunked into different phrases. After this phase, language may be more isolated where children are able to generate original sentences and phrases, as they can now isolate single words and their meanings. Finally, the development moves to stage four where children are able to generate complex sentences of their own construction (Peters, 1983).

Through the understanding of language development through the Gestalt learning style theory, it can be interpreted that Autistic individuals are actually accessing and building upon communication in a different way, thus they use scripting as a form of communication through the use of language gestalts (Blanc, 2013). This framework sets the stage for analysis of the research in the area of “mitigated echolalia”, which frames the view of scripting and evolving scripts as a movement from stage one, to stage two, where individuals begin to chunk and recombine the language, making it more their own,

and less an exact replica of language heard previously.

Looking towards Vygotsky's sociocultural theory, the emphasis is placed on the experiential social world that leads to a child's development. Learning is constantly being impacted by the environment in which it occurs, thus does not occur in a vacuum. Vygotsky emphasizes the importance of learning that is grounded in interaction with others, specifically the development of language, which is shaped by engagement in dialogue and play (Ornstein & Hunkins, 2004). A classroom is a small community of diverse learners that is reflective of the outside community. Each child is only part of a complex system that is at work in the classroom (Derry & Steinkuehler, 2003). This is critical to this study, as through interventionist research and approaches, the focus is often on ignoring, redirecting, or interrupting scripting behavior. As the theory states, individuals do not develop in isolation, they develop alongside one another, in essence a co-development. As many Autistic behaviors are often pathologized and referred to as strange, this impacts how Autistic individuals live within our world, and frames how neurotypical individuals interact with them. By eliminating a communication style we are not giving Autistic individuals the language experiences and positive communication with others to support development. "Setting up AS as a generalised deficit in society, for example, may frame social encounters with people categorised in such a way that breaches in interactions become more visible or more likely" (Milton & Bracker, 2013, pg. 63). In essence, through the negative labeling of Autistic social behaviors, such as scripting, as deviant, we are setting up Autistic individuals for social failure, which in turn impacts their development as well as their well-being. "...Wellbeing also relates to a person's ability to experience ways of being that are compatible with their dispositions,

without being forced to mimic non-Autistic behaviors that can be confusing or bewildering to them" (Milton & Bracher, 2013, pg. 64). Vygotsky also discussed "language cultures" which were specific to contexts, and the importance of students having access to practice their language skills, as if neglected they would deteriorate due to lack of practice (Ornstein & Hunkins, 2004).

Finally, the work of Yergeau (2018) gives a frame through which to analyze societal's response to communication differences in Autistic people. Her work points out the cultural stereotypes of autism that are used to dismiss the Autistic community, as individuals that lack humanity. Her work analyzes the use of language as the basis for meaningful existence, thus those who communicate alternatively, or are without oral communication are dehumanized and not valued. She also identifies the confining rules of communication, including eye contact, which act as barriers for those Autistic individuals who can speak or write. Finally, her work recognizes that in research it is assumed that Autistic people do not have anything to say, even about their own experiences, thus they are spoken for and Autistic narratives are ignored.

Theory Applied to this Study

Evidence of the implications of Gestalt language acquisition for Autistic individuals can be found throughout the research. Prizant (2015) describes Aidan, a three-year-old boy whose language was not developing as expected. Typically children move from adding one word at a time, and then lead up to building short sentences. Aidan would often surprise his parents with very sophisticated sentences that he had learned as whole units of language. For example, when meeting someone new, he would not greet them with a simple "Hello", but instead would look at them quizzically and ask, "Are you

a good witch or a bad witch?" (pg. 44). This line was a script that he had internalized as a whole to represent a greeting, as it was in The Wizard of Oz when Dorothy first meets Glinda. While Aidan was repeating a script he learned from a movie, he was also communicating a sophisticated greeting with communicative intent. His style of processing is aligned with Gestalt language.

As Vygotsky supports, children co-develop through their experiences with the world and their social relationships. Thus analysis of the Autistic experience and how it impacts development is critical to this study, as through interventionist research and approaches, society is often focused on ignoring, redirecting, or interrupting scripting behavior. If Autistic children who utilize scripting are constantly being faced with an intervention when they are attempting to communicate or self-regulate, an intervention that further isolates them, how does that impact their development? This study attempts to uncover how scripting is responded to by communication partners, as well as how these responses impact individuals. It may also be viewed that Autistic communication is its own "language culture" that exists within certain contexts, and thus must be considered as such an investigated through a cultural lens (Ornstein & Hunkins, 2004).

Yergeau's work (2018) supports the importance of this research to emphasize the voices and experiences of the Autistic community. Through this process, there is an emphasis placed on the humanization of the participants which is in contrast to how the framing of the Autistic experience is usually portrayed. As Yeregeau notes, "If one is arhetorical, then one is not fully human" (pg. 6). Thus, to highlight and to prioritize the language of the participants, is to humanize them as well.

Background and Need

While Autistic writers, activists, and leaders have found non-traditional spaces to frame their experiences and make their perspectives heard through self-publications, online forums, blogs, and video journals, the more traditional research world has fallen disappointingly behind in this recognition of knowledge. The information provided by this study will be critical, as unlike studies that came before, it will prioritize the perspectives and experiences of those who use scripting in order to shape understanding.

Research Questions

This study uses a range of qualitative methods in an attempt to answer the following research questions;

1. What benefits does scripting provide, as described by Autistic individuals that use scripting?
2. What are the communicative features of scripting as described/used by Autistic individuals?
3. How do communication partners, specifically *familiar listeners*[4], influence the use of, and effectiveness of scripting as a form of communication? How does this contrast to other communication partners?
4. From the Autistic perspective how can communication partners impact scripting, and what strategies and supports can be utilized by neurotypical individuals to improve

[4] *Familiar listener* is defined by this researcher as individuals who assist in understanding and conveying the meaning of a script (Prizant, 2015), who do not treat scripting as inappropriate behavior, and use scripting in an effort to connect, communicate, and gain the attention of their child (Barrow & Tarplee, 1999).

communication and build meaningful relationships?

5. How does scripting evolve over time as described by Autistic individuals and their familiar communication partners?

6. What outside influences and pressures impact the way *familiar listeners* react to scripting?

CHAPTER II

OVERVIEW OF THE LITERATURE

The prioritization of "normative" language structures

When discussing communication, it is important to recognize how specific communication norms are prioritized over others, and how this impacts the Autistic community. In the Western society the use of eye contact is a prioritized communication norm, it is often considered a sign of respect, and it is often demanded from children or subordinates as a symbol that one is listening and taking in the verbal information provided. Despite the voices of Autistic adults, and emic research that speaks to the difficulty that eye contact poses for Autistics, it is still a practice that is expected and "worked on" in therapy. Endow (2013) expressed, "Eye contact can be hard for Autistics for a variety of reasons. When I was a youngster I received too much bright, bold, painful sensory information from making eye contact. To guard against the intense physical pain I did not engage in eye contact. If my teacher demanded eye contact I obediently did so, but at a price. I would float out of my body, hover near the ceiling and look down, watching the little girl of me" (pg. 1). In Endow's experience, eye contact in fact hindered her ability to take in language, which has been supported by other Autistics in the research.

Robledo, Donnellan, and Strandt-Conroy (2012) recognized that multiple Autistic

individuals in their study expressed difficulty with eye contact, including Matt who stated, "' It is painful for me to look people in the eye...This lack of eye contact sometimes make people think I'm not paying attention to them" (pg. 5). Another individual in their study, Barbara, agreed and stated, "' I can hear a person better if I don't look at their face...If I'm looking at them, it's kind of a mild distraction...I feel that looking into someone's eyes is intrusive" (pg. 5). Kim in her blog "Musings of an Aspie" (2012) recognizes the complexity of eye contact and how for her it may spur a fight or flight reaction. Her responses to eye contact vary depending on the familiarity of the person, those being most familiar and least familiar creating less discomfort. She also discussed the difficulty of gaining information from the eyes and how that impacts her usage of eye contact, "Perhaps it's because I'm self-conscious about the uneven balance of social power in these situations? The other person is clearly gathering social data from my eyes, but I'm not able to do the same" (pg. 4).

American culture emphasizes the importance of eye contact and prioritizes it as a "normal communicative function", which leads to the requirement that all people communicate in this way. As Endow (2013) describes, "Yet, even when people know eye contact can be painful and that we will not pick up much social information, we are STILL expected to perform the feat for the social comfort of others. Each time we don't perform the socially expected eye contact people assign negative character attributes to us such as shifty, sneaky, untruthful, disinterested and hiding something" (pg. 2). Clearly the communication preferences of Autistic adults are not prioritized in American society. As Kim described (2012), "For NTs, eye contact is a rich and layered language. It's the conversation within the conversation. As aspies, we're largely deaf to this language. It's

no wonder it makes us so uncomfortable when others try to 'speak' to us with their eyes" (pg. 5).

Similarly, the use of scripting as a form of communication for individuals with autism is another example of an Autistic communication style that is demeaned. As scripting is often dismissed as functionless in research, and is considered atypical communication, those who engage in this type of communication are subjected to interventions focused on the eradication of scripting, and there is a lack of focus on understanding the communicative functions. For the Autistic individual, energy is often being exerted to understand the dominant normative language structures, yet there is a lack of reciprocal respect from professionals and neurotypicals in regards to scripting and other forms of Autistic communication. As traditional speaking is the privileged mode of communication, this "othering" of people with autism presents as a huge barrier of communication (Sequenzia, 2015).

Misrepresentation of Autism

The Autistic community has often criticized the research community for their lack of understanding of the foundations of autism, due to the absence of Autistic voices with in the research. This lack of representation has resulted in generally accepted characteristics and views of autism by researchers and families that are far disconnected from the beliefs and experiences of those who identify as Autistic.

An example of this phenomenon is the notion that individuals with autism lack theory of mind (TOM), which has been a widely accepted claim within much of traditional research, and is one that Yergeau (2018) has labeled as a "god theory", or "theories that purport to explain the many reasons why autistic people are nonpeople"

(pg. 11). TOM is described the ability to understand that others have their own unique feelings, and more contemporary definitions include other cognitive processes in relation to TOM, including metacognition and empathy (Yergeau, 2018). While the Autistic individuals in Robledo et al.'s study (2012) described difficulty with identifying the emotions of others, they all disagreed with the assumption that Autistics do not have TOM. "Participants expressed feelings they experienced and also spoke about relating to another person's feelings. It was apparent that for these participants there was a difference in understanding emotions, not an absence" (pg. 8). This example illustrates how neurotypical researchers can often misinterpret the behavior of Autistic individuals, which can lead to dangerous assumptions about autism. Through more traditional research, autism is often defined through the use of standardized instruments, such as the *Theory of Mind Inventory 2* (ToMI-2). As argued by Cohen-Rottenberg (2009), the standardized testing that is used to measure TOM, may not in fact clearly assess TOM, and therefore produces misleading results that negatively stigmatize the Autistic community.

Much of what traditional research utilizes in an effort to understand autism are standardized instruments, which must be vetted to understand how valid and reliable these instruments are. As exhibited by Cohen Rottenberg (2009), at times these instruments are not built in a way that is conducive to Autistic understanding, and thus may not be valid. Lecavalier et al., (2006) conducted an exploratory factor analysis utilizing the *Autism Diagnostic Interview-Revised (ADI-R*), considered a gold standard in autism identification in traditional research, in an effort to examine the consistency and validity of the instrument. The importance of this research is that the *ADI-R* categorizes

behaviors related to scripting as "repetitive behavior" versus "communication", and the researcher looked to determine the accuracy of these categorizations. The *ADI-R* provides categorical results for three domains; language/communication, reciprocal social interactions, and repetitive behaviors/interests. It is a semi-structured interview that scores 93 questions answered by the individual's primary caregiver in areas of early development, communication, play, repetitive behaviors, social development, and behavior issues. While the *ADI-R* is highly regarded in traditional research communities, there have been little independent psychometric studies analyzing its effectiveness (Lecavalier et al., 2006). Using a sample of 226 individuals, a factor analysis was conducted. While the analysis supported the validity of social, communication, and repetitive behaviors as core domains of autism, the study also looked to challenge or corroborate the placement of specific items, such as social smiling and imaginative play, into specific categories. The study concluded that "stereotyped utterances", (.625), "neologisms" (.847), and "inappropriate questions" (.594) loaded most strongly under the communication domain and not under the repetitive behavior domain (Lecavalier et al., 2006). This study supports the claim that while typically scripting is lumped into the category of repetitive behavior, in actuality it more closely fits into the category of communication. This study supports the notion that scripting should not be dismissed as a functionless act, but should be viewed as communicative in nature.

These conflicts regarding the use of eye contact, as well as the assumptions made about autism and TOM, are two examples of how often neurotypical traditional research and the Autistic experience clash. The mis-categorization of the characteristics of autism through the *ADI-R* show that the traditional and intervention-based scripting research is

yet another example of this clash. Yergeau (2018) claims that these disconnects are due to an effort to dehumanize the Autistic experience, in an effort to describe the characteristics of Autism as nonintentional, thus without intention, the Autistic community is without rhetoric, and thus lacks humanity.

Other fields are looking beyond intervention research to determine how to approach “echolalia” in relation to its function. In her review of the scripting literature, Stiegler (2015) stressed the importance of awareness, “that a radically divergent range of ideas exists within the wider corpus of research produced by professionals in other fields… (including) a long tradition of behavioral investigations and practices focused on the extinction or reduction of echolalia”(Stiegler, 2015, pg. 750). Stiegler goes on to state that interaction linguists have recognized echolalia as, “a key communicative adaptation, a cognitive tool, and a self-regulatory tool” (Stiegler, 2015, pg. 750).

Critiques of Traditional Interventions

Overall, traditional research lacks specific information regarding how scripting is handled across contexts, and how those responses impact the individual engaging in the scripting. What has been illustrated is that those working with children who engage in scripting respond to this behavior in a variety of ways. Roberts (2014), outlined how scripting was historically treated based on the dominant theoretical framework of the time period. In Kanner’s 1940’s description of autism from a psychoanalytic framework, scripting was considered to be, “a hostile behavior (Caluccio, Sours, & Kalb, 1964) indicative of a failure of ego development (Bettelheim, 1967)” (pg. 57). As behaviorism began to take shape, scripting was then seen as a self-stimulatory behavior that was interfering with learning, thus needed to be extinguished. At this point punishment was

often used, in conjunction with rewards for imitating a model, which as Roberts (2014) notes, "must have been confusing for everyone" (pg. 57).

Through his experience in both research and consultation, Prizant (2015) outlined typical reactions to scripting in his experience. He described that early in his career it was common to utilize very harsh techniques when a child engaged in scripting:

> Therapists would respond to a child's 'silly talk' with loud, annoying (to the child) noises such as clapping their hands near the child's face, the way you might try to dissuade a dog from barking in the house. In one school I visited, teachers would squirt lemon juice in a child's mouth to punish 'undesirable' behavior and remind her to speak in turn or get back on topic (pg. 39).

While Prizant noted that more recent practices are less harsh, the overarching goal is always to stop the scripting, whether through ignoring the child, or giving a firm command. Similarly, according to Wootton (1999) adults generally tended to first ignore scripting behavior, and then direct students what they considered to be a more appropriate action. As discussed in Liu-Gitz and Banda (2009), responses to scripting by teachers in a classroom setting may include, ignoring, reprimanding, and praising what was noted as "functional communication". During the baseline data collection period of the study, when the classroom teacher was prompted to interact with the students as she normally would, the Autistic child was redirected by the teacher, or asked not to whine or make inappropriate noises. As outlined in the studies above, the way in which individuals react to scripting is aligned with the medical model of disability. The general consensus throughout research is that the behavior serves no external communicative function, thus this assumption frames their reaction. Prizant stated (2015), "In their attempts to make children appear more 'normal', these "experts" were plainly ignoring what were clearly legitimate attempts at communication, and-worse- they were disrupting the child's

process of learning to communicate and connect with the world" (pg. 40).

In contrast to the intervention-based responses described above, on the other hand, *familiar listeners* may have more positive reactions to scripting, as exhibited in Tarplee & Barrow's research (1999). Kenneth's mother used scripting as a way to connect with her son, as well as a form of play and interaction. "...Echoing is by no means treated by her as an inappropriate behavior: rather it is a resource which Kenneth's mother, as well as Kenneth, can employ to initiate sequences of talk between them (pg. 472). While the importance of listeners was emphasized through this study, the impact of familiar listeners has not been specifically explored through the research.

Scripting as Meaningful

Despite the emphasis of traditional research to support interventions to eradicate scripting, other studies have concluded that scripting can provide a variety of functions for the Autistic individual. Communicative functions supported by the research include; use as an interactional resource (Prizant & Rydell, 1984), to express understanding, socialize, and communicate a need (Tarplee & Barrow, 1999), to communicate a feeling (Prizant, 2015), to reduce the stress of a situation through humor, as well as a self-monitoring strategy/ behavioral reminder (Sterponi & Shanky, 2006: Prizant, 2015; Wooton, 1999). While studies outlined below depended on researcher and listener interpretation, they open up the door to consider a wide array of communicative features of scripting.

Prizant & Rydell's (1984) research, conducted with three Autistic young men found that these individuals communicated through the use of scripting in at least 30% of

their speech. Prizant and Rydell also looked at categorizing speech into function groups, which they labeled as non-interactive or interactive speech. Through the use of structural and functional analysis, they proposed four non-interactive categories and nine interactive categories. The interactive categories they identified suggest that individuals with autism who use scripting may use these phrases in an attempt to interact with other individuals. This categorization includes functions such as: taking a turn during an exchange, an attempt to label certain objects or actions (while also showing gaze and nonverbal expectation of expected acknowledgement), providing new information to the listener, requesting an object or food, protesting something that was not desirable (often paired with a physical movement to stop), and verbal completion of an interactive routine (Prizant & Rydell, 1984).

Prizant (2015) made further conclusions based on his experience with the above study and gave context to the scripting of the participants, describing the study as the pivotal experience that helped him to understand scripting. His work clearly outlines multiple communicative functions for scripting including; expressing understanding and communicating a feeling or need. This aligns with the work of Tarplee and Barrow (1999) who concluded in their study that scripting was used as a method to engage in ongoing interactions and brought forth a relational closeness. Additionally, both studies recognize the importance of a third party whom was familiar with the scripting patterns of the participant (in both cases the mother).

To illustrate the conclusion that scripting can be an expression of understanding, Prizant (2015) described an incident with David where he scripted a similar response each time he heard the word, “No!” in school, by responding “We don’t slam doors. We

don't pee on the wall" (pg. 41), as he skipped around the room, repeating the script with a strong negative tone. This script was an acknowledgement from David, recognition that he was being scolded and that this experience, or his behavior should be filed under the same category as slamming doors or peeing on the wall, it is not allowed. In his own way, he was expressing to his teachers and staff that he understood their rules, or perhaps as a personal reminder to himself.

Prizant (2015) shared another example of scripting to communicate, but in this instance to communicate a feeling. Jeff had been behaving a bit off, with less energy than usual and began approaching adults in the classroom with an open mouth making a noise like, "Doo-aaah! Doo-aaah!" (pg. 41). This script continued throughout the afternoon, and it was not clear to the adults in the room the meaning, but what was clear was that Jeff was attempting to share something and was expecting a response from the adults around him. Upon discussion with Jeff's mom, she didn't hesitate and immediately understood what Jeff was trying to communicate. She shared that she thought he was getting sick, and when that happens she asks him to "...open his mouth and do 'Aaah'" (pg. 42). Prizant (2015), "It made perfect sense. Jeff was trying to tell us that he didn't feel well. He had a cold, or maybe a sore throat. At his developmental stage, he was unable to explain that in words, so he was acting out a scene for us, reliving what he had heard his mother say at home: 'Do Aaah'" (pg. 42). Through the use of the insight of a familiar listener, it became clear that Jeff's script was not meaningless, it was not self-stimulation, but an attempt to share information about his health and discomfort.

Conversational analysis is an approach used by researchers in the field of linguistics to dissect the use of scripting (Tarplee & Barrow, 1999; Wootton, 1999).

Tarplee and Barrow (1999), for example, used this method to analyze the speech patterns of a three-year-old boy with autism called Kenneth. Interactions were captured through the use of audiovisual recordings, and included typical interactions between the participant and his mother, the primary caregiver, across a 2-week period, with each recording lasting 20-30 minutes. These interactions were then transcribed and analyzed based on phonetic details as well as prosody [5] (Atkinson & Heritage, 1984). The echoes that Kenneth engaged in are all derived from one source, a dinosaur video The Land Before Time II, which during the study was an enthusiasm for him. The purpose was to look at how the echoes served as an interactional resource for Kenneth and his mother to interact.

The researchers noted that Kenneth and his mother often engaged in labeling tasks using photo cards, with intermittent free play, initiated by the mother that generally focused on dinosaurs. They would often engage in reciprocal echoing, where there would be several turns of echoes between the two. It was difficult for the researchers to identify the antecedents leading to Kenneth's echoing, at times it would coincide with a visual of the dinosaur toys, other times it was unclear. The scripts shared were accompanied by eye gaze towards the mother, and thus were clearly directed at her, at a rate of 90% in some examples (Tarplee & Barrow, 1999). Kenneth also would at times hold his gaze until his mother responded to the script, which suggested that he was waiting for a response, often looking for her to repeat the echo that he previously produced, as he would repeat his script if his mother did not respond in the way he was looking for. He did this if his mother did not echo him, did not make eye contact while scripting, or tried to redirect

[5] The transcription was supplemented by representations of phonetic detail, and included prosodic pitch contours placed above lines of text.

him, thus he would repeat the echo (Tarplee & Barrow, 1999). The authors conclude that due to the shared attention as evidenced by eye contact, as well as Kenneth's tendency to pause between scripts and await his mother's reply, he was clearly using the scripts as a tool for interaction.

The researchers also note that Kenneth showed visible pleasure through scripting with his mother, and that, "one might argue that it is during these echoing sequences that one feels most strongly a sense of inter-subjective alignment between Kenneth and his mother." (pg. 466). This alignment is also illustrated by Kenneth's efforts to repair miscommunications when his mother misinterprets his script for another meaning. During one exchange when he is misinterpreted, he physically freezes, engages in extended eye contact with his mother, and smiles only when she replies with the proper echo, "sharp tooth, yes", recognizing her error in understanding (pg. 469).

Kenneth's mother responded to his nuances of communication, and not only acted as a participant in Kenneth's scripts, but also at times initiated the echoes in an effort to engage Kenneth and utilize them in a meaningful context. For example, a common script "aaagh and Chomper bit me" (pg. 470) would be used after acting out a scene with dinosaur toys with one biting the other (Tarplee & Barrow, 1999). After his mother modeled and recreated the scene, Kenneth did respond with the second part of the sequence, "Chomper bit me" (pg. 471). Finally, she was also observed using the echoes as way to engage Kenneth and get his attention. In one described instance Kenneth became unresponsive and began to stare straight ahead of him. His mother attempted to get his attention in a variety of ways (whistles, taps him), but he remained unresponsive until she used a dinosaur script, to which he smiled, responded back and continued his

engagement with his mother.

The study concluded that the majority of Kenneth's echoes are in fact in an attempt to socialize, and result in inter-subjectivity, solicitation of play, and a way for others to summon attention. Tarplee and Barrow (1999) conclude,

> Our analysis makes it very clear that Kenneth's cartoon echoes serve him in important ways in his interactions with his mother. They provide him with the means to initiate social interaction with her, by bringing her with him into his cartoon world. They also provide him with the means to pursue a response from her, and thus to engage her in extended sequences of reciprocal talk (pg. 478).

While the above research shed some critical light in regards to the way scripting can be used socially, it is limited in the fact that the interpretation of the scripts relied solely on that of the researchers, with support from the knowledge of his mother as a highly skilled familiar listener.

Sterponi and Shankey (2013) more recently pursued to study how scripting can be used as an interactional resource, to build on past studies. Specifically their study concluded that their participant, called Aaron who was 5 years old at the time, had multiple purposes for his scripting depending on the social context. He was able to use scripts as humor to reduce the stress of a tense situation, to show understanding, and as self-monitoring to remind himself of expectations.

Aaron exhibited first the ability to use scripting as a way to diffuse a tense situation. In one example Aaron's mother was pushing him to describe verbally what the gardener, Roger, was doing outside. Aaron played along at first, providing concrete answers, such as "doing work" and "he's got the water hose" (pg. 288). When his mother continued to push him and then prompted him to create a complete grammatically correct sentence, Aaron responds with a personal script about germs (an area of enthusiasm),

which elicits laughter from both he and his mother, thus alleviating the tension and allowing him to escape from his mother's demands.

The second example included an echo of others, when Aaron is at the dinner table with his mother who asked him an open ended question, to which he spun his already turned body further away from her to which she responded "uh oh". Aaron then replied in a sing-song voice "you're looking at the brick stove", to which his mother echoed and adds "we are not together" (pg. 292). In this exchange Aaron echoed the sing-song tone that his mother generally used to re-engage him, as well as predicted what her next statement to him would be. His mother confirmed his prediction by echoing his response, and adding her typical next line (we're not together). Aaron then laughed, showing his pleasure that he was able to predict his mother's response, thus showing his understanding of her perspective. The authors also note that through this exchange that the back and forth between Aaron and his mother was interactional, as well as displayed a strong emotional connection (Sterponi and Shankey, 2013), which corroborates the findings of Tarplee and Barrow (1999), that through scripting strong emotional connects were made between the participants and the parent.

Finally, Aaron also used scripting through impersonal echoes, as in situations where his behavior was corrected, he would use an authoritative voice and state for example, "because it's dinner time", almost as a reminder that he had to sit at the table due to it being dinner. Generally these types of scripts were affirmed by adults and repeated to remind Aaron of what was expected. The researchers acknowledged the complexity of Aaron's scripting and its interactional importance and describe,

> ...Aaron did not simply repeat utterances; rather, he animated voices. This distinction acknowledges the child's agency and creativity related to echo

> production. We suggest that the ownership criterion, which encompasses not only the substance of what is said and who it is ostensibly direct to, but also the manner in which it is spoken, constitutes an analytic lens that can enhance our capacity to understand the complex interactional work that children with autism can accomplish through echo usage (Sterponi and Shankey, 2013, pg. 299).

This use of scripting as a behavioral reminder or reflection of understanding of expectations, is similar to Prizant's (2015) findings, when David would also echo directives in firm tones. Similarly, Wootton's (1999) research with an Autistic ten-year-old boy called Kevin, analyzed his use of scripting and it was noted that most of his echoes tended to act as behavioral and disciplinary regulators, for example he would state, "You do not touch anyone's work Kevin" (Wootton, 1999, pg. 362). It is also described that through the intonations Kevin uses when repeating these phrases, it is clear the original speech came from an adult intervening during a behavior instance. The use of this script was a self-regulation technique, and perhaps acted as a personal reminder. As Kevin's interpretation was not included in the research, it is difficult to ascertain the meaning that the script held for him, thus the research relies on the perspective of outsiders.

Building Meaning with Familiar Listeners

Through the literature, it is clear that *familiar listeners* have played an important, though understated role in research, specifically in aiding in the understanding of the origins and meanings of specific scripts (Prizant & Rydell, 1984; Prizant, 2015). Familiar listeners have also acted as models to show how scripting can be respected and utilized as a way to connect, as a form of communication, and as an interactional resource (Tarplee & Barrow, 1999). In Tarplee & Barrow's research it was clear to see how scripting can be

a bridge to form strong meaningful relationships, as well as provided interactional content for relationship building. Despite Kanner's original assumptions made about the first identified Autistic individuals, in later work he described how often scripts were found to be more relevant and communicative than originally described. Despite this very early recognition that with more experienced listening, it is possible to increase the context of understanding, there is little emphasis in the research regarding how listening experience impacts the ability of the listener to communicate effectively with the individual. Research has specifically just begun to consider that scripting services communicative needs for the individual, even if the expression and intention is not fully understood by the receiver, especially inexperienced listeners.

Stiegler (2015) stressed the importance of identifying the primary sources of the scripting in order to more fully understand the context and meaning for the individual. By doing so, a listener can more aptly identify the function of the script, as well as can identify changes in the script (Stiegler, 2015). This in essence, is what the familiar listener often shares with the participant, an understanding of the context of the original content, which then assists in bridging the understanding of the meaning of the script for the participant. Often in the research, parents were relied upon as the familiar listeners to provide the history, context, and sources for scripting (Sterponi & Shankey, 2013). Much like Kenneth, the young man explored by Barrow and Tarplee (1999), it is difficult to put context to his delayed echoes without understanding the primary source, a dinosaur movie that he watched and repeatedly used for scripting. Without the knowledge of this movie, and without the attempt to understand the motivation behind the scripts, it would be difficult to see it as an interactional feature. Researchers alone, without the support of

parents as discussed in above studies, found that the complexity of scripting was often difficult to understand, which is why they found it necessary to utilize informants familiar with their participants in order to assist with understanding the intent (Prizant & Rydell, 2984). As scripting can;

> vary as to the extent of their conventionality, which may vary with different listeners and different contexts. Those familiar with the child may comprehend the meaning and intended function of delayed echoes based upon shared experience, whereas such information may not be available to strangers (Prizant & Rydell, 1984, p. 190).

Essentially in order to truly understand the communicative nature of scripting, one may need to become a familiar listener. How can one do this if the focus is consistently on eradicating the use of this type of expression?

Through the work of Prizant and Rydell (1984), the complexity of scripting was revealed, as was the difficulty in classifying meaning to some specific scripts. It is important to note that this study, while groundbreaking in its attempt to look at the communicative nature of scripting, relied on the researchers' analysis of the social scene to determine the function behind the script. There were times that the use of family members who had more experience listening, were able to shed light on the specific meaning of a script. It was also identified through this research that as Kanner noted (1946), some echoes may be characterized as metaphoric language, and thus had "private meanings", which may only be privy to familiar listeners, and thus made them difficult to categorize. Prizant and Rydell found it necessary to utilize informants familiar with their participants in order to assist with understanding the intent of the language. As, "delayed echoes vary as to the extent of their conventionality, which may vary with different listeners and different contexts" (Prizant & Rydell, 1984, p. 190). Essentially in order to

truly understand the communicative nature of scripting, one may need to become a *familiar listener*.

In the research, at one point Prizant (2015) described a scenario where as the researcher, his experience with the participant, David, led him to be a familiar listener. Prizant when describing this experience states, “David taught me to listen” (pg. 35). David was a very verbal preschooler, whose speech relied almost solely on scripting. In one instance, David, fascinated with the pills from his sweater, began picking them and rolling them between his fingers. As Prizant described the piece of fuzz, David continually repeated, “That’s a piece of fuzz, fuzz, fuzz” (pg. 36). A similar routine happened the next day around sponge that was left on the floor, and David engaged in a similar echo, “That’s a piece of sponge, sponge, sponge “ (pg. 36). The following day upon entering the room, David sought out the spot that the sponge had been the day before, and chanted the echo. Prizant immediately recognized his script as a recount of his experience the day before, as well as his excitement about it, in essence he was using the script to tell a story. Imagine this scenario without the presence of a familiar listener such as Prizant, imagine a visitor’s interpretation of these events seeing David enter a room and seemingly randomly begin chanting “sponge”, as Prizant describes, “ The visitor might easily have dismissed the behavior as absurd. Or silly. Or random. The visitor might have questioned David’s grip on reality- or at least his understanding of the word sponge” (pg. 37).

Kanner also showed in his work that longer-term exposure to scripts as a listener can impact the meaning of that script. In his work with “Donald”, Kanner recorded that the boy would repeat phrases that seemed to hold no meaning, including, “ ‘Annette and

Cecile make purple'', while drawing with crayons. According to Silberman (2015), Kanner later reported that he discovered "Donald" had named each of his watercolor bottles, the red one being called "Annette" and the blue one "Cecile", when mixed together the two colors made purple (Silberman, 2015). This realization came later as Kanner spent more time listening and working with the individual, and my have evolved into a more familiar listener.

The importance of a familiar listener to shed light on the meaning and intent of scripting can also be useful when an Autistic person has developed a neologism. A neologism is defined as a stock phrase that has a specific meaning for the speaker, and/or an experienced listener, but has little meaning to an inexperienced listener. Prelock (2013) uses the term linguistic idiosyncrasies similarly to define a term that is a part of the native language, but is not used in the normative way. Kanner describes an example in which the word "yes" became a neologism for "Donald", as the word "yes" came to mean that Donald wanted to ride on his father's shoulders. This meaning was co-created when Donald's father was attempting to teach him the difference between the meanings of the words yes and no. During an example, Donald's father asked him, "Do you want me to put you on my shoulder?" to which Donald repeated the question, in an effort to convey that yes, he did in fact want that. His father then replied, "If you want me to, say 'Yes'; if you don't want me to, say 'No.'" (1943, p. 220). After this incident, his father as the experienced listener, and Kanner after experience, were both able to identify that the meaning of the word "yes" for Donald, in all contexts was a request to ride on his father's shoulders, and that he did not use the phrase to respond to a question with an affirmation, as might be expected. An unfamiliar listener without the contextual

knowledge of what occurred previously around the word "yes" may interpret this as meaningless, which further exhibits the importance of familiar listeners in assisting in interpreting both scripting and neologisms.

Prizant (2015) describes another example of a fifth grader with autism Eliza, who developed her own script and neologism to express feelings of stress or anxiety. When he arrived in Eliza's classroom for an observation as an unknown visitor, and approached her, Eliza immediately reacted with, "Got a splinter!" (pg. 38), to which Prizant was left confused and unsure. The teacher immediately intervened and let the girl know that it was okay, and that the new person in the room was just a visitor and a nice man, hearing which, Eliza seemed to calm down. The teacher, or familiar listener, later described that the phrase "Got a splinter!" was referring to an incident that happened two years prior where Eliza had a painful splinter. Since that incident, the script was used by Eliza to express anxiety or fear, and became a commonly used neologism.

The impact of a *familiar listener* is clearly supported by the above outlined literature, yet there remains to be an absence of the discussion of the importance of this in the research. Even further, the perspective from the Autistic point of view regarding how *familiar listeners'* impact their successful use of scripting, as well as other communication methods is also lacking.

Mitigated Scripting

Non-Autistic researchers that recognize the importance of scripting have argued that scripts evolve and change over time. Traditional research emphasizes that it leads to more original, spontaneous communication (Roberts, 2014). This is evidenced by examples of mitigated scripts, which are echoes that may change and evolve over time.

Examples show that scripts can be adjusted to fit a particular context, and thus convey more clearly shared meaning during a conversation, or can be adjusted to share the personal wants and needs of the individual.

Roberts (2014) described the longitudinal study in which data was collected between 1990 and 1995 looking at the use of mitigated scripts in Autistic children as speech and language impairments. While this study looked at immediate echolalia, it also considered immediate echolalia that was mitigated, or changed in the moment. Through an analysis of video of interactions over time, types of mitigated echolalia were defined. Recognized changes in scripts included the changing of pronouns and articles to change the meaning of a script (i.e. "You" instead of 'I"), the expansion of a script to add detail, or the omission of part of the script. Roberts (2014) supports idea that scripts may change over time in an effort to convey different meanings for the speaker, and the study also established the notion that the production of these mitigated scripts over time supported the development of more complex linguistic development.

"Diary of a Mom" is a well-known blogger who describes her experiences with her Autistic daughter "Brooke" and is viewed as a progressive activist in the autism community and the neurodiversity movement. In her blog entry entitled "Circles" she discussed an instance where Brooke is engaging in a common script of Max and Ruby, a script based on a cartoon television show in which both Brooke and mom have their lines and engage in banter regarding behavior in the library. She describes an instance in which Brooke engages in what researchers might describe as mitigated echolalia, or an evolving script.

> As per the script, I say, 'Not in the library, Max!' She giggles. And then, for the first time ever, she takes the script one step further. In Ruby's voice,

> she asks, ‘How do we look for a book in the library?’ I’ve never heard this before. I don’t have a practiced line to offer in return (pg. 2).

As a parent whom is a familiar listener to Brooke, who engages in her scripting as way to communicate with her, share joy, and understand her daughter, she is also able to identify when things go off-script, when the conversation turns and takes the script one step further. As “Diary of a Mom” describes,

> And there we are. Light-years from the tight little maze of dizzying circular conversations in which we lived for so long. We cover distance now- we move and we volley and we dance and we laugh and we skip and turn and jump and hell, even skitch down miles of road. And yet, we are still in the maze. We’re just making bigger circles (pg. 3).

Another example of the use of mitigated scripting is described by Dawson, Mottron, and Gernsbacher (2008) in an example of Bud, who often used scripts from the television show Teletubbies. The original line that Bud scripted from the show was, “ ‘One day in Teletubbyland, all of the Teletubbies were very busy when suddenly a big rain cloud appeared’” (pg. 766). This phrase was then used again weeks later, but the structure was changed to fit the context, and to convey meaning, “ ‘One day in Bud’s house, Mama and Bud were very busy when suddenly Daddy appeared’” (pg. 418). While the general syntax of the script remained intact, Bud was able to replace the nouns to build a sentence that was reflective of the current social scenario. Bud also utilized a script when he wanted to play ball, he would often say, “‘Quick, Dipsy. Help Laa Laa catch the ball.’” (pg. 766) As Bud continued to develop and advance his language, again the structure of the script remained the same, but he was able to replace the nouns in statements such as, “‘Quick, Daddy. Help Bud catch the ball’” (pg. 766). According to Roberts (2014), these would both be examples of a Type 1 syntactic edit, as Bud was able

to exchange the nouns for more specific proper nouns that fit his scenario.

Based on the clear experiences and examples described above, scripts can be changed over time and utilized in context to convey specific meaning for the speaker, that coupled with research from Roberts (2014) and his longitudinal study support the idea that examples of "mitigated echolalia" increase over time and adjust to convey meaning for the speaker.

A Shift in the View of Expertise

In order to provide a wide array of research to support the disconnect between traditional research assumptions about scripting, and the Autistic perspective of scripting, this literature review must go beyond the scope of covering conclusions solely based on peer-reviewed research and journals. The need for this speaks to the lack of authentic Autistic voices in the research, and the importance of alternative sources of expertise that are emerging through a variety of mediums. This section looks to uncover what alternative sources are telling us about scripting, including the parents of Autistics who use scripting, but more importantly the Autistic adults themselves.

Scripting as Communication Hits the Mainstream

While Ron Suskind may be criticized by some as speaking out publicly about his son's autism from the parent perspective, not necessarily from the perspective of his son Owen, he made certain strides regarding the understanding of scripting that cannot be ignored. As a Pulitzer Prize winning journalist, Suskind had the ability to do what many do not, to reach an extremely wide audience and share his family's experience with autism, and more specifically with his son's scripting. What his book also does is sheds light on the outside pressures that families receive regarding how they "should" respond

and react to their child’s scripting.

Suskind (2014) described an evolution that his family went through in regards to how they react to Owen’s enthusiasm around Disney movies. As Owen spent a lot of his time watching and re-watching Disney films, at first the family followed the advice of professionals and limited the movie time, literally put the television under lock and key, and encouraged other interests. As the majority of Owen’s speech was taking the form of scripts based on the films, it was thought by encouraging other interests he would reduce his parroting. It took some special shared experiences with Owen to note the importance that these Disney movies had for him, and how they could be a key to understanding him and having meaningful interactions with him.

Suskind (2014) addressed an event in his book where his neurotypical son Walt, became visibly upset at the end of his 9th birthday party. After witnessing this, Owen tells his parents, “‘Walter doesn’t want to grow up’... ‘like Mowgli or Peter Pan.’” (pg. 53). Suskind and his wife stood in shock, as they realized that Owen had never spoken in a complex sentence like that, a sentence that didn’t just convey a basic need or want, but showed empathy for his brother and used his understanding of Disney characters to do so. Suskind reflected,

> Beyond the language, it’s interpretive thinking that he’s not supposed to be able to do: that someone crying on their birthday may not want to grow up. Not only would such an insight be improbably for a typical six year old,; it was an elegant connection that Cornelia and I had overlooked. (pg. 53)

This experience began to unfold a different approach to connecting with Owen, instead of shirking away from his enthusiasms and limiting them, Suskind began to see them as ways to learn about his son and connect with him. Despite the advice of professionals and the pressure to react to scripting in a certain way, Suskind went with his

instinct as a father to further connect with his son. He followed up with a conversation using the puppet Iago from the movie Aladdin, which had been a common source of scripts for Owen. Suskind grabbed the puppet and in his best Gilbert Gottfried voice asked him how he is and what it is like to be him.

> Through the crease I can see him turn toward Iago. It's like he is bumping into an old friend. 'I'm not happy. I don't have friends. I can't understand what people say.' I have not heard this voice, natural and easy, with the traditional rhythm of common speech, since he was two . I'm talking to my son for the first time in five years. Or Iago is. (pg. 54).

These encounters lead to utilizing Disney and scripting as an act of connection between the family. Talking through scenes, reenacting movies as they happen, and creating plays for the family to act in based on Owen's favorite movie at the time, are all ways in which his family began to engage with him. The more time spent interacting and becoming familiar with scripts and the contexts of the sounds and expressions, the closer Suskind became to his son, he notes;

> Then it seems he was slowly learning...spoken English- by using the exaggerated facial expressions of the animated characters, the situations they were in, the way they interacted, to help define all those mysterious sounds. That's what we start to assume; after all, that's the way babies learn to speak. But this is slightly different, because of the way he committed these vast swaths of source material, dozens of Disney movies, to memory. These are stored sounds we can now help contextualize, with jumping, twirling, sweating, joyous expression- as we just managed with the Jungle Book. We after all, are three-dimensional, we have heartbeats. We can touch him, and he can touch us back. Strictly speaking we're interactive. In the parallel worlds- real and Disney- we're crossing over. (pg. 58).

The evolution of the Suskind family, and how they relate to Owen and his enthusiasm and use of scripts is an example to view through the lens of familiar listeners. To be one is to connect, to be one is to understand the source of the script, and perhaps the hidden meaning. To become one is to bring joy for all involved. As described by

Briannon Lee in the blog Respectfully Connected (2017) this type of genuine interest is an extremely meaningful way to connect, "Sharing our passions with the people we love is how we show we can and how we connect with you" (pg. 1).

Expertise from Autistic Voices

This research attempts to prioritize Autistic voices in the structure of more traditional research spaces. That being said, these experts on their own experiences, these voices of the Autistic community, have found their own avenues and mediums to share their expertise. Recognizing this first-person experience and framing this knowledge as the most critical aspect of our understanding, is the intention of this research.

Importance of Internet to the Autism Community Davidson (2008) identified the role that the internet has played in the development of Autistic culture. She described that numerous Autistic accounts emphasize the importance of written communication as a critical mode of self-expression. Davidson's work utilized over forty Autistic primary sources published in autobiographical form to emphasize the theme of the importance of the internet for Autistic individuals. Davidson refers to Singer's statement in 1999, which compared the impact of the internet on Autistics to that of sign language on the deaf, a statement that has been reinforced time and time again by other Autistic writers (2008). Davidson stated, "While those with autism have yet to literally take to the streets, increased literary presence in numerous public forums suggests that many are in fact 'coming out' with pride, asserting minority cultural status, and strengthening common ties in (virtual) space" (pg. 795). Davidson also refers to the "language games" of neurotypical communication, which hinder Autistic adults from more successful linguistic communication, as well as the importance of delayed response, which the

internet conveniently provides (2008). The culture that the internet has provided has also created connections of purpose and support, creating groups which allow the voices to grow stronger with larger audiences to receive their words in a variety of formats.

Autistic individuals share that written communication comes more naturally than oral communication. Onaiwu (2015) shared that "writing was her true 'first language'" (pg. 86), and how in face-to-face social communication experiences, it can become overwhelming and draining to participate. She compares using spoken language to that of a foreign language that never became completely comfortable for her. She writes about how the use of social media and online socialization took the pressure off communicating, as it allowed her to expand her advocacy, and took the stress out of communicating and connecting with others, allowing her to step away and log off whenever needed. The internet has opened up connections for Autistic individuals that they may shy away from in face to face opportunities, "I am myself online...Being online gives me access to people and places that are difficult to navigate" (pg. 90). The internet has also opened up an avenue for Autistic voices to connect, share their experiences, as well as their interpretations of autism.

Onaiwu described in the Real Experts (2015) how social media impacted her as;

> Even as a little girl she was better at writing than speaking ...note-passing … was her only true way of getting her real thoughts out.
> The thoughts that didn't come freely when she was speaking because speaking was so much mental effort, even though everyone considered her a pretty good orator... her best ideas came when she had pen and paper in her hand… (pg. 87).

The internet has created that space for many Autistic writers to grow and flourish. There are a huge variety of bloggers, writers, and activists who write on a variety of

topics relating to their experiences as Autistic individuals. Some of these pioneers include Ally Grace, Lydia Brown, Nick Walker, and others discussed within this work. Some of these authors speak directly to scripting/delayed echolalia in their work, some of who are referenced below.

Autistics are Sharing, but Are We Listening? Milton (2014) addressed the production of knowledge in regards to autism studies, and used Collins and Evans' (2007, as cited in Milton, 2014) framework, which looks to re-conceptualize the understanding of knowledge and its levels. Specifically, they refer to levels of specialized expertise, which runs on a scale beginning with 'beer-mat knowledge' upwards to primary source knowledge, which may lead to interactional and contributory expertise. Milton argued that, "The interactional expertise shown by non Autistic social researchers is, however, often clearly insufficient, given the criticisms made of such investigations by Autistic scholars (Arnold, 2012a, Milton and Bracher, 2013." (pg. 796). As it is assumed that immersion is the key to interactional expertise, according to Collins and Evans, Milton argued that this type of immersion is not possible for non-Autistic researchers, thus the criticism is stemming from a lack of expertise in traditional research. Thus, Milton (2014) outlines a strong argument for the involvement of Autistic scholars in research, as well as improvements in regards to how participatory methods are utilized.

Arnold (2012), an Autistic researcher along with a small group of other Autistic academics, set up *Autonomy*, a critical journal of autism studies that was created in an effort to combat the misinterpretations of autism by outside researchers, as well as to, "contribute to the wider discourse of what it means to be Autistic from within and to face the difficulties in restructuring the courses that are taught about us, in my department and

others. I have since taken on the role of researcher seeking to further redefine that discourse" (Arnold, 2012,n.p.). Arnold's intention for the journal was to implement high standards of research including peer review, while creating space and allowing for Autistic voices generally poorly represented in traditional journals.

Dowley (2016) discussed the importance of the Autistic voice in providing the first hand, insider view into autism. She identified the importance of autobiographical work, as well as the impact that it has had on researchers such as Baron-Cohen, who identified Autistic voices as a new resource for expertise. She also identifies the limitations of autobiographies, as due to the vast differences in experiencing autism, those writing autobiographical work are unable to represent autism as a whole. Dowley also identifies that often individuals that communicate differently may have restricted access to share their experiences. Dowley (2016) questions the assumption that Autistic writers may lack the communication skills and the empathy to speak effectively about their experiences.

Self-publications by Autistic authors, such as The Real Experts (2015), work to fill the void of the Autistic voice in research. These publications were written to guide parents and traditional scholars alike to understanding how best to support Autistic children. As Walker states, "...There's so much misinformation and bad advice about autism out there. Many of the standard 'expert' or 'professional' approaches to autism are badly misguided and rooted in ignorance" (pg. 6). Through their book, which includes a compilation of readings from a dozen authors, edited by Michelle Sutton, who identifies as Autistic and as a parent of an Autistic child, a wide variety of voices are shared across relevant topics.

Autistic authors address the issue that more effort needs to be put forth by the neurotypical population to understand the communication of Autistic individuals. Sequenzia (2015) discussed that much of the life of an Autistic person is spent attempting to understand the communication of neurotypical individuals. “We need to be respected because the way we communicate might mean doing things and acting in ways that might not seems to be related to communication” (pg. 98). Through these avenues, Autistics are sharing their expertise on a variety of topics, including communication and scripting specifically.

Autistic Experts and Scripting Autistic adults agree there is a social divider between Autistics and neurotypicals, due to the focus on normative communication constructs such as eye contact, and a lack of effort to understand Autistic methods of communication (Schaber, 2014; Sequenzia, 2015; Walker, 2016; Endow, 2013; Kim, 2012). Schaber (2014) noted that scripting it is often not considered acceptable behavior, as it is one of the “obviously Autistic behaviors”. It is also noted by Sibley (2013) in her blog Radical Neurodivergence, that this effort to “pass” as neurotypical and not stand out in society becomes more difficult with age, as;

> When I was 6, I could play a board game with only slightly more meltdown potential than the other little kids… At 30? Board games have largely given way to unstructured conversations, where turn taking is marked not by handing over the dice but by nonverbal cues. The length of turns and what a turn includes varies moment to moment. Talking too much, not enough, oddly? Gets noticed. Not catching nuance? It shows. Echolalia? Stands out...The skills that make you slide by in first grade are not enough in adulthood. There’s nowhere to hide. (n.p.)

In an article written on her blog Musings of an Aspie (2013), Cynthia Kim an online blogger who identifies as a woman, mother, writer, and editor, was also diagnosed with Asperger’s syndrome in her early forties. She described how echolalia can be

defined in various ways,

> Echolalia is a fancy word for the repetition of spoken words. For typical toddlers, it's a transition period in language development. For Autistic people who don't have functional language skills, it's a means of communication. For me, it feels like a kind of 'found speech', similar to the cast off pieces of pipe and rusted metal that an artist might use to make a sculpture (pg. 1).

This type of interpretation of scripting is completely absent from traditional research, yet it brings so much value to understanding how it is utilized by different individuals. Other Autistic adults have also addressed defining echolalia and scripting through the use of videos, which has been a successful tool for Autistic individuals to communicate their experiences. For example, the work of Amythest Schaber, who describes herself as Autistic, and a multiply disabled writer and activist, speaks directly to the topic of scripting. Along with her blog, she also has a series on her Youtube channel (Ask an Autistic), where she answers questions about her experiences. Schaber differentiates between the term delayed echolalia, which she described as shorter echoes that are single words or phrases, compared to echolalial scripting, which she defined as longer passages and dialogue, generally borrowed from media, such as movies or books. This differentiation between the two terms described by Schaber further exhibits the need for the research community to understand the overlaps and the contrast between the two in order to utilize terms consistently and correctly in research.

Schaber (2014) describes the use of echolalia as a "stepping stone" to "unique or original language", which supports the notion that scripting can lead to mitigated scripts, and thus original language. She also describes how the familiarity of the listener can impact the effectiveness of the use of scripting, as "The person listening now might not know what they're referencing...so in that way the listener might not actually recognize

delayed echolalia as echolalia…" (7:30).

Kim (2014) also addressed the fallacy of using the terms functional versus nonfunctional in relation to scripting, as, " Just because something appears to be nonfunctional to an observer does not mean that it is nonfunctional to the person doing it" (pg.). Schaber (2014) building upon the notion of scripting as functional, outlined reasons why Autistic individuals may use it. In summary, individuals use it as a form of communication, as routine to illicit comfort, to get their needs and wants known, as well as because it is useful to oneself. She described that delayed echolalia can be helpful as a form of self-stimulation, which soothes the person, that it can be useful to rehearse what you are going to say in a social context, or that it can be situational and just used for fun. Naoki Higashida, a thirteen-year-old boy with autism, published a New York Times Bestseller (2007), expressing himself through the use of an alphabet grid. Higashida also addressed the fun of playing with words, as he stated,

> We aren't good at conversation, and however hard we try, we'll never speak as effortlessly as you do. The big exception, however is words or phrases we're very familiar with. Repeating these is great fun. It's like a game of catch with a ball. Unlike the words we're ordered to say, repeating questions we already know the answers to can be a pleasure- it's playing with sound and rhythm (pg. 11).

Schaber (2014) also describes how delayed echolalia can make people happy, as well as it can be used to process the environment as a form of self-talk. When discussing echolalial scripting, Schaber (2014) emphasized the importance of the enjoyment of it, and refers to it as a form of sensory stimulation, or stimming. She also cautions viewing it solely as stimming, as in her experience she has had emotionally charged situations where she was unable to communicate her own novel thoughts, but was able to use echolalial scripting to share her wants and needs.

Schaber (2014) described one of the reasons for engaging in scripting as a stimming activity that Autistic individuals engage in. Cynthia Kim (2015) discussed the positive impact stimming has on her concentration, and how critical it is to her self-regulation "It's a release, like sneezing or scratching an itch. Have you ever tried to ignore an itch? What if someone told you it was wrong to scratch yourself to relieve an itch? What would that do for your concentration?" (pg. 41). In a time when more and more the sensory needs of Autistic people are being recognized, what happens when scripting is used for self-stimulation and is constantly being shut down? Kim notes (2015), "Stimming happens. It's not something Autistic people choose to do. Controlling it is like playing whack-a-mole. Stop it over here and it's just going to pop back up over there. Whack it enough times and it's going to go underground and rip up your entire yard" (pg. 39).

Kim (2015) outlined multiple forms of stimming, including making or repeating sounds, words, or phrases silently in your head or out loud. She stated, "Most Autistic people say that they finding stimming to have a regulatory function- stimulating at times, calming at other times" (pg. 103). To Kim, the action of stimming is a way to fulfill very basic needs, but unfortunately since often these sensory responses are judged, or punished, Autistic individuals find this fundamental need revoked. Kim (2015) shared her work to reintegrate self-stimulatory behaviors into her life and describes it as, "...a slow process and one that goes against the social conditioning we learn as part of learning to pass for 'normal'. But it's also an essential part of becoming my Autistic self" (pg. 109).

"Scripting can grease the social wheels and I think those of us who have trained ourselves to pass will often unconsciously default to scripting or echolalia simply to

conceal the fact that we can't find the right word or we've lost the thread of a conversation. After all, there's often subtle, unspoken pressure to keep a conversation moving along" (pg.1). As Kim describes, much like a neurotypical individual might use filler words such as "umm", the use of scripts may also be meaningful to keep the conversation going, as well as to give oneself processing time to find the right word or response.

The view of scripting as potentially "nonfunctional" is dependent on the listener's ability to connect with and understand the speaker's intent, especially when they are in "coded form". This coded form relates to the research on neologisms, where a word or phrase may have a different meaning for an Autistic individual than may be expected. In the context of conversing with a familiar listener, this "nonfunctional" script may be functional, as it would convey the intended meaning in that context. Kim describes what neologisms may look like, "...You may have the equivalent of a mental decoder that tells you that 'put on your shoes' means 'let's go to the park' and 'I want toast' means 'I'm hungry'... Sometimes it's simply a way to say, 'I'm here, I see you and I like spending time with you'" (pg. 2).

Ariane Zurcher (2014) also addressed the topic of scripting in her blog and how the key to understanding some of her daughter's scripts is not in the specific words, but in the emotion being conveyed, which she learned from Autistic writer and education professor Ibby Grace. As a familiar listener she has recognized that, "In the past I would have gotten all tangled up in the specifics of what she was saying. I would have sought to reassure her about whatever it was. But now, I can understand that these scripts can serve as so much more. They can serve another purpose. They are less about the words spoken

and more about the words that are attached to them" (pg. 1).

In conclusion, although the voices of Autistic individuals may be seemingly absent in traditional research, Autistic individuals are communicating through the internet, through blogs, through self-publications, and a variety of other means. Through the above analysis of blogs that specifically refer to scripting and delayed echolalia, it is clear that scripting is often not accepted by others (Schaber, 2014), and that Autistic individuals spend a lot of time trying to understand normative, neurotypical communication (Sequenzia, 2015). There are also conflicting definitions and terms being used in research as well as across the community. Finally, it is also outlined that there are various reasons that an individual would engage in scripting. The difficulty is, traditional research is prioritized over the voices of Autistics, and researchers are relied upon as the creators of knowledge. The goal is to shift this power of knowledge creation over to the experts themselves, Autistic adults.

Chapter III
METHODOLOGY

This chapter is divided into six sections (a) pilot study description, (b) description of the research methods, (c) information regarding the proposed sample, (d) protection of human subjects considerations (IRB), (e) the proposed instrument for the study and its developments, and (f) the step by step procedures that were implemented in the study.

Research Questions

This study used qualitative methods in an attempt to answer the following research questions;

1. What benefits does scripting provide, as described by Autistic individuals that use scripting?
2. What are the communicative features of scripting as described/used by Autistic individuals?
3. How do communication partners, specifically familiar listeners, influence the use of, and effectiveness of scripting as a form of communication? How does this contrast to other communication partners?
4. From the Autistic perspective how can communication partners impact scripting?
5. How does scripting evolve over time as described by Autistic individuals and their familiar communication partners?
6. What outside influences and pressures impact the way familiar listeners react to

scripting?

Pilot Study

A pilot study was conducted to inform the dissertation process, as a part of a doctoral level course project. Through this pilot study, a drafted semi-structured interview was constructed as a potential instrument to be utilized in the dissertation process. The drafted interview was analyzed by three members of the Autistic community who were willing to participate (See Appendix G for IRB documentation). These individuals included academics, professors, trainers and activists, all who identify with autism and are 18 years of age or older. To solicit these participants, members of the Autistic community were approached (via electronic mail), and were asked to share the information with members of their community. Then, the information gained based on the feedback lead to a change in formatting and revision of the survey.

The participants reviewed and gave feedback on the drafted digital survey to prepare it for future dissemination. Two individuals gave feedback through a digital email communication, and one agreed to a follow up interview regarding the survey. The goal of the feedback was to ensure the survey's accessibility to individuals with a wide range of communication modes (such as verbal and augmentative and alternative communication (AAC)), as well as to ensure that the format and language utilized in the survey was precise and clear.

Sam (pseudonym provided to protect identity) was selected for the follow up survey interview as he identifies as an Autistic adult, is involved in the neurodiversity

movement, and is a writer, professor, researcher, and artist. Sam was provided with a consent form to participate in the interview as a part of a doctoral level course project, as well as to assist in the creation of an instrument for a doctoral dissertation. The consent form specified that he would be audio recorded, in an effort to transcribe critical elements of the interview (See Appendix D.1.). Sam was provided with a draft interview, as well as a list of topical domains and questions one week prior to the interview. These questions included general responses to the survey and impressions, consideration regarding potential ableism, the accessibility of the survey, and also solicited feedback on the content (See Appendix G for original survey).

As the original data collection method was planned to be a semi-structured oral interview, during the interview process, Sam shared that due to the normative expectations of participation and reciprocity in conversation for the Autistic community, an online format for the survey would be more accessible, especially due to the scattered location of the Autistic community. Sam also discussed his interpretation of the difference between the terms delayed echolalia and scripting, and identified himself as a person who engages in both. Sam discussed the importance of fine-tuning the questions to make them as specific as possible. He cautioned that if the questions were not specific enough, the research questions may not be addressed. He specifically referred to question 1 (which originally asked for self-identity information) that the responses may be a very long “laundry list” of self-identities. He shared examples of more concrete questions such as, “Are you Autistic? What age did you learn it?” He also expressed concern about question 6, which originally read “How does scripting make you feel?” He reflected that the question was too big, and that Autistic emotions are often very unique and difficult to

describe. He suggested more concrete questions such as, “How do others understand your scripting?”

Through the feedback provided by the Autistic consultants, both the format and the content of the process changed (see Appendix D for revised online survey). Instead of the initially intended oral interview format, the data was collected first through an online survey, with the option of a follow-up semi-structured interview. Further revisions based on the input of Autistic people included, (a) the wording and clarity of specific items, (b) the addition of questions, and (c) phrasing to make the survey more accessible.

Dissertation Research Methods

The current study included adult participants (18 or older) who identify as Autistic. The purpose was to understand scripting through the voices and experiences of those who use it. The above research questions were addressed through an online open-ended survey and follow up interviews with a subset of Autistic adults who took the survey and agreed to a follow up digital in-depth interview.

Participants

The participants of the study included individuals 18 years of age and older that self-identified as Autistic. The potential age range of the study was from 18-75 years of age. Participants were recruited digitally utilizing connections within the research community, self-advocacy organizations, professional list-serves. Demographic and background information was collected to obtain information regarding the individual’s own identity and history including: the autism identity/diagnosis process, the type of services received privately as well as through the school district. Information regarding past eligibility for special education support/services, as well as school and classroom

placement were also included. Additional participants also included successful communication partners referred by the Autistic participants.

In an effort to protect confidentiality, all online survey participants were assigned a number, stored separately from any personal data collected, so as to avoid connection between their personal information and their names. The digital survey was distributed anonymously, using the Google Survey platform.

The digital online survey was completed by 22 participants, ranging in age from 25 to 65 years old, with the most concentrated ages reported at 30 and 51 years old. 59% of contributors identified as female, 22% as gender non-conforming, and 18% male. Participants reported finding out they were Autistic between the age ranges of seven and 41. Two participants reported discovering it for themselves prior to receiving an official diagnosis. One participant did not recall when they found out, but stated they always knew they were different.

Participants shared a variety of ways they found out they were Autistic. A few reported that the diagnosis of their own children led to a diagnostic process. The majority of participants had a formal diagnosis through a therapist, neuropsychologist, ADOS evaluation, or other formal means of identification. 14% of participants also reported that they were self-diagnosed. Of those who completed the survey, 86.4% reported they did not receive special education services, 9.1% were unsure, and 4.5% did report some level special education services. Special education services described included speech services, and being removed from mainstream classes. Another participant reported that she did poorly in school, but eventually attended an alternative high school and graduated successfully.

Protection of Human Subjects (IRB)

Original IRB approval for the above-described pilot study was gained on February 22, 2017 (IRB Protocol #758) in an effort to move forward with survey construction, which required input from members of the Autistic community on the construction of the survey. See Appendix G for original IRB documents with the project title *Understanding Scripting as used by Autistic Individuals.* A complete resubmission of the project was submitted to IRB upon the committee's approval of the proposal, and was approved on October 9, 2018.

Two different consent forms were created and submitted to IRB. The first consent form addressed consent for the completion of the digital online survey, and the second consent form was specific to the follow-up semi-structured interview conducted with Autistic adults and their familiar communication partners (See Appendices B, C).

All consent forms specified the potential risks and benefits of participating in the proposed research. It was described that participants may benefit from the study, as the purpose of the study is to give Autistic people a voice in describing scripting and the assets it provides. Thus, the results of the study may move forward the understanding of researchers, as well as the individuals that work with and communicate with Autistic children and adults. Participants were also given the option to apply for a $50 gift card drawing for their participation. If a participant has had negative experiences with the content of the survey, such as facing negative responses to the use of scripting and/or discrimination, they may have feelings of discomfort, which is a potential risk that was

outlined in the consent forms. It was clarified that at any time individuals may withdraw their consent and discontinue their participation in the online survey or interview at any time during the experience, without penalty. The procedures listed in the university's Institutional Review Board for Protection of Human Subjects Handbook were followed.

Online survey data was collected from a national sample of Autistic adults ages 18 and older, and all 21 received responses were analyzed. Connections to the Autistic community were utilized alongside self-advocacy organizations, professional list-serves, and the research community to recruit this group of participants (via Autism Women's Network, ASAN, university faculty, The Autistic Press, The Pacific Alliance on Disability Self-Advocacy (PADSA)).

Upon completion of the open-ended survey, participants were given the option to be contacted for a follow up interview to further discuss their use of scripting. Participants were also given the opportunity to share contact information of familiar communication partners who may be contacted for consent to conduct interviews. Semi-structured in-depth follow up interviews (Bogdan & Biklen, 2007) were conducted via a live document (Google Doc).

Procedures

The final version of the survey was distributed electronically to a wide audience (18 years of age or older), along with the survey consent form and specifics regarding confidentiality. Potential participants were recruited digitally utilizing connections the research community, self-advocacy organizations, professional list-serves. Participants were given the option to apply for a $50 gift card drawing for their participation. It was clarified that the information collected to apply for the drawing, will not be utilized in

any other way, and that confidentiality of responses will not be breached. Alternative methods of completing the survey were available to make the process accessible to individuals who use a variety of communication methods.

Upon completion of the online survey, participants were be asked if they would like to be contacted for a follow up semi-structured interview (Bogdan & Biklen, 2007) to further discuss the topic of scripting, and only then were they prompted to add contact information that would be kept confidential. Participants were also asked to refer any individuals who would be willing to consent to speaking further about scripting, individuals they consider familiar listeners and successful communication partners. Initially the procedures included semi-structured phone interviews to be conducted with participants who expressed interest in doing so and who completed the corresponding consent forms. Alternative methods of conducting an interview were made available to make the process accessible to all. These alternative methods included the follow-up interview conducted via live document (Google Doc), as preferred and requested by a participant. This alternative format was utilized by all three participants for the follow up interviews.

Using the data gained from the online interviews and semi-structured interviews, data was triangulated to address the research questions, as well as the themes that emerged through the research process.

Data Analysis

The first stage of analysis required the coding of the data collected from the open-ended digital online survey. The researcher began by utilizing *in vivo* coding, a method which utilizes the data itself to provide verbatim codes, that were derived from the

participants themselves. This coding approach is specifically appropriate for studies that "prioritize and honor the participant's voice" (Saldana, 2016, pg. 106). As the purpose of this study is to bring forth the importance of the often-marginalized Autistic voice, *in vivo* coding is most appropriate as it will utilize the *verbatim principle*. By relying on this principle, the researcher will rely directly on the words of the participations to generate the initial codes, in an effort to maintain the original meaning and intent (Stringer, 2014). As a non-Autistic researcher, avoiding researcher-generated codes during the primary coding cycle assisted in privileging the voice/words of the Autistic participants, who are so often marginalized and absent from traditional research.

Second cycle coding methods relied on *focused coding*, which identified the most frequently applied codes throughout the data, as well as the most significant codes in an effort to identify which categories of codes are most salient across data (Saldana, 2016). It is important to note that specific codes that were perhaps not frequently applied, but offered specific insight into the Autistic experience, were maintained in this cycle, in an effort to encapsulate the spectrum and individuality of the autism experience. *Invivo coding* methods resulted in data that is similarly coded, but not verbatim, as the codes are derived from the actual words of the participants. In the second cycle of coding, these similarly coded items were clustered into like groups and reviewed to develop major categories and/or themes that emerge from the data (See Table 1).

Throughout this process a codebook with clear definitions was created and maintained to ensure understanding of the meaning of each code. Data analysis began as soon as the first digital survey was received. Data was dually coded in the first and second cycle of coding if the set fit the definition and criteria for more than one code. In

an effort to maintain the original intent of the participant, data was coded on the complete sentence and paragraph level, so as to provide the most meaningful and precise data without taking information out of context.

In order to ensure that the codes fit the data, codes were added, collapsed, and expanded to reflect the information provided by the participants. New codes were applied to the entire data set, through the rereading of the online survey data and follow up interviews. When data was added to an existing code, the researcher also engaged in the best practice of *constant comparison*, where the newly coded item was compared to the data that was already coded in that way, through the use of the codebook, in order to ensure consistency across coding. First round *invivo* codes also moved away from being simply descriptive codes, and moved towards analytic and theoretical coding in the second level.

Reflective memos were also used to record changes in coding, longer definitions of codes, as well as thoughts and questions regarding the data analysis. Memoing began with the first data coding session, and continued throughout the data collection process. This included reflections on the data analysis, method, ethical dilemmas that arose, or points to clarify (Bogdan & Biklen, 2007).

To code the data, first each online survey was coded within, as a separate document, with primary coding methods. Then the surveys were coded as a whole, across participants, for a second level of coding. After the primary coding of the digital survey was complete, the follow up semi-structured digital interviews were also coded utilizing the same approach. The data was then viewed more holistically across the two data sets, survey and interview, in an effort to move towards more analytical coding. The data

generated from non-Autistic familiar listeners was coded separately in an effort to compare and contrast to the Autistic experience, as well as to prioritize the Autistic voices. As the data also addressed separate research questions, this was an appropriate way to handle this data. Table 1 below reflects the final levels of coding and sub coding after the final round of coding.

Table 1

Coding Table and Decision Rules

Code/Sub Code	Decision Rule	Data Sample
Defining: Scripting	Scripting is defined as the repetition of phrases to convey meaning.	*Scripting is the use of lines or actions from media to communicate large amounts or complex information about one's internal state, one's ideas, or for general information.*
Defining: Delayed echolalia	For some Autistic people, delayed echolalia is understood as having less communicative features than scripting.	*Repeating a sound or series of sounds for an extended duration.*
Defining: Delayed echolalia synonymously with scripting	For others, delayed echolalia is defined more synonymously with scripting.	*Delayed echolalia is not the immediate repetition of someone's words, but yet pulling out the relevant words at a later time to express oneself or an idea.*
Benefits: Communication, *"small talk"*	Using scripts to assist in communication during daily social graces, such as engaging in expected small talk.	*I don't know what to say a lot of times to people. I don't know how to make small talk or end a conversation. They think I am making a joke but really I am inserting a line that easier to recall than making up small talk or a conversation.*
Benefits: Communication, *"communicate complex thoughts"*	Scripts can also be useful for communicating more complex thoughts, ideas, or emotions.	*It's like memes, it's a quick and easy way to express and explain complex feelings and thoughts.*
Benefits: Communication, *"stressful situations"*	Autistic adults report that scripting supports their communication skills, especially when faced with stressful situations.	*I lose my ability to make words when conflict arises. I have a service dog who helps to create a barrier between me and the general public, but she is very attractive. I often have to tell people to leave her alone and let her*

		work. My most common scripts these days are to say, 'no thank you, she is working right now'.
Benefits: Comfort	Scripting can bring a sense of comfort and fun for Autistic adults. This includes the use of scripting as a form of stimming.	*I like to find good times to say lines that I like from the media, such as, 'I never asked for this'…It makes it fun for me and allows me to relate real life situations to the media that I like, understand, or with which I identify.*
Benefits: Career Success	Autistic adults find that scripting can support them not only in securing a job through improved job interview skills, but also in overall career success.	*At my former job, as a Client Service officer for the government, I had a specific way of addressing callers that I found lead to the least amount of resistance and resulted in the greatest degree of efficiency when answering questions. Making questions more specific, avoid using names and pronouns, and having handy stock phrases that I could use to explain the situation to the caller.*
Communication Partners: Response and Aftermath, *Isolation and Embarrassment*	Autistic adults report that memories of scripting bring forth feelings of isolation and embarrassment based on the reactions of their communication partners.	*I didn't communicate with anyone often as a child.* *I just remember not wanting to talk to people.*
Communication Partners: Response and Aftermath, *Negative Assumptions*	The participants reported that others made negative assumptions about them due to scripting including that the individual was retarded, annoying, and strange.	*A friend in college told me to stop saying all the Seinfeld lines because it made me seem 'retarded' and so it became a lot of whispering to myself and working to understand context to say lines*
Communication Partners: Neurology	Participants report that the neurology of the communication partner can impact the success of the scripts.	*I find that different scripts work with other autistic folks, and others work better with neurotypical people, and there's not much overlap.*
Barriers: Over-reliance	A participant recognized that at times, when scripts are too rigid, they actually cause difficulty for the individual.	*The kind (of scripts) I don't like is when I am taught that situation X always requires response Y no matter the context or how I feel. For examples, being taught to always act interested in other people and be obligated to listen and respond even if I don't care or don't like the subject or person.*
Barriers: Misinterpretation	Stake-holders reported that at times their scripts may be misinterpreted or not understood despite their best efforts to communicate something.	*Some people think I'm mocking them when I say certain things or imitate a character.*

Barriers: Pressure to Fit In	Contributors noted that they utilize scripts to fit in with what is expected, as they feel a pressure to be "normal" and blend in with others.	*As a teenager I'd model my language more on students at my school, so I'd be using the right slang and appear 'normal'.*
Familiar Listeners: Family	Family members were most likely to be effective communication partners and engage in scripting to connect with their Autistic family members.	*I communicated mostly with my siblings especially my older sister. I was very quiet otherwise. We communicated in Disney movie scripts a lot in the beginning. Watching movies together was a huge part of family quality time, a lot of sci fi and horror and Disney, and it shaped our communication from the very beginning.*
Features: Mitigated Scripts	Participants overwhelmingly agreed that scripts evolve over time, as they become more complex and variable based on experiences, thus are more subtle and more easily understood by others.	*I think often they don't' realize its scripting because it's become less detectable over the years.* *They evolve to meet the needs of my life.*
Features: Neologisms	Participants support the notion that neologisms exist among their scripts, that the surface level interpretation does not always take into account the depth of the intended meaning.	*A lot of my scripts come from literature and poetry, so they almost always have a deeper meaning. If I use the line ' take this cup from me' from Pasternak's poem 'Hamlet', I am generally referencing the whole poem in my own head. It makes sense to the person I am saying to while offering them a glass of wine, even if it sounds a little strange, but to me there is a whole underlying context that is not said: all the themes of the poem that have specific resonance for me. Fundamentally there is also an embedded subtext in the act of scripting that is key to my autistic identity: I am doing this because of who I am.*

The coding of the data was an ongoing evolution. As more interviews were coded, the codes changed in order to more accurately reflect the data. The codes changed in order to better reflect the themes that the participants were addressing across surveys. An important example of this is that originally the sub-code "fitting in" was included under the "benefits" code as I first interpreted normalization as a benefit that scripting provides

Autistic people. After further analysis and more data provided through the online surveys, it was clear that although Autistic adults did report using scripting in order to blend in with others, it also became clear that the negative implications of fitting in made it impossible to consider "fitting in" as a "benefit" of scripting. Thus, a new code "difficulties with scripting" and a sub-code "pressure to fit in" was developed.

The code "benefits" was altered continuously throughout the research in an attempt to group and organize the sub-codes to best reflect the data. Originally these sub-codes included: complex communication, engagement, less verbal when expected, fitting in, and communicate emotions that have no name. Under "benefits" the sub-code for "career success" was first coded as "job interviews" and then expanded when it was clarified that scripts provided benefits not just in the interview process, but also had a positive impact on job success as a whole. Further, originally under "benefits" comfort and stressful situations were lumped under one code, until the data showed that scripting can be used for pure fun, which did not encompass the theme of scripting when in stressful situations, thus that code was teased out separately.

Codes that addressed how scripting changes over time were collapsed across the coding process. To start, multiple *priori* sub-codes were created (ex. "More useful and realistic", "More subtle", "More fluid"). During the second stage of coding, it was noted that these changes in scripts were all related to the scripts becoming subtle and therefore more easily understood by others, thus the data was collapsed into that code.

First rounds of coding began with *priori* codes, which were direct quotes from the data. As the themes began to emerge, these priori codes adjusted in order to accurately communicate the emerging themes. Examples of this include, "appear normal" which

was an original *priori* code, which eventually became absorbed by the code “difficulties with scripting” and the sub-code “pressure to fit in”. Further, under the current code of “isolation and embarrassment”, originally the *priori* codes used were, “told I was strange” and “wild talk”, which were then grouped and evolved into the “negative assumptions” code.

The follow up in-depth interviews added more data to the previous codes, but also established a few new codes based on the new data collected (See Table 2).

Table 2

Additional Codes Based on the In-Depth Interviews

Code/Sub Code	**Decision Rule**	**Data Sample**
Special Education as Punishment	Data supports that special education can be used as a punishment when students act out.	*…For a while I would sometimes be sent to the special ed class if I was disruptive.*
Benefits: Stressful Situations, *Process difficult experiences*	Adults may process difficult experiences by scripting.	*I would also act out bits of the school day at home, especially if something had been difficult. It was sort of a coping mechanism.*
Barriers: Pressure to Fit In, *Anxiety and Depression*	There are consequences to the pressure placed on Autistics to normalize their behavior and fit in, which has a negative impact on mental health.	*Once I was about 13 or 14 I realized that people who acted ‘normal’ got the good stuff (eg. Not being treated like babies, being picked for things, having friends.) ..I thought ‘better try and fit that mold’…Mum always said I started to ‘come right’ once puberty kicked in. I became a lot more self conscious and aware of how other people viewed me…It certainly contributed to depression and anxiety during those years”* *“I felt incredibly isolated and alone. Always out of place, and as if the world didn’t even want me to exist… A lot of kids and adults would bully me, so I kept to myself most of the time…I was diagnosed with depression at age..13 or 14, I believe, they tried different medications for me, but none of it addressed the social factors contributing to it…Thought I’d die without ever having or experiencing joy or comradery or connection.*

Social Media as a Bridge	Autistic adults report that social media has a positive impact on their ability to connect with others socially.	*It got HEAPS better once I started opening up to people more, and people got to know me better when I got Facebook….”* *“It took a really long while to find a community, and the internet helped with that immensely.”*
Familiar Listeners: Pressure on Families to React to Scripting, *Normalization*	Families report that there is pressure placed on them in regards to how they react to their child's scripting, as there is an emphasis on becoming more normalized.	*…change her behavior towards being more social acceptable ways of being with other kids.*
Barriers: Scripting as Avoidance	It was reported that at times, scripting is used to avoid discussing real issues, which can be a barrier to relationships.	*“Our dad, who we also believe is autistic, would script with us as well, mostly about movies and music and comics…Though we had fun with our dad, it was difficult to talk about serious subjects with him. Like it felt like he relied on and used scripting constantly to avoid discussing any real issues, and so in a way, we could never be as close to him as we were to one another.*
Features: Mitigated Scripts, *Metacognitive Process*	Scripts change over time, and this process is intentional.	*At least for me scripting is something that I work on in order to engage…*
Types of Communication: Writing as a Strength	Autistic adults report that writing is a preferred mode of communication.	*“I think many of us prefer ‘talking’ through typing to speaking, for a variety of reasons, even if we tend to speak a lot. So we might be quieter or speak a lot less, but are very chatty typers and things, and that can shift as well depending on other factors…I think it's easier, at least for me, to type at the speed of thought than to control the mouth to form the words and then get them out.”*

These new codes, while related and connected to the data as a whole, emerged through the follow up in-depth interviews. In some instances, the new data set added a sub-category to a code already present, and in others, created a completely new code that was not established based on the data derived from the online survey.

Despite best effort on behalf of the researcher, transparency is a critical part of

the research process, to reflect on one's one biases and how they may have impacted the data collection and conclusions of this research.

Transparency

It is critical to acknowledge my personal neurology and the potential impact it could have on the present research. As a non-Autistic researcher who is attempting to highlight and prioritize the Autistic voice, it is important to me that through the data collection and coding process, the voice of the participants is put in the forefront of the research and its conclusions. The goal was to prioritize the Autistic voice, and to limit the impact of my own assumptions onto the conclusions of this research. Also, due to my more traditional special education experience previously, this is especially important to acknowledge. I was not only educated in a more traditional special education program as a teacher candidate, but also served students in segregated settings, such as nonpublic schools and the special day class environment. These experiences in both education and as a special education teacher impacted my view of the potential success of inclusion, as well as my view of behaviors that were not viewed as "normal" and "expected". In an effort to combat some of my own deep-rooted personal bias, a wide variety of research was presented in the literature review, to emphasize the Autistic voices present in less mainstream spaces. Also, through the selected data analysis processes, I prioritized verbatim coding, in an attempt to conserve the meaning and integrity of the data shared by the Autistic participants, to ensure that the results of this research reflect the initial meaning and intent and are not heavily influenced by my own interpretation. I also avoided coding on the word level, in order to accurately capture the intent of the writers and participants, thus providing context and leaving less room for interpretation.

Through this dissertation process and the reading of original Autistic auto-ethnographic essays my view and perception of scripting has evolved tremendously. As a result, the research questions and goals of the research have evolved alongside it, to the final form, which emphasizes the importance of deepening and furthering the understanding of scripting, and giving Autistic voices the priority in framing their experience. This reliance of Autistic people as the makers of knowledge of their own experience is key to the goals of this research. This includes their perspectives being included and respected in more traditional research as adding tremendous value to a research base that is heavily impacted by ableism. I have been committed to maintaining this authenticity throughout the entirety of the research process. In order to do so, I implemented research methodologies including the pilot study, which shared the survey with Autistic adults prior to disseminating it to a larger audience, and alterations were made to the survey based on their critical feedback. Also, including an Autistic writer, leader, and researcher as a part of my dissertation committee was another way to implement a system of checks and balances in order to keep my bias from having negative impacts on the conclusions of this research. Finally, the follow-up in depth interviews acted as a member-check, where I was able to share some of the initial conclusions of the survey data in order to check in with the Autistic community. Questions were framed such as, "Does this speak to your experience?" and "What would you add to these conclusions?" These steps were actively taken to preserve the influential information provided by the Autistic community through this research process and to ensure the integrity of the data.

Chapter IV and the subsequent Chapter V will both address the results of the data

collected through this dissertation process. Chapter IV will include the data collected from the online survey data, as well as will analyze this data in relation to the previous literature. Chapter V will look at the in depth interviews and the data they add to the current themes, and any new themes that arose after interviewing both members of the autism community and their familiar listeners.

CHAPTER IV

QUALITATIVE ANALYSIS OF ONLINE SURVEY DATA

The following section will address the data collected through the online survey, which will be organized and addressed by the original research questions. The results will be analyzed within each section, so as to relate the results of this study to the present literature, specifically the parallels offered by Autistic advocates[6] and writers as dissected in the literature review.

Defining Scripting and "Delayed Echolalia"

Although not initially identified as a key goal of the research, defining and understanding the term scripting, and how it relates and/or contrasts to the more clinical term, "delayed echolalia" emerged from the research. Overwhelmingly, participants identified that scripting is a form of rehearsal or planning for conversations. For example one participant described it as, "It means rehearsing conversations, or coming back to standard stock phrases to help move routine conversations along" (019). The sources for the scripts are reportedly variable, including the media, lines from similar situations, and from other people. As shared by a contributor, scripting is, "Using words, (fixed) sentences that are picked up from other persons or media to convey a certain idea, thought, feeling etc." (008). When defining scripting, the participants were unanimous in their reporting that scripting plays an important role in communication as it was

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[6] Identity-first language will be utilized throughout this work in an effort to respect the autism community based on the arguments presented by Brown, 2015.

described as "very important" (002), and was further exemplified as, "useful linking dialogue etc. that does not come naturally " (020). It was also established that scripting is complex, thus difficult to simply define, as "Scripting is the use of lines or actions from media to communicate large amounts of complex information about one's internal state, one's ideas, or for general information" (010). This research contrasts more traditional approaches, which does not recognize the term scripting, despite stake-holders clarifying that this is a term utilized by the Autistic community. Furthermore, in non-traditional spaces, in work driven by Autistic writers, the term scripting has a clear presence (Kim, 2013; Schaber, 2014) with consistent descriptions across reporters.

While their was consistency in the data regarding the definition of scripting, conversely, the data included conflicting reports regarding how "delayed echolalia" is defined in the Autistic community. While some participants were not familiar with the term, for other participants (28%) they defined delayed echolalia as synonymous with scripting, such as, "Repeating someone else's words, but not immediately. It can become a script" (013) and "Delayed echolalia to me is hearing a phrase, song or script, or word or way of speaking and it comes up later when triggered by a similar emotion, a trigger word, or situation" (014). For the majority of participants, the term delayed echolalia was understood as holding less meaning than scripting, and was repeatedly associated with repetition of sound as described, "Repeating a sound or word or phrase at a time later than immediately hearing it" (012). Similar descriptions of a repetition of sound was referenced by multiple participants in response to the term "delayed echolalia", yet was absent from the descriptions provided of scripting. Two participants referred to delayed echolalia as a form of stimming, specifically as a, "…vocal stim or something pleasurable

to say" (019). Yet another participant specified that delayed echolalia could fall into two different categories, "Repeating a phrase or something heard hours or days after hearing the thing. This can be a form of scripting for me but it's also a type of stimming" (022). What is resoundingly clear across participants is that in all definitions of scripting, there was a sophisticated level of communication support that it provided for Autistic adults. This communication support was a clear benefit to the success of the participants in social situations.

This variance between the usage and the meaning of the terms scripting versus delayed echolalia is supported by Schaber's work (2014), who agreed that the two terms have varying definitions, as she described echolalia as shorter repetitions in the form of words and phrases, whereas scripting includes longer passages, whose source is generally media related. Based on the typical usage of the term "delayed echolalia" in research and the reference to it as "stereotypic", and "developmentally inappropriate" (Shawler & Miguel, p. 112) and the lack of attention given to the benefits that it provides the Autistic community, it is not surprising that the autism community has created their own term, which is absent from traditional research, as a reclamation of terminology. Scripting, for most Autistic adults holds a meaning that is more communicative and functional than delayed echolalia, and it emphasizes and encapsulates the true benefits of this communication tool.

Benefits of Scripting

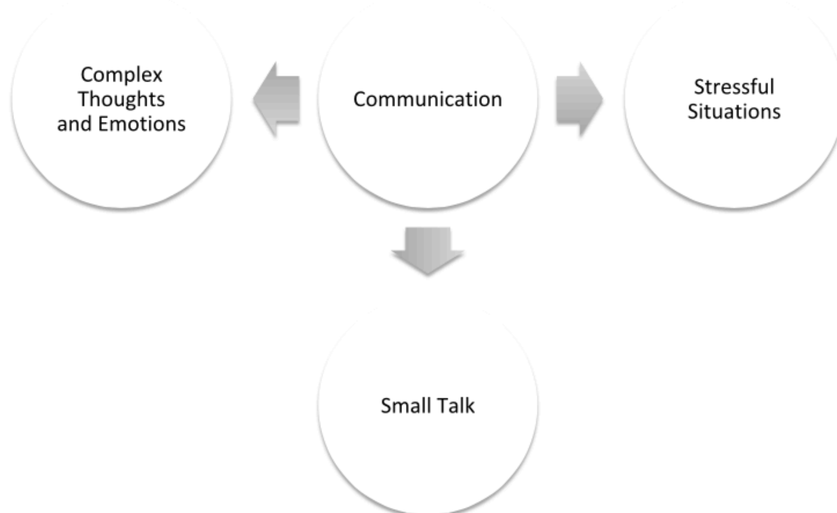
The first question the researcher attempted to address was to identify the benefits that scripting provides the Autistic individual. Participants reported a wide variety of positive benefits scripting provided throughout their experiences, both as children and adults.

Most participants concurred that as time passed, scripting became more beneficial to them as it evolved. The overarching benefits identified included **communication, comfort, and career success.** The data showed that the results of this research question overlap with the second question proposed by the researcher, which looked to understanding the communication features of scripting, as the survey participants reported a wide variety of communication purposes that scripting serves, thus both questions will be addressed in the following sections.

Benefits: Communication, "I don't know what to say a lot of times to people"

Communication is a vital reason Autistic adults use scripting. Adults report that it assists them in engaging with others for the purposes of **small talk and to communicate complex thoughts, including the expression of emotions.** Further, it is beneficial when faced with **stressful situations** (see *Figure* 1. for visual representation).

Figure 1. The benefits of scripting for communication purposes



Small talk

Small talk can be difficult to engage in, but is seen as pivotal in society. As reported, this social requirement can cause difficulty for Autistic adults as, "… I don't know what to say a lot of times to people. I don't know how to make small talk or end a conversation"(005). This type of difficulty was reported by multiple participants, who agreed that expected social graces, especially with individuals that are lesser-known present difficulty for Autistic adults. Participants reported feeling uncomfortable and needing a, "clear exit from the conversation" (019), which scripts are able to provide. A contributor described that scripts derived to address small talk were often generated from what others say, and that there is an effort made to avoid saying anything inappropriate, thus common phrases get picked up and incorporated into scripts (004). Another participant added that scripts for small talk can be helpful to "maximize efficiency when conversing with strangers, acquaintances, and service staff or customers/clients" (019). The data show that this type of small-talk scripting is often utilized in situations where the communication partner conversing was less familiar, as described, "I am most likely to resort to scripting in unfamiliar situations, when speaking to people I don't know well, or in small talk. In more intimate situations I am less likely to use it, although I still resort to it at times" (017).

At times Autistic participants report that their small talk scripts are met with a laugh, even when it is not intentional for example, "…I don't know what to say a lot of times to people. I don't know how to make small talk or end a conversation. They think I

am making a joke but really I am inserting a line that's easier to recall than making up small talk or a conversation" (005). This approach of using a laugh to end a conversation was addressed by multiple participants, "I use it successfully a lot now. Just today, a coworker asked me a question and I said, 'I'll be here all week', and he laughed because it was funny to him. He got my joke which was really a line to help me end the conversation" (005).

This use of scripting as a support for social expectations, such as small talk, is supported by the work of Kim (2015), as she described in her work that there is an "unspoken pressure" placed on Autistic people to keep a conversation moving along and she described the use of scripting in this context as an avenue to "grease the social wheels" (pg. 1). In more traditional research, the function of scripting as a means to engage in social niceties, such as small talk, have not been explored. This may be related to the data that supports that scripting changes over time, and becomes more nuanced and specialized, and thus perhaps listeners do not identify small talk scripts as scripts, as Autistic adults are utilizing it as a tool to fit in and thus, "any scripting I use would ideally not be recognized as such" (018). This conclusion is supported by Schaber (2014) who stated that if the person listening does not understand the origin of a script, they may not recognize the script as such. Scripting serves a function beyond just small talk, and can also support Autistic adults with more complex communication.

Complex thoughts and emotions

In more complex, higher-level communication exchanges, Autistic adults report that scripts can be beneficial to use as a shortcut. One contributor related it to the use of a meme, "a quick and easy way to express and explain complex feelings or thoughts"

(021). Complex feelings may be difficult to express using single words or phrases, and thus are borrowed and become scripts, as a participant described, “They are kind of like shortcuts for communicating a lot of ideas at once, emotions that have no name and can pack complex information into easily digestible bits” (010). Using these scripts to express this type of complex thinking was described as, “easier” for Autistic adults, as, “It’s easier to communicate complex thoughts by proxy…” (003). One participant shared they may use, “words or idioms from movies, memes, etc. without being able or have the choice to put it on different terms” (008). This is a critical point, as this contributor provides an example of when using a script is their only option in regards to sharing a complex thought with others. This phenomenon of reliance on a script when no other communication was feasible was reported by multiple participants and will be further explored.

Communication partners impact the effectiveness of communication, thus when discussing more complex communication it is also important to consider how the communication partner is able to read and interpret the script. The level of communication and understanding may also be impacted by the neurology of the listener. This theme emerged from the following, “Most people are familiar with the things I’m referring to and mimicking, and especially with other Autistic people, we understand it on several levels of meaning rather than simply one” (010). This point recognizes that the script being utilized for more complex communication may be interpreted differently depending on the listener, and that some of the complexity may be lost depending on the understanding of the original source, as well as the neurology of the listener. The impact of the neurology of the listener will be further explored when considering the impact of

communication partners in a subsequent chapter.

While the participants clearly outlined the benefits of scripting during typical communication exchanges, such as small talk and when sharing more complex thoughts and emotions, they also identified that their ability to communicate successfully can be impacted by stress.

Stressful Situations

Stress can impact communication, and thus is an opportune time to tap into the benefits of scripting for Autistic adults. Stressful situations defined by the stake-holders of this research include; when **anxiety is present, in times of conflict, and in novel situations**. The participants described that these stressful scenarios can lead to overstimulation and shutdown, and scripting assists to avoid that. Overall participants agreed that having scripts readily prepared during stressful situations can decrease anxiety. One participant described:

> I lose my ability to make words when conflict arises. I have a service dog who helps to create a barrier between me and the general public, but she is very attractive. I often have to tell people to leave her alone and let her work. My most common scripts these days are to say, 'no, thank you, she is working right now'…(009)

In situations of conflict, participants shared the sentiment that their ability to communicate effectively is reduced. They also note that having standard responses in stressful situations may help to avoid negative consequences such as shutting down or saying the wrong things. Saying the wrong things occurs more prevalently during times of stress, as described below:

> I use it in all novel situations or situations that I don't know how to handle or whenever I have to talk to someone who makes me nervous or when I have to override my natural desire to use a certain phrase (like not saying I want to kill someone when I'm angry which is my natural response learned as a child). (014)

This description of the natural desire to utilize a phrase that may lead to misinterpreted intent is a theme that arose across research questions. Many Autistic adults report using scripts to avoid misunderstanding.

There are other identified areas that may be anxiety producing, and thus scripting may be utilized. This includes communicating with a bully as one participant described, "I use them a lot in situations that are frustrating so like with co-worker bully I just rely on my scripts so I don't give her any ammunition" (014). Scripts can help reduce anxiety when dealing with a difficult person, but also when dealing with a difficult scenario, such as talking on the phone. One contributor noted, "I usually use them when calling on the phone, or talking to a receptionist or shopkeeper etc. as without having run through the potential conversation in my head I'm too anxious to proceed" (016). Both experiences speak to the benefits that scripting provides when anxiety is running high, and how scripting can be a tool to apply to stressful situations.

This phenomenon of utilizing scripting to combat stress and anxiety is supported by the research conducted by Sterponi and Shankey (2013) and their work with Aaron, who often utilized scripting as a mechanism to diffuse a stressful situation. He often successfully altered stressful communication with his mother by inserting a script and thus relieving the pressure of the situation. Similarly in Prizat's work (2015), Eliza utilized scripting as a reaction to feelings of stress or anxiety, as she adopted the phrase, "Got a splinter!" as script to express feelings of stress (as this was a memory that elicited anxiety), as well as in response to a stressful situation.

The data support the notion that communication is fluid- it falls on a continuum for the individual, but is also impacted by context, the situation, and the listener. During

times of stress, participants related that their ability to communicate lessened. Participants described scripting as a vital form of communication when they have no other method of sharing their experience, for example, "I also use words or idioms from movies, memes, etc. without being able or have the choice to put it on different terms" (008). In essence, to silence the script, is to silence the Autistic person. The stakeholder further explained, " Yes it's a godsend when I'm less verbal than is expected of me. When its not too bad, there are some scripts I can resort to" (008). Another participant agreed with the varying level of spontaneous communication depending on the context and described:

> It helps me respond more authentically when stress, conflict, or social anxiety tend to steal my ability to make words on the spot. The big problem is that the anxiety needs to be anticipated AND the situation as well. I'm often left completely nonverbal at times when I most need to be able to speak" (009).

This reference to the impact of anxiety on communication is supported by Schaber (2014), who also recognized that when in situations that were emotionally charged there are times when she finds herself unable to communicate via novel thoughts, and thus utilizes scripting to share basic wants and needs. Kim (2015) also described that using scripts can be a saving grace when lost within a conversation, she described, "…(we) will often unconsciously default to scripting or echolalia simply to conceal that fact that we can't find the right word or we've lost a thread of a conversation" (pg. 1). While scripting can be elicited by a response to something stressful, it can also be utilized for pure enjoyment and comfort as suggested by the data.

Benefits: Comfort "Like a game of catch with a ball"

Through the online survey data, Autistic participants expressed that scripting can be

utilized for pleasure, as it is both comforting and fun. This comfort included reference to vocal stimming, but also more complex scripts that elicited feelings of fun and laughter.

As one participant described,

> I like to find good times to say lines that I like from the media, such as, 'I never asked for this'… It makes it fun for me and allows me to relate real life situations to the media that I like, understand, or with which I identify" (007).

In this example, the script is borrowed from the media, and it utilized in conversation for the participant's own enjoyment. This enjoyment is further described by another contributor who notes her successful scripting with her siblings, "It helps us plan, cheers us up and improves our moods…" (010). This can be viewed in contrast to a different form of scripting for fun, which may include vocal stim which can be described as, "a vocal stim or pleasurable thing to say…simply for pleasure/soothing" (018). In some cases, scripting can serve dual functions by bringing forth pleasure by the repetition of the phrase itself, but also from the successful social experience that utilizing it brings forth. As one participant noted, "Generally it was frequently successful and when it was it produced the pleasure both of repeating a pleasing phrase, something satisfying to say, while simultaneously enjoying the pleasure of a successful social interaction" (018). While scripting may have many uses that are relative to the social world that the Autistic adult is living in, it is also important to acknowledge the internal need to script and the validity in that.

Higashida's book (2007) strongly supports this theme that emerged from the research, as he discussed how communication for Autistic people is effortful, but this difficulty can be alleviated through the use of repetition of familiar phrases. He refers to use of scripts as "great fun" and stated that repeating questions he already knows the

answer to can bring forth pleasure as, "it's playing with sound and rhythm" (pg. 11). Further, Kim (2015) addressed how stimming can have positive impacts beyond just fun, but to assist with concentration and self-regulation. Beyond just fun and games, scripting provides real support for Autistic adults in the workforce, as reported through the online survey.

Benefits: Career success and the "Greatest degree of efficiency"

A variety of participants reported job related successes with scripting. This included both preparation for job interviews, and overall career success. 32% of participants discussed this as a positive benefit of scripting in their adult life, for example:

> …A job interview I remember. I knew I would be asked a question along a certain line and I carefully scripted a meaningful response. It was something I believed in deeply, and I took the time to carefully craft and draft the exact response I wanted to communicate- instead of relying on what would come to me in the moment… (009).

Participants acknowledged that they were more successful in their job interviews when they created scripts for success. Similarly, scripting was reported to assist in success across a variety of fields including teaching (both at the elementary and at the college level) and government work. For example:

> I have always scripted conversations with others, particularly work conversations and phone-calls but often just social ones too. For example, in work, I will often draft a comprehensive email containing all the points I want to make. I will then go back over it adding in niceties, recalling what personal information I know about the person and adding some of that. I will also consciously recall the person's position, seniority in relation to me and perhaps bring to mind our last conversation. I am now ready to call them and am confident that my tone will be correct. If the conversation is likely to be difficult or I have to deliver bad news, I will rehearse aloud (020).

The example above shows the complexity of scripting, and how the preparation process can assist Autistic professionals in being successful with their social communication,

given high stakes. Within this research question, again emerges the concern regarding offending or saying the wrong thing in the work place. Scripting is used to counteract this concern, and when asked how beneficial it is a contributor stated, “Hugely. If I don’t script in a professional situation, I may well hit the wrong note and/or inadvertently offend. It’s not catastrophic but it’s not ideal” (020). It was reported that scripting helps to control the view others hold, for example, “I assist at graduation every year- I have a job and help people to enter and find their table. It’s all scripted for me. People think I am polite, helpful, and friendly” (002). This respondent addressed the use of scripts to shape the way the customers view them in an effort to put a positive foot forward. Going beyond the avoidance of offending others in the workplace, participants described how scripts could assist in productivity and effectiveness in the work place including,

> At my former job, as a Client Service officer for the …Government, I had a specific way of addressing callers that I found lead to the least amount of resistance and resulted in the greatest degree of efficiency when answering questions. Making questions more specific, avoid using names and pronouns, and having handy stock phrases that I could use to explain the situation to the caller (019).

For some, like the stake-holder above, creation of their own scripts emerged from experience with what was successful, while for others, work-place scripts emerge from the modeling of other more senior staff, for example,

> I teach young children music- this can be really nerve wracking, especially when managing behavior. I find it hard to tell children off when necessary- so I tend to model my language on what our programme leader says in those situations. I also model on what my teachers said to me at that age- but only the ones who respected me as a person (004).

This example shows how scripting can be effective during stressful situations in the work place, as this contributor wrote about dealing with difficult behaviors of children during music class. It is important to note the reference to adopting scripts from their own school

experience, and also the recognition that not all teachers show respect, and thus would not make respectable scripts.

While the benefits of scripting are clear, one cannot look at scripting as a form of successful communication without considering the listener. As communication is a two-way street and involves the interaction between individuals, it obviously cannot occur in a vacuum. Thus, the listener is a factor to consider in the equation, and how other's respond to scripting is a critical element to consider when discussing Autistic communication styles.

Communication Partners: How Others Respond to Scripting and its After Math

The third research question attempted to uncover the impact of communication partners and familiar listeners on the effectiveness and use of scripting. The research overwhelmingly supported that when reflecting on childhood use of scripting, participants identified that while scripting provides a multitude of purposes for them, memories of using this communication strategy brought forth feelings of **isolation** and **embarrassment**. This theme of negative responses and assumptions made about Autistic adults who script, was very well supported across participants. Specifically, the negative assumptions made by others included that the individual was **retarded, annoying, and strange**.

After Math: Isolation

Feelings of isolation in childhood were commonplace for the stake-holders that completed the survey. Comments such as, "I didn't communicate with anyone often as a child" (001), "They made me feel embarrassed and ashamed of it" (003), "I just remember not wanting to talk to people" (002), and "I was not really communicated with

in childhood" (008), are all examples of how the reactions of others to the scripting of the participants brought forth feelings of loneliness and remoteness. One participant added, " I was not really communicated with in childhood, it was more being communicated to" (008). This example exemplifies isolation, as if even when communicating with others, the participant didn't feel like a true participant, but instead a receiver of information. In contrast to the overwhelming feeling of loneliness, there were minimal examples of positive reactions to scripts. Based on others' reactions to scripting, the participants felt that others made assumptions and had negative views of them.

After Math: Negative assumptions

Contributors described the reactions to scripting, comments, and assumptions of others as overwhelmingly negative. This theme of scripting being negatively named by others is very strong in the data, as 67% of participants reported similar memories of these negative reactions. References to being retarded, annoying, and strange were strongly prevalent in the data. These negative responses could be equated to bullying due to the level of shame it brought forth upon the participants. For example, one participant reported, "A friend in college told me to stop saying all the Seinfield lines because it made me seem 'retarded' and so it became a lot of whispering to myself and working to understand context to say lines" (005). This example shows that these negative responses forced the person to adapt their behavior and abandon a strategy that provided multiple personal benefits. Another contributor described the constant redirection to stop scripting that they experienced in childhood, "They thought I was annoying, and constantly asked me to stop…They made me feel embarrassed and ashamed of it" (003). While individuals were aware that their scripting was different, it was the reactions of others that were

internalized such as, “Sometimes people think I’m stupid…People think it is weird when I have a song for every situation and song lyrics just pop out (echolalia)” (014).

Another participant stated that her scripting was referred to as “wild talk” and stated, “people were disturbed by my ‘wild talk’ and got very worried (mainly because I would physically hurt others at school as well)” (004). The negative reactions reported varied from judgments such as, “they think I’m just flaunting my knowledge of geek culture, or being quirky” (003), to others being offended by it and seeing it as, “…weird or annoying or saying that I shouldn’t be a fan of such things (especially obscure stuff)… They get offended sometimes or other times tell me I’m random, weird, need to be original, etc.” (007).

One participant discussed the difficulty of never feeling they could do anything right, as scripting was viewed negatively, but when they were unscripted, they were also judged harshly.

> Hmmmm. I don’t think my parents ever understood my scripts. I think they found them perplexing and maybe embarrassing. They may have been perceived as a falseness or an insincerity. But by the same token, when I am unscripted, they consider me too serious, too harsh, too intense…. I sometimes feel embarrassed by my daughter’s scripting and feel impelled to stop her. I suspect that is a result of experiences in my own childhood but have no clear memories of it (020).

This inability to please others regardless of using scripts or not, is a critical result of the research, it also ties into the intense need reported by Autistic people to fit in. Clearly there is disconnect between the multitude of positive supports that scripting can provide, and how unfamiliar listeners respond to scripts. There is a consistent pattern of participants altering their behavior to please others and fit in, and ignore their own personal needs.

The isolation and negative reactions to scripting are directly linked to the push to move towards a social model of disability, as the view is society itself is disabling the individual, and, isolation and exclusion are the true disabling factors impacting disabled individuals (Haegele & Hodge, 2016). Society creates these barriers, which then result in difficulties using a clearly effective communication strategy for Autistic adults.

Barriers with Communication Partners

Along with the multitude of positive ways that scripting serves the Autistic stake-holders in this research, and the overwhelmingly negative responses and assumptions made by neurotypicals, especially in their younger years when scripting was less nuanced, emerges a theme around the difficulties that arise with scripting. These reported barriers that surfaced with communication partners and the use with scripting include an **oppressive over-reliance, being misinterpreted, and a pressure to fit in**.

Barriers: Over-reliance on scripting

One participant addressed that at times an overreliance on scripts can be stifling, especially if taught simply and without understanding of the context or feelings of the person using the script. This is described as,

> The kind (of scripts) I don't like is when I am taught that situation X always requires response Y no matter the context or how I feel. For example, being taught to always act interested in other people and be obligated to listen and respond even if I don't care or don't like the subject or the person (007).

The above experience emphasizes the importance of the complexity of scripting, and if using scripting as a teaching tool, this complexity and nuance needs to be taught as well. Also, when discussing how to utilize scripts in different environments, the complexity of communication must be taken into consideration, which includes the thoughts and the feelings of the Autistic person. Without that consideration, using

scripting as a tool can be stifling, and can teach children to ignore their own needs and wants, feeding into the "normalization" of the Autistic child.

Barriers: Misinterpretation

Scripting, although often used to assist Autistic adults in being understood, can also lead to misunderstanding in certain circumstances, for example, "I often find myself in a situation where I've bent over backwards to try to explain myself, only for the listener to come to a different interpretation of what I said" (008). Another participant agreed that at times scripts are not understood as intended due to the fact that, "…the person I am scripting to does not necessarily get the reference of how it links to what they have said" (017). When this occurs, one contributor shared, "If they don't get the reference, then they may simply go on about their business or call me weird" (010).

In other circumstances, certain scripts may lead to others taking offense, "Some people think I'm mocking them when I say certain things or imitate a character" (007). This misinterpretation of being "mean" was addressed by quite a few participants, and some discussed how it led to alternations of their scripts over time in an effort to avoid this assumption. Another participant noted that, "Occasionally people think I'm mocking them because I will often copy their inotations and the like without realizing I am copying" (014). In this instance, it was the way the script was delivered that was misinterpreted, due to unintended copying of the voice of others.

At times, the reliance on scripting can also be misinterpreted, as others are not able to see the value that the script is serving the individual. For example, "My ex-husband and children accuse me of being false and manipulative because I have to preplan what I say…I may be odd. And I have a disability. But I am not evil or

manipulative because I need help making words" (009). Another participant agreed that in intimate relationships, the intention of scripting may be misunderstood as, "My husband will sometimes criticize me for giving short responses, and will sometimes get angry if he feels that I'm going through the motions of a conversation with him" (019).

At times the style of scripts may not fit mainstream expectations and thus the style of speaking stands out, as noted, "Sometimes when I use certain words they think I'm strange or arrogant, others like my use of slightly outdated or more formal language" (008). The above outlined difficulties with scripting ties in with the pressure that the participants feel to normalize their communication style and feel a sense of belonging in a heavily neurotypical world.

Barriers: Pressure to fit in

Autistic stake-holders report that using scripts is a tool to assist them in fitting in with their peers, as they can use scripts that align with what is popular or expected. The data consistently supported a need to be viewed as "normal" and an intense pressure to meet the expectations of others. For some, this seemed to be particularly important during adolescence, for example, "As a teenager I'd model my language more on students at my school, so I'd be using the right slang and appear 'normal'… Later I started using the slang I heard/saw on the Internet…" (0x). The sources of these scripts are important to note, as multiple participants discussed utilizing phrases from specific sources, such as those who were looked up to or idealized. "I adopt accents, phases, and whole speeches from people and media, especially those I admire" (010). Further, certain individuals would become the source for scripts as described by another contributor, "I would often copy my friends' voices in primary school- especially if I thought they were 'more

special' than me somehow. My parents often discouraged this, saying I should talk like myself" (004).

The pressure to say the right thing, and use the correct script in certain circumstances to please others, can be a huge barrier to enjoying life, as one participant explained the effort to let go of some of the need to fit in,

> I have started to assert my own opinions more and follow expected/taught social scripts less. I got tired of how I was missing out on life because I was so focused on saying the right thing at the right time and not being 'awkward' that I was missing out on the actual context of what was going on, and people were calling me dumb and robotic, while others still tell me that I'm not following the social scripting right and need to try harder" (007).

This dichotomy of on the one hand trying to meet the needs of some by using predictable scripts, and then being criticized by others for being too predictable, is further described as,

> My family and friends often told me to stop and to say normal and boring social scripts instead. Like I can't tell someone what they say is 'fascinating' and imitate Spock when I say it. I have to just say a polite and trite, 'That's nice' and do mundane expected stuff. They said it's confusing when I make inside references too because most people don't know what I'm referencing (007).

Further analysis regarding whether fitting in actually provides benefits to the Autistic adult, or further exacerbates a need to become "less Autistic" and fit into a normalized world is warranted. While some level of normalization may be typical for all in younger years, Autistic participants who completed the survey referred to creating a "persona", as well as copying phrases from those who were "more special", which brings forth reason for concern, assuming that the individual themselves is not worthy enough and thus must create a persona in order to be accepted by others, assumingly neurotypical peers.

Sibley's work (2013) supports this pressure to pass as neurotypical when she described how this intensity in her case actually increased with age as the expectations in

social situations became more complex, “Talking too much, not enough, oddly? Gets noticed. Not catching nuance? It shows. Echolalia? Stands out…There’s nowhere to hide” (n.p.). Kim equates this pressure to social conditioning and explained, “…we learn (this) as a part of learning to pass for ‘normal’” (pg. 109). The effort to pass as “normal” is exemplified when communicating with unfamiliar listeners specifically, while by definition familiar listeners are accepting of scripting as a communication style, and utilize it as a tool to connect with those with autism.

Familiar Listeners

Familiar listeners [7] understand that engaging in scripting along with Autistic people can assist in making connections and building relationships. While this was a focus of the researcher and addressed in the research questions, few contributors addressed this directly through the online survey. Those that did (14%), specified that it was family that was most likely to engage in scripts alongside them. Examples of this successful scripting were solely familial among this research, including a father, siblings, and mother. One contributor described whom she used scripting with for positive interactions:

> My Dad- we would play fantasy games all the time, in which I’d speak like TV and movie characters. He understood this as normal child’s play. He was worried about the ‘wild talk’- wrote a lot about it in behavior records for psychologists. But he was still interested in what I had to say in the

[7] *Familiar listener* is defined by this researcher as individuals who assist in understanding and conveying the meaning of a script (Prizant, 2015), who do not treat scripting as inappropriate behavior, and use scripting in an effort to connect, communicate, and gain the attention of their child (Barrow & Tarplee, 1999).

> ‘wild talk’- he’d ask me about the ‘evil plans’ I’d write, and keep in a ‘plans box’. (004)

In this example, despite some concerns regarding the use of scripting, the father was able to connect with his child through this type of play. He recognized the importance of this play on development, and he encouraged this by showing interest, and interacting on the level with his child. Similarly a second participant described positive interactions with family as,

> I communicated mostly with my siblings, especially my older sister. I was very quiet otherwise. We communicated in Disney movie scripts a lot in the beginning. Watching movies together was a huge part of family quality time, a lot of sci fi and horror and Disney, and it shaped our communication from the very beginning. (010)

The point that using Disney scripts as a way to communicate was utilized often “in the beginning” insinuates that it changed over time, and that by using the scripts as a bridge, communication was able to expand further. Also, in this example it was recognized that to build relationships family must engage in one another’s shared interests, which in this instance included movies and scripting. In the final example of family successfully supporting scripting, a contributor discussed how scripts played into her and her mother’s interactions, “My mother generally played along and would respond with a script from the same context or in the same vein. Although she was not diagnosed, I suspect that she was also Autistic” (017). This quote speaks to not only the utilization of scripts to have back and forth communication and connection, but also circles back to how the possible neurology of the partner could impact the exchange. This research question and the concept of familiar listeners will be further explored in the subsequent in depth interview order to more deeply explore the impact of the familiar listener.

Influences on Parent/ Familial Responses to Scripting

One of the questions addressed by the researcher included an attempt to understand the pressures that are placed on others in regards to how they react to scripting. The responses of the participants on the digital survey did not directly address this subtopic, thus it will be followed up with in the in depth interview with the familiar listeners identified by Autistic participants in the subsequent chapter.

The results of the current research are supported through Steigler (2015), whose work recognized the importance of the familiar listener within more traditional research. The connection of family as familiar listeners was also developed by previous research (Sterponi & Shankey, 2013; Barrow & Tarplee, 1999), as family members were often relied upon to provide the context and meaning for scripting when the researcher was unable to do so.

Features of Scripting

Two features of scripting that were supported in more traditional research included “mitigated echolalia”, or the alteration of scripts over time, and “neologisms”, scripts that have different meanings for the listener and Autistic communicator. As a part of the goals of this research, the researcher attempted to ascertain the point of view of the Autistic stake-holders to determine if in fact these are features of scripting that are recognized within the community.

Evolution of scripts over time

The researcher attempted to discover if evolution of scripting over time, or mitigation, is a feature of scripting according to the Autistic community. The data from the digital interview strongly supported that **scripts evolve over time to fit new**

experiences. Respondents shared that scripts become more complex and variable, which makes them more useful in day-to-day life. As scripts evolve they become more subtle, and thus more easily understood by others.

The majority of respondents reported that their scripting later in life went unnoticed as, “I think often they don’t realize it’s scripting because it’s become less detectable over the years” (008). As many are reported using scripting as a tool to “fit in”, the goal is for the scripts to go unnoticed, as one stake holder reported, “Because I’m a heavy masker, any scripting I use would ideally not be recognized as such. Hence I would be saying things that are directly relevant and easy to understand on the face of it” (018).

Overwhelmingly, the participants agreed that their scripting has changed over time. Experiences and reactions to scripts lead to this evolution. As one participant eloquently stated,

> They evolve to meet the needs of my life. When I get caught saying things I do not wish to say (saying yes creates less conflict and requires no explanation and elicits no scrutiny from others- but is very bad for ones mental health when you really mean no), I usually make an effort to create scripts around those things (009).

Based on the contributors’ responses, this idea of “mitigated echolalia”, or scripts that evolve over time, is obvious. Many responses to the question posed around if/how scripts change over time, began similarly to the following, “Of course. They get more nuanced and more complex as I develop experiences with them working or not working” (014). An increase of the complexity of scripts over time was supported by multiple participants, “Often, several scripts will combine into ever complex arrangements, allowing much more information to be communicated in brief sentences…” (010).

Autistic adults recognize that the adaptation of scripts is key to success of the scripts, and also heavily tied in with the continuous effort exerted to not stand out as different, or other.

The work of Roberts (2014) supported the importance of mitigated scripting and how changing scripts can assist in fitting scripts into different contexts and scenarios, in order to convey a more universally understood message. Autistic adults seem to have internalized this message to some extent, as the above referenced participants discussed their ongoing efforts to be understood. "Diary of a Mom" also described an example of her daughter going "off script", and while not an example of altering a script for the benefit of being understood in this context, it supports the idea that scripts are not static and adjust based on the linguistic changes of the speaker. This is also an example of how the attitude and approach of a parent can impact the level of success and comfort with scripting.

Neologisms

An area considered by the researcher was whether scripts have more in depth and/or different meanings for the Autistic individual than to an outsider or a less familiar listener. Multiple participants embraced the fact that they use scripts that may come across one way to outsiders, but actually are a "complicated social device", such as,

> 'How's it going?' is a phrase I picked up (somewhat) from the anime Death Note. I considered it a useful phrase, as it's commonly used, it sounds natural and casual, and it makes others feel like you're interested in them, and not being self-absorbed. To others it just sounds like I'm being normal and making small-talk when I say 'how's it going', when actually I'm using a complicated social device that I picked up from a random anime character! (004).

Another participant agreed that often their scripts are interpreted on a surface level, although their intent has much more depth:

> A lot of my scripts come from literature and poetry, so they almost always have a deeper meaning. If I use the line 'take this cup from me' from Pasternak's poem 'Hamlet', I am generally referencing the whole poem in my own head. It makes sense to the person I am saying to while offering them a glass of wine, even if it sounds a little strange, but to me there is a whole underlying context that is not said: all the themes of the poem that have specific resonance for me. Fundamentally there is also an embedded subtext in the act of scripting that is key to my Autistic identity: I am doing this because of who I am. (017)

An important take away from this data is that although scripts generally may be understood by listeners, the full intent and meaning of the script may be lost. This is due to the fact that scripts may serve a purpose on the surface level, but may also in actuality have a more in depth, sophisticated meaning as a whole that is not easily understood.

This result of the data is in contrast to the more traditional research base. While neologisms are recognized in the research that discusses scripting (Prelock, 2013), the emphasis was placed on scripts that are misinterpreted due to having different meaning for the Autistic child than perhaps for the listener. Prelock defines these as linguistic idiosyncrasies, and Kanner (1943) with his description of Donald and the meaning attached to the word "yes" consistently referring to wanting a ride on his father's shoulders. Through the data collected in this dissertation, it is clear that for Autistic adults, whose scripts have evolved from their childhood scripts, neologisms are more complex, and can have dual meanings for the speaker and the listener.

Summary

It is clear through the rich, and detailed information provided by the participants of this study, that they have much to share with the research community about the communication and personal benefits of scripting. As a community who is often silenced, and forced into a process of normalization in order to appease the needs of a neurotypical world, the efforts and bravery taken to speak out on this topic is important to note.

Historically, the cognitive authority has given to scientists and doctors when it comes to understanding autism and communication.

When given the opportunity to speak their own truths, the participants were able to paint a very clear picture of the benefits and difficulties that arise with scripting. The participants overwhelmingly agree that the barriers they face are the isolation and exclusion put on Autistic people, which are the real disabling factors (Haegele & Hodge, 2016). Scripting as a benefit that aids in communication helps to challenge the notion that behaviors that are “different” or “unexpected” are inherently bad, and thus support the view of autism as a disorder. As the neurodiveristy movement works to change this way of thinking, the benefits of scripting as reported by the stake-holders in this research, support this notion that autism should not be, “misconstrued as being essentially a set of ‘social and communication’ deficits” (Walker, 2014, pg.3). Instead, the data provided by participants clearly outlines the complexity of scripting, and how it acts as a tool for Autistic adults, a tool that is shaped and improved over the years based on experiences.

CHAPTER V
QUALITATIVE ANALYSIS OF IN DEPTH INTERVIEWS

In order to take a more in depth look into the relationship of familiar listeners and the success of scripting as communication, follow up in depth interviews were conducted with three participants, after the online survey data was completed. The following participants, Olivia, and her father Richard were contacted, as Olivia identified Richard as a familiar listener, and both were open to participating in further research. Zackary also showed interest in a follow up interview, and the results of that are below. The emphasis of the follow up interview was to clarify and build upon some of the responses from the online survey, as well as get feedback and experiences related to the themes that emerged through the coding of the initial online survey data. This follow up worked as a member-check with the two Autistic participants, who gave feedback regarding how some of the conclusions of the research related to their own experiences. Further, the exploration of the listener's impact on scripting was emphasized, as this research question was not fully addressed by the survey responses. These interviews were conducted in written form, using a shared document (Google document), updated in live time, as opposed to a phone interview, based on the preference of the participants.

The Pressure to "Try and Fit that Mold"

Olivia reported being diagnosed with autism at the age of 7. She also had experience in special education in New Zealand. While she reported that she didn't have much memory of school, her special education experience included the support of teacher aides at school, IEP meetings, and visits to the special education class. She spent the majority of her day in a mainstream classroom and reported a variety of challenges within

the school setting, which ultimately led to her parents decision to homeschool her. She recalled,

> …There was a period when I was homeschooled, and for a while I would sometimes be sent to the special ed class if I was disruptive. I was definitely more relaxed when I was homeschooled, and I enjoyed being in the special ed class sometimes, but I also found it scary because the teacher was a bit strict, and the other kids had meltdowns a lot. I enjoyed the activities though.

Olivia further explained that homeschooling occurred for a period of time due to her difficulty at school that resulted in aggression when she was younger. She associated more positive memories with the school she attended after homeschooling, and attributed her success to the change in environment. She reflected,

> The aggression was a thing since playcenter (preschool), and got much worse once I started school. I'd hit kids, pull their hair, etc. Once it got REALLY bad and dangerous (I was about 6) and that was when I started homeschooling. It was at my next school (a much better school) that they actually HAD a special ed class- and knew more about how to deal with autism. The violence persisted for about 2 years at that school, and then stopped altogether. I was a lot happier there.

Olivia recalled in detail how her experiences changed over time, and how the pressure to be "normal" impacted her across environments. This result was parallel with her responses from the digital survey, but she was able to share more in depth experiences through the in depth interview. She identified that her scripting mostly occurred at home, when she was able to be herself and take off the mask that she wore in public. This is important to note as Olivia was able to mask her communication differences when in the context of school, but found safety in her home environment where she could be her true self. For example,

> I tended to let it all hang out at home – I'd put on my normal mask at school, and then do all the things I was told off for at home. One of which was play-acting and when I was considered to old for it. I guess I wasn't really told off-

> just viewed weirdly. I would also act out bits of the school day at home, especially if something had been difficult. It was sort of a coping mechanism.

Olivia saw home as a place that she could be herself, and take off the mask that she showed the world. She also specified that some of her scripting, which she refers to as "play-acting" was a reenactment of what occurred during her school day, especially when she was faced with a stressful situation. She would develop scripts around her experience and role-play with her father when she got home after school, often asking him to play the role of her, while she interacted as the teacher/therapists that she had encountered throughout the day. When asked about current pressure to fight her neurology and put on a "normal mask", Olivia stated that even in her adult life, she continues to feel this pressure. She also identified the weight and stress that the process of appearing normal puts on her.

> When I was living with my boyfriend at the time, he didn't understand why I was bubbly around people I didn't know as well as him, but grumpy and unfriendly around him. I had to explain that I was tired at the end of a long day of acting 'normal' and needed alone time. I called my mask my 'retail face'- like when you work in retail and have to act nice to awful customers. I haven't worked in retail, but I feel like life can be sort of similar.

Olivia felt the consequences of this pressure to fit in, pressure to be normal, and her data includes multiple references to masking her autism, or wearing a "retail face". Consequently, she also described a period of her life where she struggled with anxiety and depression. While she reported that some of her difficulties could be relatable to typical adolescence, the pressure that she felt because of her disability was extremely heightened as a teenager. She actually reported that she began to be more successful, or as her mom described it, to "come right", when she succumbed to her own insecurities as a teenager and altered her behavior even further in an effort to fit in. She described this

as,

> …Once I was about 13 or 14 I realized that people who acted 'normal' got the good stuff (eg. Not being treated like babies, being picked for things, having friends.) I would copy what others said for that reason too- eg. Calling things I didn't like 'gay' or 'retarded' even though I didn't like using those words. It was just what others did, so I thought 'better try and fit that mold'…Mum always said I started to 'come right' once puberty kicked in. I became a lot more self conscious and aware of how other people viewed me. I may have been more self conscious and shy because of my condition- but I'm not sure. It certainly contributed to depression and anxiety during those years.

Olivia's reflection on her teenage years shows that while externally (to her parents, teachers) she may have presented as more "normal" and successful, this masking that she participated in had negative impacts on her mental health, leading to difficulty with depression and anxiety. She related with the theme that presented from the survey data that her teenage years were a time of isolation and loneliness, but reported that there were things that helped her to turn that around. Olivia reported that her latter high school years improved. She stated that, "It got HEAPS better once I started opening up to people more, and people got to know me better when I got Facebook, and started boarding at school."

Olivia relates her usage of social media as a positive outlet to assist her in connecting with others, which coincided with a more positive school and social experience. While overall her scripting was something that she engaged in at home, she also reports that it helped her build relationships with both her parents and created positive memories. While the importance of social media for the Autistic community was not a theme that emerged from this original research, the impact of the internet and the ability to communicate more effectively through writing is present in the literature (Davidson, 2008; Onaiwu, 2015). There are important implications for this, especially as

Olivia describes how social media allowed her to connect with others and had a positive impact on not only her socialization, but her mental health.

Through the follow up interview with Olivia, there were themes that had previously emerged from the online survey that were further supported by her experience, as well as themes that were further developed based on her input. As one of the only participants who identified as a special education student, Olivia had failed school experiences that resulted in home schooling during her younger years. She also identified concerns with her special education experience- the strictness of the teacher, being sent there as a punishment, and the meltdowns of the other students. This special education experience is unique in this particular data set, but is an important area to consider in regards to future research, especially considering how special education is utilized (in Olivia's case as a punishment), as well as the impact of the experiences that occur in segregated classrooms on the individuals.

Olivia also like many other participants in this study clearly felt the pressure to fit in and to normalize her behavior. She took this theme a bit further in her description of the impact of this normalization process on her mental health. Interestingly, as this process took a toll on her in her high school years, the interpretation from others was that she was doing well, and had "come right". This theme exemplifies the emphasis that neurotypicals place on fitting in, despite the impact it has on the Autistic community. What emerged from the interview is that as she masked her autistic self more adequately, she was seen as more successful externally, while doing more damage to her internal self.

Olivia provided another potential benefit of scripting that was not present in the data from the online survey, and that is the use of scripting to process difficult

experiences. Both in her survey responses, and in the follow-up interview, she discussed how scripting was a coping mechanism, and how she often reenacted difficult parts of her day, and were able to share these experiences with her dad through role playing and scripting. Her day-to-day experience became the content for her scripts, and she noted that through the process of reenactment of what occurred during her day, it was almost serving as a therapeutic process for her. Often times, this role-playing occurred between Olivia and her father, Richard. Olivia had also reported in her survey data that her father often scripted with her, and utilized it as a tool to connect with her, thus Richard was identified as a familiar listener. This connection and use of scripting as a tool was further explored through a follow up interview with Richard.

"It was Worth Going Along With her in this"

The follow up interview with Olivia's father, Richard, was conducted in order to address research question six, which looked to understand the pressures that are placed on families in regards to the way they respond to scripting. Richard had many experiences scripting with his daughter Olivia, and through the data collected from her, Richard was clearly a successful communication partner for her. He was considered a familiar listener and thus was asked to discuss his experiences and views of communicating with his Autistic daughter through scripting.

Richard recalled that Olivia would watch and re-watch television shows and movies, which became the source for her scripts. In regards to how the scripting impacted Olivia, her father noted that, "I saw that it gave her some kind of comfort and security. I didn't understand it. I went with it because I could see it gave her some feeling of control over things." Richard's reaction to Olivia's scripting was to join in, as he reported, "I

would try to be her 'partner' in her role playing", and thus used it as a tool to engage with her. Richard described that often outside therapists would push him to, "change her behavior towards being more social acceptable ways of being with other kids." While Richard recognized some of the difficulty that came with scripting, he trusted his instincts, which pushed him to use the scripting, and as a stay at home dad, he was able to connect often with his daughter in this way. The pressure from the therapists did take their toll however, as Richard discussed, "I remember feeling a bit embarrassed in doing this, so I possibly only told the therapists half of what strange roles I had to play!"

Besides the outside pressure of how to react to Olivia's different communication style, Richard also reported that engaging in the scripts and role-plays were difficult as a parent. He recalled, "It was a pretty battering experience sometimes, but I think it was worth going along with her in this… When she was stressed she would often hit me, and the repetitiveness of the roles I had to take on were very draining of my nerves some days." While the repetition of some of her favorite scripts (specifically Disney related) were tiresome, Richard can appreciate that the connection and engagement with his daughter was worth the effort.

The results of Richard's interview supported the notion that for some familiar listeners, the benefits that scripting provide are recognized. Specifically, Richard supported the theme that scripting provided a sense of comfort, which was substantiated by multiple participants in the original online survey. He made an assumption that Olivia's scripting gave her a sense of control, although this particular theme was not present in the data provided by Autistic adults. He also connected with Olivia's experience of using scripting as a way to process her day, which he related to as a

"battering experience" as he often was asked to play the role of Olivia as she reenacted her experiences at school. It is important to note that this experience for him may be representative of what Olivia experienced throughout her daily experiences, and while he experienced it as battery, Olivia's first hand experience may have included bullying or trauma, which she then brought home and created scripts around to process in a safe place with her dad. Olivia clearly used scripting and reenactment as a way to process her stress from her school day, that perhaps she would not have been able to communicate or share with her parents in any other way.

Richard, much like Suskind (2014), related that there were outside pressures from therapists, which may have shaped his thinking and responses to scripting. He described this push to normalize Olivia and teach her more "socially acceptable ways". Both Richard and Suskind shared that they trusted their instincts instead of following the recommendations of therapists. Both fathers shared that scripting became a way of connecting with their child and building meaningful relationships and connections. The importance of this in relationships and connection established by familiar and successful communication partners is exemplified by Lee (2017), "Sharing our passions with the people we love is how we show we care and how we connect with you (pg. 1).

"Thought I'd Die Without Every Having or Experiencing Joy or Comradery, or Connection"

Zackary [8] was recruited for the follow up interview, due to hir reference to successful scripting with family members, mostly hir siblings. Ze was able through this process to share some clarification of hir responses, as well as to assist the researcher in

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[8] Zackary's preferred pronouns include "ze" and "hir", thus these pronouns will be utilized throughout in reference to Zackary.

flushing out themes that emerged from the online survey data.

When defining scripting versus the more clinical term “delayed echolalia” Zackary addressed that ze falls into the camp that defines the two terms differently, ze qualified scripting being more “active”, and “delayed echolalia” as more “passive”. For Zackary,

> Scripting feels like a tool that we use to interact and usually echolalia is… kind of thoughtless like an automatic response, but less involved than scripting. At least for me scripting is something that I work on in order to engage, and when I have echolalia, it’s likely because I’m exhausted or stressed or something, and it’s just kind of blurted out against my will.

Based on Zackary’s response, scripting is a conscious process that is recognized as an important tool, and the evolution of scripts is a part of that consciousness, whereas echolalia is a less conscious process and thus is less controlled and is impacted by stress. Zackary clearly sees the benefits that scripting provides, and when discussing the themes that emerged regarding that area, Zackary identified that one of the communication tools it provides is the ability to diffuse a situation, especially through the use of humor. Zackary specifically addressed the need to use humor when faced with pressure to fit in, specifically in regards to expected gender roles. Ze explained, “I definitely felt pressure, especially around ‘acting like my gender’ while growing up. Some of it I went along with, but a lot of it I resisted”. Scripts came in handy in these scenarios, specifically as a way to exit an uncomfortable conversation. Similarly, Zackary noted the importance of scripting in regards to small talk, as ze related, “I wouldn’t be able to do any small talk at all without scripting! I still try to avoid it a lot of the time, but having a set of responses to pull out help me acknowledge people in the ways they expect to be acknowledged”. While Zackary uses scripting to engage in small talk conversations, ze also addressed the

more complex communication that ze had with his siblings, whom ze often successfully scripted with. Ze explained,

> I believe that all of us (siblings) are along the autistic spectrum. We think alike, and grew up very close, building scripts that we sometimes still use with only one another (literally whole conversations of just combined scripts and silliness; its amazing). Laughter is a wonderful bonding tool, and so we did our best to make one another laugh as often as possible.

While Zackary clearly shows how scripting can be used for connection and bonding, especially through laughter, ze also hits on another critical theme, which is how the neurology of the communication partner impacts the scripts, as ze assumes hir siblings also have atypical neurology. Further, Zackary identified that, "…I find that different scripts work with other autistic folks, and others work better with neurotypical people, and there's not much overlap".

Zackary also shared intense experiences with the difficulty of how external social factors impacted hir mental health. The isolation ze felt was paramount, as exemplified by the following;

> I felt incredibly isolated and alone. Always out of place and as if the world didn't even want me to exist. The only time I'd really feel ok and as if I belonged was with my siblings…I grew even lonelier. A lot of kids and adults would bully me, so I kept to myself most of the time. Even when I tried to speak, people would misinterpret my meaning and so I felt they'd never understand me, which made me feel even worse.

Zackary clearly felt a very strong impact from the difficulties ze faced with communicating with others, and their treatment of hir led to questioning the purpose of hir own existence. He emphasized the importance of his siblings, hir familiar listeners as hir touch point to feeling "ok". Ze, like Olivia, shared the serious implications this had on his mental health.

I was diagnosed with depression at age.. 13 or 14, I believe, and they tried

> different medications for me, but none of it addressed the social factors contributing to it. I felt so isolated that sometimes I believed it would actually be better if I didn't exist. I had huge trust issues because many people would violate my truest, take advantage of my kindness, and didn't value friendship in the same way that I did. I always felt as if I was being used up, that that's all people would ever do to me, and that I'd never get to fully express everything I was because no one would be able to handle it. Thought I'd die without ever having or experiencing joy or comradery or connection.

This painful experience shared above speaks to how Zackary, as an Autistic young adult, who did not conform to typical gender norms, experienced the social world. The pain is evident and clearly hir different identities impacted the way ze experienced the world.

Zackary's experience tied in with previous themes identified by the research. Ze was very clear that the ze related strongly with themes around communication benefits of scripting, specifically relating to the use of scripts to engage in expected small talk. Zackary also noted the difference between the terms scripting and "delayed echolalia" and really described scripting and the mitigation/change of scripting over time as a conscious metacognitive process. While mitigation is supported in previous research (Gernsbacher, et al., 2016) the research does not address the cognitive process that lends itself to a change in scripting over time. While other participants from the online survey hinted at this phenomenon, Zackary's data helped the researcher to note how active Autistic adults are in the mitigation of their scripts.

Ze also addressed the impact of the listener and their neurology, taking it even further in regards to how scripts are received, and that some are more successful when communicating with Autistic people, while others work better with Allistic individuals. Zackary's experience also takes the impact of normalization that was presented by Olivia in regards to anxiety and depression, and furthers the concern about this impact, as Zackary actually questioned hir own existence, and refers to concerns about dying

without ever feeling happiness. It is critical to note that while all experiences are individual, as Zackary identifies with multiple marginalized identities, ze is even further at risk for potentially damaging experiences.

Overall, the data from the online survey and the follow up interviews overlapped in regards to the themes that emerged. While some phenomena's were more strongly supported across participants (ex. The benefit of scripting during stressful situations), as autism is a very personal experience, it is still important to consider the data provided by all participants. The following section will attempt to understand the data in the context of the current literature, as well as will look at the implications of the results of this research moving forward in practice, as well as in future research.

Chapter VI

DISCUSSION/CONCLUSION

Summary of the Major Findings

The first major finding that is extremely clear in the data is that scripting provides a **variety of positive benefits for Autistic adults** in the area of communication including; successfully navigating small talk, communicating complex thoughts and emotions, and providing support when communicating in stressful situations. Further benefits include comfort and success within the workplace.

The second major finding is that despite these clearly outlined benefits, **communication partners and their negative responses to scripting have detrimental implications for Autistic participants**. These negative impacts include feelings of isolation and embarrassment due to the negative assumptions that are made when an Autistic individual communicates differently.

Third, the research overwhelmingly supports the conclusion that **Autistic stake-holders feel intense pressure to fit in and be viewed as normal**. This pressure can be a barrier for happiness, and requires much effort on behalf of the Autistic person. This constant effort towards normalization may have negative implications for mental health.

The fourth major finding of this research supports the notion that **scripts evolve and change over time, becoming more useful and meaningful**. Many Autistics reported that as adults their scripts go unnoticed, as they are nuanced and are applied in a meaningful context. Further, mitigation is a conscious, metacognitive process with active engagement.

Finally, this research concludes that although there are **outside pressures placed**

on the families of Autistic children in regards to how they react to scripting, there are benefits to utilizing scripting as a means for connection.

Discussion

The lack of Autistic voices in traditional research leads to deficit-based and normative-laden assumptions about scripting, and about autism as a whole. Without Autistic voices guiding the understanding of scripting, clearly the complexity of scripting as a communication tool is lost, and along with it the multitude of other benefits it provides individuals. Many of the positive benefits reported across stake-holders in this research are completely absent from traditional research of the past, which overall does not utilize the most coveted resource for understanding autism, Autistic people themselves.

It can be assumed that based on the negative assumptions placed on individuals who script, as well as the overall view of autism, researchers are not tapping into Autistic adults as a valuable source of information and knowledge, due to their own biases about the Autistic community. As Autistic adults are not seen as reliable contributors in research in more traditional spaces, the emphasis is placed instead on the professionals and researchers as the knowledge makers around the subject of autism (Milton & Bracher, 2013). Yergeau (2018) notes, “If autism has taken over our brains, are we to be trusted?” (pg. 9). The traditional framing of autism lends itself to a distrust toward the Autistic community to share their experiences. When communication differences in Autistic adults are pathologized on a societal level, it is difficult to move past this view and respect their contributions to the research world. When working from a medical

model of disability, the standard "person-fixing" approach is in the forefront, as the emphasis is placed on normalization (Haegele & Hodge, 2016) and research and interventions are considered successful when individuals are able to mask their autism and come across as "normal". The emphasis on normalization removes any expectation or responsibility of society to change and reflect on the systemic bias that is present. Instead communication differences such as scripting are judged as meaningless, and as in our society language is understood as the "basis for meaningful existence", without meaningful language the Autistic community is seen without a meaningful existence (Yergeau, 2018, pg.162). Thus, the focus is always placed on the Autistic individual as the primary source responsible for change instead of pushing for, "social acceptance of autism, accommodation of Autistic needs, removal of systemic barriers to access and inclusion, or supporting Autistic persons in thriving as Autistic persons" (Walker, 2016, pg. 1).

Further, this view of disability lends itself to a lack of presumption of competence for Autistic people in society, which spills over into the traditional research world. This bias leads to the assumption that Autistic children and adults are not able to reflect on, or discuss their own behavior meaningfully. This is especially true when looking at communication differences, as the social challenges that Autistic people face are viewed by society as an inherent part of autism, and thus it is assumed that one can not reflect or have input on it.

As Walker explained,

> …Autism has been frequently misconstrued as being essentially a set of 'social and communication deficits' by those who are unaware that the social challenges faced by Autistic individuals are just by-products of the intense and chaotic nature of Autistic sensory and cognitive experience" (2014, pg. 3).

Walker's description points to the sensory and cognitive differences in the Autistic experience that require attention and energy, and thus leave less for investment in the social world. This difference in experience is supported by the work of Manning (2013) who discusses the differences in "autistic perception" which impacts communication. These differences and the force of normalization placed by society result in repeated rejection, which leads to dangerous misconceptions and assumptions that Autistic people are loners, avoid interaction, and don't want or seek out meaningful relationships. The participants in this research overwhelmingly agreed that the isolation and loneliness, especially in childhood was an extremely negative experience and in no way does the data from this research support that Autistic adults retreat because they prefer to, but because the intense pressure they feel to mask their true selves and normalize, say the right thing, and avoid offending others is tiring and harmful.

The data presented in this research speaks for itself and offers an immense amount of insight into scripting, as well as into the self-awareness of the Autistic community. This huge gap in previous research is a real disservice to all attempting to truly understand the experience of an Autistic person as a means to alter the societal barriers that exist for the Autistic community. An important conclusion of the current research is that Autistic adults know what assists them. They know tools that support their communication, and their ability to handle stress. And yet, as children, these tools are constantly being stripped from them, and their communication style is constantly being labeled as "unexpected" or different. Thus, the participants across the board experienced an intense need to fit in, and to adapt their behavior to fit the social norms, due to intense feelings of isolation and loneliness. It is clear that scripting, and the

evolution of scripting over time is an active, metacognitive process. It is not accidental and it is something that Autistic adults "work on" in order to hone this skill and tool for their communication benefits.

The impact of this research goes far beyond that of the topic of scripting, but also addresses the overall health and wellbeing of the Autistic community. Research suggests that 40% of the Autistic population experience symptoms of anxiety, compared to 15% in the general population (Murphy et al., 2016). It remains clear through the dissection of traditional research related to "delayed echolalia" and autism, that historically researchers have ignored the impact of interventions on the internal state of the Autistic people. These interventions are based on a normative framework and understanding of disability and thus when analyzing the research tied with "delayed echolalia", the research base focused on results, and often did not consider the benefits that scripting was serving the individual (Neely et al., 2015), nor did it consider the impact those results have on the emotional well-being of their participants. On a larger scale, as a society as a whole, we force Autistic people to meet the norms and standards of the neurotypical world, regardless of the cost to the individual.

The implications of forcing Autistic children to conform to a neurotypical world are serious, as both participants Olivia and Zackary shared their difficulties with anxiety and depression. The mental health status of this population can no longer be ignored, and needs to be prioritized in order to understand how the outside pressures placed on Autistic children and adults impact their internal state. This includes dissection on a grander scale, considering therapeutic impacts, the impacts of the way special education services are delivered, and general assumptions society holds regarding people who don't

fit the standard or “norm”.

The impact of the pressure to fit in, the bullying of autistic children and adults, and the social isolation go much deeper and beyond just communication differences and scripting. This is a much larger phenomenon related to society’s inability to accept differences, especially the disabled, due to the medical model way of thinking and approaching Autistic individuals and all individuals with disabilities. This research gives but one glimpse into the impact that negative responses to Autistic neurology and way of thinking have on their overall sense of self. What is clear is the overall fixation of research to fix Autistic behavior, to normalize it, without even understanding it. As research reflects society, and vice-versa, this problem is not an isolated one. This attitude makes it impossible to survive in this society for individuals that present differently, or who are not able to “mask” enough of their differences to pass as “normal”.

Forcing others to mask their true selves comes at a cost. The question is, is it worth it? And to whom? Instead of bullying, isolating, and making negative assumptions about Autistic people who script, we need to understand what supports this tool gives them, so as family, teachers, and friends, we can alter our behavior and our way of thinking in order to create a safe place for our Autistic counterparts. Do we as a society set up Autistic people to fail? Do the social barriers that Autistic people face make it impossible to succeed in a neurotypical society? Are there changes we can make on the societal, school, policy level to alleviate this? What types of added support are required to support Autistic children during adolescence to avoid these negative mental health impacts? When asking these questions, it is important to remember where this pressure to mask the authentic Autistic self originates, as described by Echolaliachamber’s blog:

> The "Cost of Masking" Narrative further pathologize autistic self-preservation- as if we willfully choose to normalize, as if we genuinely exchange tokens for belonging, as if our money is even good in this economy. They don't want our currency. They are not fooled by our masks. But they demand we wear them anyway. This is not a fair trade.

Given all of this critical information shared by the Autistic stake-holders in this research, how does a neurotypical researcher impart change? The implications of this research are paramount, but must always be tied with the source- as it becomes dangerous when neurotypical researchers attempt to speak for Autistic adults. Therefore, it is unavoidable that the implications of this research are closely tied in with the experiences and expressions of those who framed this research, the maker's of knowledge on this topic, the Autistic participants themselves.

Implications

Through the prioritization of the Autistic voices in this research, there are important implications for those individuals working with Autistic students in the school setting, as well as for parents of children who script. It is critical that not only do Autistic voices be heard as a field of experts on the topic of scripting, but that their input alters the approaches used when working and communicating with Autistic children and adults. Thus, the following strategies and supports have been identified. In order to continue to embrace the authenticity of this research, and to respect the Autistic stake-holders as the knowledge makers on this topic, alongside the concrete recommendations includes the direct quote from participants that lead the researcher to the conclusion that this strategy would potentially be beneficial when in communication with, or teaching Autistic people. This strategy was utilized to avoid a common error when researching Autistic adults as a

non-autistic researcher, as Raymaker describes;

> When the people doing research "on" a community don't understand that community's needs, priorities, or values — and have little of their trust — there is a risk of non-representative samples, faulty assumptions, poor research design, interventions that aren't useful (or are even unintentionally harmful), and flawed or stigmatizing conclusions. When those conclusions get reported to the public and to other researchers, it reinforces them. For example, it may reinforce a belief that autistic people can't self-reflect enough to self-report in research, like the reviewer who didn't know that within the community of autistic adults, thousands of us self-reflect and self-report on our needs and experiences every day (2018, pg.1).

It is also important to note that these strategies are general guidelines supported by the research, but only the individual themselves can speak to which of these strategies have a positive impact on their personal communication and relationships. As each Autistic person has varying ways of experiencing the world, consulting with the individual regarding which strategies can be most beneficial is key.

Strategies and supports to improve communication with Autistic people

- ∞ Recognize that scripting provides a multitude of benefits for the individual, and restricting scripting has very negative implications. *"Scripts are very useful to survive in this world. They relieve some of the social anxiety" (014).*
- ∞ Engage in scripting and role-plays as a way to connect, build relationships, and understanding. *"We communicated in Disney movie scripts a lot in the beginning. Watching movies together was a huge part of family quality time…and it shaped our communication from the very beginning" (010).*
- ∞ Utilize flexible scripts to support Autistic young adults in obtaining a job, and in ongoing career success. *"Hugely beneficial. If I don't script in a professional situation, I may well hit the wrong note and/or inadvertently offend" (020).*

- Teach the important nuances of scripting and how scripts should change based on context and the needs of the autistic individual. *“The kind I don’t like is when I am taught that situation X always requires response Y not matter the context or how I feel” (007).*
- Learn the origins of scripts in order to understand the in depth meanings. *“They would always broadly understand, and I don’t think anyone ever particularly recognised a source I was scripting from”* (018). *“A lot of my scripts come from literature and poetry, so they almost always have a deeper meaning” (017).*
- Look for opportunities to connect deeply through scripts. *“My dad…he was still interested in what I had to say in the ‘wild talk’- he’d ask me about the “evil plans” I’d write…” (004).*
- View language skills as a continuum, which is impacted by context, the communication partner, and stress. Adjust expectations and support based on this flexible continuum *“It helps me to respond more authentically when stress, conflict, or social anxiety tend to steal my ability to make words on the spot” (009).*
- Provide opportunities to utilize the Internet and social media to connect and find community, and respect the authenticity of relationships built through social media. *“It got HEAPS better once I started opening up to people more, and people got to know me better when I got Facebook…” (004).*
- Recognize the pressure that autistics constantly feel to fit in and behave “normally”. Act as a respite for this phenomenon and offer spaces for individuals to truly be themselves. *“…I was tired at the end of a long day of acting ‘normal’*

and needed alone time. I called my mask my 'retail face'…"(004)

- Look for signs of anxiety and depression in adolescents with Autism, consider the social factors that may be contributing it and look for support in this area. "*I was diagnosed with depression…and they tried different medications for me, but none of it addressed the social factors contributing to it" (010).*
- Give the option of choices of output in school, research, etc. noting that the writing process may be an area of strength for the individual, and thus should be available. *"I think many of us prefer 'talking' through typing to speaking, for a variety of reasons, even if we tend to speak a lot… its easier, at least for me, to type at the speed of thought than to control the mouth to form the words and then get them out" (010).*

It is critical that we drive our recommendations, and the practical implications of this research from the experts themselves, thus in conclusion, Olivia shared the following information regarding communicating with an Autistic child that uses scripting:

> I guess I'd say be patient with them, and don't be afraid to play along. You can find out a lot from what they say, and it can help them. But it's also ok to tell them that most people don't script like they do - as long as you explain it in a way that doesn't make them feel like freaks or something. Because they're not alone. (004)

Future Research

This research emphasized and prioritized the Autistic voice in shaping meaning and understanding around autism. This approach needs to be embraced in more mainstream research in order to begin to break down the barriers that the medical model

of disability has created for Autistic people. Further, as Walker describes autism, "Despite underlying neurological commonalities, autistic individuals are vastly different from one another" (2014, pg. 3). It is important to recognize that autism is such a unique experience, thus hearing more individual voices will help to develop a more complex, unique shared understanding of the spectrum of autism. Due to this, more voices need to have access to sharing their experience in research. Communication barriers for alternative communicators also need to be considered, in order to make participation in building knowledge around autism a more inclusive practice.

There are complex themes that arose from the in depth interviews that need to be more closely analyzed and teased out. This includes the notion that the masking and normalization process that Autistic individuals go through have negative mental health implications, such as leading to depression and anxiety. While general negative impacts were reported across the participants, due to the seriousness and levity of this conclusion, more research should be conducted looking at the mental health needs of Autistic adults, and the factors that play into these difficulties. This potential future research would have critical implications for practice, and for how scripting is viewed and handled by professionals. It is the hope of the researcher that by further understanding the depths of the repercussions of limiting scripting, and forcing Autistic children to fit a mold, change will be spurred in regards to how we view differences. Through this process the goal is for the neurodiversity movement to find a place in more mainstream understanding, and overall respect for individuals with disabilities would be at the forefront of societal goals.

Future research should also carefully consider the data collection method being utilized when working with Autistic participants in an effort to challenge the normative

view of how data should be collected and provide accessible options for sharing information. It should be considered that in the present research, due to the utilization of the in-depth interview format (as this research was done in real-time through via shared dialogue in Google docs), perhaps Autistic participants felt more comfortable sharing information. Given this particular output, it may have created a higher level of comfort to share openly and honestly about highly sensitive topics, specifically around their battle with anxiety and depression. This may not have been the case if the in depth interview was viewed solely as an oral conversation between two people, and if the participants were not given input regarding their preferred mode of conducting the interview. Zackary when discussing the accessibility of the follow-up interview addressed this notion of comfort, and how the option decreased stress throughout the research process. As described by Zackary,

> I realized I actually felt relief when I realized I could type instead of talk, because it's a much simpler process…this feels also a little less intimidating than even filling out a form or survey in some ways too. I guess because it's more like your genuinely listening and it feels like there's less pressure in that it's not like a 'test' if that makes sense.

Reducing the pressure of expectations of research, through varying the format and offering choice, should be considered in future research. As this research concluded, communication falls on a continuum for Autistic adults, which is impacted by external factors, so to be attuned to those factors and attempt to alleviate some of the anxiety that may be present, may lead to more in-depth responses and results.

One potential area of exploration that emerged from the research is the impact of intersectionality on the Autistic experience. This would look more in-depth into how the experiences of Autistic people are impacted by their other identities, outside of their

Autistic neurology. This theory recognizes that a person that has ties to multiple oppressed groups will have a vastly different experience than an individual belonging to just one (Saxe, 2017). As the participants of this research included a high percentage of women (in relation to the general representation), as well as gender non-conforming individuals, future research should focus on how the unique experiences of Autistic individuals with multiple identities impact their overall experience and perception. Along side this potential for future research, includes looking more in depth at the Autistic experience of sexuality, and gender norms, as Zackary noted,

> Gender was something that didn't really make sense to me as it was typically taught, a common occurrence among autistic people. When I finally did realize I was autistic that part of my life and that resistance to being boxed in made sense in a new light. I was like that about a lot of things regarding social roles and things, and didn't really know why I thought the way I did.

The interpretation of gender through the lens of Autistic neurology has yet to be explored in more traditional research spaces and based on Zackary's feedback, there is a disconnect between the way gender is taught and how the Autistic community experiences gender.

Finally, as a neurotypical researcher, recognizing the need for more research led by Autistic researchers and writers is critical. The research process of this dissertation was heavily impacted by members of the Autistic community through a variety of means. While efforts were made to let the real experts drive the data and conclusions, it is critical to note that the neurology of the researcher could not be separated from this work. Thus, a call to action for Autistic researchers to spearhead studies that address the disconnect between the Autistic experience and more traditional research conclusions is required. Alternatively, more recognition, prioritization, and respect for the work that Autistic

adults are producing, outside of the mainstream research journals is also needed. As scholars, we need to expand our view of what constitutes "research" and note that formal peer-reviewed research is not the only way to produce meaningful data. Especially in the Autistic community, much important work is being done in varying forms including blogs, self-publication, videos, and autoethographic writing. Only when the research is filled with the voices of the community experts, will true change emerge.

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APPENDIX A
INFORMED CONSENT FORM
CONSENT TO PARTICIPATE: PILOT STUDY

You have been asked to participate in reviewing and revising an online survey, as a part of a pilot for a doctoral dissertation.

What the interview is about:
The survey will be conducted digitally, and the questions will be posed to Autistic adults who have identified themselves as having engaged in (or currently engage in) scripting (or delayed echolalia) as a form of communication. The goal is to gain insight into the use of scripting from the point of view of the individual using it. I am interested in how it relates to communication, the different reasons an individual might engage in it, how the outside world reacts to it, and if the language changes over time. My hope is that through this process, therapists, teachers, parents, and researchers can gain a better understanding of scripting.

What we will ask you do:
You will be asked to read a draft of the survey, and make comments regarding your general impressions, accessibility, and ableism. You can either email comments directly, or make comments directly onto the survey. You may be asked to participate in a follow up phone interview.

Duration and Location:
This survey will take place digitally and can be accessed at your own pace.

Potential Risks and Discomforts:
If you have had negative experiences with the content of the survey (faced negative responses to the use of scripting, discrimination), you may have feelings of discomfort during the review. If you wish, you may choose to withdraw your consent and discontinue your participation at any time during the experience, without penalty.

Benefits:
By giving your feedback on this survey, you are assisting to ensure that the goals of the survey are aligned with the goals of the Autistic community, and that the content will be constructed to include the voices of the community.

Audio Recording:
Audio Recording may occur as a part of the follow-up phone interview. The audio will be transcribed by the researcher, and will be provided to you at your request.

Privacy/Confidentiality:
Any data you provide in this study will be kept confidential unless disclosure is required

by law. In any research we write, we will not include information that will make it possible to identify you or any individual participant. Specifically, we will use a pseudonym and omit any information that could connect you to the comments made.

Compensation for Participation:
There is no compensation for participation.

Offer to Answer Questions:
If you have any questions at any time, please contact Colleen Arnold (415) 516-0482.
You can also email your comments to:
colleen.arnold@dominican.edu

I HAVE READ THE ABOVE INFORMATION. ANY QUESTIONS I HAVE ASKED HAVE BEEN ANSWERED. I AGREE TO PARTICIPATE IN THIS RESEARCH PROJECT AND I WILL RECEIVE A COPY OF THIS CONSENT FORM.

X____

Date: ____________________

APPENDIX B
INFORMED CONSENT FORM

CONSENT TO PARTICIPATE: Online Survey

You have been asked to participate an online survey, and/or a phone interview, for doctoral dissertation research.

What the online survey is about:
The survey will be conducted digitally, and the questions will be posed to Autistic adults who have identified themselves as having engaged in (or currently engage in) scripting (or delayed echolalia) as a form of communication. The goal of the survey is to gain further insight into the use of scripting from the point of view of the individual using it. The researcher is interested in how it relates to communication, the different reasons an individual might engage in it, how the outside world reacts to it, and if the language changes over time. Through this research process the goal is that therapists, teachers, parents, and researchers can gain a better understanding of scripting.

What we will ask you do:
You will be asked to respond to approximately 15 interview questions, most of which are open ended.

Duration and Location:
This survey will take place digitally, and should take approximately 45 minutes to an hour and a half of your time.

Potential Risks and Discomforts:
If you have had negative experiences with the content of the survey (faced negative responses to the use of scripting, discrimination), you may have feelings of discomfort during this interview. If you wish, you may choose to withdraw your consent and discontinue your participation in this interview at any time during the experience, without penalty.

Benefits:
By giving your feedback on this survey, you are assisting to ensure that the goals of the interview are aligned with the goals of the Autistic community, and that the interview will be constructed with the voices of the community.

Audio Recording:
Audio recording will not occur.

Privacy/Confidentiality:
Any data you provide in this study will be kept confidential unless disclosure is required by law. In any research we write, we will not include information that will make it

possible to identify you or any individual participant. Specifically, we will use a pseudonym and omit any information that could connect you to the comments made.

Compensation for Participation:
For participating, you may choose to be eligible to win a $50 gift card.

Offer to Answer Questions:
If you have any questions at any time, please contact Colleen Arnold (415) 516-0482.

I HAVE READ THE ABOVE INFORMATION. ANY QUESTIONS I HAVE ASKED HAVE BEEN ANSWERED. I AGREE TO PARTICIPATE IN THIS RESEARCH PROJECT AND I WILL RECEIVE A COPY OF THIS CONSENT FORM.

X____

Date: ____________________

APPENDIX C
INFORMED CONSENT FORM

CONSENT TO PARTICIPATE: Interview

You have been asked to participate in a follow up, semi-structured interview, based on your responses to an online survey, or you have been referred by an individual who took an online survey.

What the interview is about:
The interview will focus on clarifying responses to an online survey regarding the use of scripting as a form of communication.
The goal of the interview is to gain further insight into the use of scripting from the point of view of the individual using it, and their familiar communication partners. The researcher is interested in how it relates to communication, the different reasons an individual might engage in it, how the outside world reacts to it, and if the language changes over time. Through this research process the goal is that therapists, teachers, parents, and researchers can gain a better understanding of scripting.

What we will ask you do:
You will be asked to respond to questions, as honestly as possible, during an interview. The interview will be conducted over the phone, in person, or through video conferencing.

Duration and Location:
This interview will take place at a mutually agreeable time between the researcher and participant. The interview is expected to last approximately 30 minutes to one hour. For in person interviews, a location that allows confidentiality will be agreed upon.

Potential Risks and Discomforts:
If you have had negative experiences with the content of the interview (faced negative responses to the use of scripting, discrimination), you may have feelings of discomfort during this interview. If you wish, you may choose to withdraw your consent and discontinue your participation in this interview at any time during the experience, without penalty.

Benefits:
By giving your feedback on this survey, you are assisting to ensure that the goals of the interview are aligned with the goals of the Autistic community, and that the interview will be constructed with the voices of the community.

Audio Recording:
Audio Recording will occur. The audio will be transcribed by the researcher, and will be provided to you at your request.

Privacy/Confidentiality:
Any data you provide in this study will be kept confidential unless disclosure is required by law. In any research we write, we will not include information that will make it possible to identify you or any individual participant. Specifically, we will use a pseudonym and omit any information that could connect you to the comments made.

Compensation for Participation:
For participating, you may choose to be eligible to win a $50 gift card.

Offer to Answer Questions:
If you have any questions at any time, please contact Colleen Arnold (415) 516-0482.

I HAVE READ THE ABOVE INFORMATION. ANY QUESTIONS I HAVE ASKED HAVE BEEN ANSWERED. I AGREE TO PARTICIPATE IN THIS RESEARCH PROJECT AND I WILL RECEIVE A COPY OF THIS CONSENT FORM.

X____

Date: ____________________

APPENDIX D

DIGITAL SURVEY

Scripting: How Autistic Adults Use Language to Communicate

Online/Digital Survey

Background/ Demographic Information:

1. Male/Female/Gender nonconforming?

2. Current age?

3. At what age did you find out you were Autistic?

4. How did you find out you were Autistic?

5. Did you receive special education services?
Yes, No, Maybe

Open-Ended Questions

6. Please describe your special education experiences and the type of services you received.

7.What does the term “scripting” mean to you? Can you describe it?

8. What does the term “delayed echolalia” mean to you? Can you describe it?

9. In this survey, we will be talking about scripting, which will be defined as using language that was gained from a previous source, like a TV show, book, movie, or language someone else used in the past. I am really interested in knowing if scripting is a part of the way that you communicate? YES OR NO. (No survey ends, Yes go on to next question)

10. Can you tell me about it?

11. Describe some of the verbal scripts you have used in the past, or that you currently use.

12. Have your scripts evolved over time? How?

13. Does scripting assist you in communication? How?

14. How do others understand your scripting?

15. How do others react to your scripting?

16. Think about an individual in your life whom you spent a lot of time communicating with as a child, describe a memory of how they reacted to and understood your scripts.

17. Can you describe an experience when you used scripting successfully?

18. Have you ever been discouraged from scripting? By whom? What did that look like?

18. Can you describe a specific script that has a different meaning for you than one might interpret on the surface level?

19. Is there anything else you would like to share on this topic?

20. Are you interested in participating in a follow-up interview? Is there someone you communicated well with, that may be interested in a follow-up interview? If we may contact you for more information, OR if you would like to be entered to win a $50 gift card, provide an email address below.
Digital survey can be viewed:
https://docs.google.com/forms/d/1wM2eHE52emsgOUnvA9PpbYUieun8dXbnmEktHHmAqp0/edit?usp=sharing

APPENDIX E
Follow Up Semi-Structured Interview (A)

1) Can you tell me more about how you found out you were Autistic?

2) What are the reasons, besides communication, that you use scripting?

3) Tell me about a person who understood/understands your scripting.

4) Tell me about a person who had a negative reaction to your scripting. What did this look like?

5) Do you still script today? Does it look different or similar than when you were younger?

6) The research uses the term "delayed echolalia", which traditional research defines as as "socially awkward or developmentally inappropriate…consist(ing) of repetitive sounds, words, breathing, and/or delayed echolalia of previously heard dialogue" (Shawler & Miguel, p.112). It has also been defined as non-contextual or nonfunctional vocalizations (Colón, Ahearn, Clark, & Masalsky, 2012; Liu-Gitz & Banda, 2009), "including repetitive babbling, grunts, squeals, and phrases unrelated to the present situation (Colón, Ahearn, Clark, & Masalsky, p. 109).

Do you agree with this definition? Is scripting the same as delayed echolalia? Do you use these terms interchangibly? If not, how are they different? How are they the same?

APPENDIX F
Follow Up Semi-Structured Interview (B)

Scripting: How Familiar Listeners impact Communication Success

Follow Up: Semi-Structured Interview

1) What is your relationship to the person that referred you for this interview?

2) Do you recall that person using scripting in their childhood? Can you tell me about that?

3) In general, how did you respond to scripting?

4) What influenced you and how you responded to scripting? Did you feel pressure from others?

5) How did others respond (family, professionals, doctors) to the scripting?

6) Does the person still engage in scripting? Is it different in anyway?

7) Can you give an example of the use of scripting successfully?

8) Can you describe an example of the use of scripting that was not successful?

APPENDIX G

UNIVERSITY OF SAN FRANCISCO

CHANGE THE WORLD FROM HERE

APPLICATION FOR IRB REVIEW OF NEW RESEARCH INVOLVING HUMAN SUBJECTS

If you believe your study meets the criteria for expedited review or full IRB review, complete the following form and upload this document to the online IRB system in Mentor.

1. RESEARCH PROJECT DESCRIPTION

Duration of study project

The project will last in duration for 12-24 months, including revision of survey and member checks, distribut of survey, and collection of data.

Clearly state the purpose of the study (Usually this will include the research hypothesis)

The purpose of this study is to understand the use of echolalia by Autistic adults, as a communication tool. information will be gained through interview of individuals that use this type of communication. First, the research will look to define and differentiate the difference in meaning between "echolalia" (the term more commonly used in research), and scripting, (the term more often used by individuals with autism). The researcher is defining scripting as the use of language gained from a previous source, such as a TV show, b movie, or language someone else used in the past. The second is to understand how the use of scripting rel to communication, the different reason individuals might engage in it, how the outside world reacts to it, anc changes over time.

Background (Describe past studies and any relevant experimental or clinical findings that led to the plan for this proj

Individuals with a diagnosis of autism spectrum disorder (ASD) may display behavior that is considered "stereotypic" including verbal stereotypy. This is defined in the research as verbal utterances that may be s as uncommunicative in nature, from an external standpoint, as they serve no communicative function. This may include behavior that is described as echolalic, which echoes the language of others, in either an imme or delayed fashion. It is important to note, that researchers have used varying definitions to classify what is considered verbal stereotypy. It has been defined as "socially awkward or developmentally inappropriate…consist(ing) of repetitive sounds, words, breathing, and/or delayed echolalia of previously he dialogue" (Shawler & Miguel, p.112). It has also been defined as non-contextual or nonfunctional vocalizatio (Colón, Ahearn, Clark, & Masalsky, 2012; Liu-Gitz & Banda, 2009), "including repetitive babbling, grunts, squ and phrases unrelated to the present situation (Colón, Ahearn, Clark, & Masalsky, p. 109). Delayed echolalia, the repetitive use of language usually borrowed from previous conversations, television, movies, or other sources, is a language difference that many people with autism engage in. From a behaviorist perspective, i be a behavior that serves no external function, and therefore needs to be extinguished. Much of the researcl regards to echolalia has a focus on supporting the strategies that can best decrease echolalic language, anc turn increase what is defined as "functional language". Strategies such as Response Interruption Redirectio (RIRD) has shown to have impact on reducing the use of echolalic language in children with autism in the cli setting (Ahrens et al., 2011; Colón et al., 2012; Saini et al., 2015; Schumacher & Rapp, 2011; Shawler & Migue 2015).

The body of current research has a very medical model approach, in which there is an intervention that i into place in order to alter the behavior of an individual with autism. There is very little research to look at actually understanding the use of echolalic language. As research drives practice, we have teachers, speecl pathologists, and administrators whose sole response to the use of this language is to extinguish it, often leaving individuals with autism without a mode of communication

Research plan (Provide an orderly scientific description of the intended methodology and procedures as they directly affect the subjects)

-The first step is getting input on the survey itself through members of the Autistic community. These memb checks will serve to ensure that the survey is accessible and clear to a variety of communicators. These individuals will include academics, professors, trainers and activists, all who identify with autism and are 18 years of age or older. To solicit these participants, members of the Autistic community will be approached to participate (via electronic mail), and will be asked to share the information with members of their community below, survey entitled "Member Check: Survey Response" the first survey below the application).

-The information gained from the member checks will lead to revision of the survey.

-Next, the survey will be distributed electronically to a select group as a part of a pilot (also 18 years of age o older), along with the survey consent form and specifics regarding confidentiality. Potential participants will recruited digitally utilizing connections the research community, self-advocacy organizations, professional l serves.

. Participants will be given the option to apply for a $50 gift card drawing for their participation.

-Upon review of the piloted survey data, and feedback, the interview will be revised and edited as needed to a final draft.

-The final version of the survey will then be distributed electronically to a wider audience (also 18 years of ag older), along with the survey consent form and specifics regarding confidentiality. Potential participants will recruited digitally utilizing connections the research community, self-advocacy organizations, professional l serves. Participants will be given the opportunity to apply (optional) to win a $50 gift card for their willingnes participate. Alternative methods of completing the survey would be available to make the process accessibl individuals who use a variety of communication methods. These alternative methods may include Skype (or other video conferencing), phone, or other approach as warranted.

-Upon completion of the survey, participants will be asked if they would like to be contacted for a follow up s structured interview to further discuss the research questions, only then will they be prompted to add conta information.

-Semi-structured phone interviews will be conducted with participants who expressed interest in doing so. Alternative methods of conducting an interview would be available to make the process accessible to all including Skype, phone, or other approach as warranted.

-With approval and signed consent, documents from those who participate in the semi-structured interview

be collected. These documents include components of their Individual Education Plan (IEP) including but no limited to: previous IEP documentsessment Reports written in relation to the IEP process, Speech and Lang Assessments, IEP goals, and Functional Behavior Assessments (FBA) and Behavior Intervention Plans (BIP -Using the data gained from the online interviews, semi-structured oral interviews, and document analysis, c will be triangulated to address the research questions, as well as the themes that emerge through the resear process.

Give the location(s) the study will take place (institution, city, state, and specific location)
The study will be based in Novato (Marin County), California and the surrounding Bay Area cities, although t online survey will be available on a much larger scale, as will follow up interviews, which will take place over phone.

Duration of study project
The project will last in duration for 12-24 months, including revision of survey and member checks, distribut of survey, and collection of data.

2. PARTICIPANTS

2(a) Participant Population and Recruitment

Describe who will be included in the study as participants and any inclusion and exclusion criteria.
Inclusion criteria includes individuals 18 years of age and older that currently self-identifies as Autistic and also received special education services under the eligibility of autism during K-12 schooling. Exclusion criteria includes any individual under the age of 18, and any individual who does not identify as Autistic.

What is the intended age range of participants in the study?
The age range of the study is from 18-75 years of age.

Describe how participant recruitment will be performed.
Participants will be recruited digitally utilizing connections the research community, self-advocacy organizations, professional list-serves.

Do the forms of advertisement for recruitment contain only the title, purpose of the study, protocol summary, basic eligibility criteria, study site location(s), and how to contact the study site for further information? ☒ Yes ☐ No

*If you answered "no," the forms of advertisement must be submitted to and approved by the IRB prior to their use.

2(b) Participant Risks and Benefits

What are the benefits to participants in this study?

Participants may benefit from the study, as the purpose of the study is to give individuals with autism a voic describing a scripting as a form of communication, thus the results of the study may move forward the understanding of researchers, as well as the individuals that work with people with autism, including parent teachers, and therapists. Participants will be given the option to apply for a $50 gift card drawing for their participation.

What are the risks (physical, social, psychological, legal, economic) to participants in this study?
If a participant has had negative experiences with the content of the survey (faced negative responses to the of scripting, discrimination), they may have feelings of discomfort during the interview. It will be made clear at any time individuals may withdraw their consent and discontinue their participation in the online survey o interview at any time during the experience, without penalty.

If deception is involved, please explain.
There will be no deception involved in this study.

Indicate the degree of risk (physical, social, psychological, legal, economic) you believe the research poses to huma

subjects *(check* ***the one*** *that applies).*

☒ MINIMAL RISK: A risk is minimal where the probability and magnitude of harm or discomfort anticipated in the proposed research are not greater, in and of themselves, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

☐ GREATER THAN MINIMAL RISK: Greater than minimal risk is greater than minimal where the probability and magnitude of harm or discomfort anticipated in the proposed research are greater than those ordinarily encountered daily life or during the performance of routine physical or psychological examinations or tests. **If you checked "Gre than Minimal Risk",** provide a statement about the statistical power of the study based on intended sample size, de etc. to test the major hypotheses)

2(c) Participant Compensation and Costs

Are participants to be financially compensated for the study? ☐ Yes ☒ No If "yes," indicate amount, type, and so of funds.

Amount: Source: Type (e.g.,. gift card, cash, etc.):

Will participants who are students be offered class credit? ☐ Yes ☒ No ☐ N/A

If you plan to offer course credit for participation, please describe what alternative assignment(s) students may comp to get an equal amount of credit should they choose not to participate in the study.

Are other inducements planned to recruit participants? ☒ Yes ☒ No If yes, please describe.

Participants may elect to be included in a drawing to win a $50 gift card.

3. CONFIDENTIALITY AND DATA SECURITY

Will personal identifiers be collected (e.g., name, social security number, license number, phone number, email addr photograph)? ☒ Yes ☐ No

Will identifiers be translated to a code? ☒ Yes ☐ No

Describe how you will protect participant confidentiality and secure research documents, recordings (audio, video, photos), specimens, and other records.

All subjects will be assigned a number, stored separately from any data collected, so as to avoid connection between their personal information and their names. The digital survey will be anonymous, but the semi-structured interview and document analysis will require that personal identifiers such as name, email addres and telephone number, be collected.

Any documents received for analysis will be coded with the number assigned, and all identifying informatio be redacted (name, address, student ID).

4. CONSENT

4a. Informed consent

Do you plan to use a written consent form that the participant reads and signs? ☒ Yes ☐ No

***If "no," you must complete Section 4b or 4c below.**

If "yes," describe how consent will be obtained and by whom.

Prior to accessing the online survey, all individuals will read the survey consent form, and be asked to give consent (digitally). For the semi-structured interview and document analysis, forms will be sent and receive prior to any data collection.

If the participants are minors under the age of 18 years, will assent forms be used? ☐ Yes ☐ No ☒ N/A

If "no," please explain.

Upload to the online IRB system the consent form(s) that the participants and/or parent/guardian will be req to sign, and the assent forms for children under the age of 18, if applicable.

Note: All consent forms must contain the following elements (quoted directly from Office for Human Research Protec regulations, available at: http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm#46.116). The IRB has cor

templates containing all required elements, **and we ask that you use these templates**.

If you believe it is important to create your own consent form, you are free to do so but please ensure that your cons form has each of the following elements and indicate you have done so by checking this box:

☐ I have chosen to create my own consent form and have ensured that it contains the 8 essential elements listed be

(1a) A statement that the study involves research, (1b) an explanation of the purposes of the research, (1c) t expected duration of the subject's participation, (1d) a description of the procedures to be followed, and (1e) identification of any procedures which are experimental;

(2) A description of any reasonably foreseeable risks or discomforts to the subject;

(3) A description of any benefits to the subject or to others which may reasonably be expected from the rese

(4) A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantag to the subject;

(5) A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained;

(6) For research involving more than minimal risk, an explanation as to whether any compensation and an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist o where further information may be obtained;

(7) An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a research-related injury to the subject; and

(8) A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits which the subject is otherwise entitled, and the subject may discontinue participation at any time without pen or loss of benefits to which the subject is otherwise entitled**."**

4b. Waiver of documentation of written informed consent (Complete only if answered "no" 4a)

The regulations allow instances in which the IRB may waive the requirement for documentation of informed consent, is , the collection of a signed consent form. If you are requesting a waiver of written documentation (signed) of inform consent, please answer the following questions:

Will the only record linking the participant and the research be the consent document and the principal risk to the participant would be from breach of confidentiality? ☐ Yes ☐ No

Do you consider this a minimal risk study that involves no procedures for which written consent is normally required outside of research (see 2B above for definition);? ☐ Yes ☐ No

Explain why you are requesting waiver or modification of documentation of written (signed) informed consent and ho you plan to obtain consent.

4c. Waiver or modification of informed consent (Complete only if answered "no" to 4a)

The regulations also provide an opportunity for the IRB to waive the requirement for informed consent or to modify th informed consent process, provided the protocol meets the following criteria:

(1) The research involves no more than minimal risk to subjects (see 2b above for definition);
(2) The waiver of alteration will not adversely affect the rights and welfare of the subjects;
(3) The research could not practicably be carried out without the waiver or alteration; and
(4) Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

If you are requesting a waiver or modification of informed consent (e.g., incomplete disclosure, deception), explain h
your project meets the requirements for waiver or modification of informed consent, as outlined above. .

Member Check – Survey Response

Please note that this survey is in draft form, and your feedback will be critical in bringing this survey into its final form. Here are some guiding questions to consider:

1. What are your general impressions of this survey?
2. Are there any abelist views that are perpetuated through this survey?
3. Is the language in the survey accessible? Clear?
4. Is the wording of this survey in such a way that a variety of communicators (AAC, sign) would have access?
5. Is there anything missing or that requires revision?

Background

Before you review this survey draft, I would like to give you some background as to the purpose. As a researcher, I have always had an interest in "delayed echolalia", which for my purposes today I am referring to as "scripting"* as I feel it is a term more embraced by the autism community. When I originally began my research, I read article after article that focused on how to stop the use of echolalia, as much of the information out there focuses on intervention. Through my coursework in the area of Disability Studies, I began to recognize the issues with this type of research, and began to notice the lack of Autistic voices within the research. My goal is to truly gain a deeper understanding of the use of scripting, from the point of view of the individual using it. I am interested in how it relates to communication, the different reasons an individual might engage in it, how the outside world reacts to it, and if the language changes over time. My hope is that through this process, therapists, teachers, parents, and researchers can gain a better understanding

of scripting, which may impact the way in which they respond to it, as well as the direction of future research.

(*Scripting may be defined as using language that was gained from a previous source, like a TV show, book, movie, or language someone else used in the past)

Echolalia and Scripting: How Autistic Adults Use Language to Communicate
Online/Digital Interview

1. Are you Autistic?
2. At what age did you find out?

3. How did you find out?

4. Did you receive special education services under the category of autism?
5. In this interview, we will be talking about scripting, or using language that was gained from a previous source, like a TV show, book, movie, or language someone else used in the past. I am really interested in knowing if scripting is a part of the way that you communicate? Can you tell me about that?

6. Describe some of the verbal scripts you have used in the past, or that you currently use.

7. Have your scripts evolved over time? How?

8. Does scripting assist you in communication? How?
    a. Other reasons for using it

9. How often do others understand your scripting?
10. How is it received by others?
11. Think about an individual in your life whom you spent a lot of time communicating with as a child, describe a memory of how they reacted to and understood your scripts.

a. Parent/teacher/friend?
b. Across environments?
c. Person in your life currently?

12. Can you describe an experience when you used scripting successfully?
13. Have you ever been discouraged from scripting? By whom? What did that look like?

14. Can you describe a specific script that has a different meaning for you than one might interpret on the surface level?

15. Is there anything else you would like to share on this topic?

Echolalia and Scripting: How Autistic Adults Use Language to Communicate
Online/Digital Interview

1. Are you Autistic?
2. At what age did you find out?
3. How did you find out?
4. Did you receive special education services under the category of autism?

5. In this interview, we will be talking about scripting, or using language that was gained from a previous source, like a TV show, book, movie, or language someone else used in the past. I am really interested in knowing if scripting is a part of the way that you communicate? Can you tell me about that?

6. Describe some of the verbal scripts you have used in the past, or that you currently use.

7. Have your scripts evolved over time? How?

8. Does scripting assist you in communication? How?

b. Other reasons for using it

9. How often do others understand your scripting?

10. How is it received by others?

11. Think about an individual in your life whom you spent a lot of time communicating with as a child, describe a memory of how they reacted to and understood your scripts.

d. Parent/teacher/friend?

e. Across environments?

f. Person in your life currently?

12. Can you describe an experience when you used scripting successfully?

13. Have you ever been discouraged from scripting? By whom? What did that look like?

14. Can you describe a specific script that has a different meaning for you than one might interpret on the surface level?

15. Is there anything else you would like to share on this topic?

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Echolalia and Scripting: How Autistic Adults Use Language to Communicate
Follow Up: Semi-Structured Interview

1) Can you tell me more about how you found out you were Autistic?

2) What are the reasons, besides communication, that you use scripting?

3) Tell me about a person who understood/understands your scripting.

4) Tell me about a person who had a negative reaction to your scripting. What did this look like?

5) Do you still script today? Does it look different or similar than when you were

younger?

6) The research uses the term “delayed echolalia”, which is defined as “socially awkward or developmentally inappropriate…consist(ing) of repetitive sounds, words, breathing, and/or delayed echolalia of previously heard dialogue” (Shawler & Miguel, p.112). It has also been defined as noncontextual or nonfunctional vocalizations (Colón, Ahearn, Clark, & Masalsky, 2012; Liu-Gitz & Banda, 2009), “including repetitive babbling, grunts, squeals, and phrases unrelated to the present situation (Colón, Ahearn, Clark, & Masalsky, p. 109).

Do you agree with this definition? Is scripting the same as delayed echolalia? If not, how are they different? How are they the same?