

USING AN INSTRUCTIONAL PACKAGE TO SUPPORT ADULTS WITH
AUTISM IN COMMUNICATING WITH A MEDICAL PROVIDER

by

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This dissertation was prepared under the direction of the candidate's dissertation advisor, Dr. Charles Dukes, Department of Special Education, and has been approved by the members of her supervisory committee. It was submitted to the faculty of the College of Education and was accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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ABSTRACT

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Adults with autism spectrum disorder (ASD) often experience co-occurring physical and mental health challenges throughout their lives. At the same time, they often face many barriers to accessing proper care. Strategies to improve communication and understanding can help to mitigate some of these barriers. This study examined the effects of an instructional package, including a video module accompanied by guided notes, the Autism Healthcare Accommodations Tool (AHAT), and behavior skills training (BST) to teach adults with autism to communicate their unique needs and request accommodations from a medical provider. Participants completed a self-guided video module that guided them through the process of completing the notes and AHAT to identify appropriate accommodations and prepare for a doctor's appointment. Once completed, participants learned to verbalize their needs and accommodations through BST. Results showed that the participants' communication skills increased after the introduction of the instructional package, generalized to a novel *doctor* and maintained

once the instructional package was removed. Implications and suggestions for future research are discussed.

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CHAPTER 1: INTRODUCTION AND REVIEW OF LITERATURE

Individuals with autism spectrum disorder (ASD) often learn and behave differently from others, sometimes resulting in challenges with social communication and interactions. Many experience the world in a unique manner (Centers for Disease Control [CDC], 2022). In comparison to other disabling conditions, understanding and accurately diagnosing autism is relatively new, particularly for adults with autism, without accompanying intellectual disability (ID). For many years, autism was considered a “childhood disorder” and, therefore, a great deal of research and resources have focused on younger populations with autism (Mandell, 2013; van Dooren et al., 2016). Although approximately 50,000 individuals with autism reach adulthood each year in the United States, only about 2% of autism research funding focuses on adult issues (Interagency Autism Coordinating Committee [IACC], 2017). There is an urgent need for increased understanding of ageing with autism into midlife and beyond.

Research that has examined outcomes for adults with autism thus far is not promising (Bishop-Fitzpatrick et al., 2016; Deserno et al., 2018; Howlin & Magiati, 2017). Many adults on the autism spectrum have multiple unmet needs and experience a decreased quality of life when compared to their peers without autism (Hendricks & Wehman, 2009; Howlin & Magiati, 2017; Mukaetova-Ladinska, et al., 2012; Vogan et al., 2017). Access to appropriate accommodations, assistive technologies, and therapies that aim to improve independent functioning and communication can substantially increase the quality of life for a person on the autism spectrum (Nicolaidis et al., 2014);

however, many adults report challenges in accessing such interventions and supports (Dern & Sappok, 2016; Hand et al., 2020; Raymaker et al., 2017; Saqr et al., 2018; Stein Duker et al., 2019).

Adults with autism experience high rates of co-occurring psychiatric and medical conditions (Cashin et al., 2018; Croen et al., 2015; Lever & Guerts, 2016; Vohra et al., 2017) which, in turn, exacerbates the core deficits of autism, adversely affects activities of daily living (ADLs), and quality of life (Kamp-Becker et al., 2010; Lai et al., 2019). Adults with autism are at an increased risk for early mortality when compared to their peers without autism (Hirvikoski et al., 2016; Schendel et al., 2016; Woolfenden et al., 2012). Unfortunately, many adults with autism experience significant healthcare disparities and barriers preventing them from accessing effective preventative care (Croen et al., 2015; Dern & Sappok, 2016; Hand et al., 2020; Raymaker et al., 2017; Saqr et al., 2018). Given the increased health risks faced by this population and their adverse effects, inequitable access to primary healthcare services is of particular concern.

Health Status of Adults with Autism

Children with autism have higher rates of physical and mental health comorbidities, including autoimmune disorders, seizure, sleep disorders, gastrointestinal (GI) disorders, metabolic disorders, anxiety, depression, attention deficit hyperactivity disorder (ADHD), and oppositional defiant disorder, when compared to the general pediatric population (Croen et al., 2015). Despite these findings, there is a marked paucity of research examining the health status and needs of adults with autism. Preliminary research does however demonstrate an increase in comorbid mental and physical health conditions (Cashin et al., 2018; Croen et al., 2015; Lever & Guerts, 2016;

Vohra et al., 2017) and premature mortality in older populations with autism when compared to those without (Hirvikoski et al., 2016; Schendel et al., 2016; Woolfenden et al., 2012). Evidence also suggests that the health needs of individuals with autism often change significantly across the lifespan (Cashin et al., 2018; Croen et al., 2015) and the health gap becomes larger with age (Bishop-Fitzpatrick & Rubenstein, 2019). This underscores a dire need to better understand the health profiles, trajectories, and predictors of health conditions from childhood through adulthood, as well as appropriate supports for accessing preventative healthcare services for individuals with autism.

Physical Health

Except for infections and genitourinary disorders, adults with autism are at an increased risk for most major chronic medical conditions when compared to adults without autism. This includes conditions that have previously been associated with children with autism, such as autoimmune conditions, and GI, sleep, and seizure disorders (Croen et al., 2015; Nicolaidis et al., 2014; Tyler et al., 2011). When compared to peers without autism, adults with autism are more likely to develop chronic conditions such as hypertension, dyslipidemia (Bishop-Fitzpatrick & Rubenstein, 2019), diabetes, obesity, thyroid disease, stroke, Parkinson's disease, vitamin deficiency, and vision and hearing impairments (Croen et al., 2015). In one study, Jones et al. (2016) calculated an average of 11 comorbid physical health conditions per adult with autism, with the highest rates amongst females and those classified as obese. Furthermore, Hand et al. (2020) found that conditions that are frequently associated with aging in the general population, such as osteoporosis, cognitive disorders, heart disease, cancer, and osteoarthritis, were also significantly more common among adults with autism 65 years of age and older.

Mental Health

As with comorbid physical health conditions, prevalence of mental health comorbidities among adults with autism is significantly higher than those without autism. Such conditions include anxiety, depression, bipolar disorder, obsessive-compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), and schizophrenia (Cashin et al., 2018; Croen et al., 2015; Vohra et al., 2017). Croen et al. (2015) found that adults with autism are at almost three times the risk of depression and 22 times the risk of schizophrenia when compared to adults without autism. Although variations in previous research, such as data sources, study period, type of autism spectrum disorder examined, and limited sample sizes create challenges in determining an exact percentage, it is estimated that anywhere from 54–81% of adults with autism will experience at least one co-occurring psychiatric condition in their lifetime (Croen et al, 2015; Lever & Geurts, 2016; Vohra et al., 2017). This may exacerbate the condition, as people with mental health conditions also experience higher rates of physical health conditions and barriers to appropriate preventative healthcare (Cashin et al., 2018).

Mortality

Although research on mortality rates in autism are quite limited, preliminary evidence suggests that people with autism have a 20 to 30 year decreased lifespan than those without autism (Guan & Li, 2017; Hirvikoski et al., 2016). Besides infection, individuals with autism are at increased risk for premature mortality across all categories of disease than the general population (Hirvikoski et al., 2016; Schendel et al., 2016). Furthermore, individuals with autism are at an increased risk of self-injury (Camm-Crosbie et al., 2019), and are at a five times greater risk of suicide, suicidal ideation or

attempts (Hirvikoski et al., 2016) than those without autism. This evidence underscores the importance for individuals with autism, their families, and healthcare professionals to recognize the effects that comorbid conditions may have, as well as the importance of preventative measures to protect against associated mortality risk.

Barriers and Facilitators to Healthcare

Although adults with disabilities generally experience more barriers to effective preventative healthcare than those without disabilities, adults with autism experience them at higher rates than those with other disabilities (Raymaker et al., 2017). Multiple complex barriers have been identified as contributing to the healthcare disparities faced by this population (Dern & Sappok, 2016; Mason et al., 2019; Nicolaidis et al., 2015, 2021; Raymaker et al., 2017; Saqr et al., 2018; Vogan et al., 2017) and can be placed into three broad categories: patient-level, provider-level, and system-level (Nicolaidis et al., 2015; Raymaker et al., 2017). All three levels must work in accordance in order to facilitate access to essential preventative healthcare for adults with autism.

Patient-level Barriers

Many patients with autism attribute factors directly related to their autism diagnosis as the primary challenges they experience in receiving effective healthcare. Social communication is a challenging core deficit of autism (CDC, 2022). Expressive and receptive language difficulties often interfere with the patient's ability to describe his/her symptoms, answer questions, and process information during a medical appointment (Croen et al., 2015; Dern & Sappok, 2016; Nicolaidis et al., 2015; Raymaker et al., 2017). Many adults share that appointments are generally too short and too rushed to accommodate their communication needs (Raymaker et al., 2017). Furthermore,

interpreting information and questions literally has been identified as a challenge (Nicolaidis et al., 2015). For example, if asked, “On a scale from one to ten, how bad is your pain?”, the patient may not understand how to accurately *weigh* his/her pain. Many individuals with autism experience challenges with sensory input (CDC, 2022). Waiting rooms and examination rooms may be overstimulating and enduring the actual physical exam or procedure can often be difficult (Croen et al., 2015; Dern & Sappok, 2016; Nicolaidis et al., 2015; Raymaker et al., 2017). Furthermore, sensory issues may also contribute to challenges with bodily awareness, making it hard for the patient to accurately describe or locate pain or symptoms (Nicolaidis et al., 2015).

Other autism-related characteristics that may interfere with the healthcare experience include difficulty with executive functioning (e.g., scheduling and keeping appointments, self-monitoring medication schedules, and completing follow-up instructions) (Nicolaidis et al., 2015), a need for predictability (e.g., knowing what to expect throughout the appointment, waiting time, adhering to a schedule), and consistency (e.g., seeing the same staff each visit) (Dern & Sappok, 2015; Nicolaidis et al., 2015; Raymaker et al., 2017; Saqr et al., 2018). Emotional regulation, fear, anxiety, and distrust based on previous unpleasant experiences have also been reported as patient-level barriers to accessing quality healthcare (Dern & Sappok, 2015; Raymaker et al., 2017).

Provider-level Barriers

Patient-level barriers have often been reported to impact provider-level factors. Adults with autism and their supporters frequently describe a provider’s lack of knowledge about autism, particularly in adulthood, as well as previously held notions and

misconceptions as barriers to receiving appropriate care (Dern & Sappok, 2016; Nicolaidis et al., 2015, 2021; Raymaker et al., 2017). Additionally, many patients with autism report that providers may misinterpret their behaviors and actions or fail to take their input seriously because of communication challenges (Raymaker et al., 2017). A provider's ability to incorporate supporters may also influence the care received. Some providers may exclude the patient from important discussions regarding his or her own health, or they may fail to include a supporter when his/her input is desired or needed (Nicolaidis et al., 2015). Furthermore, a provider's lack of flexibility in making necessary accommodations, using accessible language, and allowing written communication during the appointment may also serve as a barrier (Dern & Sappok, 2016; Nicolaidis et al., 2015; Raymaker et al., 2017; Saqr et al., 2018). Finally, many healthcare providers report having insufficient skills, training, and tools to care for patients with autism, and therefore, may be unwilling to treat them (Maddox et al., 2020; Nicolaidis et al., 2015, 2021; Unigwe et al., 2017; Zerbo et al., 2018).

System-level Barriers

The quality of healthcare a patient receives is also influenced by the larger context in which he/she lives and receives care. Across the board, very few supports, both formal and informal, exist to support adults with autism in accessing appropriate healthcare (Nicolaidis et al., 2015; Raymaker et al., 2017; Vogan et al., 2017). Many report challenges with navigating the complexities of the healthcare system and are unsure how or where to find help (Nicolaidis et al., 2015; Vogan et al., 2017). As a result, many rely on family members or supporters to help them identify providers, make appointments, and advocate for their needs (Nicolaidis et al., 2015; Raymaker et al., 2017). Stigma

about autism has also been cited as a major barrier to effective healthcare (Nicolaidis et al., 2015; Vogan et al., 2017). Many adults are hesitant to disclose their autism diagnosis with a medical provider because they fear discrimination or a provider's preconceived notions about autism (Nicolaidis et al., 2015). Furthermore, societal concerns may also influence healthcare for adults with autism. Many face challenges with obtaining and maintaining employment, causing them to live in poverty, unable to pay for their own healthcare, and facing disparities in health insurance (Nicolaidis et al., 2015; Vogan et al., 2017).

Facilitators

Positive healthcare experiences have been noted when patient-, provider-, and system-level factors interrelate (Mason et al., 2019; Nicolaidis et al., 2015, 2021; Raymaker et al., 2017). When a provider understands autism and has received proper training and tools to treat adults on the spectrum, they are generally more flexible and skilled at providing patient-centered accommodations and communicating with both the patient and supporters (Nicolaidis et al., 2021). With accommodations in place, patients are generally more independent in navigating their own healthcare, can more comfortably endure physical examinations and procedures, and place more trust in their provider (Nicolaidis et al., 2015, 2021; Raymaker et al., 2017). When patient and provider-level factors effectively interact, patients may receive additional resources in navigating the healthcare system and increasing their own healthcare self-efficacy, thereby reducing system-level barriers (Nicolaidis et al., 2015; Raymaker et al., 2017; Vogan et al., 2017).

Healthcare Service Usage

Given the complex health needs of adults with autism, combined with multiple barriers to accessing appropriate healthcare, patterns of healthcare service use are quite unique amongst this population. Despite facing an increased number of access barriers, adults with autism use lower-level healthcare services, such as primary and out-patient mental health services, to an equal or greater degree as adults without autism (Gilmore et al., 2022; Weiss et al., 2018; Zerbo et al., 2018). Generally, increased use of primary care services by adults is associated with lower use of tertiary services, such as the Emergency Department (ED) and hospitals (U.S. Department of Health and Human Services, 2021); however, this does not hold true for adults with autism. Tertiary healthcare services are used at a higher rate by adults with autism when compared to the general population (Gilmore et al., 2022; Liu et al., 2017; Shields et al., 2019). Furthermore, some studies have found that adults with autism were more likely to be hospitalized for ambulatory care conditions (conditions that could be prevented with quality primary care services) than those without autism (Hand et al., 2019; Zerbo et al., 2018).

Such utilization patterns may indicate that this population is seeking services to treat co-occurring mental and physical health conditions (Vohra et al., 2016); however, the care received in these settings may not adequately meet their needs or prevent frequent use of tertiary healthcare services (Gilmore et al., 2022). Increased primary care services could also indicate a “cycling through” and searching for healthcare providers who understand autism in adults and can provide quality care (Unigwe et al., 2017; Zerbo et al., 2015, 2018). As a result, many adults with autism (who are generally under-insured) incur high costs for healthcare services that may not be truly meeting their needs

(Zerbo et al., 2018) and an undue strain is placed on the healthcare system in terms of provider time and resources (Gilmore et al., 2022; Schott et al., 2021; Shea et al., 2018). These findings underscore how largely underprepared the healthcare system in the United States is to meet the unique needs of individuals with autism, especially as they age into middle and late adulthood.

Supports for Accessing Healthcare

With so many challenges faced by adults with autism in receiving quality healthcare in the United States, there is a clear need for increased training, interventions, and supports for adults with autism, their supporters, and healthcare providers. Thus far, much of the research in this area has recognized barriers and intervention targets (Mason et al., 2019; Nicolaidis et al., 2014, 2016; Raymaker et al., 2017; Zerbo et al., 2015); however, few have identified evidence-based interventions to improve healthcare for this particular population (Mason et al., 2019).

Several interventions have been identified to improve healthcare outcomes for adults with intellectual and developmental disabilities (IDD) (Heifetz & Lunksy, 2018; Lennox et al., 2010, 2016; Nguyen et al., 2013; Tyler & Wells, 2021). The use of a health diary or passport led to increased discussion and awareness about health conditions and personal health issues for adults with IDD (Heifetz & Lunksy, 2018). Lennox and colleagues (2010) found that a Comprehensive Health Assessment Program (CHAP) enhanced interactions between adults with IDD, their caregivers, and their primary care physician (PCP). Furthermore, the use of a health intervention package, including a school-based health curriculum, CHAP, and a personalized hand-held health diary, improved preventative healthcare activity for adolescents with IDD (Lennox et al., 2016).

Given that many of the obstacles faced by adults with autism, however, are directly associated with the core characteristics of autism, there is a dire need for additional efforts and interventions focusing explicitly on empowering patients with autism and reducing barriers to healthcare (Nicolaidis et al., 2015 & 2016; Raymaker et al., 2017; Vogan et al., 2017). Such interventions should focus on preparing for a healthcare visit, increasing patient self-efficacy, educating, and training providers, and promoting the use of accommodations in healthcare (Nicolaidis et al., 2021).

The Academic Autism Spectrum Partnership in Research and Education (AASPIRE, 2020) is a collaborative team of academic researchers, adults with autism, their supporters, family members, service providers, clinicians, and healthcare providers conducting research pertaining to the needs of adults with autism. Improving healthcare access for adults on the autism spectrum is one of AASPIRE's main pillars of focus. The Partnership has conducted research examining the healthcare experiences, disparities, and the use of a Healthcare Toolkit for adults with autism. The online, open-access Healthcare Toolkit provides information and resources for patients, their supporters, and healthcare providers. The Autism Healthcare Accommodations Tool (AHAT) is one component of the Toolkit. Patients can access this survey-based tool online to create an individualized accommodations report for their healthcare provider. Nicolaidis et al. (2016) found that patients with autism who used the AHAT experienced improved access to healthcare, faced fewer barriers overall, and reported a higher level of healthcare satisfaction and self-efficacy. Although this is a promising start, it is essential to identify additional interventions designed to specifically meet the needs of this population.

Low-level Interventions

To improve preventative measures, the United Kingdom Department of Health's Think Autism Report (United Kingdom Department of Health, 2014) emphasizes the need for *low-level* support services for adults with autism who do not have an accompanying intellectual disability. Low-level supports refer to “non-intensive services aiming to provide general support, which is not directed at treating a clinical problem or deficit, to people in their everyday lives” (Lorenc et al., 2016, p. 8). The aim of low-level supports can be diverse and can be delivered in a variety of settings, including health services, social and community supports, and telephone or internet-based services (Lorenc et al., 2016). Such supports have been associated with positive outcomes for accessing resources and information, education, employment, health and well-being, and daily self-management for adults with autism (Southby & Robinson, 2017).

Internet-based low-level supports have promoted skill acquisition for adults with autism (Gaigg et al., 2020; Nicolaidis et al., 2016; Southby & Robinson, 2017; Westerberg et al., 2021). Internet-based treatments (IBTs) allow for increased flexibility and convenience in accessing supports, potentially increasing access and use of preventative healthcare supports for adults with autism (Westerberg et al., 2021). IBTs also reduce cost and transportation barriers often associated with accessing care (Gaigg et al., 2020). Moreover, research has found that adults with autism report a preference for self-paced IBTs as they afford increased processing time, less anxiety concerning social communication factors, and increased control over their communication (Westerberg et al., 2021). Several studies have found self-guided IBTs to effectively treat mental health conditions in adults with autism (Gaigg et al., 2020; Wattanawongwan et al., 2022;

Westerberg et al., 2021). These results, in combinations with the promising outcomes of AASPIRE's online Healthcare Toolkit, demonstrate the need for additional research focusing on the use of self-guided, internet-based interventions to reduce barriers to appropriate healthcare services for adults with autism.

Behavior Skills Training (BST)

Treatment packages that include behavior skills training (BST) have been effective in teaching social and communication skills to adults with autism (Grob et al, 2019; Kornacki et al., 2013; Nuernberger et al., 2013; Ryan et al., 2019). BST includes direct teaching of the targeted skill, modeling the target skill, providing the participant with opportunities to practice, and providing constructive feedback (Nuernberger et al., 2013). Providing individuals with opportunities to practice targeted skills and receiving corrective feedback is essential when teaching specific social and conversational skills to individuals with autism (Leaf et al., 2009). Additionally, BST promotes generalization of new skills to in-situ environments (Grob et al, 2019; Nuernberger et al., 2013). Ryan and colleagues (2019) found that BST effectively increases appropriate verbal and non-verbal conversational skills to six adults with autism. They also found that skills maintained 4 weeks post-intervention. Grob et al. (2019) implemented BST to teach multiple workplace social skills for three adults with autism. The intervention was effective in increasing targeted skills and promoted generalization to a novel environment and conversational partner. Using an instructional package that incorporates a self-paced internet-based video module and BST may offer another support to adults with autism in accessing quality preventative healthcare.

Significance of the Study

Quality healthcare is essential for all adults as they age; however, given the added risks that many adults with autism will face, it is essential that they have fair access to appropriate and timely care. To optimize the health and wellbeing of this population, additional interventions targeting autism-specific barriers must be identified to promote equitable treatment for adults with autism in primary healthcare settings. This study aimed to employ the use of an instructional package to further the currently limited understanding of how to decrease access barriers and to improve patient-provider communication. To our knowledge, this is the first study using an instructional package to support adults with autism in communicating their needs and requesting accommodations from a PCP during an initial visit.

Problem Statement

The goal of this study was to determine the effectiveness of an instructional package, including a video module accompanied by guided notes, the Autism Healthcare Accommodations Tool (AHAT), and behavior skills training (BST) to teach adults with autism to communicate their unique needs and request accommodations from a medical provider during simulated doctor's appointments. This study also sought to determine whether the newly acquired skills would generalize to a novel PCP and maintain after the instructional package was removed.

Research Questions

This research sought to answer the following questions:

1. What is the effect, if any, of an instructional package, including a video module accompanied by guided notes, the AHAT, and behavior skills training on the ability of

adults with autism spectrum disorders to communicate their unique needs and request accommodations from a medical provider?

2. If the instructional package is effective, will the skills maintain after the intervention has been discontinued?

3. Will the effects of the instructional package generalize across providers?

CHAPTER 2: METHOD

Participants

Purposive, convenience sampling was used to recruit participants through the Florida Center for Autism and Related Disabilities (CARD) constituency databases. CARD is a community-based, technical assistance center providing support, consultation, and training to individuals with autism, their families, professionals, and community members who serve them.

The criteria for inclusion in this study were:

1. 40 years of age or older;
2. Diagnosis of an autism spectrum disorder, as confirmed by registration with a Florida CARD Center;
3. Currently report challenges in finding a primary care physician that understands his/her needs;
4. Regular access to the internet and a computer or tablet, and
5. Able to provide written consent to participate in this study.

The interventionist identified all potential participants 40 years of age or older who were registered in the FAU CARD constituency database. Within those results, the interventionist reviewed each file for documentation of autism diagnosis from a medical or mental health professional. All individuals who met these criteria were provided information about the study via email and were asked to reply to the interventionist if they were interested in learning more. To extend the potential participant pool, a

recruitment flyer was emailed to constituents registered with the University of Miami (UM) CARD and University of Central Florida (UCF) CARD centers who were over the age of 40. The interventionist contacted all individuals who responded to the recruitment emails to conduct an informal telephone interview to determine if the potential participant met all inclusionary criteria. Recruitment ended once all respondents had been contacted. Three individuals initially met inclusionary criteria; however, due to personal and health reasons one participant resigned from the research after completing one baseline session. At that time, the recruitment flyer was again emailed to the potential participants who had not previously responded. One additional individual responded and met inclusionary criteria to join the study. All individuals were informed that participation was voluntary. An electronic consent form was sent to each qualifying participant.

Three adults with autism (aged 42–67) participated in this study. All three participants had previously received a diagnosis of autism through a comprehensive psychological evaluation. To assess the social functioning levels of each participant, the interventionist administered the Social Responsiveness Scale, Second Edition: Adult Self-Report (SRS-2). The SRS-2 contains 65 items that assess the two core deficits associated with autism: Social Communication and Interaction and Restricted Interests and Repetitive Behaviors. The instrument breaks Social Communication and Interaction skills down further into four subscales: Social Awareness, Social Cognition, Social Communication, and Social Motivation. The SRS-2 generates a Total score for all 65 items. A Total *T*-score is then calculated and is based on ratings collected in the nationally representative standardization sample. *T*-scores have a mean of 50 and a standard deviation of 10. *T*-scores are also calculated for each subscale. *T*-scores of 59 (or

59T) and below reflect normal limits, or behaviors not clinically significant for autism spectrum disorder. Individuals with very mild autistic syndromes may show scores in the upper end of the normal range if they are well adjusted and have relatively strong adaptive functioning. Scores of 60T–65T reflect mild deficiencies in reciprocal social behavior associated with autism. Individuals in this range may experience mild to moderate interference with daily social interactions. Scores between 66T and 75T reflect moderate deficiencies in reciprocal social behaviors that substantially interfere with everyday social interactions. Scores of 76T and higher reflect severe deficits in reciprocal social behavior and lead to enduring interference with everyday social interactions.

Ryan

Ryan, a 42-year-old, white-Hispanic male, reported that he previously had experienced some difficulty communicating with doctors. He felt that doctors mostly talked directly to his mother (who attended all appointments with him) about his healthcare, rather than speaking to him directly. He also shared that challenges with delayed processing interfered with his ability to self-advocate and ask questions in the medical setting. Ryan reported that he had no prior instruction on interacting with medical providers.

Ryan's Total *T*-score on the SRS-2 was 61T, reflecting overall mild social impairments associated with autism. His scores on the Social Awareness (60T), Social Communication (62T), and Social Motivation (60T) subscales demonstrated mild impairments in these areas. His scores on the Social Cognition (68T) and Restricted Interests and Repetitive Behaviors (71T) subscales were slightly more elevated to reflect moderate impairments in these areas.

Phil

Phil was a 67-year-old, white male. He reported challenges with communicating with medical providers in the past. He also described his difficulties with social communication, as well as challenges with expressing himself and effectively communicating with doctors. Phil also shared that although he often felt prepared for an appointment, he had a history of becoming very anxious during the appointment, inhibiting his communication. Phil reported that he had no prior formal instruction on communicating with medical providers.

Phil's Total *T*-score on the SRS-2 was 84*T*, demonstrating acute impairments associated with autism. His score on the Social Awareness subscale (66*T*) demonstrated moderate impairments; his scores on the remaining four subscales, Social Cognition (79*T*), Social Communication (89*T*), Social Motivation (79*T*), and Restricted Interests and Repetitive Behaviors (78*T*), demonstrated severe impairments in these areas.

Samuel

Samuel was a 43-year-old, black male. He shared that he experienced challenges with everyday reciprocal social interactions. Samuel reported that he relied heavily on his caregivers to communicate with medical providers. He shared that he did not interact regularly with health care providers and often avoided medical appointments because they were unpleasant for him. He reported that he had no prior instruction on communicating with medical providers.

Samuel's SRS-2 Total *T*-score of 70*T* reflected moderate impairments associated with autism. His score on the Social Motivation subscale (60*T*) reflects mild impairment. His scores on the Social Awareness (68*T*), Social Cognition (72*T*), and Social

Communication (74*T*) subscales demonstrate moderate impairments in these areas. His score on the Restricted Interests and Repetitive Behaviors subscale (80*T*) reflects severe impairment.

Confederates

Student volunteers were recruited from the FAU College of Medicine to act as confederates for this study. Two confederates were designated as Primary Care Physicians (PCPs). The confederates prompted study participants to exhibit specific communication skills during each data collection probe. Both confederates were in their second year of medical school at the time of this study. They each had previous experience working with individuals with developmental disabilities. Participants were not given background information about the confederates. They were not directly informed that the confederates were medical students; they were under the impression that they were practicing medical providers throughout the study.

Setting

All sessions were conducted virtually using the online videoconferencing software, Zoom, and included one participant, the interventionist, and a confederate PCP. A secondary data collector was present for a small percentage of sessions within each experimental condition to collect treatment fidelity and interobserver agreement (IOA) data. The secondary data collector was a special education graduate student and had experience working with adults with developmental disabilities.

Prior to beginning data collection, participants were asked to establish a distraction-free, individualized home workspace where they had a stable internet connection and access to a computer or tablet. To minimize outside bias, participants

were asked to either wear headphones or to ensure their home workspace was in an area where others would not be present during their research sessions. Each participant completed the instructional package and attended Zoom sessions from their established workspace. Investigators participated in sessions from individualized home or office workspaces that were free of distractions.

Independent Variable

The independent variable was an instructional package consisting of: (a) a video module, titled the Module for Autism Self-efficacy in Healthcare (MASH), (b) Guided Notes, (c) the Autism Healthcare Accommodations Tool (AHAT), and (d) Behavior Skills Training (BST).

Module for Autism Self-efficacy in Healthcare (MASH)

MASH is a researcher-created, three-part video module that was available online to participants for one week. Part one of the video module introduced the instructional package and reviewed the goals of the intervention. It also included a “Commitment to Promoting Independence,” intended for supporters, if applicable. In this section, supporters were encouraged to assist the participant in accessing the online tools, if needed; however, they were asked to refrain from providing any teaching or guidance on communicating with a medical provider until the completion of the study. Part two of MASH provided instructions on accessing the AHAT online (Nicolaidis et al., 2016) and creating an Accommodations Report. Participants were then prompted to pause MASH and complete the AHAT. Part three demonstrated how participants should use their Support Statement Guided Notes to identify the most pertinent recommendations from

their Accommodations Letter and to formulate a Support Statement that could be communicated verbally with a PCP.

Autism Healthcare Accommodations Tool (AHAT)

The AHAT is a component of the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit (2020). It can be accessed online via <https://autismandhealth.org/>. The AHAT creates an individualized Accommodations Letter for adults on the autism spectrum to give to their primary care provider. After completing a survey, the tool formulates a letter with information about the patient and provides recommendations for steps that can be taken before, during, and after an appointment to make primary healthcare more accessible. A maximum of 35 accommodations can be listed in the report. The report can be accessed and edited online at any time and can be saved electronically or printed.

Support Statement Guided Notes

The Support Statement Guided Notes is a researcher-created handout that participants used to formulate a brief Support Statement. The purpose of this statement is to have a brief verbal script that the patient can recall when speaking with their PCP. The Support Statement was composed of four essential elements, including a statement describing the individual's need for extra support (i.e., full or partial disclosure of disability) and three pertinent accommodations. Participants were instructed to practice verbalizing their Support Statement so that they might be comfortable communicating their needs and accommodation requests.

Module Culmination Meeting

Participants were given one week to view all parts of MASH and to complete the AHAT and their Support Statement Guided Notes. At the end of that week, access to MASH was blocked, and the interventionist met individually with each participant to determine if all components were complete. The interventionist reviewed the participant's AHAT Letter to verify that it was complete and used a researcher-created data sheet to determine if all elements of the Support Statement were present. The data sheet listed the four essential components of the Support Statement. A plus sign indicated complete and a minus sign indicated an incomplete for each component on the data sheet. The total number was calculated for the completed elements. If all elements were complete, the participant was given instructions for moving into intervention. If not, the interventionist would remind the participant of the four essential elements and ask the participant to fix the errors. A second meeting would then be scheduled to review the participant's updated Support Statement. If all elements of the statement were complete at that time, the participant would be prepared to move into intervention. If not, the interventionist would review the AHAT with the participant and provide guidance to complete the Support Statement Guided Notes together. Once completed, the participant would then be prepared to move into intervention. No teaching of target behaviors occurred during these meetings.

Behavior Skills Training (BST)

The final component of the instructional package was the use of behavior skills training to teach participants to communicate their unique needs and request accommodations from their PCP. BST consisted of instruction, modeling, rehearsal, and

feedback. The mnemonic *GREEN* was used to help the participant remember the targeted communication steps. The steps in GREEN included: **G**reeting; **E**xplain the **R**eason for your visit; **E**xplain your need for **E**xtra support; **E**xplain two or three accommodations; **A**sk questions about **N**ext-steps and following-up. To begin, the interventionist provided instruction on each step of the mnemonic. The participant then observed the interventionist and the confederate PCP simulating a doctor's appointment. In this rehearsal, the interventionist assumed the role of the *patient* and followed the steps in GREEN. Finally, the participant rehearsed the simulated appointment using GREEN with the PCP, and the interventionist provided positive reinforcement and constructive feedback as needed.

Prior to beginning this research, three practice participants were asked to view MASH and complete the AHAT and Support Statement Guided Notes within a one-week timeframe. While completing components of the instructional package participants were asked to take written notes about the structure and delivery of MASH, as well as the feasibility of accessing the module and its related activities. The interventionist then met with each practice participant individually to discuss their notes and feedback. Modifications were made to MASH based on the feedback received. The practice participants met all inclusion criteria for this study, with the exception of the age criterion, under the age of 40.

Dependent Variable

The dependent variable was the percentage of targeted communication steps in the mnemonic GREEN that were completed correctly and independently by the participant. Responses were recorded as correct on a researcher-made data sheet if the

step was completed in sequence and was initiated independently either within 5 seconds of the provider's prompt or within 5 seconds of completing the prior step. Additionally, errors were recorded by type to identify any error patterns: (a) omission, (b) sequence error, and (b) latency error.

Five steps in the GREEN mnemonic were targeted:

1. **G**reeting
2. Explain the **R**eason for your visit
3. Explain your need for **E**xtra support
4. **E**xplain two or three accommodations
5. Ask questions about **N**ext-steps and following-up.

See Appendix A for Dependent Variable Data Collection Sheet and the IOA Form

Procedure

All procedures were approved by the university Institutional Review Board (IRB) prior to conducting the study. See Appendix B for IRB Approval Letter. Every session in each condition began with a data collection probe. To minimize distractions and bias within the virtual environment, a remote interaction protocol was developed. All investigators kept their cameras and microphones off while inactive. They also removed their names from the screen so that participants could only see an empty black box on the screen in Zoom. This was to ensure that the participant could only see and hear the interventionist or confederate PCP, minimizing the probability of having an unintended reactive influence on the participant's performance.

Baseline

Baseline sessions were conducted prior to implementing any components of the instructional package. All sessions began with the participant, a confederate PCP, and the interventionist logged into Zoom. The interventionist's name was removed from her screen and her video and microphone were off. The confederate greeted the participant and asked him or her to share some personal information and their medical needs. No additional coaching was provided. The interventionist recorded the number of steps in GREEN that were performed correctly and incorrectly, as well as any errors by type. The confederate PCP ended the baseline session if the participant made errors on two consecutive steps, did not respond verbally for 10 seconds, or stated that he was unsure of what to do. The participant's performance was observed during several sessions. Participants were moved from baseline to intervention once at least three data points demonstrated low and stable or decelerating rate of skill performance (i.e., 40% or fewer steps completed correctly or independently). One generalization probe was conducted during baseline for each participant.

Intervention

Upon reaching mastery criteria for baseline, the interventionist met with the participant individually. Following a loose script, the interventionist introduced MASH, the AHAT, and the Support Statement Guided Notes. The interventionist then sent an email with a link to access MASH and the related materials. Each participant was given one week to complete all components of the video module. As described previously, the interventionist conducted a Module Culmination Meeting at the end of that week to

determine if all tasks had been completed. Once completed, the participant received behavior skills training.

All BST sessions included the participant, a confederate PCP, and the interventionist. The first BST session began with the interventionist ensuring that the participant had his or her Support Statement Guided Notes readily available for reference. The confederate PCP's video and microphone were off. The interventionist explained,

We are going to learn steps to communicate with a primary care physician, or PCP. These steps will help you share your needs with the doctor and request accommodations that will help make your visits more comfortable and effective.

First, I will teach you the steps, and then Dr. ___ will join us so you can watch us model the steps. Next, you and Dr. ___ will practice together.

The BST sequence was then implemented: (a) the interventionist taught each step of GREEN, (b) the interventionist and the confederate PCP modeled a doctor's appointment, with interventionist acting as the patient and following the steps in GREEN, then (c) the participant rehearsed the steps in GREEN during a simulated appointment with the confederate PCP. The interventionist implemented an error correction procedure as needed during the rehearsal component.

After the initial BST session, each intervention session began with a data collection probe via Zoom, following the same protocol used in baseline sessions. Once data was collected, the confederate PCP turned off his/her video and microphone, and the interventionist began the BST sequence. Once a participant reached mastery criteria of three consecutive sessions at 100% correct and independent, intervention sessions were terminated for that participant, and a maintenance condition was implemented.

Error correction. If an error occurred at any step during the rehearsal phase of the behavior skills training, an error correction procedure was implemented. The first time that an error occurred in a step, the interventionist identified the error, provided a verbal correction, and asked the participant to repeat the correction for clarification. The confederate PCP then resumed rehearsal at the step in which the error occurred. If an error occurred again in that same step, the interventionist identified the error, provided a verbal correction, and asked the participant to practice the entire step. Rehearsal once again began at the step in which the error occurred. If a third error occurred in the same step, the interventionist identified the error, modeled the step with the confederate PCP and asked the participant to practice the entire step.

Generalization

To determine if skills transferred across providers and gender, one generalization probe was completed during baseline, intervention, and maintenance phases for each participant. The generalization sessions followed the same procedure as the baseline sessions but included a novel, female confederate PCP. No additional teaching was provided during generalization sessions; the novel confederate prompted the participant by saying “Hi _____, I’m Dr. _____. Please share a little about yourself and your medical needs.” No additional coaching was provided. The session was ended if the participant made errors on two consecutive steps, did not respond verbally for 10 seconds, or stated that he was unsure of what to do. The interventionist kept her name hidden and video and microphone off while collecting data on the number of steps that were performed correctly and independently, as well as error types.

Maintenance

Three maintenance probes were conducted with each participant at 2, 4 and 6 weeks after removal of the intervention. Maintenance procedures mirrored baseline procedures. The participant, confederate PCP and the interventionist logged into Zoom. The confederate PCP prompted the participant to share about themselves and their medical needs. No additional coaching on the targeted behaviors was provided during these sessions. The interventionist recorded the number of steps in the task analysis that were performed correctly and independently, as well as the types of errors that occurred, if any. The second maintenance probe was also a generalization probe, including a novel confederate PCP.

Data Collection

Data on the dependent variable were collected three times per week for each participant, prior to beginning BST. This ensured that at least 24 hours had passed between teaching and data collection, mitigating immediate practice effects. A researcher-created data sheet was used to record the number of steps in GREEN that the participant completed correctly or incorrectly. Correct responses included those that were completed in sequence and were initiated within either 5 seconds of the provider's prompt, or within five seconds of completing the prior step. If incorrect, the error type (omission, sequence, or latency error) was recorded to identify any patterns. To reach mastery, 100% of the steps needed to be performed correctly for three consecutive sessions. The data were converted to percentages for graphing. For example, there were five targeted communication steps. If one step was performed accurately during the first baseline session, the first data point would be recorded at 20%. After six intervention

sessions, if four of the five steps were completed accurately, then the data point would be recorded as 80% for that session.

Interobserver Agreement

To enhance the reliability of the data, interobserver agreement (IOA) data was collected for at least 33% of sessions within each experimental condition. This involved comparing independent observations of the same event from the interventionist and a secondary data collector. Training for the IOA observer involved the secondary data collector watching a video of the interventionist and the confederate PCP simulating a doctor's appointment, following the steps in the mnemonic (without any participants present). The observer then practiced using the data sheets while watching the video and discussed the scores with the interventionist. No disagreements were noted.

To minimize distractions and bias during secondary data collection sessions, the observer removed her name from the Zoom screen and kept her microphone and video off. The secondary data collector recorded data on the dependent variable. The IOA was computed by counting the number of agreements between the interventionist and the secondary data collector. That total was then divided by the total number of agreements plus disagreements and multiplied by 100 to calculate a percentage. 100% agreement was found between the interventionist's and secondary data collector's observations for each participant. A summary of IOA data for each participant is reported in Table 1.

Table 1

IOA Summary Data

Participant	Percent of Sessions	Percent Agreement
Ryan	33% (4/12)	100%
Phil	38% (5/13)	100%
Samuel	38% (6/16)	100%

Treatment Fidelity

Treatment fidelity data was also collected by the secondary researcher to evaluate the degree to which each experimental condition was implemented as intended. A researcher-created fidelity checklist was used during data collection probes in all three conditions to ensure that experimental procedures were followed, but no part of the intervention was delivered. An intervention fidelity checklist was used during the BST sessions to ensure that the intervention was implemented accurately. Training involved the secondary data collector watching a video of the interventionist performing the behavioral skills training with a confederate PCP, without any participants present. The secondary data collector then practiced using the data sheets while watching the video and discussed the scores with the interventionist. No disagreements were noted. Data were collected on 37% of the data collection probes with 100% fidelity. Data were collected on 37% of the BST sessions with 95% fidelity. See Appendices C and D for Treatment Fidelity Checklists.

Social Validity

Social validity data was collected from participants, the medical student volunteers (confederates) involved in this study, and two PCPs in the local community. A Likert-type scale was used to address three levels of social validation including socially important goals, socially acceptable procedures, and socially significant outcomes (Wolf,

1978). Two different scales were used to assess this validity. Both scales had six items asking the same information; however, one scale included items directed at participants and the other at medical students and providers. A 4-point scale with response choices including—Strongly Agree (4), Agree (3), Disagree (2), and Strongly Disagree (1)—was used to respond to each item. Both versions of the questionnaire were transferred to an online anonymous survey platform. The scales were developed based on the input of experts in the medical and disability fields who were familiar with this type of tool.

Respondents completed the social validity assessment midway through the study and then again after the completion of the study. To gain an understanding of the goals, procedures, and outcomes of the intervention, PCPS were asked to view MASH, as well as two videos of each participant receiving BST and performing the targeted communication skills before responding to the social validity assessment. The video recordings were shared via a secured internet link. Each PCP had access to the video recordings for a limited amount of time only and settings were implemented to prohibit saving the video to personal devices or files. Results were analyzed by calculated means for each group of respondents at each level of social validity. See Appendices E and F for social validity assessments.

Design

This study used a multiple probe design across participants, consisting of three experimental conditions (i.e., baseline, intervention, and maintenance). Each participant participated in the study three days per week for approximately 15 minutes each day, over 6 weeks.

Data Analysis

Investigators used visual analysis to determine the levels and trends of individual data points and to make decisions regarding phase changes (Gast & Ledford, 2014). Researchers also calculated measures of central tendency and ranges for each participant's skill acquisition during baseline, intervention, and maintenance phases. Effect size was calculated using percentage of non-overlapping data (PND), which is the most used effect size estimate for single-subject research over the last three decades (Scruggs & Mastropieri, 2013). This method is appropriate to use for baselines that do not show outliers (Rakap, 2015). PND was determined for each participants' baseline and intervention differences, as well as baseline and maintenance differences. The effectiveness ratings were based on criteria generated by Scruggs and Mastropieri (2013), defining interventions as (a) *highly effective* when 90-100% of data do not overlap with baseline, (b) *moderately effective* when 70-90% of data do not overlap with baseline, (c) *minimally effective* when 50-70% of data do not overlap with baseline, and (d) *ineffective* when 50% or more of data do not overlap with baseline. A post-hoc analysis of Tau-*U* was also calculated to determine the true effect size based on each participants' weighted average of baseline and intervention differences. In single-case designs, examining within-trend and across-phase differences with Tau-*U* provides useful descriptive and inferential insights into the data (Brossart et al., 2018). The Tau-*U* web-based calculator was used for this analysis (Vannest et al., 2016).

CHAPTER 3: RESULTS

The effects of the instructional package on individual participant performance are shown in Figure 1. A summary of performance changes within each condition and effect size is shown in Table 2.

Baseline

As seen in the section labeled BL (Baseline) in Figure 1, data remained low and stable for each participant during the baseline phase. No participant accurately completed each step in the GREEN mnemonic. Ryan and Phil completed 40% (or two out of the five steps) correctly during each baseline probe. Samuel completed 20% (or one out of the five steps) correctly during each baseline probe.

Intervention

Following the completion of MASH and the related activities, behavior skills training was implemented. Upon the introduction of BST, all participants began to steadily complete the targeted communication steps in the GREEN mnemonic with increased accuracy. Ryan and Phil both jumped to 80% accuracy (four out of five steps correct) after their first teaching session and required a total of five teaching sessions to reach mastery. The mean of both Ryan and Phil's responses was 4.8, with a range of four to five correct responses. See the section labeled IV (Intervention) in the top and middle panels of Figure 1. Samuel jumped to 60% accuracy following the initial teaching session. His performance varied slightly upon receiving BST. He required nine teaching

sessions to reach mastery. The mean of Samuel's responses was 4.33, ranging from three to five correct responses. See the bottom panel of Figure 1.

Maintenance

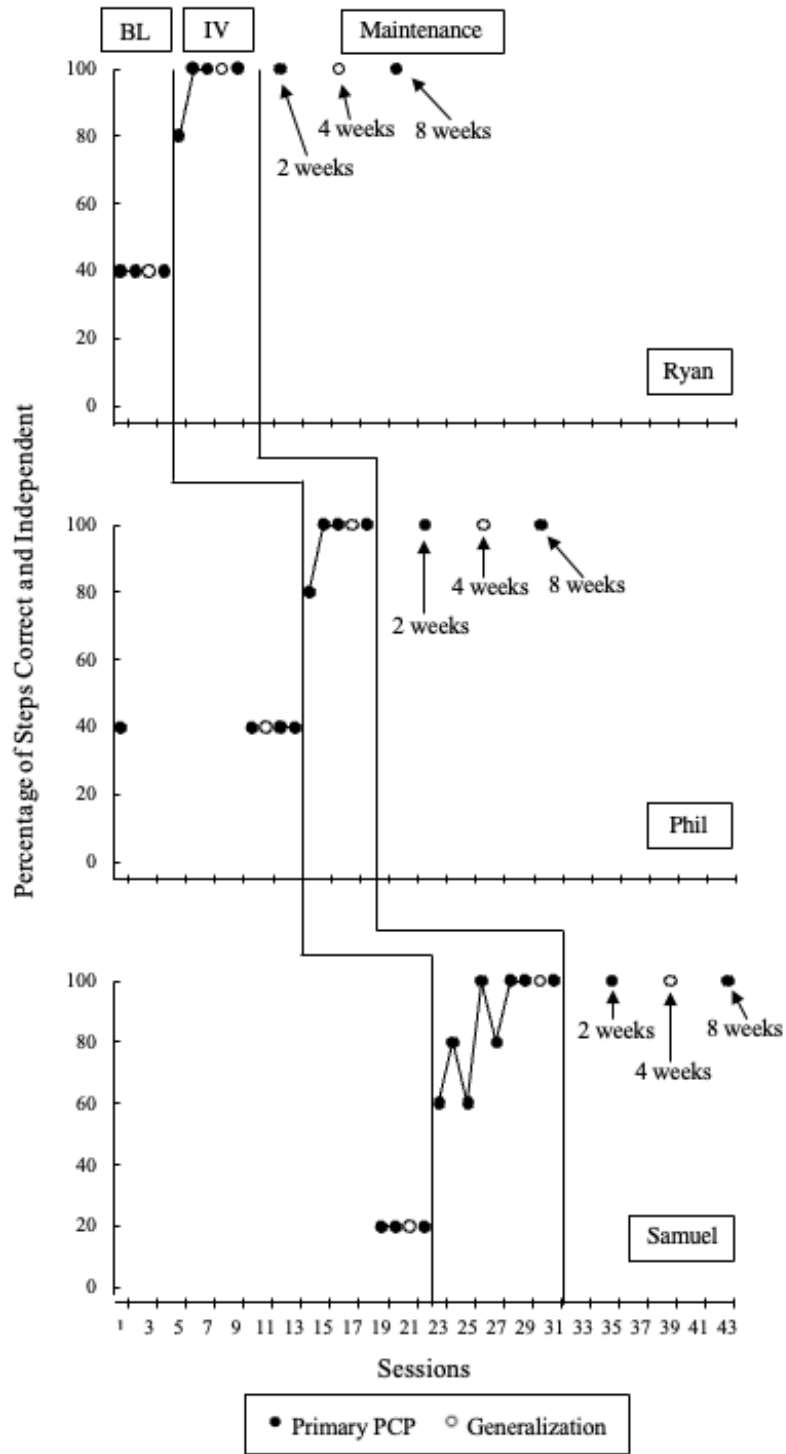
As seen in section labeled Maintenance in the top panel of Figure 1, Ryan's accuracy remained at 100% accuracy at 2, 4, and 6 weeks following the removal of BST. Phil's accuracy also remained at 100% 2, 4, and 6 weeks post-intervention (see the middle panel of Figure 1). Samuel also maintained 100% accuracy on all steps 2, 4, and 6 weeks following the removal of BST. See the bottom panel of Figure 1.

Generalization

As seen in Figure 1, one generalization probe was conducted with each participant in each phase. During these sessions a novel, female PCP conducted the simulated appointment with the participant. During the baseline generalization session Ryan and Phil both completed 40% (or two out of five steps) correctly. They both jumped to 100% accuracy (or five out of five steps) during the intervention generalization session. Samuel was able to conduct 20% (or one out of five) steps accurately during the baseline generalization session. He jumped to 100% accuracy (or five out of five steps) during the intervention generalization session. A maintenance generalization probe was conducted with all participants 4 weeks after the removal of the intervention. All three participants maintained 100% accuracy during these sessions.

Figure 1

Participant Communication Skills Across All Conditions



Post Hoc Analysis and Effect Size

A post-hoc analysis of the findings using percentage of non-overlapping data (PND) indicated that the instructional package was highly effective based on the criteria described by Scruggs and Mastropieri (2013). Ryan's PND between baseline and intervention was 100%; between baseline and maintenance Ryan's PND also was 100%, indicating the intervention was highly effective. Phil's PND between both baseline and intervention and baseline and maintenance was 100%, indicating a highly effective intervention. Samuel's PND between both baseline and intervention and between baseline and maintenance was also 100%, indicating the impact of the intervention was highly effective. The post-hoc analysis using the Tau-*U* results showed an overall effect size of 1.0 for the instructional package. This demonstrates a robust effect size across the participants (Parker et al., 2011). Table 2 summarizes performance changes across phases and effect sizes.

Table 2*Performance Changes Across Phases and Effect Sizes*

Participant	Baseline	Intervention	Maintenance
Ryan			
Mean	2.0	4.8	5.0
Range	2.0	4.0 – 5.0	5.0
Standard Deviation	0.0	0.4	0.0
Effect Size		100%	100%
		Highly Effective	Highly Effective
Phil			
Mean	2.0	4.8	5.0
Range	2.0	4.0 – 5.0	5.0
Standard Deviation	0.0	0.4	0.0
Effect Size		100%	100%
		Highly Effective	Highly Effective
Samuel			
Mean	1.0	4.3	5.0
Range	1.0	3.0 – 5.0	5.0
Standard Deviation	0.0	0.8	0.0
Effect Size		100%	100%
		Highly Effective	Highly Effective

Note. Effect size reported as percentage of non-overlapping data (PND) by comparing Baseline to Intervention, and Baseline to Maintenance.

Social Validity

To determine the social validity of this intervention, the participants, the medical student volunteers, and two PCPs in the local community completed a social validity assessment. Respondents completed the questionnaire at two different points in time. The participants completed the assessment initially after their third intervention session. The confederates and PCPs completed it after Phil’s third intervention session. PCPs viewed four videos of BST being implemented and data collection probes with Ryan and Phil being prompted to complete the targeted communication skills. All respondents completed the assessment again following the completion of the study. At this time, PCPs

viewed videos of the final two intervention sessions and one maintenance session with each participant before completing the assessment.

Overall, all respondents perceived the goals of the intervention to be significant. The participants' perceptions of the goals of this intervention scored an average of 3.67 (out of 4.0) at the midway point and increased to 3.83 after the study was complete. The medical student volunteers responded with an average of 3.5 initially and increased to 3.75 following the study. The PCPs reported an average of 3.75 agreement that the goals of this intervention were socially significant at both data collection points.

The respondents perceived the procedures used in this study to be highly socially acceptable. At the midway point, participants responded with an average of 3.5 and increased to 4.0 after completing the study. The medical student volunteers strongly agreed that the procedures used were socially acceptable, rating them at an average of 4.0 at both assessment points. The PCPs rated social acceptability at an average of 3.75 initially and increased to an average of 4.0 following the completion of the study.

All respondents agreed that the outcomes of the intervention were effective. The participants responded with an average of 3.83 at both assessment points. Both the medical student volunteers and PCPs perceived the outcomes to be significant at an average of 3.75 at both assessment points. See Table 3 for each group of respondents' average responses for the three levels of social validity.

Table 3*Average Social Validity Responses by Level and Respondent Group*

Level	Significance of Goals	Acceptability of Procedures	Impact on Outcomes
Participants			
Midway	3.67	3.5	3.83
Final	3.83	4.0	3.83
Medical Students			
Midway	3.5	4.0	3.75
Final	3.75	4.0	3.75
PCPs			
Midway	3.75	3.75	3.75
Final	3.75	4.0	3.75

Note. Scores ranged from 1 (low social validity) to 4 (strong social validity).

CHAPTER 4: DISCUSSION

The purpose of this study was to determine whether an instructional package consisting of a video module, the AHAT, guided notes, and behavior skills training was effective in teaching adults with autism to communicate their needs and request accommodations from a medical provider during a doctor's appointment. This study also sought to determine whether the newly acquired skills would generalize to a novel PCP and maintain after the instructional package was removed. After receiving the instructional package, all participants were able to communicate their needs with the PCP and describe three accommodations that would help them in the medical setting. All participants were able to generalize this skill to a novel PCP of the opposite gender, and the skills maintained after the intervention was removed. To our knowledge, this is the first study incorporating a low-level, internet-based treatment with behavior skills training into an instructional package to support adults with autism in communicating their needs during a doctor's appointment.

The results of this study are encouraging. All participants mastered the targeted communication skills with 100% accuracy. Two participants required only five intervention sessions to reach mastery criteria. One participant required nine sessions to reach mastery criteria, which establishes a relatively efficient treatment. All participants demonstrated an immediate increase in skills upon receiving the intervention. Given the often-complex healthcare needs of adults with autism, combined with the barriers faced

in accessing appropriate preventative care, and the dearth of interventions available, this research is a promising start to meeting the needs of this population.

Furthermore, all participants were able to generalize 100% of the targeted skills to a novel PCP during both intervention and maintenance conditions. For this study, the primary confederate PCP was a male. This matched the gender of all three participants. The confederate PCP used for generalization probes was a female. Due to many factors in the healthcare system, patients may not always see the same provider with every visit. Because of this, it is important that the participants could generalize their newly acquired skills, not only to a new provider, but also to a provider of the opposite gender.

All participants maintained 100% accuracy of the targeted communication skills at 2, 4, and 6 weeks after the intervention was removed. This shows that the effects of the intervention sustained after receiving the intervention or any continued teaching of the target skills. Because some time may pass between doctor's visits, it is essential that the targeted communication skills maintain after the intervention is removed so that they can be applied on an on-going basis.

This instructional package proved to be an ecologically valid low-level internet-based support for the participants. It directly addressed several barriers to healthcare that many adults experience because of the core deficits of autism. It helped the participants to prepare for a doctor's appointment and promoted the use of appropriate accommodations through conversation. By completing the instructional package, each participant also had an individualized AHAT report that could further doctor and staff understanding of the patient's unique needs. As a result of this instructional package, patient-provider communication improved, which may ultimately lead to improved

access to appropriate preventative healthcare and increased self-efficacy for adults with autism.

This study extends the research on using internet-based, low-level supports for adults with autism (Gaigg et al., 2020; Lorenc et al., 2016; Nicolaidis et al., 2016; Southby & Robinson, 2017; Westerberg et al., 2021). The video module and related activities were flexible and convenient to access online around the individual's schedule. They eliminated cost and transportation barriers by offering a free resource that could be accessed from anywhere with internet connection. The self-paced nature of this intervention also addressed common challenges that many adults with autism have reported when accessing supports. It allowed participants to have additional processing time as needed, decreased potential social communication angst, and increased the individual's control over their own communication.

Additionally, this research adds to previous research on the use of behavior skills training with adults with autism (Grob et al., 2019; Kornacki et al., 2013; Nuernberger et al., 2013; Ryan et al., 2019). By completing the video module and related activities, the participants were able to prepare for the doctor's appointment. Using behavior skills training, they were able to practice the communication skills necessary for informing the doctor of their unique needs and describe at least three appropriate accommodations. BST is a straightforward intervention that does not require a great deal of resources or prior training for parents and caregivers or providers to implement.

Furthermore, this instructional package was determined to be socially valid by three groups of stakeholders (i.e., adults with autism, medical students, and practicing physicians). They found the goals of this intervention to be meaningful and significant to

helping adults with autism. They agreed that the procedures used throughout the instructional package were socially acceptable and practical. They also determined that the effects of this intervention were beneficial and useful to increase communication skills for adults with autism in the medical setting.

Limitations

Several limitations should be noted when analyzing the results of this study. All participants in this study were verbal and had adequate expressive language skills. It is not known how adults with autism who are non-verbal, have limited verbal abilities, or use an augmentative and alternative communication (AAC) device would respond to this intervention. Additionally, all participants in this study were males over the age of 40 who were registered with a CARD program within the state of Florida. The results may have been impacted by the limited diversity within the population sample. Finally, all simulated doctor's appointments in this study were delivered virtually, via teleconferencing. Variables impacting an in-person doctor's appointment may result in a different outcome.

Implications for Future Research

Future research should address the limitations of the current study. To determine if the effects of this intervention will generalize across other populations with autism, the sample of future studies should be diversified to include individuals with autism who have varying verbal abilities or use AAC devices. Additional research should also include females, young adults, and individuals across a broader geographic region. Furthermore, because environmental factors and social interaction variables may impact an individual's

ability to communicate in medical settings, future research should focus on the generalization of this intervention to in-person appointments.

Additional research should include other medical specialists and preventative healthcare settings. This may include specific screenings and medical tests, vaccinations, and well-women exams. Furthermore, because not every adult with autism may have a caregiver or supporter who can implement BST with them, additional research may incorporate other evidence-based practices within the instructional package. Practices such as video modeling, social narratives, or self-monitoring can be used independently and could be used in a more self-directed manner.

Conclusion

This study demonstrates the effectiveness of the instructional package in improving communication for adults with autism in medical settings. Fostering patient-provider communication is an essential step to reducing barriers and promoting fair and timely access to healthcare and equitable treatment for adults with autism. Improved communication may lead to more effective use of preventative health measures and, therefore, decrease tertiary health services. In turn, this could mitigate an undue stress that is currently being placed on the healthcare system in America and may increase healthcare self-efficacy, satisfaction, and trust for adults with autism. Providing this intervention for adults on the autism spectrum is a promising step towards improving their health and wellbeing as they age into middle and later adulthood.

APPENDICES

Appendix A: Data Collection Sheet and IOA Form

Participant:
Confederate:

Data Collector:
Date & Session:

SCORING	+1	0
1) G reeting (i.e. Hello; My name is...; How are you?, etc.)	Yes <input type="checkbox"/>	Error <input type="checkbox"/> Type: _____ <input type="checkbox"/> omission <input type="checkbox"/> sequence <input type="checkbox"/> latency Error #
2) Explain the R eason for the visit (i.e., To get to know you; to identify if you are a good fit, etc.)	Yes <input type="checkbox"/>	Error <input type="checkbox"/> Type: _____ <input type="checkbox"/> omission <input type="checkbox"/> sequence <input type="checkbox"/> latency Error #
3) Describe the need for E xtra Support	Yes <input type="checkbox"/>	Error <input type="checkbox"/> Type: _____ <input type="checkbox"/> omission <input type="checkbox"/> sequence <input type="checkbox"/> latency Error #
4) E xplain 2 – 3 accommodations: <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3	Yes <input type="checkbox"/>	Error <input type="checkbox"/> Type: _____ <input type="checkbox"/> omission <input type="checkbox"/> sequence <input type="checkbox"/> latency Error #
5) Ask questions about N ext steps/following up: <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 Additional: _____	Yes <input type="checkbox"/>	Error <input type="checkbox"/> Type: _____ <input type="checkbox"/> omission <input type="checkbox"/> sequence <input type="checkbox"/> latency Error #
TOTAL PERCENTAGE	/5 %	

Appendix B: IRB Approval Letter



Institutional Review Board
Division of Research
777 Glades Rd.
Boca Raton, FL 33431
Tel: 561.297.1383
fau.edu/research/researchint

Patricia Maslin-Ostrowski, Ed.D., Chair

DATE: July 1, 2022

TO: Charles Dukes, EdD, PhD

FROM: Florida Atlantic University Social, Behavioral and Educational Research IRB

PROTOCOL TITLE: Using an Instructional Package to Support Adults with Autism in Communicating with a Medical Provider

IRBNET ID #: 1872536-3

SUBMISSION TYPE: Response/Follow-Up

ACTION: APPROVED

APPROVAL DATE: June 29, 2022

NEXT REPORT DATE: June 29, 2023

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # B7

Thank you for your submission of Response/Follow-Up materials for this research study. The Florida Atlantic University Social, Behavioral and Educational Research IRB has APPROVED your Response/Follow-Up. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission. NO CONTINUING REVIEW IS REQUIRED FOR THIS PROTOCOL. Please complete and upload "Form 02A - Progress Report for Minimal Risk Research" as a new package by the Progress Report Due Date.

- This study is approved for a maximum of **6** subjects.
- Please submit a progress report before the indicated date.
- It is important that you use the approved, stamped consent documents or procedures listed below:
 - Recruitment Email (stamped)
 - Recruitment Interview (stamped)
 - Consent Form - Student Volunteer Minimal Risk Research Waiver of Documentation Consent.docx (stamped)
 - Advertisement - Confederate Recruitment Email[1].docx (stamped)
 - Adult Consent Form
 - Consent Form - Video Release Consent Form.docx (stamped)
- ****Please note that any revision to previously approved materials or procedures, including modifications to numbers of subjects, must be approved by the IRB before it is initiated.** Please use the amendment form to request IRB approval of a proposed revision.
- All SERIOUS and UNEXPECTED adverse events or unanticipated problems must be reported to this office. Please use the appropriate serious adverse event (SAE)/ Unanticipated Problems (UP)

report form for this procedure. All regulatory and sponsor reporting requirements should also be followed, if applicable.

- Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.
- Please note that all research records for federally funded or non-funded investigator initiated studies must be retained for a minimum of three years after completion of the research. For multisite, international studies conducted under ICH Guidelines, records must be retained until notification by the sponsor that all marketing applications have been completed. Research records involving protected health information (PHI) must be retained for a minimum of six years.
- Please submit an IRB final report when the study is completed or discontinued.

[If applicable] This approval is contingent on the successful execution of a [material or data] agreement.

If you have any questions or comments about this correspondence, please contact Judith Martinez at:

Institutional Review Board
Research Integrity/Division of Research
Florida Atlantic University
Boca Raton, FL 33431
Phone: 561-297-0777
researchintegrity@fau.edu

* Please include your protocol number and title in all correspondence with this office.

**This letter has been electronically signed in accordance with all applicable regulations,
and a copy is retained within our records.**

Appendix C: Baseline and Follow-Up Treatment Fidelity Checklist

Participant:
Confederate:
Date:

Data Collector:
Session:

Y = Yes it occurred, N = No it did not occur

1. **Participant, confederate PCP, and data collector logged into Zoom** Yes No

2. **Participant and confederate PCP video and microphone on.** Yes No

3. **SD given – “Hello _____. Thank you for meeting with me today. Please tell me a little about yourself and your medical needs.”** Yes No

4. **No further instruction given.** Yes No

5. **End session after 2 consecutive errors, ten seconds on nonresponding, a verbal statement of unsure what to say/do, or after 5 correct and independent responses.** Yes No

Total: _____

%: _____

Appendix D: Intervention Treatment Fidelity Checklist

Participant:
Confederate:
Date:

Data Collector:
Session:

Y = Yes it occurred, N = No it did not occur

- | | | |
|--|-------------------------------------|------------------------------------|
| <p>1. Participant, confederate PCP, and interventionist logged into Zoom</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>2. Only participant and interventionist video and microphones on</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>3. Instruction: Interventionist explains purpose of using GREEN & each step of the mnemonic.</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>4. Model: Confederate PCP turns on video and microphone. Interventionist & confederate PCP model doctor’s appointment, following steps in GREEN.</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>5. Rehearse: Confederate PCP prompts participant to rehearse doctor’s appointment following steps in GREEN.</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>6. SD given – “Hello _____. Thank you for meeting with me today. Please tell me a little about yourself and your medical needs.”</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>7. Feedback: Interventionist provides feedback, as appropriate:</p> | <p>Yes <input type="checkbox"/></p> | <p>No <input type="checkbox"/></p> |
| <p>a. Praise for steps completed correctly</p> | | |
| <p>b. Error 1: identify the error, provide a verbal correction, and ask participant to repeat the correction.</p> | | |
| <p>c. Error 2: identify the error, provide a verbal correction, and prompt participant to practice entire step. Begin rehearsal again beginning at the step in which the error occurred.</p> | | |
| <p>d. Error 3: identify the error, model the step with the confederate PCP, ask the participant to practice the entire step. Begin rehearsal again beginning at the step in which the error occurred.</p> | | |

Total: _____

%: _____

Appendix E: Social Validity Assessment Student and Professional Perceptions

Using an Instructional Package to Promote Communication with a Medical

Provider for Adults with Autism

Directions: Please view the videos of adults with autism communicating with a medical provider following the use of an Instruction Package. Then fill out your response to each of the 6 items below. Please remain anonymous.

Significance of the Goal

1. I believe it is *important* for adults with autism to communicate effectively with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

2. I believe that adults with autism *are interested* in learning how to effectively communicate with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

Acceptability of the Intervention

3. I believe spending time and effort to teach adults with autism communication skills in the medical setting *is appropriate*.

Strongly Agree Agree Disagree Strongly Disagree

4. I believe using this Instructional Package to teach adults with autism to learn effective communication skills in medical settings *is socially acceptable*.

Strongly Agree Agree Disagree Strongly Disagree

Effective? Impact on the Outcomes; Satisfied with Results

5. I believe that by using this Instructional Package, adults with autism *did learn* to communicate in medical settings.

Strongly Agree Agree Disagree Strongly Disagree

6. I believe that using this Instructional Package is a *useful strategy* to teach adults with autism how to communicate with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

Appendix F: Social Validity Assessment Participant Perceptions

Using an Instructional Package to Promote Communication with a Medical Provider

Directions: Please fill out your response to each of the 6 items below. Please remain anonymous.

Significance of the Goal

1. I believe it is *important* for me to communicate effectively with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

2. I *am interested* in learning how to effectively communicate with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

Acceptability of the Intervention

3. I believe spending time and effort to learn communication skills in the medical setting *is appropriate*.

Strongly Agree Agree Disagree Strongly Disagree

4. I believe that using this Instructional Package to learn effective communication skills in medical settings *is socially acceptable*.

Strongly Agree Agree Disagree Strongly Disagree

Effective? Impact on the Outcomes; Satisfied with Results

5. I believe that by using this Instructional Package, *I did learn* to communicate in medical settings.

Strongly Agree Agree Disagree Strongly Disagree

6. I believe that using this Instructional Package is a *useful strategy* to learn how to communicate with medical providers.

Strongly Agree Agree Disagree Strongly Disagree

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