

Evidence-Based Toolkit: Clinical Pathway for High-Functioning  
Autistic Adults in Rural Areas

Sharon Lorraine Colley

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Dedication

This is dedicated to my daughter who was the inspiration for this project work and who has been a valuable source of support and insight throughout.

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### Abstract

Adults with high-functioning autism are often not diagnosed and consequently experience poor outcomes, particularly in rural areas. The literature provides clear support that providers of care often have little understanding of this condition and fail to recognize key symptoms that would suggest the need for referral. Research also indicates that interventions directed at providers of care, patients, and patients' families can lead to enhanced outcomes for patients, as well as increased confidence levels for providers of care in recognizing symptoms in patients. The purpose of this project was to develop a preliminary screening tool, a clinical pathway, and a resource repository that can be used by providers and ultimately patients and their families. These were based on the extant literature, and providers of care received education and support for their use. Pre- and post-surveys were used to evaluate the providers of care confidence and knowledge levels, their use of tools and resources, and their self-reported number of testing referrals, before and after education and support was provided. Results indicated that education and provision of a toolkit with resources increases providers of care knowledge and confidence levels in caring for adults with high-functioning autism. Limited results related to use of assessment tools and referrals indicated there was no increase in use of assessment tools or numbers of referrals made for diagnostic testing had occurred. Recommendations include requiring education for providers of care, sustaining change through use of champions within the organization, and shifting language away from high- and low-functioning to avoid confusion.

***Keywords:*** *high-functioning autism, screening tool, resources, rural, adult*

## Evidence-Based Toolkit: Clinical Pathway for High-Functioning Autistic Adults in Rural Areas

Autism is a neurodevelopmental condition that occurs across a spectrum and impairs communication, social interaction, and is characterized by repetitive and restricted behaviors as well as sensory processing issues (American Psychiatric Association [APA], 2013). As a condition occurring on a spectrum, autism can present with wide variations in symptoms and levels of intellectual functioning. Revisions for the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) were made in 2013, and resulted in the merging of autistic disorder, Asperger's syndrome, childhood disintegrative disorder, Rett's Disorder, and pervasive development disorder – not otherwise specified, under the umbrella of autism spectrum condition (APA, 2013). What was previously called Asperger's is now considered to be at the high-functioning end of the Autism Spectrum Condition (ASC), while autistic disorder and childhood disintegrative disorder are primarily low-functioning. Throughout this proposal, autism spectrum disorder will be referred to as ASC to align with the neurodiversity movement that is attempting to reduce the stigma and pathologizing associated with the term *disorder*. Autism spectrum condition is now diagnosed in 1 of 59 children in the United States, and it is estimated that 1% of the global population meets criteria (Centers for Disease Control [CDC], 2018). These are significant increases in recent years and due in part to improved childhood screening of blacks and Hispanics as well as changes in diagnostic guidelines (Baio et al., 2018; CDC, 2018).

The terms *high-* and *low-functioning* or *mild* and *severe* can be misleading, as severe challenges occur across the spectrum. Symptoms associated with high-functioning autism spectrum condition (HFASC) are often less overt or are attributed to other mental health conditions. As a result, many with HFASC are not diagnosed until they are adults or are never diagnosed (Lehnhardt et al., 2011). Those who receive a diagnosis as an adult or who never

receive a diagnosis often have extreme challenges and struggle to access services traditionally available to pediatric populations (Hassrick, Shattruck, & Carley, 2018). A noteworthy statistic is that ASC is diagnosed in 1 of 37 males, but only 1 of 151 females (CDC, 2018). The reasons for this higher occurrence in males have yet to be explained, but it is theorized that females are underdiagnosed due to better masking of symptoms (Holliday-Willey, 2015; Hull et al., 2017; Lai et al., 2011; Tint & Weiss, 2017).

Transition to adulthood can be challenging, particularly for individuals with subtler autism symptoms (Kapp, 2018); often these individuals have as serious, albeit less visible disabilities. These challenges may be related to heightened self-awareness as well as increased victimization in the form of bullying for those with less discernible disability and higher intellectual skills (Kapp, 2018). The labels of high- or low- functioning tend to convey expectations that are often inaccurate in terms of the distinctive adversities that manifest across the spectrum. Individuals who are considered high-functioning based on no intellectual impairment are often assumed to require no support (Frank et al., 2018; Tint & Weiss, 2017). Adults with HFASC struggle with quality of life as employment, school, and relationships are difficult to navigate (Frank et al., 2018; Hassrick, Shattruck, & Carley, 2018). Few resources exist for adults on the autism spectrum, and often there is an unwillingness to accept available services due to the lack of perceived supportive relationships with therapists and providers of care (Tint & Weiss, 2017; Nicolaidis et al., 2015). The extant literature largely focuses on pediatric populations, and while this is indubitably logical to ensure early diagnosis and treatment, it does reveal a significant gap in the evidence to support diagnosis and care for the HFASC adult population. The purpose of this paper is to share the work and results of a project intended to improve confidence and knowledge levels of providers of care during delivery of care to high-functioning autistic patients



and their families and to increase the number of self-reported referrals made for diagnostic testing.

### **Problem Statement**

Autism spectrum condition is a neurodevelopmental condition characterized by several core traits that present in wide degrees of variability among individuals; impaired social communication, repetitive behaviors, resistance to change, restricted interests, and sensory issues are common (APA, 2018). Nearly 60% of those with ASC also have a learning disability, or other mental health conditions such as obsessive-compulsive disorder, anxiety, or depression (National Institute of Mental Health, 2016). There are numerous ways these traits manifest in individual clients, making diagnosis even more complicated and challenging. Further, ASC occurs on a continuum with individuals without intellectual disability or verbal limitations referred to as being on the *mild* or *high-functioning* end of the spectrum. However, this can be very misleading in terms of the degree of overall level of functioning of these individuals and often results in a delay in diagnosis and early treatment, which can lead to lifelong challenges and costly care.

Autistic adults without intellectual disability or verbal limitations who are at the high-functioning end of the continuum, have few supports or resources available (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017). Despite sometimes overwhelming challenges associated with HFASC such as sensory issues, lack of executive functioning, repetitive behaviors, and medical or mental health co-morbidities, the term *high-functioning* can imply that those with HFASC should be able to do well with basic life skills. It is important that *high-functioning* not be confused with a *low severity level* as defined by the DSM-V. A high-functioning autistic individual can be a Level 3 severity rating (requiring substantial support) or conversely be a Level 1 severity rating

(requiring support) (American Psychiatric Association, 2013). Failure to recognize these distinctions between high and low-functioning and levels of severity can result in disparities in care. This in turn leads to poor health outcomes and further isolation for both clients and families. Communication and interaction strategies for use with the HFASC population are deficient and create an unnecessary healthcare burden (Nicolaidis, Kripke, & Raymaker, 2014). Further, female clients with HFASC are often known to mask their symptoms by mimicking behaviors and communication styles they see as socially appropriate, further limiting providers of care' ability to recognize symptoms (Holliday-Willey, 2015; Hull et al., 2017; Tint & Weiss, 2017).

There are many adults who struggle to cope with symptoms associated with undiagnosed HFASC, and environments with healthcare staff who lack understanding and knowledge on how to effectively interact with and care for these clients (Lesko, 2017; Nicolaidis et al., 2015; Tint & Weiss, 2017). The struggles manifest in greater unmet healthcare needs (Murphy et al., 2016; Nicolaidis et al., 2015). Often it is a traumatic experience for the individual to see a physician, related to social issues, phobias, and sometimes real or perceived demeaning treatment by providers of care (Nicolaidis et al., 2015; Tint & Weiss, 2017). There is increased emergency department usage as often problems wait until they become severe, or they occur suddenly, and mental health services are often not readily available (Cohen-Silver, Muskat, & Ratnapalan, 2014; Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015; Kalb, Stuart, Freedman, Zabotsky, & Vasa, 2012; McGonigle et al., 2014). Further, generalized anxiety and associated panic attacks can result in symptoms that mimic a heart attack or other medical condition, leading to increased emergency department use (Foldes-Bsuque et al., 2017; Vohra, Madhavan, & Sambamoorthi, 2016). A subsequent concern is that patients may ignore symptoms of a genuine heart attack in

the future thinking it is yet another panic attack. Sensory issues further complicate healthcare experiences for HFASD patients. For example, patients may have hyper- or hypo- pain sensitivity causing confusion for providers of care who may be unable to accurately interpret pain responses (Lesko, 2017; Moore, 2015). Fear of pain from injections or intravenous placement may be significantly more pronounced for those with hypersensitivity to pain, while lack of response to pain such as a fracture for those with hyposensitivity may result in misinterpretations of these reactions.

Clients receive less preventative care, as often they do not seek care until it cannot be avoided (Nicolaidis et al., 2012). There is less satisfaction with healthcare which is often due to lack of understanding by providers (Anderson et al., 2018; Nicholas et al., 2016; Nicolaidis et al., 2012; Read & Schofield, 2010; Sarris, 2015). Stigma associated with autism behaviors increases anxiety when accessing healthcare (Lum, Garnett, & O'Connor, 2014; Mattys, Noens, Evers, & Baeyens, 2018). Many adults with ASC live with parents during their adult years (Farley et al., 2018). While it is more common among individuals with intellectual disability, many with HFASC continue to live with parents and remain unemployed as adults (Gray et al., 2014). It is common for parents, spouses, significant others, or caregivers to also be treated disparagingly, or even blamed for the child's or adult's behaviors (Allen, 2017; Read & Schofield, 2010; Waltz, 2015). This leads to further avoidance of care and yet another barrier to receiving timely treatment or diagnosis. Caregivers also experience negative consequences of chronic tension and worrying placing them at risk for more serious mental health issues (Grootscholten, Wijngaarden, & Kan, 2018). This suggests a need for greater support for caregivers as well.

While ASC does not necessarily preclude someone from being healthy, there are certain medical conditions and associated complications that have an increased prevalence in those with

the condition or that are amplified by a lack of diagnosis (Cohen-Silver, Muskat, & Ratnapalan, 2014; Croen, 2015; Treating Autism, 2013). These include gastrointestinal problems, immune dysfunction, epilepsy, sleep disturbances, dental issues, obesity, and feeding issues (Cohen-Silver, Muskat, & Ratnapalan, 2014; Croen et al., 2015; Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015). Mental health co-morbidities often include anxiety, depression, obsessive-compulsive disorder, suicide attempts, and attention-deficit and hyperactivity disorder (Buck et al., 2014; Houghton, Ong, & Bolognani, 2017). Earlier diagnosis and intervention can lead to preventative care that could reduce the incidence of and economic costs associated with these conditions. Further, failing to diagnose ASC leads to focus being placed on the co-morbidity with subsequent polypharmacy treatment that does not address the primary condition.

Differences in information processing may require adaptation of environments and development of supportive resources and systems that allow autistic individuals to live authentically. Communication and interaction can be challenging as individuals with HFASD often perceive others' statements in a literal sense (Holliday-Willey, 2015; Lesko, 2017). The problem is that little is being done to address priorities of high-functioning autistics, or to involve them in the scientific processes necessary to understand their critical perspectives (Kapp, 2018; Nicolaidis et al., 2012). Many adults with ASC experience lifelong problems with sustaining employment, relationships, and independent living (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017; Frank et al., 2018). There is little knowledge of modifiable factors that can improve quality of life for adults with ASC. Social support can lead to better health outcomes (Desjardins, 2016; Lakey & Orehek, 2011); however, lack of trust and difficulty regulating relationships with providers of care can impact autistic individuals' willingness to accept supportive measures (Lakey & Orehek, 2011).

Autistic adults experience significant disparities related to health care (McNeil et al., 2018; Nicolaidis, Kripke, & Raymaker, 2014). Effective interactions between physicians and clients lead to improved outcomes (Nicolaidis, Kripke, & Raymaker, 2014), while impairments to social communication and cognition in adults with ASC can lead to sub-optimal outcomes (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017). Autistic adults note that providers of care are often unaccommodating and fail to recognize needs associated with their diagnosis (Lesko, 2017; Nicolaidis et al., 2015; Nicolaidis, Kripke, & Raymaker, 2014). These findings suggest a need for greater knowledge and awareness of HFASC in the adult population, that may improve rates of referrals for diagnostic testing and enhance the level of care and support provided to clients.

### **PICOT Question**

There are two questions that guided the work of this project. First, how do providers of care who are provided education on HFASC and use of preliminary screening tools and resources, perceive their knowledge and confidence levels in caring for clients who have or may have high-functioning autism, before and three months after education? Second, do caregivers who use a screening tool as compared to no use of a screening tool make a greater number of referrals for high-functioning autism testing?

For purposes of this project, the population was providers of care and this term referred to nurses, nurse practitioners, physicians, physician assistants, health care technicians, or any employee directly involved with care of clients in the healthcare setting. The group considered by providers of care was any client in the healthcare setting who was age 18 and over and who displayed symptoms or characteristics indicative of HFASC. The intervention consisted of educational sessions offered to two rural healthcare organizations. These occurred during three, sessions for a total of 3.5 hours of education. Individual sessions and follow-ups were also

offered. This education provided information on high-functioning autism in adults, best practices in communication and resources, and a clinical pathway with preliminary screening tools and interventions. At the beginning of the first educational session, a survey was given to attendees that included both quantitative and qualitative questions that explored current levels of knowledge regarding HFASC and recognition of same, as well as confidence levels in providing appropriate care. Additionally, caregivers were asked to provide the number of referrals made in the previous three months for autism testing. This same survey was provided three months after the educational sessions. Data was then analyzed to determine whether providers of care were using the tools and whether the intervention was effective in increasing their knowledge and confidence levels in caring for patients with HFASC, and whether they used screening tools and had increased the number of patient referrals for autism testing.

### **Conceptual and Theoretical Framework**

Several theories provided a framework for this project. Autism spectrum condition is a complicated disorder that manifests in a variety of ways. This suggested a need for an amalgamation of theories that would optimally support development of a clinical pathway, education, and resources for this project. Theories of neurodiversity, client-centered therapy, interpersonal relations, and relational regulation were included.

#### **Neurodiversity Theory**

The emerging theory of neurodiversity identifies neurological differences, including autism, as variations in human wiring rather than diseases or disorders (Baron-Cohen, 2017). While acknowledging that disability may result, the neurodiversity framework contends that autism should not be pathologized (Baron-Cohen, 2017). The literature evidence is growing to support the idea that the primary characterization of ASC is merely a difference in how individuals

process information (Jaarsma & Welin; 2012; Nicolaidis, Kripke, & Raymaker, 2014). In fact, self-advocacy groups have reclaimed autism as a part of identity and use language that speaks to an *autistic person* rather than a *person with autism* (Kapp, 2018), and *autism spectrum condition* rather than *autism spectrum disorder* (Baron-Cohen, 2017). Neurodiversity proponents acknowledge inherent disabilities that can be part of ASC, while recognizing the many strengths and contributions of individuals with ASC (Armstrong, 2010; Silberman, 2016). Singer (2017) shares how the disability rights community has countered the traditional “medical model of disability” with a “social theory of disability”, and redefined disability as a result of “disabling barriers and social practices” (p. 34).

### **Carl Rogers’ Theory of Client-Centered Therapy**

The project was viewed through the neurodiversity lens and reinforced by several theories that provide a supportive framework. These include Carl Rogers’ (2013) humanistic theory of client-centered therapy, Hildegard Peplau’s (1988) nursing theory of interpersonal relations, and Lakey and Orehek’s (2011) social support theory of relational regulation. An amalgamation of these theories provided the strongest framework for development of a clinical pathway and associated resources that addressed HFASC and the pursuant dissemination to providers of care.

Rogers’ theory of client-centered therapy makes several significant assertions that served to support proposed communication interventions used with autistic patients. Autism spectrum condition has long been associated with a lack of empathy, which would seem to preclude Rogers’ theory as applicable. However, recent research has provided a divergent view that more convincingly elucidates the dichotomous nature of autistic individuals’ expressions of empathy and may help to explain why some with autism are extremely empathetic while others appear to not be. Alexithymia is a personality construct associated with lack of awareness of emotions in

self or others (Brewer, 2016; Cook, Brewer, Shah, & Bird, 2013). This construct can occur independent of or as a co-morbidity of autism (Brewer, 2016; Bird, Brindley, Frith, & Singer, 2010). This understanding is critical as it mitigates trepidation with use of Rogers' concepts in communicating with autistic individuals and allows the critically important therapeutic relationship to develop. Notable, is that Rogers' theoretical approach has been successfully used with individuals who appear to have alexithymia with or without autism (Bettelheim, 1974; Buck & Buck, 2006).

Rogers (1995) popularized the use of the term client as opposed to the more medical-model patient terminology, which was intended to recognize and support the client as a *responsible individual* rather than a *dependent patient*. Several key concepts figure prominently in Rogers' theory. Rogers theorized that human beings require unconditional positive regard and approval from others, and that they change to acquire that positive regard and approval. This can result in anxiety if the person lacks congruence in self-perceptions of real self (who the client truly is) versus ideal self (who the client would like to be), and the change to self is made only to garner acceptance from others. Rogers believed clients could recognize what areas of life were causing pain and could reorganize their living conditions to move toward self-actualization and greater internal comfort in their environments. He supported a non-directive methodology that avoided advice, suggestions, and subjective interpretations, and instead focused on acceptance and empathy for who and where the client was at a given point in time. Rogers' work demonstrated that clients who were provided a therapeutic environment exhibited growth and change. Concepts associated with a therapeutic environment included: a) unconditional positive regard of the client as a person of inherent value, b) empathy for the client's personal struggles and associated feelings, and c) a sense of congruence by being genuine and authentic with the client.



When Rogers' theory is applied to HFASC, the potential implications are significant. Adults with HFASC often struggle with self-esteem issues, guilt, and feelings of hopelessness. These manifest as a result of years of not understanding their own symptoms, receiving inaccurate diagnoses, and at times having their honesty questioned. Those with HFASC affirm that healthcare experiences are fraught with challenges in communication and perceived disrespect from providers of care (Nicolaidis et al., 2012; Nicolaidis et al., 2015). Effective use of Rogers' theory to frame providers of care approaches to communicating with HFASC clients could greatly enhance outcomes.

### **Hildegard Peplau's Theory of Interpersonal Relations**

Peplau's (1988) nursing theory of interpersonal relations amalgamated with Rogers' client-centered care theory strengthens the functionality of communication and interaction approaches used with HFASC clients. Peplau recognized that humans experience tension as a result of unmet needs. Individuals with HFASC may have difficulty identifying or communicating their needs to others, including providers of care. This difficulty is compounded if providers of care lack skill or knowledge of effective communication approaches. Peplau believed that the nurse took on several roles including a teacher and counselor, and through these roles enabled the client to increase personal autonomy and maturity. The interpersonal relations theory contends that clients' behaviors are goal oriented toward feelings of security and satisfaction. These goals may not always be obvious from the behavior and can be misconstrued by providers of care. Frustration and anxiety can result if providers of care inadvertently place barriers that block goal attainment. For clients with HFASC, these barriers are often perceived in the form of condescending or demeaning communications.

Peplau (1988) asserts that only clients can identify their own needs and that sometimes they cannot communicate them. This leads to frustration at unmet goals unless the nurse can develop an interpersonal relationship in order to help the client self-identify needs and move toward achieving those needs. As needs are met, more mature needs emerge, and the client progresses toward a more personally fulfilling life.

### **Lahey and Orehek's Theory of Relational Regulation**

The Relational Regulation Theory (RRT) is a relatively new theory and was developed to address the question of how perceived social support is linked to emotional disturbances such as anxiety and depression. Both anxiety and depression are frequently found as co-morbidities in clients with ASC, and social support is often lacking. These unique qualifiers make this theory particularly relevant to consider when providing support to individuals with HFASC.

Lahey and Orehek (2011) establish that social interaction is relational based on the individual. In other words, interaction that works for one person may not work for another. Relational regulation also occurs through ordinary social interactions as opposed to interactions focused on stressors. For example, an individual with ASC may perceive a supportive relationship with a provider who discussed a topic of interest such as Star Wars movies, as opposed to a provider who only inquired into levels of pain or stress. Clients who perceive a supportive interaction with the care provider will be more likely to accept resources and care interventions that will optimize outcomes. Another principle associated with the theory is that effective regulation is more likely if there is a wide diversity of providers of care who can support client needs. Lahey and Orehek contend that clients who seem unable to regulate themselves with current support systems, may indicate that the client has not yet found a relationship that achieves regulation. This indicates a pronounced need for knowledgeable and

confident providers of care who can support relational regulation in HFASC clients, particularly in rural areas where there are fewer available providers.

### **Synthesis of the Literature**

The intent of this project was to improve providers of care knowledge and confidence levels in providing care to HFASC clients, and to improve referral rates of diagnosis testing for ASC in adults. A review of the extant literature revealed several themes that provided evidence to inform the PICOT questions for this project. The questions asked were: a) how do providers of care who are provided education on HFASC and use of preliminary screening tools and resources, perceive their knowledge and confidence levels in caring for clients who have or may have HFASC, before and three months after education; and b) do caregivers who use a screening tool as compared to no use of a screening tool make a greater number of referrals for high-functioning autism testing?

Multiple systematic electronic searches were conducted in several databases including PubMed, CINAHL, Google Scholar, and PsycINFO, using a date range of 2011-2018, and a variety of terms including high-functioning autism spectrum condition, Asperger's syndrome, adult, healthcare, diagnosis, interventions, and outcomes. Studies that included individuals with ASC under age 18 or with an associated intellectual disability were not included, unless it was relevant based on certain criteria that was pertinent across age and intellectual status.

### **Dissatisfaction with Healthcare Experiences**

The literature consistently suggests that autistic adults have less satisfaction with healthcare experiences than non-autistic adults (Griffith, Totsika, Nash, & Hastings, 2011; Nicolaidis et al., 2012; Nicolaidis et al., 2015; Tint & Weiss, 2017; Weiss et al., 2018), and that this leads to lower self-efficacy and reduced use of preventative services (Anderson, Sosnowy, Kuo, & Shattuck,

2018; Griffith et al., 2011; McGonigle et al., 2014). Nicolaidis et al. (2012) found that client-provider communication was perceived negatively by HFASC adults, and that they had higher unmet healthcare needs and increased use of mental departments. Other studies noted that family members who were caring for an adult child with ASC sustained high levels of worry and concern for the future and often felt unsupported by providers of care (Anderson et al., 2018; Nicholas et al., 2016; Read & Schofield, 2010; Sarris, 2015).

Several studies focused on the experiences of women related to their healthcare services (Baldwin & Costley, 2016; Bargiela, Steward, & Mandy, 2016; Lum, Garnett, & O'Connor, 2014; Tint & Weiss, 2017). Females are diagnosed at a much lower rate than males, and this may be due to less externalization of behaviors and greater social motivation (Head, 2014). Additionally, while research is still in its infancy related to autism manifestations in females, initial research indicates that internalizing behaviors are more common in females leading to anxiety, eating disorders, and depression (Mandy et al., 2012). Due to masking of symptoms and associated lack of diagnosis, women are at higher risk for negative healthcare experiences (Bargiela, Steward, & Mandy, 2016; Tint & Weiss, 2017). Lum, Garnett, and O'Connor (2016) found in a qualitative study of 32 adult females with HFASC, that 100% were frustrated with their providers lack of knowledge related to autism. Further, this same study revealed that 75% of participants had not revealed their diagnosis to a provider because of a fear that it would affect their treatment or communication (Lum, Garnett, & O'Connor, 2016). Providers of care were viewed as disregarding and misunderstanding the health care needs of women or discounting their HFASC and missing connections of other issues such as anxiety or depression (Baldwin & Costley, 2016; Bargiela, Steward, & Mandy, 2016; Tint & Weiss, 2017). These same studies illuminated issues of years of misdiagnosis and mistreatment ranging from multiple personality

disorder to major depressive disorder, while concomitantly being told they did not have ASC because their presentation did not appear to be that of stereotypical versions of the condition.

The included literature denotes consistent evidence that negative healthcare experiences contributes to an avoidance of healthcare and poor outcomes for both patients and their families. Studies also support that adults with HFASC possess character strengths including open-mindedness, creativity, and love of learning (Kirchner, Ruch, Dziobek, 2016) as well as honesty, loyalty, and attention to detail (Schipper et al., 2016). These findings suggest that individuals with HFASC could be ideal patients who would adhere to care guidelines and be honest with their providers of care; however, their condition must first be understood and treated appropriately by those providers. Addressing knowledge deficits through appropriate training, tools, and resources could enrich the healthcare experiences of patients as well as providers of care.

### **Providers of Care Lack Education and Training**

An associated common theme in the literature is providers of care self-identified need for further education and training on ASC (Giarelli, Ruttenberg, & Segal, 2012; Wachab & Pesci, 2017; Will, Barnfather, & Lesley, 2013; Zerbo et al., 2015; Zwaigenbaum et al., 2016). While the literature tends to focus on ASC in general, it has implications for the more narrowed focus of HFASC in adults. Despite the recent emphasis on ASC due to the increasing prevalence, there is still little time spent preparing providers of care to care for this population (Erickson-Warfield, Crossman, Delahaye, Weerd, & Khulthau, 2015; Zerbo et al., 2015; Zwaigenbaum et al., 2016). It can be inferred that the lack of training and education is more pronounced in the less discernible condition of HFASC.

Research conducted among various disciplines of providers of care invariably recognized the need for more training to successfully care for the ASC population (Bruder et al., 2012; DaSilva et al., 2016; Thomas, Blake, Morris, & Moles, 2017; Wachab & Pesci, 2017). Adding to the challenges associated with provision of healthcare to adults with HFASC, is that many adults present with behavioral issues that cause providers to associate this with mental health issues rather than medical co-morbidities that may be causing the behavioral issues (McGonigle et al., 2014; Zwaigenbaum et al., 2016). Both physicians and psychiatrists acknowledge they have minimal training in the area of autism that leads to frustration and challenges during provision of care as well as lack of recognition of symptoms that would indicate a need for a testing referral (Brookman-Frazeo et al., 2012; Chiri & Warfield, 2012; Sarris, 2015).

Lack of knowledge and training results in missed referrals for diagnoses that could improve outcomes for both clients and families (Bargiela, Steward, & Mandy, 2016; Lehnhardt et al., 2013; Pilling, Baron-Cohen, Megnin-Viggars, Lee, & Taylor, 2012). Maloret and Scott (2018) found that even when a diagnosis is present, lack of knowledge on the part of providers of care can negatively impact outcomes. Patients with ASC admitted as inpatients to mental health facilities experienced heightened anxiety and an associated lack of support and understanding from mental health care providers (Maloret & Scott, 2018). These studies highlighted the need for more effective and supportive care for autistic adults and their families.

### **Education and Resources for Providers of Care Enhance Outcomes**

The extant evidence supports that education and resources offered to providers of care improves confidence and knowledge levels, leading to improved outcomes (Giorelli, Ruttenberg, & Segal, 2012; Havercamp et al., 2016; McGonigle et al., 2014). Wachob and Pesci (2017) partly supported these findings, noting that emergency department personnel felt increased

confidence but not knowledge associated with training; they did find that exposure to individuals with ASC increased both knowledge and comfort levels. Further, clinical pathways or models of care that clearly delineate directives for care of individuals with ASC have shown to be successful in promoting enhanced care and significant improvements in outcomes for clients and families (Rogers & Zeni, 2015; Rutherford et al., 2018). Unigwe et al. (2017) found that greater confidence resulted in more referrals for ASC testing. This implies that development of a clinical pathway and educational opportunities with associated provision of resources will lead to improved care and diagnosis of ASC in adult clients.

Screening tools have been extensively studied in the last two decades, leading to more valid and reliable methods of determining a diagnosis (Fusar-Poli et al., 2017; Grodberg et al., 2014; Hirota, So, Kim, Levanthal, & Epstein, 2018; Lundquist & Lindner, 2017; Sizoo et al., 2015; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). While most caregivers are not prepared to use these tools or diagnose, the tools serve to inform general providers of care on potential client symptoms or complaints that could indicate a need for a referral for testing. Review of the tools provides commonalities that can be considered during assessment.

Hirota et al. (2018) completed a systematic review of screening tools for older children and adults to ascertain the validity. The study found that only three screening tools were studied sufficiently to support use in assessment of ASC; these were the Autism-Spectrum Quotient (AQ), the Social Communication Questionnaire (SCQ), and the Social Responsiveness Scale (SRS). The AQ is a self-administered test designed for those without intellectual disability (Bishop & Seltzer, 2012). HFASC Ruzich et al. (2015) completed a comprehensive systematic review of the AQ; the AQ is a 50 item self-report tool originally designed for use in adults, but later used with children. Often these tools are used in combination to diagnose, but Ruzich et al.

(2015) focused on the AQ to arrive at an estimated reliable score for diagnosis based on findings of nearly 7,000 participants. This study further supports the validity of the screening tool as it identified a mean score of 16.94 in those without ASC and a score of 35.19 in those with ASC (Ruzich et al., 2015).

However, the AQ's utility has been questioned in other studies. Bishop and Seltzer (2012) found AQ scores were higher among HFASC adults who self-tested compared with lower scores among those with intellectual disability and with less insight into their difficulties. Ashwood et al. (2016) found that a generalized anxiety disorder may mimic ASC and result in false negatives with self-report scores. These findings suggest that the test may be more valid in adults without intellectual disability or generalized anxiety disorder.

The AQ-10 is a briefer version of the AQ intended to save time and focus on the 10 most informative aspects of the AQ; it is a test recommended by the United Kingdom's National Institute for Health and Care Excellence to provide a preliminary assessment that may indicate a referral for more comprehensive assessment (Lehnhardt et al., 2013; Pilling, Baron-Cohen, Megnin-Viggars, Lee, & Taylor, 2012). As a preliminary screening tool, it may provide direction for further testing if used in adult populations with average or above IQ and without generalized anxiety disorder.

The literature indicates that valid tools are available to assist providers of care in recognizing characteristics of HFASC in adults. However, knowledge regarding these tools and interventions on how to administer them effectively is lacking. The wide variation in characteristics presented by those with HFASC as well as differences in gender presentation can present challenges to recognizing and applying interventions. Education and provision of a clinical pathway and



resources may ameliorate some of these challenges and lead to improved care for adults on the spectrum.

### **Diagnosis and Interventions Increase Satisfaction with Healthcare**

The literature cited in this section is consistent in noting the need for environmental adaptation and communication interventions to improve the care experience for HFASC clients and their families. While for purposes of this project, the focus is on HFASC adult clients, these adaptations were noted to significantly improve the care experience across the autism spectrum regardless of age. The following studies support the need for improved communication strategies, interaction tools, and environmental adaptations to enhance the healthcare experience for adult HFASC clients and their families.

A systematic review found that clients who are diagnosed and can recognize personal talents associated with HFASC experience positive effects to self-concept (Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2018). Other studies support that HFASC adults are more likely to follow care provider treatment plans, seek preventative care, and have better outcomes if the healthcare experience is improved (Bekhet, Johnson, & Zauszniewski, 2012; Gerber et al., 2017; Lewis, 2017; Rogers & Zeni, 2015). A significant finding from Betz (2013) was that programs to help individuals with special needs transition to adulthood were primarily led by interdisciplinary teams that did *not* include nurses. This represents a clear need for greater involvement and direction from nurse leaders.

Receiving a diagnosis was perceived by HFASC adults as improving their outlook and self-understanding (Rutherford et al., 2018). Outcomes were improved and mental health problems were diminished with a better understanding of their condition and how to avoid triggers that exacerbated symptoms (Mandy et al., 2018). While some clients had an increase in depressive

symptoms in the period immediately following diagnosis, progress was observed in the long-term and resulted in improved quality of life (Mattys, Noens, Evers, & Baeyens, 2018).

Diagnosis guides providers of care to appropriate interventions and resources to optimize outcomes for adults with HFASC (Bishop-Fitzpatrick & Minshew, 2013; Nicolaidis, Kripke, & Raymaker, 2014). This implies that diagnosis is essential to improve quality of life and long-term outcomes for clients with HFASC.

Sensory issues present substantial challenges for adults with HFASC and subsequently for providers of care (McGonigle, 2014; Smith & Sharp, 2013; Tavassoli, Miller, Schoen, Nielsen, & Baron-Cohen, 2014). Pain may be perceived more acutely, yet not outwardly expressed resulting in missed care by those providing care (Moore, 2015). Pain is often expressed as a change in behavior such as agitation or anxiety, with subsequent treatment for the behavior rather than the source of pain (Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015; Kowalczyk, 2009). Providers of care are often ill-equipped to handle the multiple sensory issues of HFASC adults (Carter, Broder-Fingert, Neumeyer, Giauque, Kao, & Iyasere, 2017). Recognition and adaptation of environmental factors that contribute to anxiety and agitation such as lighting, sounds, touch, smells, and tastes can improve healthcare encounters and patient outcomes (Elwin, Ek, Schroder, & Kjellin, 2012; Watling & Hauer, 2015). Weitlauf, Sathe, McPheeters, and Warren (2017) completed a systematic review of randomized control studies and found that sensory integration-based interventions can improve sensory and motor skills in children. There is a lack of evidence to support similar approaches in adults, but this study certainly suggests a need for further research for that population.

Avoidance of healthcare is common for a multitude of reasons including lack of resources for HFASC in rural settings (Antezana, Scarpa, Valdespino, Albright, & Richey, 2017), long

waits in crowded areas, anxiety related to sensory issues in the healthcare setting, and negative prior experiences (Lum, Garnett, & O'Connor, 2014). This avoidance leads to increased use of emergency departments (Kalb, Stuart, & Freedman, 2012; Weiss, 2018). Telehealth services is increasingly noted as being an alternative approach to working with adults who may avoid office visits or for whom access to knowledgeable providers is not available (Antezana et al., 2017; Sutherland, Trembath, & Roberts, 2018).

Low levels of social support and perceived stress in adults with HFASC were found to correlate to poor subjective and objective quality of life (Bishop-Fitzpatrick, Mazefsky, & Eack, 2017). Interestingly, this study found that social support failed to buffer perceptions of stress and the effect on quality of life. These findings are consistent with those of Hong et al. (2016) and Hirvikoski and Blomqvist (2015) who found adults with ASC who perceived high levels of stress also perceived poor quality of life. While this may seem an obvious finding, the premise that social support did not buffer perceptions of stress may imply that difficulties with social interactions reduce the effectiveness of social support as an approach to relieve stress. A randomized control study that examined the effects of a year-long group leisure program found that quality of life was significantly enhanced in four measured areas and stress was significantly lower in a group of adults with ASC (Garcia-Villamizar & Dattilo, 2010). Finally, Murza et al. (2014) conducted a randomized control trial that suggested interventions for HFASC adults improved their ability to discern inferences in reading and enhanced other metacognitive functions; however, results did not generalize to social communication contexts. Findings from these studies suggest a need for greater awareness of the challenges associated with social interaction, and development of targeted interventions to promote productive healthcare communication and interaction.

Adults with HFASC face numerous challenges that result in high levels of unemployment, difficulties with independent living, and chronic medical and mental health issues. Even if employed, challenges in the workplace are common related to issues with communication, social interaction, stress, and other mental health problems (Hayward, McVilly, & Stokes, 2018; Howlin & Magiati, 2017). Appropriate supportive resources can improve outcomes for both adults with ASC and their families. Transition services to adulthood that include employment assistance and independent living skills have shown promise (Hedley et al., 2017; Westbrook et al., 2014). Social skills interventions have shown mixed results. Wang, Parilla, and Cui (2013) conducted a meta-analysis of social skills interventions that demonstrated effectiveness. Another systematic review indicated that social skills interventions enhance social functioning, reduce loneliness, and have the potential to reduce mental health symptoms such as anxiety and depression (Spain & Blainey, 2015). Several systematic review studies support that various psychosocial interventions show promising effects but acknowledge that there is sometimes a lack of quality in the studies that limits findings (Bishop-Fitzpatrick, Minshew, & Eack, 2013; DeVries, Beck, Stacey, Winslow, & Meines, 2015; Weaver, 2015; Wong et al., 2015). A systematic review of mind-body therapies by Hourston and Atchley (2017) found that mental health issues benefitted from these therapies but acknowledged the limitation of sufficient data and a wide range of ages. Quality of life was significantly enhanced in four measured areas and stress was significantly lower in a group of adults with ASC following a randomized control study that examined the effects of a year-long group leisure program (Garcia-Villamizar & Dattilo, 2010). An interesting finding of several studies suggested that use of technology in this population may enhance social engagement and perceived quality of life (denBrok & Sterkenburg, 2015; Finke, Hickerson, & Kremkow, 2017; Nicolaidis et al., 2012). Finally,

several randomized control studies demonstrate that cognitive behavior therapy is effective in reducing anxiety and obsessive-compulsive disorder symptoms in individuals with ASC (Luxford, Hadwin, & Kovshoff, 2017; Maddox et al., 2017; Russell et al., 2013). As these are common co-morbidities of ASC that can be debilitating, it is critical that patients and their families be informed of these potential interventions and resources.

It is important to recognize that research on interventions for HFASC adult clients is still in its infancy, and many of the studies were small and lacking in rigor. This creates challenges in attempting to generalize the findings or in some cases to replicate the studies. However, the consistencies within the available research is promising and supports the use of interventions that consider individual symptoms and identified needs. There are also areas identified by patients and families as being needed to enhance quality of life; among these were teaching of life skills to promote independence in adulthood and increased support for higher education to optimize chances of success (Gelbar, Smith, & Reichow, 2014; Pellianno, Dinsmore, & Charman, 2014).

### **Practice Recommendations**

The synthesis of the extant literature established a need for enhanced care for HFASC adults. There is extensive research being done on pediatric populations, but substantially less at the adult level. There is also a plethora of research on ASC, but minimal studies being done on HFASC specifically. Several studies were qualitative in nature, limiting their generalizability. However, the qualitative studies were very effective in revealing both providers of care' and HFASC adults' or families' perceptions and experiences during healthcare interactions. The meaningful insights divulged in the studies could not have been attained quantitatively, and therefore were strong support for the purpose of understanding these groups' perspectives. Quantitative studies including systematic reviews provided a robust foundation for care interventions and diagnostic

tools that could reinforce preliminary assessments. Both qualitative and quantitative studies were consistent in findings, with the exception of an occasional outlier. There is certainly a need for additional research that focuses on the adult population and that establishes stronger methodological rigor. However, there were a few studies of ASC in general that aligned with and informed this project work. More studies that focus specifically on the adult HFASC population would have been helpful; however, the lack of studies in this area did provide validation of the need for greater scientific endeavors.

The evidence revealed a lack of knowledge and confidence levels in providers of care that affects the level of care provided to clients. Further, this lack of knowledge and confidence results in fewer adults with HFASC being diagnosed. Lack of diagnosis creates numerous challenges for adult clients, and greater healthcare costs. Even when a diagnosis is made, rural areas offer fewer resources and providers of care with knowledge of HFASC.

The literature review provided support for several recommendations. Education is needed for providers of care to increase knowledge and confidence levels in their ability to recognize symptoms and adjust care environments and delivery of care to improve outcomes. A clinical pathway or model of care for ASC helps organizations improve client outcomes and care providers' satisfaction with the level of care they can provide. Clients with ASC have greater satisfaction with healthcare and willingness to follow care provider recommendations when appropriate communication and interactions are used, and when environments are adapted.

Resources for providers of care should be available to share with clients and families. A plan for sustaining the project work would require development of web-based educational sessions that can be accessed by all providers of care. Additionally, providers of care should have knowledge of and access to websites that provide resources for clients and families. Provision of

resources and education may instill knowledge and confidence in providers of care and inspire referrals for ASC testing.

### **Project Design**

This was a mixed methods project design. Initially, an extensive literature review was conducted to analyze and synthesize the available evidence on the topic of assessment and care of adults with HFASC. This led to the development of a toolkit including a mini-preliminary screening tool and a clinical pathway as well as communication interventions, resources, environmental adaptations, and family supports to be provided to providers of care during educational sessions. A pre- and post- intervention survey that includes quantitative questions in the form of a Likert scale and demographic questions, as well as qualitative narrative style questions was employed. These surveys were used to compare the knowledge and confidence levels of providers of care before and after education and between the various groups of participants. Self-reported referral rates prior to and after implementation of the clinical pathway were also collected and analyzed. Greater knowledge and awareness of ASC in adults with availability of resources and tools for referrals and provision of optimal care was a very practical approach to improving outcomes for HFASC clients in rural communities where typically few resources exist. The results from the surveys revealed whether knowledge and confidence levels increased among providers of care, and whether their rates of referral for autism testing had changed.

### **Project Setting**

This project took place at two Spectrum Health Hospital locations in rural Central Michigan; Spectrum Health Big Rapids and Spectrum Health Reed City. The mission of Spectrum Health (2018) hospitals is “to improve the health of the communities we serve” (¶ 1) and the vision is

“to be a national leader for health by 2020” (§ 1). These statements align with the mission and vision of this project which are to improve the health outcomes for adult clients with HFASC and their families, and by doing so be a leader in providing evidence based progressive care to this population.

The Chief Nursing Officer for both organizations indicated that no similar program existed at these locations and that the project was needed (C. Ring, personal communication, August 13, 2018). Spectrum Health Big Rapids and Reed City are in Mecosta and Osceola counties respectively; these counties have a combined estimated population of 66,651 as of 2015 (United State Census Bureau, 2017a; United States Census Bureau 2017b). Considering rates of autism are currently 1 in 59 individuals in the United States, this suggested that over 1,100 individuals could have autism within these two counties alone. This number represented a clear need for awareness and resources for this population.

### **The Participants**

Primary participants in this project included physicians, physician assistants, nurse practitioners, nurses of other levels of practice, and any interested provider of care within the facilities. For purposes of this project, these individuals were collectively referred to as *providers of care*. Patients cared for by these participants were involved in an indirect way by being a recipient of any adaptation to care delivered by these providers of care.

Participants received education, resources, and tools that they could use in their practice to better recognize symptoms of HFASC in adult clients. The participants were also provided tools and resources that can be used when working with individuals who present with characteristics of HFASC. The education occurred during three, 1-1.5-hour sessions delivered at two rural Spectrum Health hospitals (Reed City and Big Rapids locations). Voluntary implementation of



the assessment tool, interventions, and resources occurred post-education. I offered my availability for questions or assistance with use of tools or resources.

There were approximately 40 total attendees at the educational offerings with 20 of these who agreed to participate in the project survey. This number dropped to 16 after the post-survey. An email invite and flyers were distributed with the aid of the Spectrum Health education and marketing departments. Any provider of care at either Spectrum location or their affiliated office settings was eligible to participate in this project. Providers of care outside of these organizations were excluded from participation. It was a consideration that there could be differing levels of knowledge among the participants related to ASC, and that some may have personal experience with ASC. However, this was determined in the pre-intervention survey and compared to post-survey responses as an anticipated and considered variable. Differences between the various sub-groups was another variable that was considered in demographic information obtained in the surveys.

### **Quality**

Participants were a representative sample of providers of care including physicians, nurses, and other disciplines and degree levels from Spectrum Health Hospitals of Big Rapids and Reed City campuses. All providers of care who work in these environments were invited to participate. A potential concern related to bias was considered as those who chose to not attend the educational session could differ in some way from those who did choose to attend. Incentives of continuing education units were offered to nurses to reduce this risk among that sub-group, and CMEs were offered for physicians. Informational sessions were offered at times that worked best for the majority of potential participants to promote participation.

Original surveys that reflected the goals of the project were carefully developed to avoid leading questions that could have inadvertently caused participants to select one response over another. Survey questions were reviewed by two other individuals familiar with Likert style questions in an effort to avoid a biased tool. Another possible bias that was considered was whether participants would feel the need to provide answers that they deem to be socially acceptable. For example, providers of care may have felt they should have greater knowledge and awareness of HFASC and be hesitant to admit that the care they provide may not be meeting the needs of clients. Anonymity in responses was provided by allowing participants to self-select a pseudonym when responding to the pre- and post- surveys. Hard copy surveys were stored in a locked file accessible only by the project leader for three years and then destroyed by shredding. Electronic data is kept in a password protected file accessible only by the project leader and will also be deleted after three years.

### **Ethics and Human Subjects Protection**

Human subjects internal review board (IRB) approval was sought and approved through both Ferris State University and Spectrum Health Hospitals. The project was determined to fall under the exempt category, as risks to human subjects were minimal. There was a small risk that admission of a lack of knowledge could be uncomfortable for some providers of care to share, and so participants used a self-selected pseudonym to minimize that potential risk. No other risks to participants were anticipated.

Providers of care were asked to respond to both quantitative and narrative style survey questions, and disclosed demographic information related to their discipline, years of practice, and prior knowledge or close experience with a person with HFASC. Surveys were completed pre- and post- educational intervention with use of pseudonyms selected by the participants so

that comparison of survey responses could be completed. Participant anonymity will also be maintained using pseudonyms in any disseminated published articles or presentations related to this project.

Potential benefits of this project included improved healthcare provider knowledge and confidence levels related to their knowledge of HFASC and methods to enhance the client care experience. This project could also lead to a greater number of referrals for ASC testing, which could result in earlier diagnosis and appropriate care for clients.

### **Budget**

Expenses included travel to and from sites, printing of brochures, and materials purchased such as fidget spinners, modified toothbrushes, and tinted glasses used for calming patients in the healthcare or home settings. I covered the cost of these materials, but Spectrum Health covered the cost of all meals provided during the educational setting as well as handouts that were printed for participants. See Table 1 for an itemized list of expenditures.

### **Strengths and Weaknesses**

An analysis of strengths, weaknesses, opportunities, and threats was conducted to determine the status of the current organization in relation to the care of HFASC and the implementation of the project within the settings. A need was clearly established for this project, and a supportive environment that has recently adopted a patient-centered medical home model was deemed a strength as well as an opportunity. Weaknesses and threats were also noted including the array of changes occurring within the healthcare system, as well as the time challenges associated with infusion of yet another care expectation. A visual of the SWOT analysis is available as appendix C.

## Project Description

### Change Model

Kotter's Change Model (2012) is an 8-step process for leading change. This project used Kotter's model as a structure to implement from an organizational perspective. A schedule of the project is available as Appendix E.

**Step one.** The first step was to establish a sense of urgency (Kotter, 2012). This was accomplished first through completing an extensive literature review to synthesize the best evidence on the topic. This occurred during the summer and fall semesters of 2018. In summer semester, a meeting was held with key stakeholders within the organizations to discuss the need for the project as well as the proposed idea. The urgency is apparent, as adults with undiagnosed or diagnosed ASC are not having their needs met, are going undiagnosed or misdiagnosed, and costs for care are escalating over time. Escalating costs were elucidated during meetings related to individuals not seeking care until it is an emergency, non-reimbursed services, and even care that may involve 1:1 safety monitoring.

**Step two.** Building a guiding coalition was the second step, and this was accomplished by identifying stakeholders who would support the project and would ensure that providers of care were encouraged to attend educational sessions and participate in the implementation of resources and tools provided (Kotter, 2012). These individuals became evident during initial meetings as those who were early recognizers of the benefits and who may have special skills in the needed areas. Hospital leaders may more readily communicate the change in a way that could achieve greater buy-in from those who will be accessing and using resources. An interdisciplinary team was necessary for effective collaboration (Patton, Zalon, & Ludwick, 2015), and this team included individuals in leadership positions at both Spectrum Health Big

Rapids and Reed City, the education department, marketing department, and an individual from the radiology department who had received the President's scholar award to work on an autism project with another focus.

**Step three.** The third step was to form a strategic vision and strategy (Kotter, 2012). It was important to inform stakeholders of how this change will improve on what has been done in the past and lessen rather than increase workload. Educational sessions included strategies to streamline the process as much as possible, and to show visible reductions in the current approach to caring for patients using current practices. Examples of this were environmental adaptations and availability of autism tools for individuals who present with characteristics of ASC could garner their trust, reduce behavioral problems that result in increased cost and staff time, and increase the likelihood that they will adhere to healthcare recommendations and follow up care.

**Step four.** Enlisting a volunteer army was the fourth critical step, and this essentially would mean achieving buy-in from as many stakeholders as possible (Kotter, 2012). The greater the buy-in, the more successful the change effort. Much of the buy-in depended on the first step of establishing a sense of urgency. I felt that I was able to convey the information effectively largely due to the extensive literature review and certification I had completed. This was conveyed and received by the broader community/system during stakeholder meetings and educational sessions and helped to establish greater buy-in. Additionally, collaboration with the radiology staff person was instrumental in conveying the importance of the project from an inside source who was trusted. This piece was essential and necessitated additional communications and meetings throughout the project timeframe. These activities took place in late fall semester and spring semester.

**Step five.** A fifth step was to enable action by removing barriers (Kotter, 2012). It was important to examine inefficiencies currently in the system as well as determine if there are departments or personnel who were working in silos, that could derail the change process. The guiding coalition members were leaders in helping to identify these barriers, but it was important to gain perspectives of other staff as well. Nurses from the quality improvement department and social workers were additional attendees at stakeholder meetings who were further able to address questions or concerns related to institutional barriers. As anticipated, the greatest barrier revealed was the lack of time and resulting pressures felt by staff, as well as other change initiatives that were occurring. Leaders noted a barrier as the inability to make changes to the electronic health record (EHR) which would capture the data for referrals made. Ideas were put forward to still garner the data through use of hard copy or addition of comments on the EHR, however, none were particularly practical, and it was decided that this would be self-reported estimates rather than actual data trends. Educational offerings were provided in March with as needed availability in April and May. The pre-implementation survey was given prior to the first educational session, and the post-implementation survey was given three months after providers of care were provided education with assessment tools and resources.

**Step six.** Sixth, it was necessary to generate short term wins (Kotter, 2012). Early in the change process, a means to track progress and identify successes was vital. This was accomplished by sharing results with all stakeholders and participants following the post-implementation survey analysis. Conveying positive gains to all stakeholders will hopefully inspire forward movement and sustain the change effort.

**Step seven.** This segues into the seventh step which was to sustain acceleration. Kotter (2012) emphasizes the importance of maintaining or even accelerating the change efforts once

initial successes are identified. A plan to promote additional enhancements to the initial change that would improve the process further or spreading the change to additional areas. I have planned educational sessions for units/areas at Spectrum Health to occur in fall 2019 and this will be in collaboration with the radiology staff person. The point is to not lose ground, but to continue moving forward without letting up to maintain enthusiasm which fuels momentum.

**Step eight.** Finally, step eight will be to institute change (Kotter, 2012). It is important to identify the change as the new normal. This may require additional communications or meeting that make connections between the successes within the individual organizations, and the change to ASC resources and assessment tools. Establishing web-based educational offerings that are required yearly will be a recommendation and is something that leadership has expressed interest. Ensuring that follow-up is done that clearly conveys how change efforts have improved knowledge and confidence levels for providers of care, is likely to engender positive responses that will inspire stakeholders to accept the change as the new standard for care.

### **Leadership Role and Style**

As the leader of this project, my role was to facilitate each of these steps and to seek interdisciplinary support along the way to ensure success. The leadership styles most suited for this project and that closely align with my personal leadership philosophy are servant and transformational leadership. Reflection on the concepts inherent to these theories guided my approach to the work of this project.

**Transformational leadership.** Burns (1978) recognized the effectiveness of a transformational leadership (TFL) style in affecting change. There have been several descriptors associated with TFL in the ensuing years, including participative, emancipatory, and inspirational (Fischer, 2016; Shirey, 2006). Characteristics used to describe transformational

leaders include genuine, trustworthy, reliable, empowering, visionary, passionate, and loyal (Fischer, 2016; Shirey, 2006). Critics of this theory feel the concepts are ambiguous and that there is no clear distinction from other forms of leadership (Eisenbeiss, vanKnippenberg, & Boerner, 2008). A concept analysis was completed to more clearly define the integrative style of the transformational leader and competencies associated with that style (Fischer, 2016). Fischer (2016) contends a transformational leader is “enthusiastic, emotionally mature, visionary, and courageous lifelong learner who inspires and motivates by empowering and developing followers” (p. 2650), and requires competencies in “emotional intelligence, communication, collaboration, coaching and mentoring” (p. 2650). My enthusiasm and passion for this project was evident to stakeholders and attendees of the meetings and educational sessions. This was expressed verbally to me and shared in the session evaluations. Earning certification as an advanced autism specialist and pursuit of a second doctoral degree is further evidence of my belief in lifelong learning, and I believe this was also recognized by those I worked with during this project.

**Servant leadership.** Servant leadership was first conceived by Greenleaf (1970), who explained the premise of serving as a natural feeling that a person has which is followed by a choice to lead. Servant leaders take a bottom-up approach and foster others in an organization to excel. They recognize the inherent strengths and weaknesses of colleagues and place these individuals in positions that will allow them to use their strengths to advantage. Practice in humility is a key concept and one that will be important during project work. Awareness of not having all the answers or even understanding all the answers is critical to convey to team members. Savel and Munro (2017) note that “humility is consistent with a healthy ego and is not a sign of weakness” (p. 98). Humility is an important tenet of leadership, and one that can create



a greater sense of team commitment to the project. Aspects of servant leadership overlap with transformational leadership, such as recognizing strengths in others and inspiring them to excel. However, recognition of the additional concepts associated with servant leadership will strengthen the leadership style used in implementation of this project.

One example of how I demonstrated servant leadership during this practicum was my work with the radiology staff person. This was a person with exceptional strengths and abilities who did not seem to possess self-confidence or recognize her own contributions. I was truly in awe of her gifts of interaction and ambitious and industrious nature. I sincerely and frequently complimented her on these traits and encouraged her participation and insights throughout our work together. Her strengths were utilized and obvious during the autism open house and community health fair, as she excels at engaging with initial small talk and interacting with all ages on a comfortable level. I recognize these as areas I have less strength and we discussed how to optimize our roles at these events.

### **Project Evaluation and Results**

The evaluation of this project was completed through analysis of pre- and post- surveys completed by participants (see Appendix D). Collection of primary data included Likert style questions that provided quantitative data, and narrative style questions that provided qualitative data on providers of care' experiences with and knowledge of HFASC. Participants also provided self-reported use of assessment tools and numbers of referrals made during set time periods before and after information sessions.

Recruitment of participants occurred through email and posted flyers on bulletin boards and other Spectrum Health employee communications. All providers of care working in Spectrum Health Hospitals Big Rapids or Reed City were invited to participate. Notification of the

informational sessions was provided two months in advance of the sessions and repeated at least twice in the time approaching the sessions. Incentives to participate included continuing education units offered to nurses and continuing medical education to physicians who attended, provision of meals, and times structured according to what best met staff needs.

Extraneous variables related to demographics of the participants were considered. Collection of demographic data included years of experience, personal knowledge or experience with a HFASC individual, and professional discipline. This data helped identify potential variables that could impact results. While these could not be controlled, results were analyzed with consideration to the different factors to equalize the findings within the sub-groups. Awareness of extraneous variables were considered during data analysis and interpretation.

The Likert scale is a widely used tool in research, and when unbiased survey questions are developed, is a reliable and credible method of procuring data. Validity can be compromised if participants respond in what they perceive to be a socially acceptable manner, which in this case could be giving responses that demonstrate competence in their role or not acknowledging lack of confidence in knowledge or provision of care to individuals with AFC. The use of pseudonyms on both surveys may reduce this potential risk, increase validity, and protect participants by reducing the minimal risk that disclosure of lack of knowledge or confidence could cause. Analysis of narrative qualitative questions consisted of initially color-coding key words and phrases, and then refining these to similar themes during subsequent analysis. Analysis of the Likert style questions was completed, using descriptive statistics that compare percentages as well as mean responses between various providers of care groups and between the pre- and post- survey to evaluate differences and similarities for all survey questions. All surveys are stored in a locked or password protected file within the project leader's personal home office.

There were 16 participants who completed both the pre- and the post-survey. Of these, 10 were RNs who worked in a variety of areas including bedside, quality improvement, and management. Three participants were physicians; one from pediatrics and two in family practice. Three participants were from other areas including two from radiology and one social worker. Interestingly, 15 of 16 participants knew someone with autism; however, none of the participants responding had ever had continuing education on autism. This suggests that despite a personal interest in the topic, no education had been pursued or perhaps offered or made available to them.

### **Quantitative Data Responsive to PICOT Question 1**

Five questions were evaluated quantitatively. These were measured from a score of 1 meaning not at all confident (knowledgeable), 2 meaning little confidence (knowledge), 3 meaning neutral related to confidence (knowledge), 4 meaning confident (knowledgeable), or 5 meaning very confident (knowledgeable). During data analysis, scores that fell in the 4 or 5 were compared pre- and post-survey.

The first question measured participants' self-perceived knowledge level related to autism in general. This was a way to measure knowledge levels more broadly related to autism. The pre-survey results indicated a mean score of 2.5 which rose to 3.375 on the post-survey. Percentage of participants who selected a score of 4 or 5 was 12.5% on the pre-survey and this rose to 56% on the post-survey for an increase in self-perceived knowledge level of 43.5%. When compared between groups, RNs went from a pre-survey 0% to post-survey 60%; physicians stayed the same at 66% pre-survey and post-survey; and those falling under "other" disciplines went from 0% pre-survey to 33% post survey (see Figure 1).

Question two measured participants' self-perceived confidence level in recognizing autism in an adult patient. Again, this was related to autism in general. The pre-survey results indicated a mean score of 2.38 which rose to 3.375 on the post-survey. Percentage of participants who selected a score of 4 or 5 was 21% on the pre-survey and this rose to 62.5% on the post-survey for an increase in self-perceived confidence level of 41.5%. In comparing between groups, RNs again demonstrated the greatest growth at 10% pre-survey to 60% post-survey; physicians again stayed consistent from pre- to post-survey at 66%; and those in "other" disciplines rose from 0% pre-survey to 66% post-survey (see Figure 2).

The third question narrowed the focus further to measuring participants' self-perceived confidence in recognizing high-functioning autism spectrum condition in adult patients. The goal of moving from broad to a narrower focus was to determine differences in understanding and awareness of the lesser known autism levels.. The pre-survey results indicated a mean score of 2.44 which rose to 3.125 on the post-survey. Percentage of participants who selected a score of 4 or 5 was 19% on the pre-survey and this rose to 44% on the post-survey for an increase in self-perceived confidence level of 25%. A group comparison showed RN growth went from 10% pre-survey to 30% post survey; physicians showed growth in this area, from 33% pre-survey to 66% post-survey; and "other" disciplines also showed similar results rising from 33% pre-survey to 66% post-survey (see Figure 3).

Question four measured participants' self-perceived knowledge level related to autism in adult patients. The pre-survey results indicated a mean score of 2.375 which rose to 3.19 on the post-survey. Percentage of participants who selected a score of 4 or 5 was only 6% on the pre-survey and this rose to 50% on the post-survey for an increase in self-perceived knowledge level of 44%. Group comparisons shows RN growth rose from 0% pre-survey to 50% post-survey;

physicians increased from 0% pre-survey to 66% post-survey; and “other” disciplines stayed consistent pre- and post-survey at 33% (see Figure 4).

Finally, question five measured participants’ self-perceived knowledge level related to high-functioning autism in adults. The pre-survey results indicated a mean score of 2.44 which rose to 3.19 on the post-survey. Percentage of participants who selected a score of 4 or 5 was again only 6% on the pre-survey and this rose to 50% on the post-survey for an increase in self-perceived knowledge level of 44%. Comparison of groups demonstrates that RNs showed an increase from 0% pre-survey to 40% post-survey; physicians again increased from 0% pre-survey to 66% post-survey; and “other” disciplines increased from 33% pre-survey to 66% post-survey (see Figure 5).

These results demonstrate significant growth in knowledge and confidence in all areas, but most substantially in areas related to adult and high-functioning autism. This answers the project question: How do providers of care who are provided education on HFASC and use of preliminary screening tools and resources, perceive their knowledge and confidence levels in caring for clients who have or may have high-functioning autism, before and three months after education? All participants perceived growth in some areas, with RNs acknowledging growth in all areas. Physicians’ growth was noted to be in areas related to high-functioning and adult autism, and other disciplines’ growth was increased in all areas except for knowledge of adult autism which was unchanged. These results suggest that providing education and a toolkit with resources increases knowledge and confidence levels related to ASC for providers of care. This increased knowledge and confidence implies that providers of care will be able to provide more informed care to patients with ASC and in particular HFASC.

### **Quantitative Data Responsive to PICOT Question 2**

Limited results were obtained to inform question 2; do providers of care who use a screening tool as compared to no use of a screening tool make a greater number of referrals for high-functioning autism testing? These responses would suggest that providers of care do not make a greater number of referrals for diagnostic testing after education and provision of screening tools. However, only three physicians participated in both the pre- and post-survey and all three indicated that they had not changed their assessment practice following provision of education and assessment tools, and none had increased rates of referrals for diagnostic testing. Only two physicians responded to the question that asked whether they were satisfied with options available for referrals and both responded “no” (see Figure 6). With such a small response rate, it is difficult to draw any clear conclusions from this data. However, these limited findings may suggest that physicians may require additional education and support before making changes to practice. Additionally, the lack of satisfaction with available options could be impacting their willingness to utilize assessment tools or make referrals for their patients.

### **Qualitative Data**

Two qualitative open-ended questions were asked related to participants’ understanding of autism spectrum condition and high-functioning autism specifically. Themes that emerged from this data included: (a) intelligent, savant-like; (b) communication and social challenges; (c) sensory issues; (d) high-functioning are able to deal well with life; (e) wide-ranging symptoms; and (f) high- to low-functioning spectrum. Themes were repeated throughout the responses in either the pre- or post-survey or both. Comparison between themes pre- and post-survey were also conducted to determine changes in participant perceptions. Each of these themes will be elaborated on with examples to support.

Theme 1 was coded as *intelligent, savant-like*. A number of participants' responses indicated they believed autistic individuals to be highly intelligent or gifted in a specific area. Participants referenced *Sheldon* from the television program *The Big Bang Theory* as an example of autism. Other participants used the terms "savant-like" or "savant" in describing autism. Figure 7 demonstrates that this perception decreased after the educational intervention, which is positive given that this is a stereotype that sometimes can be detrimental to care approaches. While high intelligence can be a strength of many high-functioning autistics, this is not always the case and is not an assumption that should be made any more than cognitive impairment should be assumed.

*Communication and social challenges* was the code assigned to Theme 2. Examples of pre-survey statements were "unable to speak coherently", "not social", and "non-verbal". Post-survey responses were more focused on "difficulty with social interactions" and "how one interacts with his/her environment" which is more representative of the range of challenges affecting the autistic person. Figure 7 depicts that the awareness of communication and social challenges was higher on the post-survey, suggesting higher levels of understanding in this area.

Theme 3 was coded as *sensory issues*. Pre-survey responses tended to be limited in terms of describing this as simply "sensory issues", and one participant noting "everyone reacts differently to noise, lights, touching, etc.". Post-survey responses elaborated that the sensory issues derive from how stimuli are processed. Several participants portrayed this in a rather positive manner noting individuals with HFASC "are more able to process sensory stimuli" and "higher functionality in the processing of stimuli". While this was not necessarily how sensory challenges were presented in the educational session, it may suggest that participants have developed a more appreciative and perhaps less stereotypical view of the autistic person in this

regard. Figure 7 again shows the greater awareness of sensory issues as a component of autism after the educational sessions and resources were provided.

A fourth theme was identified as *high-functioning autistics deal well with life*. Participants in the pre-survey noted that HFASC patients are “able to function in the real world” and “high-functioning Asperger’s syndrome can function well in society. They might be considered quirky and may be often alone and not have friends”. The latter comments seemed to be rather paradoxical as “functioning well in society” was juxtaposed with “often alone and not have friends”. Post-survey responses had an increased number of comments related to this theme with participants noting “people with high-functioning autism have the ability to better function in social situations, such as holding a job and carrying out the activities of daily living than a person that is not high-functioning” and “high-functioning means the person can function quite well with the disorder. They may have jobs and families and do quite well in social situations”. This finding was surprising given the educational sessions had a major focus on challenges associated with high-functioning autism, and the lack of employment and inability to live independently for many. Figure 7 indicates the increased inclusion of *high-functioning autistics deal well with life* on the post-survey as compared to the pre-survey.

Theme five emerged as participants’ recognition and awareness of the *wide-ranging symptoms* associated with ASC. Rather than assuming that all individuals with autism present with similar symptoms, participants recognized the diverse presentations of ASC that complicate assessments and diagnoses. Participants noted “wide range of presentations” and “wide variety of symptoms” in the pre-survey and expanded to “no one is the same” and “can vary from an individual that is non-verbal to a person that appears to be socially ‘normal’” in the post-survey.



The qualitative responses indicated an increased awareness of *wide-ranging symptoms* from the pre- to the post-survey (see Figure 7).

Finally, a sixth theme was coded as an awareness that autism occurs on a spectrum from *high to low-functioning*. While similar to the *wide-ranging symptoms* theme, the distinction is that symptoms within the same level of functioning can be very different as well. In other words, *wide-ranging symptoms* addresses that no two high-functioning autistic patients will present with the same symptoms or challenges. Conversely, the theme *high to low-functioning* speaks to the variation in cognitive differences and verbal capacity that differentiates one level from the other. In reality, the differentiation is based more on the severity of symptoms and the level of support that is required (American Psychiatric Association, 2013). Participants' responses in the pre-survey indicated awareness as "I know there are different types of functioning (low & high)" and "low function to very high-functioning aspergers". Post-survey responses indicated similar responses noting "some have mild cases while others have severe. Some are high-functioning while others are low-functioning". The number of codes attributed to the pre- and post-survey were the same indicating a static awareness in this area (see Figure 7).

Findings from qualitative data support the quantitative findings as they demonstrate increased awareness of specific autism traits. One theme showed an unanticipated finding related to *high-functioning autistics deal well with life*. Participant responses showed a post-survey increase related to an understanding of high-functioning autistics as being able to function well. While this is true of some, the educational sessions shared the challenges that those with high-functioning autism can encounter in all areas of life. This suggests that participants may have focused on the presented strengths more so than on the challenges. The perception that *high-functioning autistics deal well with life* could potentially be problematic as providers of care may

be less concerned with modifying environments and care approaches for these patients.

However, overall results suggest that the educational sessions and resources increased participants' knowledge levels related to HFASC with the implication being more informed care for this population.

### **Evaluation of Overall Project Success**

The overall success of the project was evaluated through a self-review of the process and achievement of goals, as well as from attendees' evaluations of each of the educational sessions. Each session was evaluated as to achievement by attendees of the objectives, as well as the overall effectiveness of the presentation and presenter in providing the education. One hundred percent of attendees at each of the three sessions indicated that: (a) activity objectives were defined adequately and met by this presentation; (b) expectations of the activity were adequately met; and (c) I will be able to use this information in my practice, directly or indirectly (when advising patients). Several attendees noted that they would make changes in specific areas such as: (a) patient management / treatment; (b) recommendations/education of patients; and (c) policies, protocols, procedures. This feedback provided validation of the education and resources provided and supported direction for future endeavors and any disseminated works. The low attendance by physicians was a challenge, but one that suggests that collaboration with a physician when presenting the information may be helpful in garnering greater recognition of the applicability of the sessions to their discipline. An additional challenge of ensuring strong attendance was met by offering sessions during times most could attend which was the lunch and dinner hour and providing CEUs and CMEs. These are important considerations for successful future implementation of similar programs in other organizations.

### **Discussion and Implication for Nursing and Healthcare**

The literature review reflected that a clinical pathway with associated resources and educational interventions positively affects providers of care knowledge and confidence levels related to ASC and leads to improved healthcare interactions with individuals who exhibit characteristics or symptoms of HFASC ((Bekhet, Johnson, & Zauszniewski, 2012; Gerber et al., 2017; Lewis, 2017; Rogers & Zeni, 2015). The results of this project partially support these findings, with significant growth in providers of care self-perceived levels of knowledge and confidence related to ASC and HFASC specifically. Nurses had the least self-perceived knowledge in most areas, but also showed the most pervasive growth and this suggests a need to ensure nurses are provided education to appropriately care for the ASC population. As providers of care who often spend the most time with patients, it is important that nurses are prepared with knowledge, confidence, resources, and tools to support patients and families. Nurses who have knowledge and confidence and who have adequate assessment tools available to them, can support patients and families by making recommendations for referrals for diagnostic testing. Research supports that patient satisfaction and outcomes is improved when they feel supported and understood by healthcare providers (Bekhet, Johnson, & Zauszniewski, 2012; Gerber et al., 2017; Lewis, 2017; Rogers & Zeni, 2015).

The literature also supports that providers of care *recognize* their own insufficient knowledge and confidence related to differentiating HFASC and caring for this population (Giarelli, Ruttenberg, & Segal, 2012; Wachab & Pesci, 2017; Will, Barnfather, & Lesley, 2013; Zerbo et al., 2015; Zwaigenbaum et al., 2016); the data from this project also supports this finding. Deficient knowledge and confidence levels are associated with lack of diagnosis, misdiagnosis, and disparities in care provided to individuals with ASC (Bargiela, Steward, &

Mandy, 2016; Lehnhardt et al., 2013; Pilling, Baron-Cohen, Megnin-Viggars, Lee, & Taylor, 2012). Education that provides screening tools, communication approaches, environmental adaptations, referral sources, and appropriate resources, could improve rates of diagnosis so that clients are appropriately treated and guided toward effective supports (Rogers & Zeni, 2015; Rutherford et al., 2018; Unigwe et al., 2017). Improved client outcomes could result as clients are more likely to be receptive to providers of care who engage effectively and offer beneficial resources (Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, 2018). Improved outcomes may reduce rates of recidivism associated with lack of proper diagnosis and treatment, and in turn could reduce costs and emergency visits (Buescher, Cidav, Knapp, & Mandell, 2014; Jennings, 2019; Leigh & Du, 2015; Mandy et al., 2018). Client satisfaction scores could improve if communication was effectively geared toward the needs of HFASC clients (Bekhet, Johnson, & Zauszniewski, 2012; Gerber et al., 2017; Lewis, 2017; Rogers & Zeni, 2015).

An unexpected finding for this project was the post-survey increase in the theme *high-functioning autistics deal well with life*. This suggests that despite education sharing the numerous challenges associated with HFASC, the term *high-functioning* may itself be leading to a misunderstanding of ASC severity levels. As noted earlier, *low-* or *high-functioning* have been terms traditionally used to differentiate those who have verbal or intellectual limitations from those who do not. However, the terms are not interchangeable with *levels of severity* as defined in the DSM-V (American Psychiatric Association, 2013). It should also be noted that the autism community has debated the use of the high- and low-functioning terminology in large part due to this lack of understanding (Rudy, 2019). Recent research has illuminated the problem that this terminology creates for those with HFASC, noting that the term high-functioning is an imprecise predictor of true functionality (Alvares et al., 2019). An implication based on the Alvares et al.

research study and this project's supportive data findings is that providers of care should move to terminology that focuses on levels of severity with associated limitations or strengths defined as opposed to high- or low-functioning. For example, an autistic individual may be described as having a Level 3 severity (requiring substantial support) with no verbal or intellectual impairments. This would better describe the individual's condition without infusing terminology that may be misleading by its very name. This was a significant finding, given the work of this project was largely defined by the term *high-functioning*.

Finally, while use of assessment tools and referral rates were not increased among physician participants in this project, it is important to consider this pragmatically given the small number of participants in this group. Concerns with lack of resources and referral sites was a noted concern in the data, and this was also anecdotally addressed by several attendees during the educational sessions. These factors can limit the usefulness of assessment tools and referrals in the minds of care providers if the ability to provide patients with a site and practitioner who can diagnose is limited by availability and wait times. This suggests the need to advocate for more diagnostic testing sites as well as nurse practitioners who can diagnose to better meet the needs of patients with ASC.

There were limitations to this project work. The sample size was small, and the physician, physician assistant, and nurse practitioner group was not well represented. The survey was not validated as no instrument was found that addressed the relevant questions, but development of the tool was based on extant literature findings related to providers of care knowledge and confidence levels of HFASC. As an implementation project, this is not a generalizable study. However, this project work can certainly act as a model for other such implementation projects, and add to the translation of evidence into practice.

The results from this project indicate that education and resources improve providers of care knowledge and confidence levels related to HFASC in adults. The use of assessment tools and referral rates did not increase in the small number of physicians who participated in the surveys, but this could be attributed in part to the noted lack of options related to referral sources. These positive findings may promote sustainability within the organizations and education departments should be encouraged to incorporate required learning modules into their staff programming. Champions to support sustainability efforts is also recommended.

### **Dissemination**

There are several ways the findings from this project will be disseminated. First, findings were shared with the institutions where the project took place and all stakeholders were invited to that session. Second, I have written an article for publication in the *Journal of Nursing Care Quality*, which is published by Lippincott Williams and Wilkins Limited. This is a peer-reviewed journal with a high impact factor that publishes scholarly work intended to improve delivery of care. Finally, a presentation on this project will be planned at a state nursing conference, such as the Michigan Nursing Summit or the Michigan Chapter of the American Psychiatric Nurses Association.

### **Conclusion**

This project was intended to improve providers of care knowledge and confidence levels regarding care of HFASC adults, and to improve referrals for diagnostic testing. This was accomplished by using the best available evidence to create a clinical pathway that includes assessment tools, communication interventions, environmental adaptations, and resources for both clients and families. Educating providers of care on this clinical pathway and associated tools and resources was evaluated using pre- and post- surveys that measured knowledge and

confidence levels as well as referral rates for providers of care. Results indicated that education and appropriate resources significantly increased knowledge and confidence levels, but that use of assessment tools and referral rates remained unchanged. Additional research should focus on HFASC patients' and families' care outcomes and satisfaction with care delivery.

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Table 1

## Budget

<b>EXPENSES</b>		<b>REVENUE</b>	
Direct		Billing	0
Salary and benefits	0	Grants	0
Supplies (handouts/brochures/materials)	228.43	Institutional budget support	0
(simulation materials, autism toys, toothbrushes, glasses, etc.)	141.13		
Printing supplies home computer	43.00		
Books	231.89		
Indirect			
Travel estimate	100.00		
Total Expenses	\$744.45	Total Revenue	0
Net Balance			0

Figure 1

Results of Confidence in Knowledge r/t Autism

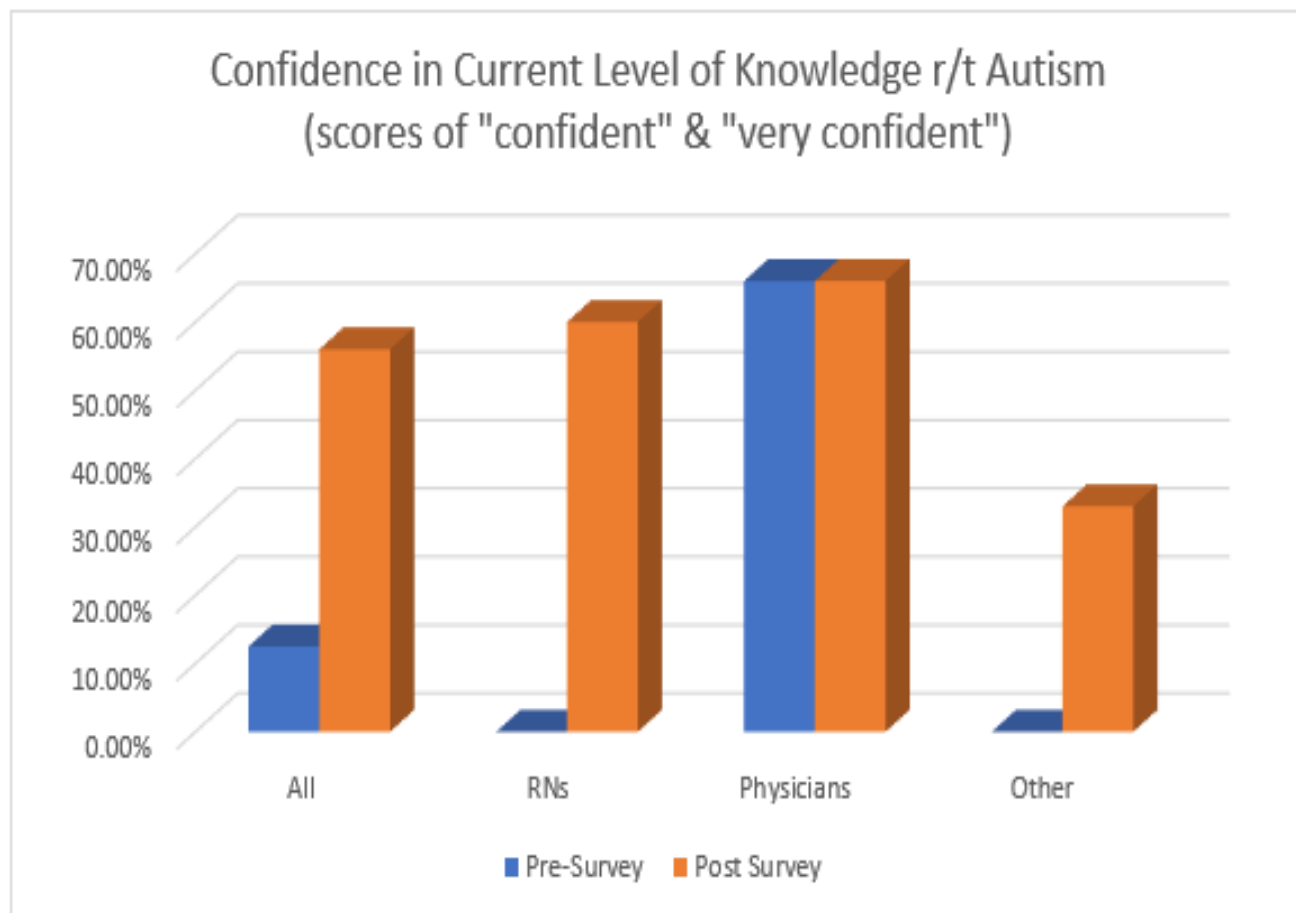


Figure 2

Results of Confidence in Recognizing Autism in Adult

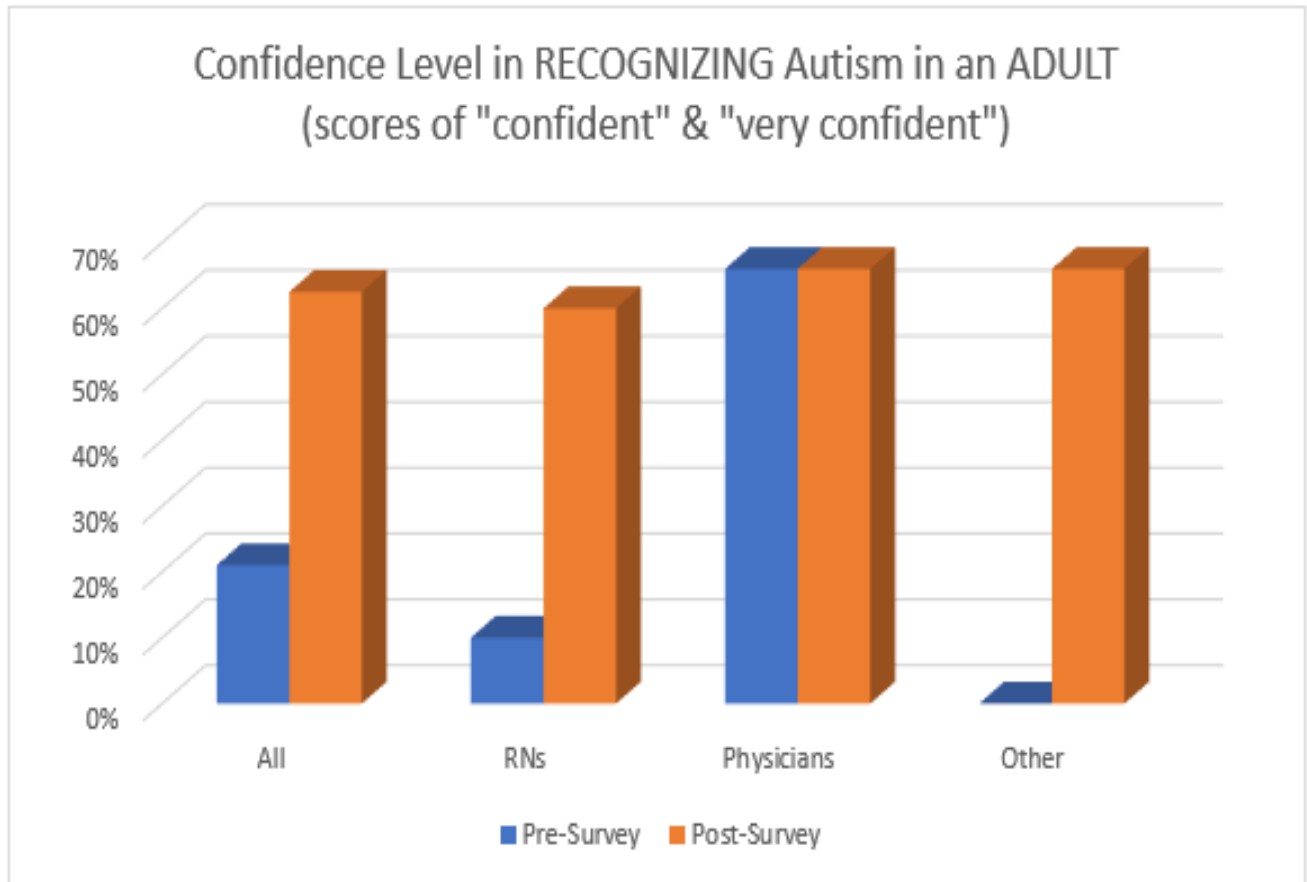


Figure 3

Results of Confidence in Recognizing High-Functioning Autism in Adult

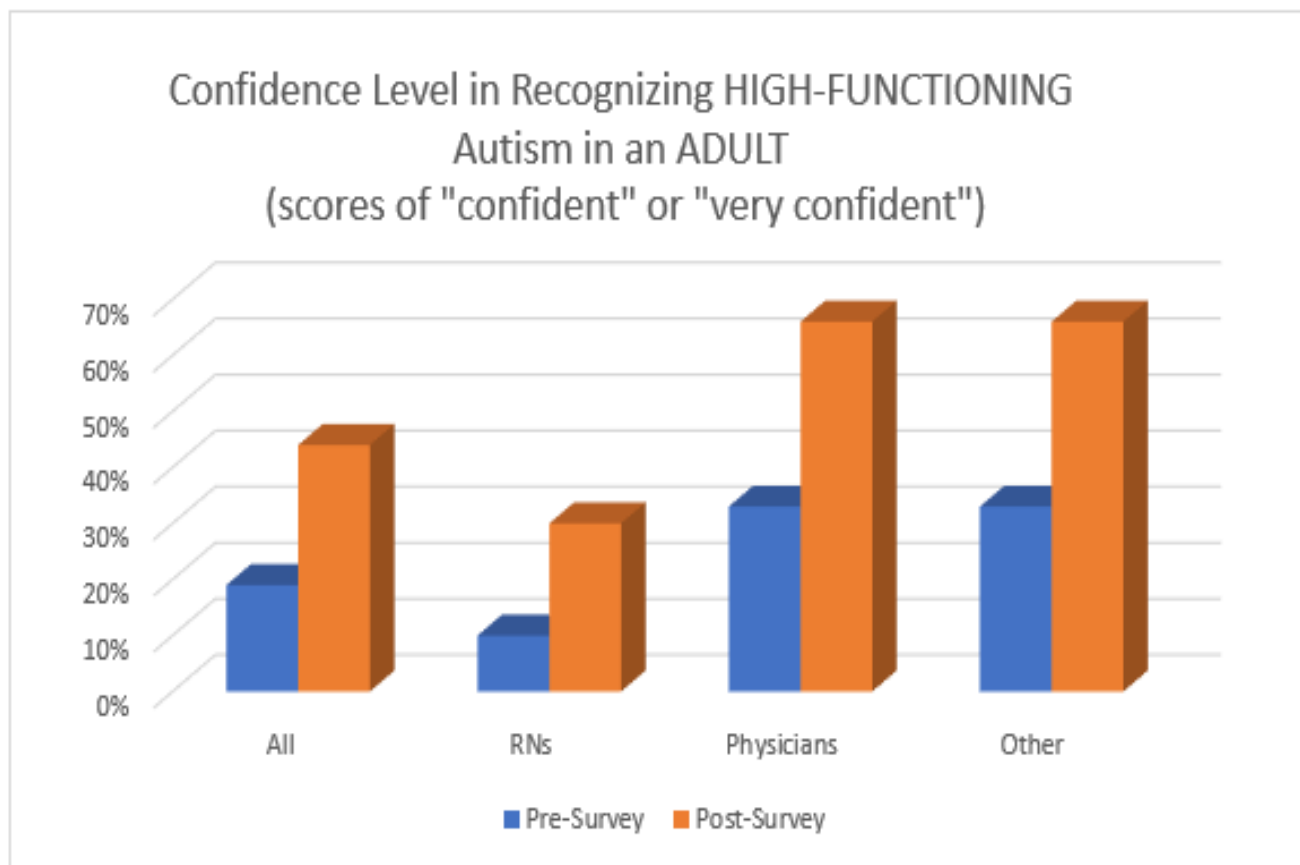




Figure 4

Results of Knowledge r/t Autism in Adults

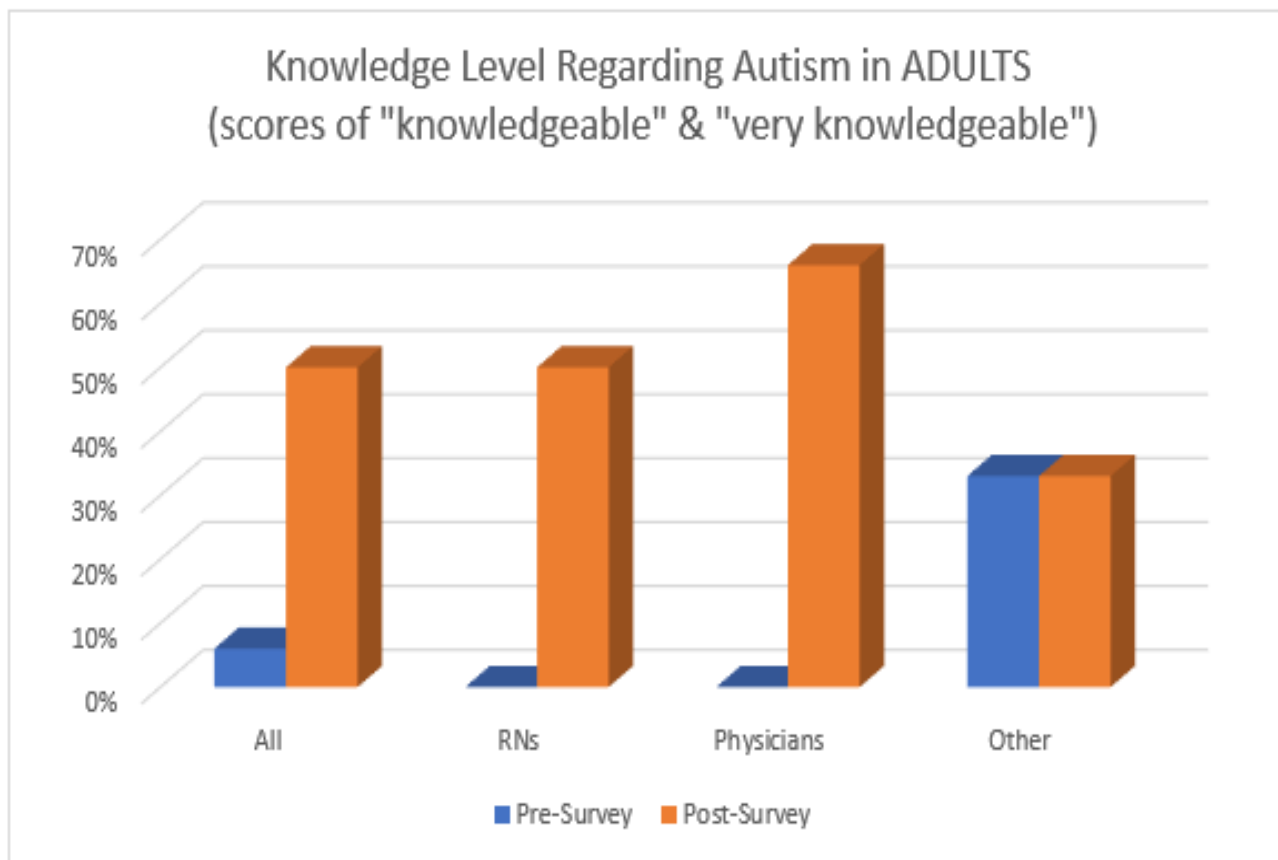


Figure 5

Results of Knowledge r/t High-functioning Autism in Adults

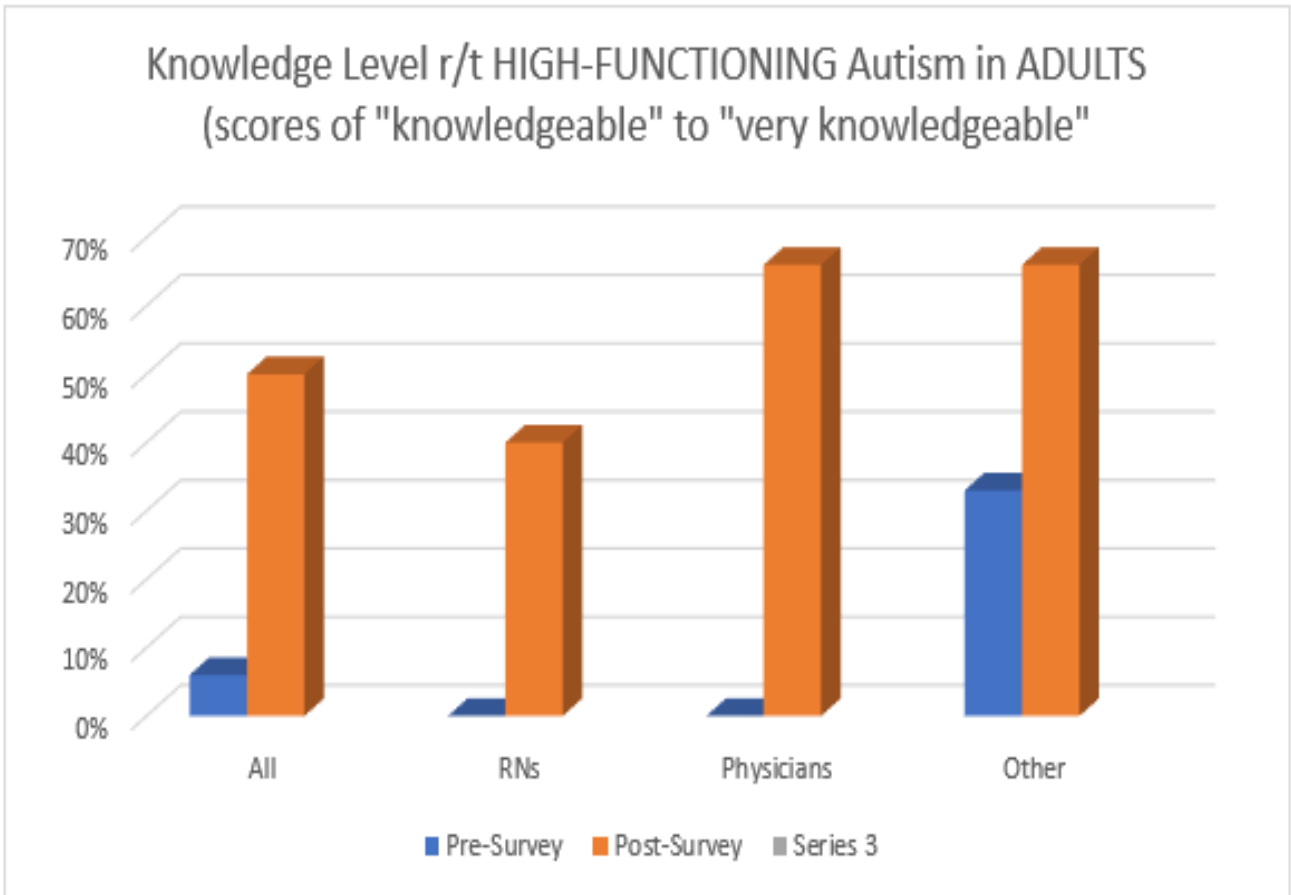


Figure 6

Limited Data r/t PICOT Question 2

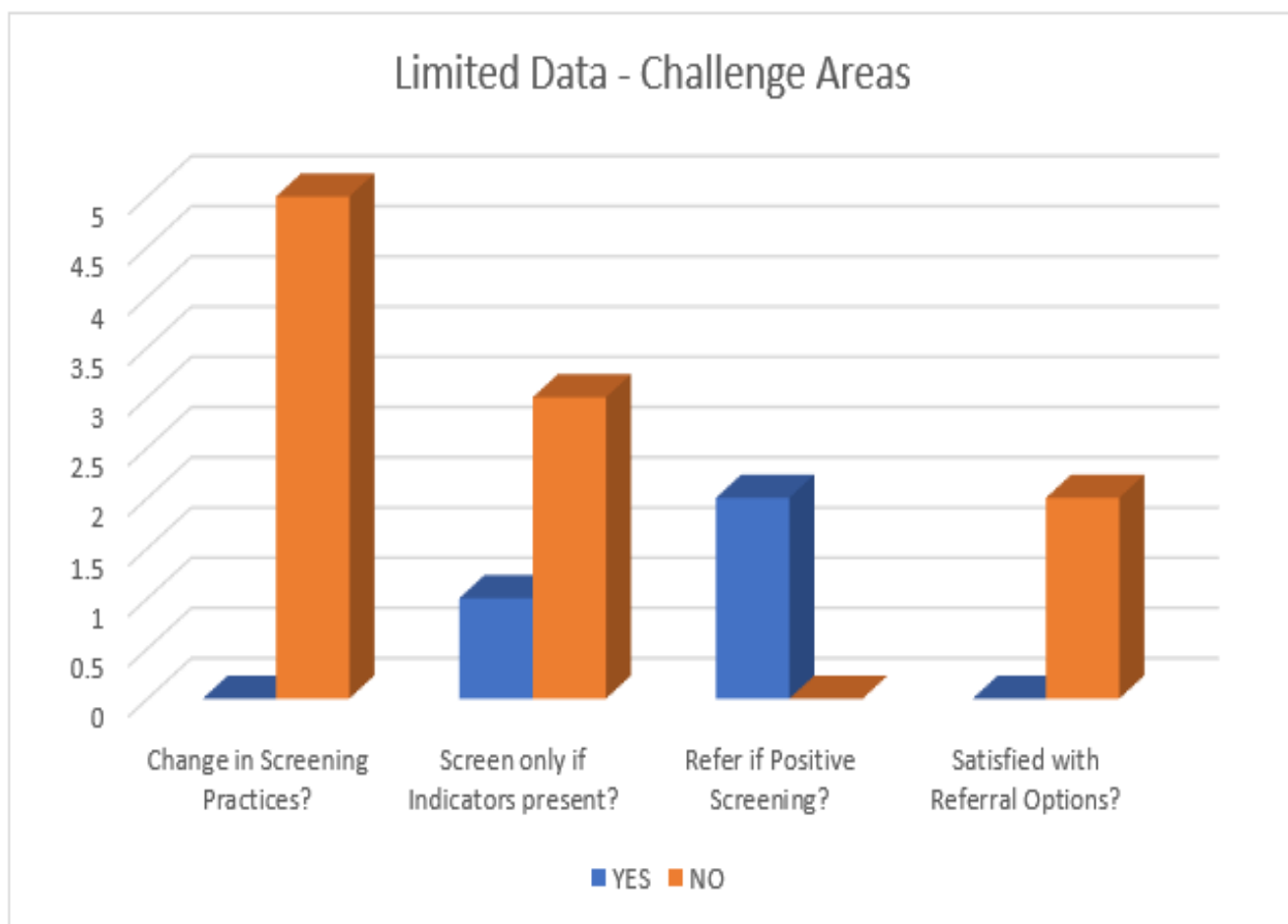
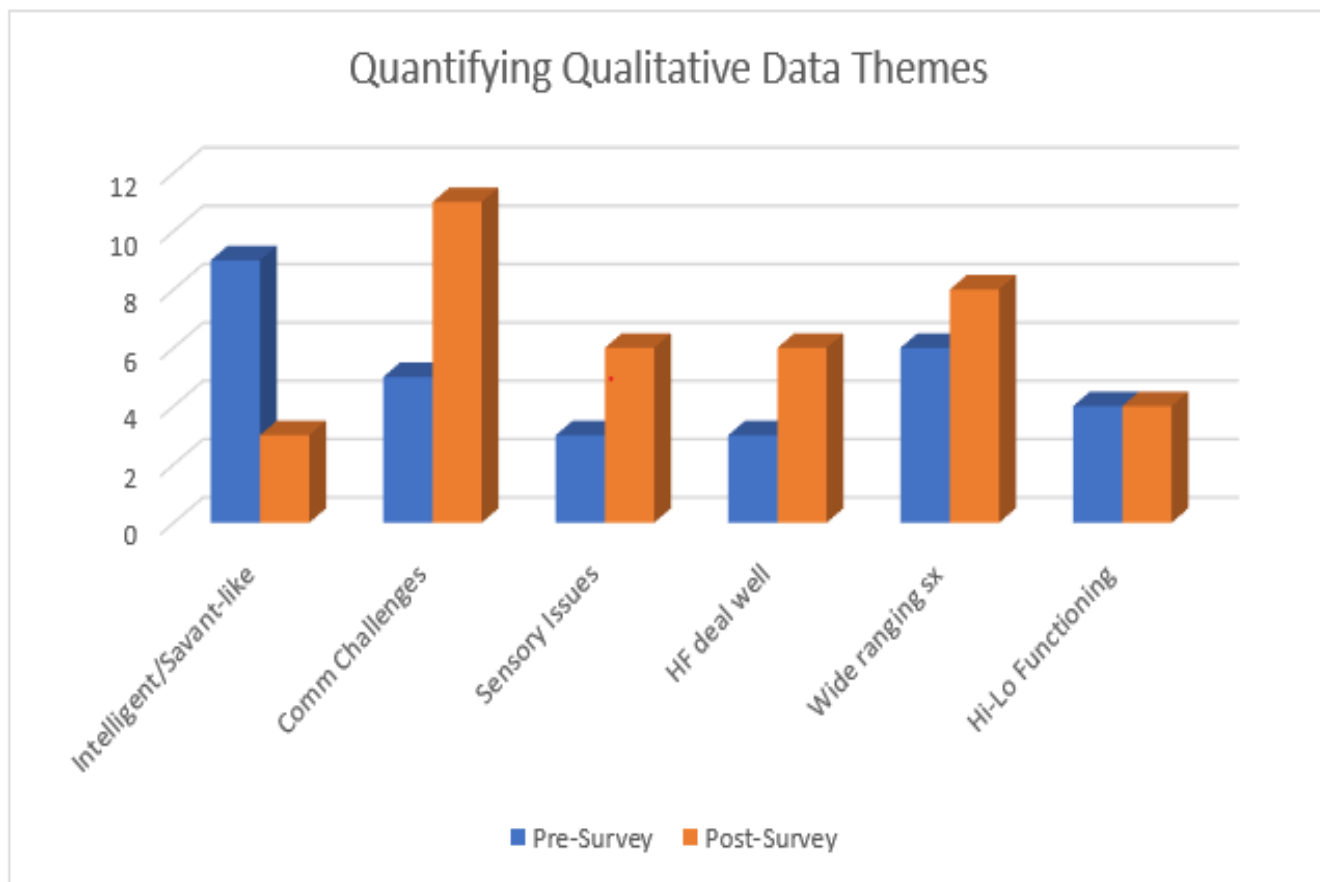


Figure 7

Qualitative Data Theme Comparison



Appendix A

Summary of Primary Research Evidence \* Content within table is often taken directly and verbatim from article in most cases

\*\*Levels of evidence determined from <http://libguides.ohsu.edu/ebptoolkit/levelsofevidence#s-lg-box-8119321>

Citation	Question or Hypothesis	Theoretical Foundation	Research Design (include tools) and Sample Size	Key Findings	Recommendations/ Implications	**Level of Evidence
Griffith, Totsika, V., Nash, & Hastings, (2011).	How do individuals in middle adulthood with Asperger syndrome perceive its effects on their lives, their previous experiences of support and their current support needs?	Not stated, but appears to align with Heidegger’s hermeneutic philosophy.	Interpretive phenomenological analysis, 11 adults with aspergers.	4 themes: living with Asperger syndrome, employment issues, experiences with mainstream support and future steps to support. Anxiety, depression, and comm. difficulties are experienced. Available supports are unsuitable. All want independence & feel individualized approach would be beneficial.	Social skills straining is needed. Individualized support assessments recommended.	III
Nicolaidis, Raymaker, McDonald, Dern, Boisclair, Ashkenazy, & Baggs (2012).	What are the healthcare experiences of autistic adults? Hypothesis is that disparities may exist.	Not stated.	Cross sectional survey of 209 autistic adults and 228 non autistic adults	Autistic adults reported lower satisfaction with patient provider communication, general healthcare self-efficacy, and chronic condition self-efficacy, higher odds of unmet needs for both physical & mental health, lower rates of preventative care, and increased use of EDs	Community based facilitated research approach may facilitate inclusion of autistic adults as participants to better address needs. Providers need to be aware of potential disparities to address. Accommodations include alternatives to overcrowded waiting rooms, communicating in preferred mode, extra time, clarifying role of provider.	III
Nicolaidis, Raymaker, Ashkenazy, McDonald, Dern, Baggs, Kapp, Weiner, & Boisclair, (2015).	What are autistic adults’ experiences with healthcare and their recommendations for improving care?	Not identified.	Community based participatory research approach. Sample was 39 autistic adults and 16 supporters.	Autistic adults experience significant disparities; providers were perceived as lacking knowledge and interactions were	CBPR can enable autistic adults to participate in research. Healthcare providers need training about autism in adults that	III

				problematic with lack of respect for strengths and unwillingness to accommodate needs	focuses on knowledge, but also attitudes, skills, & behaviors needed to provide respectful care and communicate appropriately. Also to incorporate supporters in care. Individualized care Resources are needed to increase self-efficacy. System level changes needed.	
Tint & Weiss, (2017)	How do women with ASD perceive their service and support experiences? What if any are the unmet service needs of women with ASD? What if any barriers to care do women with ASD identify?	Not stated.	Qualitative exploratory study using five focus groups. 20 women with ASD. NVivo 11 software used.	Women mask service needs, there is miscommunication with providers, and accessing appropriate services is a constant struggle. Service providers knowledge, communication skills and attitudes were barriers to effective care.	Providers need to pay attention to mask social communication deficits. Services need to be developed that provide personalized services and supports (person-centered services).	III
Weiss, Isaacs, Diepstra, Wilton, Brown, McGarry, & Lunsky (2018).	What are the patterns of health needs and health service use in young adults with ASD compared to young adults with other DD and to the general population? Hypothesis is that young adults with ASD would have higher rates of common chronic medical or psychiatric diagnoses and greater care sought than those in other categories.	Not stated.	Quantitative population based study of 5,095 ASD, 10,487 with other DD, and general population 393,263. Sample drawn from data within the health administrative data in Ontario.	Individuals with ASD were more likely to have all identified clinical health issues, and 5x more likely to have at least 1 psych dx. Those with ASD were more likely to see providers, visit ED, and be hospitalized.	Rise in prevalence of ASD means more adult healthcare need and tools are needed to help providers and families navigate transition to adult health. Mental health supports are needed.	III
Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, ...Cohen-Silver (2016).	How are ED services accessed and navigated by children with ASD and their families? How is the ED experienced by these children and their families?	Not stated.	Qualitative study using grounded theory approach Interviews of 31 parents and 4 children with ASD who were treated in the ED.	Experiences were mixed, but negative experiences were more often described. Issues related to staff interaction,	Wait time management, sensory environment contained, collaboration with family, responsiveness in care, rapid assessment of	III

				environment, ED procedures which were more challenging . Participants identified needs of child/family centered care with respect, collaboration, information sharing and partnership. Not using proactive approaches may lead to suffering and escalate sensory responses and behavioral challenges with aggression and need for restraint use.	ASD need, and respect for child family.	
Read & Schofield (2010).	How can CAMHS services better meet the needs of children with autism and their families, including improvements in the transition to adult services?	Not stated.	Mixed methods with qualitative discussions and quantitative and qualitative surveys with a total of 445 parents and focus group participants.	Challenges in accessing service initially is very difficult. Getting an initial referral is challenging. Some waited 2-3 years for appt only to be told no supports were available. Negative influences on child's mental health was lack of understanding and support for autism. Professionals do not understand autism or how to communicate with their child, leading to inappropriate, ineffective and harmful treatment. Professionals id'd complexities and lack of knowledge as well. Parents were blamed.	Mental health services need to work with whole family. Need emergency support services in place. Adequate services need to be available and based on insights of families and patients.	III
Baldwin & Costley (2015).	What are the health, education, work, social and community activities of adult females with HFASD? What are ways in	Not noted.	Study was a subset of a larger study conducted by the same authors. This sample was of 82	Females are historically disadvantaged by lack of accurate/timely diagnosis.	Providers should be aware of fewer female diagnosed and masking behaviors to support	III

	<p>which the experiences of females with HFASD differ from a comparable sample of males?</p>		<p>females and 200 males with ASD use questionnaire methodology to survey experiences, needs, and aspirations.</p>	<p>Females had high aptitude for learning. Females had higher stress/worry daily and more mental health issues. Masking was supported by this study. Females did not differ from males in symptoms in most ways. Social aspects are less apparent with females.</p>	<p>diagnosis and care. Educators need to be aware/alert for female students with ASD.</p>	
<p>Bargiela, Steward, &amp; Mandy (2016).</p>	<p>What is the nature of female autism phenotype as experienced by late-diagnosed women with ASC? How does the female autism phenotype influence young women's experiences of diagnosis, misdiagnosis, and missed diagnosis? How do late diagnosed women with ASC adapt in response to the challenges they face?</p>	<p>Not noted.</p>	<p>Qualitative study of 14 women with ASC who were diagnosed late. Data collection of semi-structured interviews. The AQ-10 was used to "confirm" clinical diagnosis and to indicate severity. The General Health Questionnaire-12 was also used as a screening tool to assess current mental state. Hospital Anxiety &amp; Depression Scale was also used and the Wechsler Test for Adult Reading to offer verbal IQ.</p>	<p>Findings supported the idea of "pretending to be normal"/camouflaging. Challenges r/t culture having set expectations. Women experience conflict between feminine and autistic identity. Four themes: you're not autistic, pretending to be normal, passive ivty and social naivety, and forging an identity as a woman with ASC. Sexual abuse was "widespread" in the sample.</p>	<p>Training for teachers and clinicians is needed for timely diagnosis and interventions to mitigate risks and promote well-being.</p>	<p>III</p>
<p>Lum, Garnett, &amp; O'Connor, (2014).</p>	<p>What are the challenges in healthcare communication for HFASD adults? Hypothesis: Women with high-functioning ASD experience greater healthcare challenges compared to women without ASD.</p>	<p>Not noted.</p>	<p>Pilot study of 58 adult females...32 with ASD and 26 without. Exploratory questionnaire to obtain qualitative feedback . Quantitative data obtained on 16 questions survey.Tool</p>	<p>The hypothesis was partially supported. Statistically significant difference found for healthcare anxiety, communication under emotional distress, anxiety in waiting room, support during</p>	<p>Make environmental accommodations for healthcare appts such as appt outside peak times, quieter area reserved for waiting, headphones. Improved clinician awareness of ASD and stigma. Understanding</p>	<p>II</p>



			developed by researchers in consult with consultants.	pregnancy, and communication of pain and needs during childbirth. 100% of women with ASD perceived more dissatisfaction/difficulties with healthcare than those without ASD. Sensory experiences in waiting area caused anxiety. 100% experienced frustration with uninformed clinicians.	women report with reduced communication during stress may guide clinical adjustments. Communication enhancements.	
Head, McGillivray, & Stokes (2014).	Hypothesis: Females with ASD will display better social skills than males with ASD on test of friendship and social function	Not noted.	Mixed methods of 101 total participants into 4 groups (males and females with ASD 25 each) (males and females without at 25 & 26 each). Interviews, and tools used were FQ (friendship quality)	Females demonstrated higher scores on the FQ than males. Regardless of gender, children with ASD had lower scores than typically developing children. Females with ASD and typically developing males scored similarly for FQ.	Reconceptualization of current autism diagnostic criteria for ASD differentiating social skills apparent in females with ASD compared to males with ASD. Need for social intervention specifically tailored for females with ASD. Research is needed to examine underlying causes for this difference.	II
Mandy, Clarke, McKenner, Strydom, Crabtree, Lai, C...Skuse (2017).	What is the validity and utility of the 3di-Adult tool?	Not noted.	Prospective Comparative Control Study with 3 groups with total of 88 participants with ASC(39), people without ASC from gen pop (29) and people getting psych care for mental issues(20)	3Di-Adult had strong content validity, criterion validity was established. Reliability and validity were demonstrated. Suggests can be used to assess ASC in adults based on DSM5 criteria.	Test can be used to improve diagnosis and whether to refer for comprehensive assessment but needs more rigorous study.	II
Kirchner, Ruch, & Dziobek (2016).	What are the character strengths in individuals with ASD vs neurotypical controls? What strengths are most often signature strengths? What are	Not noted	32 adults with ASD without intellectual impairment and 32 matched neurotypical controls. Tools vVIA-IS	ASD character strengths were open-mindedness, authenticity, love of learning, creativity, fairness. Control groups	Importance of training social and emotional competencies to improve SWL.	II

	associations between character strengths and satisfaction with life?		and SWLS were used. Questionnaires with multivariate analysis of variance . MANOVA.	were openmindedness, fairness, humour, kindness, and love. SWL was associated with hope, zest, kindness humor, social intelligence and teamwork with those with ASD. Loneliness was associated with decreased levels of SWL.	Consider fit between environment and task with character strengths for ex with work.	
Schipper, Mahdi, DeVries, Granlund, Holtmann, Holtmann, M...Bolte (2016).	What are the opinions and experiences of international experts on functioning and disability in ASD?		Email survey using protocol from WHO of 225 experts from 10 disciplines worldwide	Gender difference found-males externalize more than females; females internalize. Positive characteristics are honesty, loyalty, attention to detail, and creativity.Core traits consistent with findings; disability/challenges assoc with care for self, participation in school, work, social life, sensation, speech, digestion. Males have less concerns with social fitting in.	Enhanced communication between stakeholders is necessary to improve functioning and QOL.Provide professionals and other stakeholders with terminology and dfinitions of functionary that are universally applicable and understandable globally.	III
Giarelli, Ruttenberg, & Segal (2012).	What is the perceived value to nurses of a CEUon comprehensive care of patients with ASD across practice settings?	Not noted	37 participants in an evaluation pilot study.	All participants valued the education. 77% had incorporated into practice.	Education for multiple stakeholders can be beneficial to improving care.	III
Gray, Keating, Taffe, Brereton, Einfeld, Reardon, & Tonge (2014).	What are the outcomes in a community sample of adults with autism in relation to community inclusion and living skills? What are the predictors of these outcomes?	Not identified	Prospective Longitudinal Cohort Study Developmental Behavior Checklist for parent or carer, and adult version (DBC-P and DBC-A) Index of Social Competence	“Majority of individuals with autism were either living with their parents or were in care” “parents are bearing much of the burden of caring for their adult children” “only 18% of HFASC adults were employed” “adults with	“highlights need to look at type of activity and number of hours spent in the activity for more complete picture of employment & daytime activities” “paid employment and post-secondary education associated with better	II

			Social-Economic Indices	autism are more likely to engage in activities that are organized and designed by others”	living skills and living independently” “research needs to address best way to improve poor living skills assoc with poor social outcomes and help to facilitate community inclusion”	
Havercamp, Ratliff-Schaub, Macho, Johnson, Bush, & Souders (2016).	What is the effectiveness of ASD training for medical students?	Not noted	99 3 <sup>rd</sup> year med students at OSU. Post evaluation survey of quant and qual measures. Mixed methods approach.	Participants reports positive or very positive changes with respect to caring for pts . Males were less likely to report changes in competence or when asked about challenges faced by pts/families. Confidence & comfort was increased. Communication and ability to provide better care were significantly higher than previous.	Future healthcare providers should learn disability and be given opp to develop KSAs to prepare them for quality care.	II
Wachab, & Pesci (2017).	What are the current levels of knowledge, familiarity, and comfort that EMT and Paramedics have regarding autism and responding to individuals in emergency situations?	Not noted	Descriptive qualitative study of 73 participants.	Having autism specific resources were significantly associated with higher levels of comfort. Knowledge was not affected. Newer and younger professionals had higher knowledge and comfort compared to older and experienced profs	First responders should be properly prepared. Exposing professionals to autism community might enhance ability to interact and treat during emergency. ASD and families may benefit from interacting with EMTs. Equip responders with resources at their disposal (brochures, videos, etc.)	III
Rutherford, Forsyth, McKenzie, McClure, Murray, McCartney, D....O’Hare (2018).	Does implementation of Flightgate practice development interventions reduce waiting time for ASD diagnosis?	Not noted	39 males and 25 females used nested structure of cases within services.	Average wait time for diagnosis was reduced from 149.4 to 119.5 days or 29.9 days overall.	Flightgate may be promising framework for service improvement to reduce wait time for diagnosis.	II

<p>Will, Barnfather, &amp; Lesley (2013).</p>	<p>How do primary care NPs perceive their level of competency and what barriers do they experience when providing primary care to children with ASD compared to children with ND and CC?</p>	<p>Not noted</p>	<p>Self-report survey using Likert scale to 126 participants</p>	<p>Competency was ranked sig lower when caring for ASD compared to control. Lack of care coordination was identified as significant barrier. NPs expressed desire for more education on ASD.</p>	<p>Future research that examines parental perception of care provided by NPs. Expand discussion of need for further ASD training for NPs.</p>	<p>III</p>
<p>Zerbo, Massolo, Qian, &amp; Croen (2015).</p>	<p>What are adult providers of care' general knowledge about autism and their comfort level treating clients with ASC, and to gauge their specific needs in caring for adults with ASC? What is the variability in provider knowledge, comfort level, and needs across three types of providers?</p>	<p>Not identified</p>	<p>Mixed methods, with Online survey and follow up phone interviews. 11 question Survey tool developed using DatStat software. 922 participants</p>	<p>“Providers across all departments reported having inadequate knowledge skills and tools” “some believed ASC only affected children” ”Findings clearly support the need for provider training on effective communication strategies and management of their healthcare visits.</p>	<p>. “Given the increasing numbers of children with ASC approaching adulthood, improvements in the transition from pediatrics to adult medicine are urgently needed.” ”Findings clearly support the need for provider training on effective communication strategies and management of their healthcare visits.” “Future research will be needed to evaluate effectiveness of provider training and new transition processes to settings where they are implemented”.</p>	<p>II</p>
<p>Zwaigenbaum, Nicholas, Muskat, Kilmer, Newton, S., Craig....Sharon (2016).</p>	<p>What challenges do HCPs in the ED face in providing care to children and youth with ASD? What strategies are needed to optimize ED care for children and youth with ASD?</p>	<p>Not noted</p>	<p>Grounded theory design with naturalistic inquiry approach. Individual interviews and child-behavior checklist was used.</p>	<p>Factors contributing to challenging care delivery: characteristics of child; ED not optimal environment for child with ASD (sensory triggers); achieving ideal care of children with ASD due to competing demands.</p>	<p>Additional training for HCPs needed. Partnering with experts on ASD. Process changes-triage quicker/expedite care Change environment and space, available resources.</p>	<p>III</p>

				Facilitated effective ED care provision: Communication strategies, more times, attention to non-verbal, assessing anxiety and stress levels while engaging. Involving parents; calming environment, training and teamwork		
Erickson-Warfield, Crossman, Delahaye, DerWeerd, Khuithau, (2015).	What are the experiences of health care providers when providing medical care to adults with ASD, what training have they received, and what do they lack?	Not noted	Qualitative study using indepth case studies of 10 health care professionals who provide primary care to adults with ASD	Challenges to provision of care: shortage of services and supports, lack of providers willing to work with adults with ASD, financial disincentives r/t time, reimbursement and need for additional staff. Waiting room environment. Communication. Complexity of family involvements. Elevators/stairs Lack of formal education training provided to physicians during medical school	Increase awareness of needs and rewards of caring for adults with ASD. Connect physicians to programs and services. Health reform for better services. Expand training for medical students and residents.	III
Bruder, Kerins, Mazarella, Sims, & Stein (2012).	What is the prevalence and needs of primary care physicians in caring for adults with aSD?	Not noted.	Mailed survey. 346 physicians completed survey of multiple choice questions and 4 open ended responses	Inadequate training in care of adults with ASD. Physicians have interest in obtaining training. Mental health and dental care are reasons ASD pts seek treatment. Many live with family. Physicians reported conferences or workshops were their	Education is needed for providers and must be delivered in the most effective means possible.	III

				preferred method of training.		
Thomas, Blake, Morris, & Moles, (2017).	What are the dental experiences of UK parents of children with autism and how do they feel primary care dental services can be improved?	Not noted.	Qualitative study of 17 parents using semi-structured interviews and thematic analysis.	Key themes: flexibility of dental team, value of clear communication, confidence of parents to advocate for children’s needs, clear referral paths to specialist services. Issues of hyper-empathy, the dental chair, waiting room challenges, medical authority and continuation of care.	Strong relationships needed with dental team and patient and entire family. Family centered care is supported.	III
Brookman-Fraze, I., Drahota, & Stadnick, (2012).	What are therapists’ participation in comprehensive training? What are therapists’ use of AIM HI? What are therapists’ perceptions of utility of the intervention? What changes in child’s behavior were noted after 6 months of AIM HI from CMH therapists?	Not noted.	13 dyads of therapist/family who met criteria participated. Training was provided on AIM HI (parent resource package of EBP strategies to reduce behavior problems). Multiple methods of measuring therapists use of EBP AIM HI protocol were used.	Therapists reported sig higher knowledge levels related to working with children with ASD. Behavior problems in children were significantly reduced after 5 month implementation. Therapists perceived AIMHI as useful for children with ASD.	Support for training on use of AIMHI or EBP strategies is important. Larger scale studies using training of AIM HI should be explored.	II
Chiri, & Erickson-Warfield (2012).	What are the healthcare experiences of children with ASD? What are their unmet needs, and what type or problems do they encounter when accessing needed care?	Not noted.	Data from 2005-2006 National survey of Children with Special Health care needs was used with final sample size of 38,373. Weighted logical regression used to examine difference in parent reports of unmet needs vs. 3 dif health conditions.	Children with ASD were significantly more at risk for unmet needs. Families were more likely to report provider lack of skill to treat the child as barrier to obtaining therapy and mental health services.	Further research to determine why greater difficulties. Providers need to reduce barriers by awareness of ASD needs.	III
Maloret, & Scott, (2017).	What are the emotional and psychological experiences of being a mental health inpatient living with an ASC?	Not noted.	Qualitative naturalistic research design. Semi-structured interviews of 20 adults in east	Response patterns noted as themes: isolating selves from others, ceasing to eat and sleep,	Thoughts, feelings, and responses of autistic patients need to be understood and support	III

			England who were former inpatient psych pts.	self-harming, or aggressive/violent responses. Anxiety was provoked by fear, lack of routine/structure, sensory issues on unit, food issues due to sensory issues	offered to reduce anxiety, self-harm, and violent acts during mental health inpatient stays. Providers of care need to be aware of and responsive to unique issues that impact patients with ASD.	
Unigwe, Buckley, Crane, Kenny, Remington, & Pellicano,(2017).	What are GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum and the factors affecting this?	Not noted	Mixed methods study of 304 individuals who responded to online survey and met criteria. Correlational analysis and regression analyses as well as descriptive analysis were used.	34% of GPs never received any training on ASD. Participants reported good knowledge of key features, but still had limited confidence in identifying and managing care of ASD patients. Barriers were identified overwhelmingly as failing of system and lack of clarity with referral pathways, lengthy delays between referrals and diagnosis.	Confidence levels may play a role in decision to refer or not children or adults for diagnostic assessment, so effort to enhance self-efficacy are much needed. Initiative targeted toward training in autism and greater clarity around referral pathways should go some way to improving GPs confidence.	II
Fusar-Poli, Brondino, Rocchetti, Panisi, Provenzani, Damiani, & Politi (2017).	What is the sensitivity and specificity of the ADOS and ADI-R in diagnosing ASD in adults?	Not noted	Quantitative study of 113 participants who met criteria. Administration of ADOS—2 Module 4 and ADI-R.	Findings cautiously confirm accuracy of ADOS-2 Module 4, and suggest that ADI-R might not be reliable in adults without intellectual disability.	Training and experience remains primary importance when assessing adults who could potentially be on the spectrum.	III
Grodberg, Weinger, Halpern, Parides, Kolevzon, & Buxbaum (2014).	What is the clinical utility of the AMSE in the diagnostic assessment of verbally fluent adults who are suspected of ASD?	Not noted	50 adults participants at risk for ASD were tested using AMSe (autism mental status exam), ADOS-G Module 4, and ADI-R.	Results indicated optimized sensitivity and specificity for the group. Holds promise as a diagnostic assessment tool.	Should not be used by clinicians without diagnostic expertise. Can be used quickly and accurately to support diagnosis in verbally fluent adults.	III
Lundqvist, & Lindner (2017).	Is the autism spectrum quotient a valid measure of traits associated with the autism spectrum?	Not noted	Total of 349 adult participants; 130 with autism; and 219 without.	Analysis indicated 50 item AQ could be reduced to 12 item subset with little loss of	Research to replicate findings should be done. 12 item may be beneficial for ASD patients	III

			Quantitative study with Rasch analysis.	explanatory power to efficiently measure degree to which adults with & without ASD show autistic traits.	who have challenges completing lengthier version.	
Sizoo, Horwitz, Tenunisse, Kan, Vissers, Forceville, ....Geurts (2015).	What is the predictive validity of self-report questionnaires in the assessment of ASD in adults?	Not noted	Quantitative analysis using ANOVA in sample of 210 qualified participants. All wer given the ADS-R, AQ28 and AQ10.	ADS-R was most sensitive, and AQ had greater specificity. None demonstrated sufficient validity to predict a diagnosis of ASD in outpt settings.	Decision whether to refer for full assessment should not be solely based on these instrument scores but also on careful clinical scrutiny of all additional information.	III
Woodbury-Smith, R., Robinson, Wheelwright, & Baron-Cohen, (2005).	What is the usefulness of the AQ screening questionnaire in distinguishing between those individuals who turned out to have AS and those who do not?	Not noted	Quantitative study of 100 participants evaluated with AQ, then sent for further assessment.	Results found it has good discriminative validity and good screening properties at a threshold score of 26.	The AQ can be a useful screening tool in clinical practice with quick, reliable method of determining likelihood of any individual falling on high end of autism spectrum and warranting further assessment. Suggestion of score of 26 would help ensure false negative are limited and avoid slipping through the cracks.	III
Ashwood, Gillan, Horder, Hayward, Woodhouse, McEwen, ....Murphy (2016).	What is the predictive ability of the AQ as to who will go on to receive a diagnosis of ASD in adults?	Not noted	Quantitative study of 476 adults, seen consecutively at a national ASD diagnostic referral service for suspected ASD. We tested AQ scores as predictors of ASD diagnosis made by expert clinicians according to International Classification of Diseases (ICD)-10 criteria, informed by the	Of the participants, 73% received a clinical diagnosis of ASD. Self-report AQ scores did not significantly predict receipt of a diagnosis. While AQ scores provided high sensitivity of 0.77 [95% confidence interval (CI) 0.72-0.82] and positive predictive value of 0.76 (95% CI 0.70-0.80), the specificity of 0.29 (95% CI 0.20-0.38) and	AQ's utility for screening referrals was limited in this sample. Recommendations supporting the AQ's role in the assessment of adult ASD, e.g. UK NICE guidelines, may need to be reconsidered.	III



			Autism Diagnostic Observation Schedule- Generic (ADOS-G) and Autism Diagnostic Interview-Revised (ADI-R) assessments.	negative predictive value of 0.36 (95% CI 0.22-0.40) were low. Thus, 64% of those who scored below the AQ cut-off were 'false negatives' who did in fact have ASD. Co-morbidity data revealed that generalized anxiety disorder may 'mimic' ASD and inflate AQ scores, leading to false positives.		
Bishop & Seltzer (2012).	What is the criterion related validity of the AQ in a sample of adults with ASD? What is the use of the AQ in adults with ASD with below average intelligence?	Not noted	65 participants drawn from ongoing longitudinal study. Mixed methods including interviews with Vineland Screener and administration of AQ and WRIT.	There was low sensitivity of the AQ cutoffs in group of individuals known to have substantial ASD related impairment. Adults with higher IQs differed substantially in their self-ratings than those with lower IQs. AQ scores may not accurately reflect likelihood of ASD in individuals with limited insight and high social interest.	AQ should be used cautiously to measure autistic traits in clinical or general population samples to avoid erroneous conclusions.	III
Gerber, McCormick, Levine, Morrow, Anders, & Sheinkopf, (2017).	What is the level of healthcare satisfaction and factors contributing to satisfaction in adults with ASD?	Not noted	Quantitative study of 92 adults with ASD completing a medical health questionnaire and a healthcare survey an ADOS-2 clinical assessment.	Higher levels of healthcare satisfaction were found in adults with ASD who were under 26. These individuals were more likely to live at home, have private health insurance, and have others making their healthcare decisions than those over 26 (who were less likely to be satisfied.	Good family and community support is needed to improve satisfaction with healthcare.	III

<p>Lewis (2017).</p>	<p>What barriers do adults with ASC face in reaching a formal diagnosis? What is the incidence and severity of each of these barriers?</p>	<p>Wylie’s 9 state model for stages of diagnosis for adults with ASD</p>	<p>Mixed-methods/exploratory sequential design</p>	<p>Significant barriers exist in obtaining formal diagnosis. Symptoms may actually prevent diagnosis...ie. Severe anxiety prevents person from making appt. Females may be more likely to experience delayed diagnosis compared to males</p>	<p>Professionals must actively engage in trust building with this population. Research should focus on exploring barriers within sub-populations, and pilot interventions to facilitate diagnosis should occur.</p>	<p>III</p>
<p>Mandy, Chilvers, Chowdhury, Salter, Seigal, &amp; Skuse (2012).</p>	<p>What is the presence and stability of ASD sex differences throughout childhood and adolescence?</p>	<p>Not noted</p>	<p>A sample of 52 girls and 273 boys with HFASD were included in this mixed methods study using a semi structured parental interview and the 3Di assessment tool, and the ADOS, SDQ, and IQ.</p>	<p>Findings support that there are subtle but important differences between males and female ASD phenotype. Females different quan. &amp; qual on repetitive stereotyped behaviors (RSB). Females had superior fine motor skills. Females were reported by parents to have worse emotional difficulties. Males had higher interpersonal problems and externalization.</p>	<p>Females are diagnosed later than males, and the reason may be due to differences from males who externalize behaviors so are picked up sooner. RSB may be lower in females which and since RSB is stressed in the new DSM, it may lead to even more females not being diagnosed. Consideration to lower RSB threshold for females should be considered.</p>	<p>III</p>
<p>Mattys, Noens, Evers, &amp; Baeyens (2018).</p>	<p>What are the developmental themes that are relevant for young adults with ASD?</p>	<p>Social-constructivist epistemology</p>	<p>Qualitative study using interviews with 14 young adults with ASD, 12 professionals, and 2 focus groups with 7 parents each</p>	<p>ASD adults and parents search for balance when met with society expectations they find hard to meet. Adulthood began at later age than was “normal” Felt “left behind”. Parents are central to development and well-being. Searching for an environment to thrive in. Hiding need for support to fit in leads to chronic overestimation</p>	<p>Social motivation needs further research since this was prevalent theme, but needs to be supported in way that HFASD experience and ways they want to socialize. Transitions for ASD to adulthood are absent and need to be developed. Finding options to allow individuals to fully engage in the</p>	<p>III</p>

				and less support options. HFASD are more likely to have no activities than low-functioning ASD, and are at higher risk for depression/suicide	community re needed. Help in establishing personal relationships is needed. A focus on the associated issues and less on the diagnosis of ASD itself is identified by participants to avoid stigma	
Tavassoli, Miller, Schoen, Nielson, & Baron-Cohen (2014).	Do adults with ASC report more sensory over-responsivity than adults without ASC? Are autistic traits in adults with and without ASC associated with sensory over-responsivity?	Not noted	402 participants; 221 with ASC and 181 controls. Quantitative study using AQ, SP scale, and RPM. MANCOVA conducted.	Adults with ASC report sensory over-responsivity overall and in each sensory modality. Increased sensory sensitivity was associated with more self-reported autistic traits between both groups. Co-morbid anxiety and sensory issues compromise ability to function in daily life. Depression and anxiety is associated with higher sensory issues.	Highlights importance of assessing for sensory symptoms in ASC and classifying hyper or hypo. SP scale could be useful clinical tool to measure over-responsivity. Sensory domains should be measured separately rather than combining scores. Interventions to address specific sensory issues can lead to improved QOL.	III
Elwin, Ek, Schroder, & Kjellin, (2012).	What are the sensory experiences in Aspergers syndrome or HFA?	Theory of mind	Qualitative content analysis of 10 autobiographical texts of persons with AS/HFA	All authors described sensory modulation problems still in adulthood. All had hypersensitivity to some and 9 of 10 had hyposensitivity. Fluctuating between these 2 Encounters with mental health services can elicit strong negative sensory reactions. Hypersensitivity makes person vulnerable to environmental circumstances and cause	Reduce stimuli in environments. The sensory issues needs to be recognized as a problem in healthcare encounters and adaptations made. Education of mental health nursing and patients and family about sensory issues. Assessment tool for needs may be helpful to guide care.	III

				disorientation and stress.		
Finke, Hickerson, & Kremkow (2018)	What are the perceptions of individuals with ASD who play videogames as their primary leisure activity regarding the role of videogames in their lives and their motivations for playing videogames?	Not noted	Qualitative interview methodology with 10 adults with ASD.	Results suggest videogames is a good use of time and has a positive impact on their lives in several ways including career skills, socializing, and being creative. Also physical skills in terms of coordination, feelings of being happy, and taking pride in achievements.	Clinical consideration is taking what a person is good at or interested in and using that as a center of instruction or communication based interventions. People with ASD have the fewest # of friendships of all disabilities. This may serve as a way to improve outcomes in that area.	III
Bishop-Fitzpatrick, Mazefsky, & Eack, (2017).	What are the differences in group characteristics between adults with aSD and typical community volunteers in social support and QOL? What is the direct effect of perceived stress on QOL and a potential stress buffering effect of social support on the relationship between perceived stress and QOL of adults with ASD and typical community volunteers? Hypotheses: Adults with ASD will have lower levels of social support and lower levels of QOL than typical community volunteers. There will be a significant negative association of perceived stress on QOL for both adults with ASD and typical community volunteers.	Not noted	Quantitative study of 40 adults with ASD from a study of comparative study of 2 psychosocial interventions CET and EST. 25 participants from typical community volunteers served as matched group. ISEL and PSS were measurement tools	Data did not reveal a buffering effect of social support on the relationship between perceived stress and QOL in either group. Adults with ASD have significantly lower levels of social support and QOL. Perceived stress and social support had direct effect on QOL, but social support did not buffer the effect of stress on QOL.	Interventions are needed to teach ASD adults skill to help them better manage stress and cultivate supportive social relationship to improve QOL	I
Hong						
Luxford, Hadwin, and Kovshoff, 2016	What is the effectiveness of a school-based Cognitive Behavioural Therapy (CBT) on symptoms of anxiety, social worry and social responsiveness,	Not noted	Randomized control study of Thirty-five young people (11–14 years; IQ [70] with ASD and elevated teacher or parent reported	The intervention (compared to the wait-list control) group showed positive change for parent, teacher and self-reported	Highlights the potential value and limitations of school-based CBT for young people with ASD.	I

	and indices of attentional control and attentional biases to threat in adolescents diagnosed with Autism Spectrum Disorder		anxiety were randomly assigned to 6 sessions of the Exploring Feelings CBT intervention (Attwood in Exploring feelings (anxiety)	anxiety symptoms, and more marginal effects of increased teacher-reported social responsiveness		
Hirvikoski & Blomqvist, 2014	The first aim of this study was to describe level of self perceived stress in intellectually able adults with ASD. We hypothesized that adults with ASD would describe more subjective distress and poorer coping ability than typical adults. The second aim was to study the hypothesis that autistic traits are correlated with both perceived stress (distress) and perceived coping ability.	Not noted	Quantitative study of 53 adults (25 with autism spectrum disorder and 28 typical adults from the general population) completed the Perceived Stress Scale.	Adults with autism spectrum disorder reported significantly higher subjective stress and poorer ability to cope with stress in everyday life, as compared to typical adults. Autistic traits were associated with both subjective stress/distress and coping in this cross-sectional series.	The long-term consequences of chronic stress in everyday life, as well as treatment intervention focusing on stress and coping, should be addressed in future research as well as in the clinical management of intellectually able adults with autism spectrum disorder.	II
Murza, Nye, Swartz, Ehren, & Hahn-Vaughn, 2014	What is the efficacy of the ACT & Check strategy intervention to improve inference generation when reading, metacognitive ability, general reading comprehension, and social inference ability in adults with HFASC?	Not noted	Randomized control trial of 25 adults randomly assigned to treatment or control group.	Treatment group demonstrated significantly superior performance on 1 of 2 measures of inference generation in reading and 1 measure of metacognitive ability. Sig differences were not found on measures of reading comprehension or social inference ability	Suggests need to explicitly teach inference generation to address a reading inference deficit in adults with HFASC	I
Garcia-Villamizar & Dattilo, 2010	What are the effects of a leisure programme on quality of life and stress of individuals with ASD?	Not noted	Randomized control study of 37 participants who had intervention of year long recreation programme and with ASD compared with 34 participants with ASD who did not have intervention.	Significant decrease in overall stress levels and significant increase in 4 factors of quality of life . Control group demonstrated no sig improvement in QOL or stress.	Participation in recreation activities positively influences stress and QOL and should be interventions used to promote person centered care.	I

Murphy et al., 2017	How does CBT compare to a counselling intervention for anxiety in young people with ASD? How do outcomes compare for social skills between the 2 interventions?	None noted.	Randomized control trial with CBT intervention of the MASSI versus counseling in 36 divided into 17 for CBT and 19 for counseling.	No significant differences were found between the groups.	Larger studies should be conducted as prior studies have differed in results.	I
Russell et al., 2013	What are the effects of CBT for OCD adapted for people with ASD compared with a plausible control treatment (AM= anxiety management) ?	None noted	Randomized control trial with 46 participants using the YBOCS scale,	Both treatments produced sig reduction in OCD symptoms.	Both CBT and AM can be effective interventions for anxiety and OCD in individuals with HFASC	I
Maddox et al., 2017						
Iannuzzi, Cheng, Broder-Fingert, & Bauman (2015).	What are the most common presenting problems for individuals with autism compared to non-ASD individuals who present to ED for emergency medical care?	Not noted.	Total sample of 128,958,353 ED visits pulled from Nationwide ED sample of which 109,021 were IDd as having ASD and analyzed by age categories. Discharge diagnosis was obtained.	Most frequent among all was epilepsy or seizure behaviors. Among adults highest was epilepsy, followed by psychiatric issues. GI disorders in ASD but not in general pop.	Preventative care and education is needed to prevent costly and avoidable ED visits. Assumptions of behaviors should not be made that it is psychiatric or behavioral in nature as it results in medical errors and exacerbation of presenting disorders.	III

Legend:

Appendix B

Summary of Systematic Reviews (SR) \* Content within table is often taken directly and verbatim from article in most cases

\*\*Levels of evidence determined from <http://libguides.ohsu.edu/ebptoolkit/levelsofevidence#s-lg-box-8119321>

Citation	Question	Search Strategy	Inclusion/Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/Implications	Level of Evidence
Anderson, Sosnowy, Kuo, & Shattuck, (2018).	What are the transition experiences of youth and young adults with ASD?	“Electronic databases” was all that was identified.	Published between 200 and 2015; had to focus on youth or young adults with ASD; had to have used qualitative methods to look at perspectives of ASD indiv. & support people; primary aim had to be describing supports, services, or policies related to life exper. Only peer reviewed and in US	Scoping review with thematic analysis. 17 studies qualified that included 121 ASD and 186 caregivers/parents, and 192 professional support.	Major barriers to transition included poor person environment fit (needs vs environment).;Individualized supports needed; uncertainty about parent role; gradual transition to diverse supports; lack of comprehensive integrated services; health care professionals lacked training, but also time to attend training and are not reimbursed for additional time to care for complex needs. Health care professionals recommended educational resources for families and lists of providers who are knowledgeable about ASD.	Providers should consider changes to social and physical environments to accommodate needs and lessen challenges. Person-centered planning may help providers tailor supports to needs of individuals.	III
Nunes-DaSilva, Gimenez, T., Souza, Mello-Moura, Raggio, Morimoto, ...Tedesco, (2016).	What is the prevalences of dental caries and periodontal disease in individuals with autism?	Lit search through PubMed, MedLINE, Web of Science, & Scopus using dental caries, tooth decay, Asperger syndrome, autism spectrum etc.	Had to evaluate oral health status of ASD clients,; cross-sectional or longitudinal observational studies; peer reviewed	Systematic review and Meta-analysis using random effects models, and sensitivity analysis. Information was collected by reviewer and cross-checked by 2 <sup>nd</sup> . 7 of	There is a high prevalence of dental caries and periodontal disease in individuals with ASD and associated with difficulties with dental hygiene.	Need for oral health policies focused on this population.	III

Citation	Question	Search Strategy	Inclusion/Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/Implications	Level of Evidence
				928 potential studies were included.			
Rogers, & Zeni, M. (2015).	In adolescents and young adults living with ASD, how does implementation of a healthcare transition model compared with usual care affect access to a medical home in early adulthood?	Searches in CINAHL, Medline, ERIC, PsycINFO, PubMed, and Psychology & Behavioral Sciences Collection. Key words autism, adolescent, young adult, transition, medical home, healthcare model, and intervention.	Had to be within last 10 years. Included all research articles that reported outcome results of implementation of medical home model. English language. Excluded those with other chronic conditions.	Systematic review; identified 9 articles; only 4 met criteria.	No articles addressed medical model homes to transition to adulthood. Evidence is lacking. Adolescents are less likely to achieve medical home attainment than other populations.	Nurse should work within interdisciplinary framework to educate healthcare providers on needs of adolescents living with ASD and evaluate medical home transition models for this vulnerable population.	III
Hirota, So, Kim, Leventhal, & Epstein, (2018)	What is the validity of screening tools for ASD in non-young children and adults?	Searches in MEDLINE, EMBASE, PsychINFO, Cochrane Library and CINAHL. Key words autism, ASD, Asperger syndrome, ADOS, ADI, etc.	English, children over 4, adolescents and adults, study needed to investigate validity of ASD screening tool against the ADOS or ADI-R and provide info about screening tools.	Independently extracted by 2 authors and then compared. Systematic review using QAUDAS-2. Independently assessed by 2 authors. 947 was reduced to 14 studies.	SCQ, ASQ(AQ), & SRS may assist in differentiating ASD from other disorder in children. Paucity of research limits findings in adults.	The AQ may be useful for all populations but more research needed to replicate findings.	III
Ruzich, Allison, Smith, Watson, Auyeung, Ring, & Baron-Cohen, (2015).	What is the distribution of autistic traits in adults males and females between clinical and non-clinical samples?	Searches in PubMed, Scopus, PsycINFO, & Web of Science. Terms for various autism names and AQ test.	Inclusion: peer reviewed empirical research, in English, 50 item adult AQ test used, males and females over age of 18.	Systematic review exploring distribution of single variable of AQ score in 73 studies with 6,934 non-clinical participants. 43 studies contained data on 1963 individuals with ASC.	Mean score of AQ in typical sample nonclinical is 17; the mean score for those with ASC is 35. Males and females have significantly different AQ scores with males scoring higher. There is fluctuation in reported mean AQ scores for those with ASC, but remain fairly stable in general population.	Consideration of average AQ scores with and without ASC and differences with males vs. females. Future research should avoid bias risk by caution in recruitment strategy for both groups and report strategy in published work.	II
Zimmerman, Ownsworth, O'Donovan, Roberts, & Gullo, (2018).	What are the factors associated with psychosocial	Systematic electronic searches of Ovid, Proquest, PubMed,	Sample had to be minimum of 16 yo. Needed formal	Metanalysis not used due to high variability in sample	“Factors consistently found to relate to poor psychological, social,	Further longitudinal study is needed to look at complex or bi-	VI



Citation	Question	Search Strategy	Inclusion/Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/Implications	Level of Evidence
	outcomes of adults with HFASC?	Science Direct, Scopus, and Web of Science. Search terms of autism spectrum condition or Asperger or high-functioning autism with and without hyphen and HFASC. Also outcome, psychosocial, mental health, depression, anxiety, self esteem. Limited to adults. Specific autism journals also reviewed.	diagnosis of ASC. Intellectual disability was excluded.	characteristics. Results synthesized qualitatively. Initial search yielded 843 articles which was reduced to 27 that were eligible for review.	and adaptive outcomes included greater symptom severity, lower childhood IQ, impaired nonverbal learning, cognitive shifting deficits, negative thinking styles, and perceptions of low social support.”	directional relationships among factors. Key risk factors should be addressed.	
Bekhet, Johnson, & Zauszniewski, (2012).	How does resiliency affect family members who caring for person with ASD?	Searches in Medline/ PsycINFO, Proquest, Web of Science, and CINAHL with key words: autism, caregivers, mothers, fathers.	Inclusion: English, studies with samples of children with ASD separate from other disabilities.	Systematic review 22 articles selected from 58 articles that met inclusion.	Parents who possess indicators of resilience are better able to manage adversity associated with caring form children with AD.	Nurses should be aware of importance of resiliency and consider interventions to enhance.	III
Bishop-Fitzpatrick, Minshe, & Eack, (2013).	What is the efficacy of psychosocial interventions for adults with ASD?	Searches in PsycINFO, Medline, and Web of Knowledge using: autism, Aspergers, adult, adolescent, intervention, treatment, therapy etc.	Inclusion: single case study, non-controlled trial, non- randomized control trial, or RCT design with pre-post-data; age 18 or over; with ASD.	Systematic review. 1217 reviewed with 13 meeting criteria. Meta-analysis could not be conducted due to small number of studies.	Psychosocial interventions were largely positive, but quality and quantity of studies is limited. Interventions addressed key areas with communication, social interaction, and flexibility of thinking/behavior. Computer based training was used for some, social cognition training.	Future studies should have more rigor and methodology. However, findings all supported that psychosocial interventions are helpful for adult populations. Researchers have opportunity to make significant contributions to how adults with ASD are treated.	II
Moore (2015).	Do individuals with ASD have different	Search of PubMed and PsycINFO from 1865 – 2013. Terms include:	Inclusion: English, clearly defined and valid population with	Systematic review led to total of 626 studies. 8 studies met criteria.	Found little objective evidence for reduced	While there may be differences providers should not consider	II

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
	sensitivities to pain stimuli and how do they communicate pain to those around them?	pain, noxious, nociception, autism Asperger etc.	ASD, focused on degree of pin response. Exclusion: no distinct ASD population		pain thresholds compared to controls.	this the norm. Do not assume individuals with ASD to be pain insensitive.	
Watling, & Hauer, (2015).	What is the evidence for sensory integration intervention and SBIs within the scope of occupational therapy practice to improve performance in daily life activities and occupations for children with autism spectrum disorders?	Search between 2006-2013. Search of MEDLINE, PsycINFO, CIHAHL, ERIC and OTseeker. Terms were developed in consultation with AOTA staff but not shared in article.	Inclusions: English, peer-reviewed, direct service to study participants with ASD, and between Jan 2006 and April 2013. Exclusions: presentations, conferences, dissertations and these. Included Level 1, II, and III evidence.	Systematic review. 368 studies reviewed and 23 met inclusion.	Mixed results to interventions. There is wide variability in how sensory approaches are implemented. Very limited research and small studies. Effectiveness of sensory approaches to interventions is in infancy.	Perform higher level studies with larger samples using Fidelity Measures in studies of ASI. Individualized sensory processing patterns should guide use of SI and SBIs in practice.	II
Sutherland, Trembath, & Roberts (2018).	What is the use of telehealth in ASD for the type of service delivered, the recipients of the telehealth service, and the outcomes of the telehealth services provided?	Search of Medline, PsycINFO, ERIC CINAHL, and PUBMED articles up to 2016 with search terms to describe telehealth and ASD.	Inclusions: English language, and peer reviewed.	Systematic review of 155 articles with 14 meeting inclusion representing 284 participants.	Results suggested services delivered via telehealth were equivalent to services delivered face to face, and superior to comparison groups without telehealth sessions.	Suggests a range of benefits for telehealth for assessment, training and intervention for individuals with ASD & families. Research regarding use with children is needed.	III
Wang, Parrila, & Cuu (2013).	What is the effectiveness of social skills interventions for individuals with ASC	Ovid MEDLINE, PsychINFO, ERIC, Web of Science, & Toc Premiere with keywords: autism/autistic, social or psychosocial, therapy or training or intervention or treatment. Between	DVs needed to be related to social skills & involve interactions with humans, an intervention had to be included, single case research design needed to be used, and at least ½ of participants were children diagnosed with ASC	Meta-analysis of 115 single case studies with 343 participants	Social skills interventions are effective for individuals with ASC. Multiple baselines or reversal designs had better outcomes than other single case research designs, but outcomes didn't vary related to length of	"Provide strong support for making SSIs available for children with ASC" Use of SSI with individuals with ASC may improve social behavior.	II

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
		1994 and 2012 and in English.			intervention, gender or age.		
Spain & Blainey (2015).	What is the effectiveness of social skills interventions for adults with HFASD?	Search of MEDLINE, PsycINFO and Embase from inception to 2014. Terms used included autism, aspergers, AND social skills training, social cognition, etc.	Inclusions: primary empirical studies; peer reviewed; English language; specifically investigating efficacy of group based clinician facilitated SSI; aged 18 or > and diagnosed with ASD. Employed at last 1 self- informant- or clinician rated outcomes measure of social skills	Systematic review of 1369 studies with 5 studies ultimately included.	Group social skills interventions may be effective for enhancing social knowledge and for understanding, improving social functioning, reducing loneliness, and potentially alleviating co-morbid psychiatric symptoms. Studies were small and reliability and validity were questionable in some areas.	Consider aims of group based ssi...several introductory sessions may be necessary to reduce initial anxiety. Consider age range and relevance of topics to participants age. Smaller groups with consistent facilitators may be better tolerated. Combination of techniques may work best with frequent opportunities to practice. Research needed to determine client response to groups in terms of satisfaction and acceptability of group.	II
DeVries, Beck, Stacey, Winslow, & Meines (2015).	What are the evidence based outcomes of music when used as an intervention with children on the autism spectrum? What type of music work best as intervention with ASD? With what severity of autism does music work best. What freq & duration is required	17 databases including CINAHL Plus, Education Resource Complete, Oxford Music, Health and Wellness Resource Center, Proquest Medical, SportDiscus,. Keywords included autism, children interventions, music, and recreational therapy.	Inclusions: music as a therapeutic interventions with ASD children aged 0-18; published since 2000;Exclusion studies that examined children with musical knowledge.	Systematic review of 15 studies that met inclusion.	Increase in socially acceptable behaviors, social response behaviors, verbal communication, and decrease in anxiety.	Music can be used by recreational therapist. Classical music and nature sounds can be used more often. Assess clients interests and responses. Varying level of functioning can use. Sessions of 30-60 minutes 4-5 times a week is recommended. Predictable environments work best (home or school).	II

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
	for significant outcomes? What is the most successful environment for administering music as intervention for greatest benefits?						
Weaver (2015).	What is the evidence for the effectiveness of interventions within the scope of occupational therapy practice to improve performance in ADLs, AIDLs, education, work, rest, and sleep for people with ASD?	Searches of Medline, PsycINFO, CINAHL, ERIC, and OTseeker using terms developed by consultants to the AOTA project and advisory group.	Inclusion: Peer reviewed, English, studies within scope of OT, between 2006 and 2013 and individuals with ASD. Exclusion: Conferences, presentations,	Systematic review 2649 references were found. 23 were included for final review as meeting criteria.	Use of mobile & tablet technologies for vocational skills was supported. COOP, sensory integration, and contextual interventions may increase occ performance. Daily yoga and brief exercise may improve classroom performance and behavior.	Studies needed that investigate interventions for sleep. Implications for OT: use technology to teach voc task, individualized approach with COOP, intensive clinic based OT-SI can result in increased independent ADLs.	II
Weitlauf, Sathe, McPheeters, & Warren, (2017)	What is the effectiveness and safety of interventions targeting sensory challenges in ASD?	Searches of Medline database via PubMed, Embase, and the Cochrane Library from January 2010 to September 2016 using a combination of controlled vocabulary and key terms related to ASD and sensory challenges (eg, autism, ASD, and sensory integration).	Randomized controlled trials [RCTs] and prospective or retrospective cohort studies) and studies published in English. We required that eligible RCTs have a total minimum sample size of 10	Systematic review of 24 randomized controlled trials (RCTs), were included.	Sensory integration-based approaches improved sensory and motor skills-related measures (low SOE). Environmental enrichment improved nonverbal cognitive skills (low SOE).	Needs exist for continuing improvements in methodologic rigor. Improvements are modest and short-term	I-II

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
Gelbar, Smith, & Reichow (2014).	What are the experiences of individuals with ASD attending degree granting colleges and universities?	Searched Medline, Embase and PyscINFO using aspergers or childhood developmental disorders AND undergraduate or college or university or postsecondary etc.	Inclusion: individuals with ASD who were attending college; 1 <sup>st</sup> hand description of services, supports, or experiences of one or more individuals; published in English in a peer reviewed journal.	Systematic review. Initial 3553 was pared to 15 that met criteria.	Major finding is there is scarce research on this topic and more is needed. Only 2 studies included experimental manipulations. HFASDs are assumed to be able to be successful at college, but this is contradicted in the literature. Depression, anxiety, and loneliness were apparent.	More research needs to be done on this topic. Support in college is needed. There is a need for academic and non academic supports in college.	III
Holyfield, Drager, Kremkow, & Light (2017).	“Are augmentative and alternative communication interventions effective for adolescents and adults with ASD? If effective, what intervention characteristics are specifically effective for this group and what types of changes are they effective in making?” p. 202	PyscINFO, PyscArticles, ERIC and PubMed. Numerous words. First searched 2015 and repeated in 2017	Articles sought were peer reviewed after 1995, were original intervention studies, AAC intervention was independent variable only above age 11, published in English.	Systematic review Cochrane handbook for Systematic Reviews of Interventions used as guide for search, coding and reporting. All articles coded per protocol. Shared extensive information on methods so that was replicable.	AAC intervention appears to be highly effective with all age groups included. Numbers of ASC participants who used AAC was small limiting findings. AAC can support adults with performing tasks more effectively and promote participation in daily living contexts.	ASC adults are excluded from many aspects of life and this has extended to AAC intervention. Clinicians should be providing adults with ASC and speech challenges access to AAC interventions. Clinicians should integrate professionals into interventions to promote positive communication outcomes.	II
Wong, Odom, Hume, Cox, Fetting, Kucharczyk, ...Schultz (2015).	What focused intervention practices are supported as EB by literature? What outcomes are associated with EB focused interventions? What are the emerging practices	CINAHL, MEDLINE, EM-BASE, ERIC, PyscINFO, Academic Search Complete, search terms . Multiple terms associated with autism and practice, to be inclusive as possible.	Peer-reviewed, English language between 1990 and 2011, that tested efficacy of intervention practices ages birth to 22 years and identified as ASC	Comprehensive systematic review. Protocols established for reviewing group design and studies was using Gersten et al protocols.	EBPs of prompting, reinforcement, antecedent based intervention, differential reinforcement, and video modeling have substantial support for efficacy.	Use the EBPs generated by the research and prepare practitioners to use judgment in ways that lead to effective programs for ASC learners.	I

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
	in the field? What are recommendation for the future?						
Hourston & Atchley (2017).	What types of mind-body practices, outcomes, and accessibility adaptations have been used with people with ASD?	Searches of PubMed, PsycINFO, and Scopus using terms for ASD and mind-body therapies.	Inclusion: individuals with ASD; interventions that utilized some form of mind-body therapy. Multiple design included RCTs, quasi-experimental, and feasibility studies. Exclusions were neurofeedback, kinesiology, massage, aromatherapy and acupuncture because they weren't focused attentional or mindful components. No single retrospective case reports.	Systematic review of 193 that was reduced to 16 studies for final review.	Multiple studies showed improved mental health with different mind-body therapies with people with ASD. Yoga improved classroom behaviors, Small sample sizes and lack of methodology rigor limited findings.	More studies with control group and RCTs are needed. Consideration of mind-body interventions may improve behaviors/anxiety.	II
Hayward, McVilly, & Stokes, (2018).	What is known regarding the challenges for adult females with HFA in the workplace?	Searches of Academic Search Complete, MEDLINE, PsycARTICLES, PsychEXTRA, PsychINFO, CINAHL and many more. Terms used: women, female, ASD, HFA, Asperger; work, job, vocation, employment and occupation.	Inclusion: 18 or older, with HFA, female, non-supported employment, and results based on original data.	Systematic review of 1947 reduced to 11 meeting criteria representing 731 participants.	Females with ASD have challenges with communication, social interaction, stress, and negative mental and physical health.	Workplace policy and practice may need to be considered to address challenges and gender based differences. Further research needed with larger studies that explore labor market participation of females and compare with males.	III
Howlin& Magiati (2017).	What are the outcomes for adults with ASD?	Searches of PsycINFO, Medline, and Google Scholar. Terms were not identified.	Inclusion: peer reviewed, English, between 2015-2016. Focus on broader social lifetime	Systematic review of 1525 articles with 43 meeting inclusion criteria.	Adults with ASD have limited social integration, poor job prospects and high	Systematic research is needed to delineate patterns of development in	II

Citation	Question	Search Strategy	Inclusion/Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/Implications	Level of Evidence
			outcomes in ASD, n>20, 18 or>.,.		rates of mental health problems. Death from suicide is elevated.	adulthood and factors influencing. Implications not discussed but providers awareness of these issues should be inferred.	
Hedley, Uljarevic, Cameron, Halder, Richdale, & Dissanayake (2017).	What are the outcomes of currently available support programs and predictors of successful outcomes for individuals with ASD?	Searches of Web of Science, Medline, PsychINFO, ERIC and Scopus from inception to 2015. Multiple terms that addressed population intervention and domain were used.	Inclusion: English, empirical, peer reviewed, reporting on employment related interventions, voc programs or implementation of employment related supports, studies of 18 years or older with ASD	Systematic review of 50 empirical and 10 review studies were included.	Adults with ASD face disadvantage in labor market despite high education. Lack of support and understanding. Services improve employment outcomes. And increasing earning potential. Earn less, work fewer hours. Some services are more useful for males. More likely than other disability groups to be denied services due to severity of disability.	Behavioral intervention techniques and technological aids in improving workplace skills in adults with ASD and have been shown to support wide variety of skills.	II
Westbrook, Fong, Nye, C Williams, Wendt, & Cortopassi, (2015).	What works in transition programs to help students with ASD obtain competitive employment after graduation?	30 different databases were reviewed using numerous terms associated with the population, age, treatment, domain, and design.	Inclusion: transitioning ASD individual between 14-22 yo, interventions with transitions,	Systematic review of RCT and additional designs of 85 studies.	Due to low levels of employment assoc with a program evaluation ti was difficult to determine changes in behavior or skills. No experimental control group were included. Quality of scientific studies is weak.	Research on programs to transition need to be more robust. Interdisciplinary programs are needed. Family members are important to support, but their employment preferences should not take precedent over that of the person with ASD.	II
denBrok, & Sterkenburg (2015).	What does the literature say regarding use of mobile devices, robots, and VR	Searches of PyscINFO, PubMed, & ERIC with terms associated with each of the potential	Inclusion: mild to moderate ID and or ASD, technology used as intervention, Exclusion	Systematic review of 911 of which 28 met criteria.	Skills and concepts are learned through prompting, interaction with devices, and practicing in VR	Use of technology may be effective tool to support learning for those with ASD. Technology facilitates	II

Citation	Question	Search Strategy	Inclusion/ Exclusion Criteria	Data Extraction and Analysis	Key Findings	Recommendation/ Implications	Level of Evidence
	technologies in relation to learning and independence for people with ASD and/or ID?	technologies and autism specific words.	: severe or profound ID or multiple disabilities.		environments. VIR is effective for attaining cognitive concepts.	learning in different way depending on features of technology. May be used to attain ADLs and cognitive concepts. More research needed on using technology to teach skills with an affective component.	

Legend:



Appendix C

Project Schedule

Activity	Semester and Course # Spring/Summer NURS 823								Semester and Course # Summer (no course)								Semester and Course # Fall 2018 NURS 820 Residency Courses								Semester and Course # Spring/Summer 2019					
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Literature review to include readings, organization, and syntheses	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X						
Prepare project proposal	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X						
Site Communication				X																										
Content Expert Communications				X			X																							
Creation of screening tool, resources, evaluation tools, etc.																	X	X	X	X	X	X	X	X						
IBR application																						X	X							
CEU/CME applications																						X	X							
Communication with site						X									X						X			X	X	X	X	X	X	
Implementation of Intervention																									X	X	X	X		
Analysis & Dissemination																								X	X	X	X	X	X	

## Appendix D

**Pre-Intervention Survey****Demographics**

1. Please identify your role as a provider of care. Circle one.

- Nurse
- Nurse Practitioner
- Physician
- Physician Assistant
- Health Care Technician
- Other \_\_\_\_\_

2. Do you know someone with an autism spectrum disorder/condition? Circle one. YES NO

3. Have you had previous continuing education on autism spectrum disorder? Circle one. YES NO

4. How many years have you been in your current role as a provider of care? # of years \_\_\_\_\_

**Survey Questions**

1. Share your understanding/definition of autism spectrum disorder.

2. Share your understanding/definition of how high-functioning autism spectrum disorder differs.

3. What is your *confidence* level with your *current level of knowledge* regarding autism spectrum condition?

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

4. What is your confidence level in *recognizing* autism spectrum condition in an adult patient?

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

5. What is your confidence level in recognizing *high-functioning* autism spectrum condition in an adult patient.

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

6. What is your *perceived* level of knowledge regarding autism spectrum disorder in adults?

1	2	3	4	5
Not at all Knowledgeable	Little Knowledge	Neutral	Knowledgeable	Very Knowledgeable

7. What is your *perceived* level of knowledge regarding *high-functioning* autism spectrum condition in adults?

1	2	3	4	5
Not at all Knowledgeable	Little Knowledge	Neutral	Knowledgeable	Very Knowledgeable

8. Do you routinely screen patients for ASD? Circle one.                    YES            NO  
 Do you screen only if key indicators are observed? Circle one.    YES            NO  
 If yes to either of these, please share the tool or approach you use to screen patients. *If no to both, skip to question 9.*

Tool/Approach \_\_\_\_\_

9. If a screening is positive, do you refer the patient for further assessment? Circle one.    YES            NO

If yes, are you satisfied with options available to you for referrals? Circle one.            YES            NO

10. Please share an estimate of how many referrals you have made in the last 3 months for diagnostic assessment for autism spectrum disorder (may include both pediatric or adult individuals).

Estimated # of Referrals \_\_\_\_\_

## Post-Intervention Survey



### Demographics

1. Please identify your role as a provider of care. Circle one.

Nurse

Nurse Practitioner

Physician

Physician Assistant

Health Care Technician

Other \_\_\_\_\_

2. Do you know someone with an autism spectrum disorder/condition? Circle one.

YES

NO

3. Have you had previous continuing education on autism spectrum disorder? Circle one.

YES

NO

### Survey Questions

1. Share your understanding/definition of autism spectrum disorder.
2. Share your understanding/definition of how *high-functioning* autism spectrum disorder differs.

3. What is your *confidence* level with your *current level of knowledge* regarding autism spectrum condition?

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

4. What is your confidence level in *recognizing* autism spectrum condition in an adult patient?

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

5. What is your confidence level in recognizing *high-functioning* autism spectrum condition in an adult patient.

1	2	3	4	5
Not at all Confident	Little Confidence	Neutral	Confident	Very Confident

6. What is your *perceived* level of knowledge regarding autism spectrum disorder in adults?

1	2	3	4	5
Not at all Knowledgeable	Little Knowledge	Neutral	Knowledgeable	Very Knowledgeable

7. What is your *perceived* level of knowledge regarding *high-functioning* autism spectrum condition in adults?

1	2	3	4	5
Not at all Knowledgeable	Little Knowledge	Neutral	Knowledgeable	Very Knowledgeable

8. Have you changed your practice for screening patients for ASD? Circle one.      YES      NO  
 Do you routinely screen only if key indicators are observed? Circle one.      YES      NO  
 If yes to either of these, please share the tool or approach you use to screen patients. *If no to both, skip to question 9.*

Tool/Approach \_\_\_\_\_

9. If a screening is positive, do you refer the patient for further assessment? Circle one.      YES      NO

If yes, are you satisfied with the options available to you for referrals? Circle one.      YES      NO

10. Please share an estimate of how many referrals you have made in the last 3 months for diagnostic assessment for autism spectrum disorder (may include both pediatric or adult individuals).

Estimated # of Referrals \_\_\_\_\_

Appendix E

