AUTISM SPECTRUM DISORDER (ASD) IN NORTH DAKOTA: DATABASE TO SCREENING: BRIDGING THE GAP BETWEEN WHAT WE KNOW AND WHERE TO GO

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

DOCTOR OF NURSING PRACTICE

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ABSTRACT

Autism spectrum disorder (ASD) is a developmental disability that can cause persistent deficits in social communication, behavior, and development. The effect of ASD differs from individual to individual, thus it is considered a spectrum disorder. Early screening and intervention are essential for improving outcomes. However, primary care providers' screening rates remain low even though the diagnosis of ASD is possible in children who are 2 years old or younger. On average, children are 4 years or older at the time of diagnosis.

The purpose of this project was to provide primary care providers with the tools needed to screen for ASD at well-child visits and to provide a list of resources for local ASD services. The second purpose was to form an alliance with the North Dakota Department of Health for the purpose of producing and distributing the toolkit to healthcare providers statewide. The ASD toolkit includes an ASD screening algorithm, M-CHAT-R, and a local resource guide.

At the Autism Spectrum Disorder Task Force's business meeting on August 20, 2018, seventeen members listened to a presentation about the project. Following the presentation, members provider verbal input and feedback about the project; however, members did not return the survey about the toolkit. That task force verbally offered support to move forward with the toolkit project.

A second survey requested feedback from primary care providers about the effectiveness and utility of the ASD toolkit. The small return rate, N=10, was disappointing and not sufficient for generalized results. However, provider respondents showed an interest in ASD education, and that the toolkit would be useful in practice.

Future research should include a larger population working in primary care in urban and rural settings. Data obtained after the providers had the opportunity to use the toolkit in practice

would allow for analysis of the toolkit's usefulness. Instead of only surveying providers prior to toolkit use, in the future, provider surveys conducted after 3, 6, and 12 months of toolkit use in practice are recommended.

ACKNOWLEDGEMENTS

I would like to thank Dr. Tina Lundeen, my advisor and committee chair as well as members of my committee Dr. Allison Peltier, Abigail Vetter, and Dr. Tom Stone Carlson.

Though the rain comes in torrents and the floodwaters rise and the winds beat against that house, it will not collapse because it is built on bedrock. Alexis you are my foundation built on bedrock. Without your love, compassion, and support my house would not be as strong to stand against the many floodwaters.

To my beautiful daughter, CoraLena Jaye Stavig. You are the light in my life. Your unconditional love gave me the strength to achieve my dream. I will always love you.

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CHAPTER 1. INTRODUCTION

Once considered a rare disorder, autism spectrum disorders (ASDs), affect 1 in 59 children (Robins et al., 2016). Because the prevalence of ASD has increased, healthcare providers have focused on identifying children with symptoms of ASD as early as possible (Pierce, Courchesne, & Bacon, 2016). The American Academy of Pediatrics (AAP) (2015) recommends that primary care providers administer standardized screening for developmental problems at the 9-, 18-, and either the 24- or 30-month well-child visits, and autism-specific screening at 18 months. Subsequently, the AAP's Autism Expert Panel recommended screening for autism at both the 18- and 24-month visits to capture children without recognizable symptoms until 18 months of age (Centers for Disease Control and Prevention [CDC], 2016). At 15- 18 months about 25% to 30% of children with ASD have a first presentation in which they experience gradual or sudden regression of social and communication skills, with other studies have shown evidence of up to 50% of children with ASD experiencing regression (Christensen et al., 2016).

Background and Significance

A substantial increase for the estimated prevalence of young people diagnosed with ASD in the United States has been reported since the early 1990s (Christensen et al., 2016). ASD is a developmental disability associated with impairments in social behaviors and communication, and repetitive or restrictive behaviors (Huerta & Lord, 2013). There are no biological or laboratory tests for diagnosing ASD. Diagnosing ASD can be difficult because behaviors seen in a child are often dependent on several non-autism-specific factors, including cognitive functioning and age (Huerta & Lord, 2013). The ASD diagnosis is further complicated because

of the interactions which occur between normal development and ASD symptoms (Christensen et al., 2016).

Common behavioral symptoms on the spectrum include lack of eye contact; a lack of response to hearing one's name; a lack of communicative gestures; repetition of others' speech; repetitive motion with hands, arms, or other body parts; strong adherence to routines; and restricted interest in objects or topics (Crais et al., 2014). Individuals with ASD often have special health needs because of a variety of associated illnesses, including an increased risk of seizures, gastrointestinal problems, sleep disturbances, and various behavioral or psychiatric conditions (Minnesota Department of Health, 2014).

Children diagnosed with ASD can pose significant challenges to families, medical professionals, and educational services as well as affecting educational, social, and medical systems (Minnesota Department of Health, 2014). Core family members face emotional distress and financial struggles when raising a child diagnosed with ASD (Maenner et al., 2013). Families can experience substantial economic changes, which result from the cost associated with multiple therapies and reduced work hours due to the time demands of a child with ASD (Huerta & Lord, 2013).

Autism Spectrum Disorder (ASD) Database

In 2013, the North Dakota Legislature passed North Dakota Century Code chapter 23-01-41, requiring the North Dakota Department of Health (NDDoH) to develop and maintain a database of individuals diagnosed with ASD for the purpose of completing epidemiologic research, and the provision of ASD services (NDDoH, 2016). Physicians, psychologists, and any healthcare professional who are qualified by training, licensure, and certification to diagnose ASD are mandated reporters. The reporter or the reporter's designee must report, to the

NDDoH, any person who is a resident of North Dakota, or whose parent/guardian is a resident of North Dakota and has a diagnosis of ASD based on Diagnostic and Statistical Manual of Mental Disorders V (DSM-5) criteria (NDDoH, 2016). The information collected in the database will help shape policy and practices to improve services and support for individuals with ASD (NDDoH, 2016). The goal of the database is to inform public policy decisions, improve community awareness, aid in the identification of risks and support for people with ASD.

Screening

The American Academy of Pediatrics (2014) and the American Psychological Association (APA) (2015) recommend an approach to the identification of ASD that involves stepwise and, at times, recursive surveillance. The AAP (2014) and APA (2015) also recommend screening all children for developmental delays and disabilities during the well-child visit at: 9-, 18-, 24-, or 30- months. Providers may screen more often if a child is at an elevated risk for developmental problems because of preterm birth or low birth weight (CDC, 2017). Barton, Dumont-Mathieu, & Fein (2012) found that ASD could be reliably diagnosed at 18 months or younger. However, numerous children do not receive a final diagnosis until they are much older, which places many children at a disadvantage (AAP, 2014). Screening is warranted when (a) the cost of not detecting the disease is high, for example in terms of prevalence, severity of disease, cost of treatment, (b) diagnostic criteria are identified, (c) treatment is available, (d) early treatment is more effective than later treatment, and (e) an appropriate screening instrument is available (Robins et al., 2016).

Statement of the Problem

In North Dakota, 45% of children are at 5-8 years of age at the time of first ASD diagnosis (North Dakota Department of Health ASD Database, NDDoH, 2017). Ideally, healthcare providers would recognize the symptoms and refer for diagnosis of ASD as early as 18 months of age (NDDoH, 2016). The gap in the age of optimal and actual diagnosis in North Dakota coincides with diagnostic ages seen across the country. What have other states done to combat the diagnosis age gap? Other states, including North Dakota, have created an autism spectrum task force, or a similar committee, to address and to reduce delayed diagnosis. The primary goal of an ASD task force is the promotion and oversight of an evidenced-based, streamlined, and age-proper screening approach (NDDoH, 2016).

Fewer than 25% of healthcare providers are regularly incorporating screening with standardized instruments into well-child visits and fewer than 10% of healthcare providers are using ASD-specific screening instruments (Robins et al., 2016). Healthcare providers blame time as one of the primary reasons for skipping formal development screening at well-child visits (Will et al., 2013). How can healthcare providers increase screening and decrease the age gap in diagnosis? Using a screening toolkit specifically created for healthcare providers seeing children has been identified as a way to combat the low screening rates (Robins et al., 2016).

Project Description

Project Purpose

The purpose of this project was two-fold. The first purpose was to improve the screening process of ASD in primary care with the creation and implementation of an ASD toolkit. To improve screening practices, a health care provider input is crucial in the creation of an ASD

toolkit (AAP, 2015). The second purpose was to collaborate with the NDDoH and implement the toolkit statewide.

Project Objectives

Project objectives guide project design, implementation, and evaluation. The project objectives:

1. The creation of an ASD toolkit with evidence-based screening recommendations,
2. The identification of current screening gaps and additional training needed by healthcare providers in North Dakota, and
3. Collaboration with North Dakota's Autism Spectrum Disorder Task Force and ASD leaders to improve ASD screening in primary care.

CHAPTER 2. LITERATURE REVIEW

The Literature Review focuses on barriers to ASD screening, ASD prevalence, screening in primary care, evidence-based ASD screening tools. Additionally, the review of the literature centers on the development and sustainability of a state ASD task force, the development and use of an ASD toolkit, and methods to improve ASD screening. Chapter 2 concludes with a discussion about the project's conceptual and theoretical framework, the project's implementation, and project's evaluation.

What is ASD?

Once considered a rare disorder, autism spectrum disorders (ASDs), affect as many as 1 in 59 children according to estimates from Centers for Disease Control and Prevention's (CDC), Autism and Developmental Disabilities Monitoring (ADDM) Network (2018). Autism spectrum disorder is a developmental disability that can cause significant social, communication and behavioral challenges (CDC, 2016). ASD is a spectrum disorder and, therefore, affects everyone differently. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people (CDC, 2016). The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged.

Causes of Autism Spectrum Disorder

About 10% of ASD cases occur secondary to other primary health conditions, including fragile X syndrome, untreated phenylketonuria, tuberous sclerosis, and fetal alcohol syndrome (CDC, 2017). The exact cause for the majority of ASD is currently unknown and is thought to be multifactorial with ongoing research about the ASD causes (CDC, 2016). Various environmental, biologic, and genetic elements have been associated with ASD. Congenital

rubella and prenatal exposure to such prescription drugs, such as valproic acid and thalidomide have been associated with ASD (CDC, 2016). In the past, there have been poorly designed and falsified research about vaccination contributing to development of ASD. The pathophysiology and theories about ASD are beyond the scope of this dissertation.

Prevalence

Population prevalence measures the burden of ASD in a defined population (Minnesota Department of Health, 2014). Understanding the ASD prevalence is essential for planning and evaluating public-health programs, developing, and updating policies, or making decisions about resource allocation (Snyder, & Iverson, 2006). Estimating the ASD population prevalence is not as straightforward as many would like. The difficulty in tracking the prevalence lies in the wide variety of symptoms, access to healthcare, and healthcare follow-up (Siller, Morgan, Swanson, & Hotez, 2013).

To track the prevalence, state governments have created databases and task forces. Healthcare providers use the databases to report ASD cases. When reporting an ASD case, no personal information on the individual is included. The purpose of the ASD database in North Dakota is to track the prevalence of ASD, to complete epidemiological surveys, and to provide services to individuals diagnosed with ASD (NDDoH, 2016). The database is the responsibility of the North Dakota Department of Health, specifically the Autism Spectrum Disorder Task Force.

Autism Spectrum Disorder prevalence has steadily risen; however, the reason for the increase in prevalence is unclear (Autism Speaks, 2018). Has the number of individuals with an ASD diagnosis increased or is the reason better ASD reporting and a heightened ASD awareness (U.S. Preventative Services Task Force, 2016)? For example, researchers that accessed school

and health records reported a higher prevalence than researchers that retrieved health records only (American Speech-Language-Hearing Association, 2019). A majority of researchers believe that the increased prevalence of ASD may reflect changes in practices for diagnosing autism (U.S. Preventative Services Task Force, 2016).

Established data show that ASD prevalence varies by gender and race/ethnicity. A CDC study found that prevalence was 18.4 per 1,000 (1 in 54) among males and 4.0 per 1,000 (1 in 252) in females (2018). The Prevalence among non-Hispanic white children (12.0 per 1,000) was significantly greater than among non-Hispanic black children (10.2 per 1,000) and Hispanic children (7.9 per 1,000) (American Speech-Language-Hearing Association, 2019). Given that there are no clearly documented differences between these groups in terms of risk factors for ASD, disparities in prevalence estimates suggest under-identification among Hispanic and non-Hispanic black children (American Speech-Language-Hearing Association, 2019).

The National prevalence was compared to the state prevalence for similarities in gender, race/ethnicity, and average age of diagnosis. The ratio of male to female prevalence in ND mirrored the national data. The ethnic prevalence in ND differed from the national statistics, due to lack of diversity in ND. Males are 73% of individuals diagnosed with ASD, while females comprise 23% in North Dakota.

Financial and Family Responsibility

According to a CDC (2016) study, the average annual medical costs for Medicaid-enrolled children with ASD were $10,709 per child, which was about six times higher than costs for children without ASD ($1,812) (CDC, 2012). Intensive behavioral interventions for children with ASD can cost $40,000 to $50,000 per child per year (CDC, 2008). Early identification and intervention reduce the lifetime costs associated with ASD by as much as two-thirds, equating to

$1 to 2 million per person over the individual's lifespan (Minnesota Department of Health, 2014).

Core family members face the greatest responsibility when raising a child with ASD (Siller et al., 2013). The responsibility comes both in the form of emotional distress and financial struggles with the greatest emotional effects on siblings, mothers, and fathers (Buescher, Cidav, Knapp, & Mandell, 2014). Mothers primarily struggle with negative emotions, leading to an increased rate of depression (Autism Speaks, n.d.). In addition, mothers are less likely to take part in social activities due to the increased time requirement of a child with ASD, which only increases the emotional burden (Buescher et al., 2014). The responsibilities can take a heavy toll on the parent's relationship. Parents of a child diagnosed with ASD have more conflict, lower marital happiness, higher stress, less adaptability, and a higher-than-average divorce rate (Buescher et al., 2014).

The financial strain of ASD within a family is similarly substantial. The results from the prohibitive costs associated with multiple therapies or interventions, including intensive behavioral intervention, comprehensive educational interventions, speech language therapy, social skills instruction, and occupational therapy and life skills support (Minnesota Department of Health, 2014). On average, household earnings were 28% or $17,763 dollars less than families with children having no health limitations (Buescher et al., 2014).

Awareness of Autism Spectrum Disorder

ASD-awareness efforts are acts by individuals and/or organizations to promote and to educate the public about ASD and its many complexities (Autism Speaks, n.d.). ASD-awareness efforts are on the rise; however, far from complete (Siller et al. 2013). An example is research data from the CDC (2004) showing that 63% of parents reported not knowing what behaviors

most-suggested ASD, and that 57% of the parents did not know best time to get help for children with ASD (Siller et al., 2013). Not only is there a lack of information for parents, but also according to Crais et al. (2014), healthcare professionals also need more information on developmental milestones and developmental disabilities; providers felt they lacked the necessary resources to educate parents.

Strategy to Enhance Awareness

The USA's Combating Autism Act of 2006 provides culturally competent information regarding these disabilities and evidence-based interventions for individuals through state and federal programs as well as community organizations (CDC, 2016). Apart from the Centers of Excellence, founded by the Centers for Disease Control and Prevention (CDC), the act mandated the establishment of a continuing education curriculum and an Interagency Autism Coordinating Committee (CDC, 2016). In the age of technology, using social media and the internet to spread positive and truthful information regarding ASD is being done to enhance and to improve public awareness (DeVilbiss and Lee, 2014). Overall, creating a supportive environment for individuals to change behavior has proven to increase awareness (Siller et al., 2013).

The creation of ASD-specific materials, such as TV commercials, social media, and community events, for public awareness has proven to be effective (CDC, 2016). DeVilbiss and Lee (2014) gave an example of a campaign which used familiar images, such as a growth chart, except modified, to encourage and support the tracking of emotional, cognitive, and social development. The education created for healthcare providers included fact sheets with milestones and red-flag warning signs by age as well as informational cards to encourage healthcare provider-parent dialogue (Siller et al., 2013).

Screening Options for Autism Spectrum Disorder

Healthcare agencies including the CDC and AAP, agree that universally screening of all children for ASD should be part of healthcare visits (Carbone, Farley, & Davis, 2010). The agreement is present; however, according to a recent survey of healthcare providers; fewer than 25% of them regularly incorporating screening with standardized instruments into well-child visits, and a second study found that fewer than 10% of pediatricians are using ASD-specific screening instruments (Crais et al., 2014). According to the most current statement by the American Academy of Pediatrics, which was released in 2016, primary care providers and pediatricians should incorporate standardized developmental screenings into three well-child visits (9, 18, and 24–30 months), with added ASD-specific screening at 18 and 24 months (Dreyer, 2016).

Developmental screening tools offer providers a standardized method to screen children for developmental delays. Screening tools can be specific to a disorder (for example, autism) or an area (for example, cognitive development, language, or gross motor skills), or they may be general, encompassing multiple areas of concern (CDC, 2017). Screening tools do not provide conclusive evidence of developmental delays and do not result in diagnoses (Huerta and Lord, 2013).

Screening tests should be both reliable and valid, with good sensitivity and specificity (Maxim, Niebo, Utell, 2014). Reliability is the ability of a measure to produce consistent results (Maxim et al., 2014). The validity of a developmental screening test is how well the tool measures what the screening tool is meant to measure (Carbone et al., 2010). Sensitivity is the accuracy of the test measuring the proportion of actual positives that are correctly identified as such (e.g., the percentage of sick people who have the condition) (Maxim et al., 2014). The

CDC and the AAP recommend screening children with the Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R) based on the M-CHAT-R being reliable and valid, and having good sensitivity and specificity (AAP, 2017). If a child screens positive on the 20 questions form the M-CHAT-R, there are follow-up questions based on the specific items for which the child failed (Autism Speaks, n.d.). The revised version (M-CHAT-R/F) has a reduced false-positive rate (which means fewer children are given a high-risk result when they truly do not have autism) (Robins et al., 2009).

Barriers to Screening

Well-child visits are key opportunities to screen for developmental, physical, and emotional delays, including ASD (CDC, 2012). Despite recommendations, healthcare professionals are not practicing by the recommended guidelines (Robins et al., 2016). Identifying barriers is the first step when determining the best process for routine standardized screening for ASD (Barton et al., 2012).

Parental compliance with the preventive pediatric healthcare schedule has been an identified barrier for screening (Glascoe, 2014). According to AAP research, on average, parents attend about three of four AAP recommended well-child visits (Glascoe, 2014). In addition, findings reveal large variation in well child visit attendance based on the families' socioeconomic status, access to resources, and geography (Siller et al, 2013).

Another known barrier to screening is the lack of a plan for practice-wide system change (Siller et al, 2013). Successful implementation requires more than educational opportunities for individual staff members; instead, change that supports organizational restructuring will result in the greatest success (Minnesota Department of Health, 2014). That is, practices need to develop,

evaluate, and refine system-wide implementation plans that divide responsibilities among staff members at multiple levels in the organization (Siller et al, 2013).

A final barrier to the use/implementation of ASD screening is the competing priorities, time, and reimbursement constraints of the well-child visits. During the last decade, multiple institutions have put forth recommendations on screenings for well child visits (AAP, 2017). With the overwhelming amount of screening and competing priorities such as time, parent questions, and an exam, health care providers find it difficult to screen children in the time allotted difficult (Crais et al, 2014).

ASD Toolkit

The primary healthcare provider plays a critical, although often underappreciated, role with the screening of and coordination of children and youth diagnosed with ASD. In fact, primary care 50%–60 % of individuals diagnosed with ASD through screening before the parents or healthcare providers had concerns (Christensen et al., 2016). With multiple competing priorities and a profound delay of diagnosis occurring by the age of 3, how can the health care provider overcome the barriers of screening and prevent delays of early intervention (Huerta, & Lord, 2013)? One way to simplify the work process was to incorporate an ASD toolkit in the primary care setting (Hyman, & Johnson, 2013).

The ASD toolkit contained evidence-based resources for health care providers. The ASD toolkit was user-friendly, quick to follow, and up-to-date (AAP, 2016). The ASD toolkit promoted early identification and early interventions that fostered the best outcomes (AAP, 2015). The purpose of the ASD toolkit was to give providers the tools needed for the identification, referral, and ongoing management of medical needs for children with ASD (AAP, 2015). The ASD toolkit had general information about ASD as well as general developmental

screening for a quick reference for the health care provider (AAP, 2015). The ASD toolkit also contained ASD algorithm, a local resource guide for health care referrals, information for families, and an example of the M-CHAT-R and follow-up questionnaire.

The Minnesota ASD Task Force has outlined multiple strategies to incorporate ASD screening. Figure 1 illustrates several strategies and interventions for the primary care provider to implement ASD-specific screening. State ASD task forces, including the North Dakota task force, use the Minnesota ASD Task Force's strategies for the implementation and advancement of ASD awareness and legislation (NDDoH, 2016).

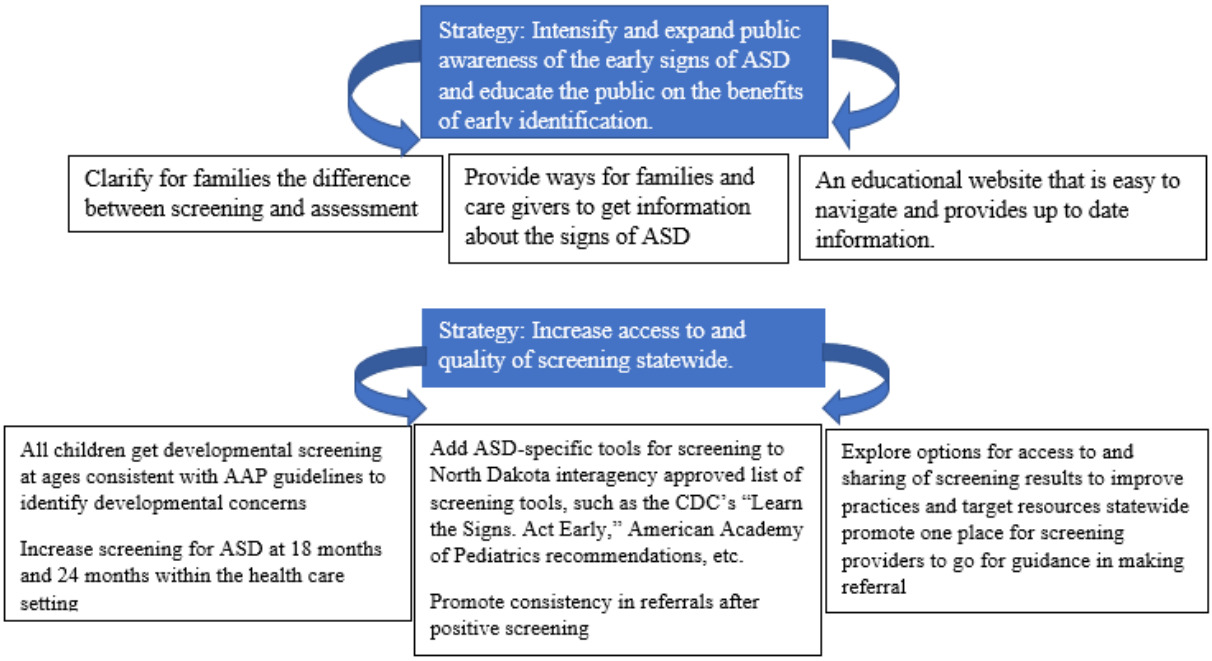

Figure 1. Strategies to achieve goals of autism spectrum disorder screening

ASD Task Force

The ASD task force's mission was to create a statewide strategic plan for ASD (NDDoH, 2016). The strategic plan encompasses ASD awareness, early diagnosis, early intervention, and treatment for individuals with an ASD diagnosis (US Preventative Services Task Force, 2016).

The task force worked in collaboration with multiple agencies and groups that provide ASD services in North Dakota (NDDoH, 2016).

The North Dakota ASD task force collaborated with the North Dakota Department of Health to create a state plan for ASD funding, and ASD screening within the state. The role of the task force was to review and periodically update or amend the plan to meet the needs of individuals with autism spectrum disorder in North Dakota (NDDoH, 2016). The task force prepares an annual report for the governor and the legislative council about the ASD State Plan. The goals of the Autism Spectrum Disorder Task Force are as follows (NDDoH, 2016):

> Early, prompt, and continuous accessible screening and assessment; competent practitioners and supportive communities, coordination of services and access to services throughout the state of North Dakota; and the use of data from the continued use of the ND ASD Database for informed policy making as well as the ongoing emphasis of a strategic plan.

ASD screening is fraught with barriers; a lack of provider time, inconsistent use of screening tools, delayed screening, and a lack of organizational commitment to screening (Hyman & Johnson, 2013). Other documented barriers include a lack of provider confidence identifying ASD red flags, unfamiliar of screening tests, and a lack of insurance reimbursement (Will, Barnfather & Lesley, 2013). Sometimes, the barriers are overwhelming, and research continues to show that providers are missing the mark and that ASD children are going undiagnosed and untreated (CDC, 2018).

Another intervention to combat the barriers was the creation of an ASD task force (Minnesota Department of Health, 2014). The task force's job was multifaceted and focused on obtaining research on the prevalence, cost, barriers, scope of the problem in the United States

(U.S. Preventative Services Task Force, 2016). North Dakota created a task force to meet the needs of the population. The ASD task force created key goals of early intervention, provider education, prevalence, and continued presence in ND legislation (NDDoH, 2016).

Theoretical and Conceptual Framework

The Breakthrough Series Collaborative Model (BSCM) developed by the Institute of Healthcare Improvement (IHI), improved pediatric practices' delivery of preventive services, as well as newborn hearing screen follow-up and referrals to mental-health services (Institute of Healthcare Improvement, 2003). The BSCM is the result of evidence-based research. The analysis and synthesis of costs and outcomes of earlier ASD healthcare practices provided the groundwork for the BSCM, however much of the science lies fallow and unused in daily work (Institute of Healthcare Improvement, 2003).

The BSCM's purpose was to help organizations by creating a structure in which interested organizations can easily learn from each other and from recognized experts in topic areas where they want to make improvements (Institute of Healthcare Improvement, 2003). The area of need lies in the implementation process. Using a toolkit can increase the probability of screening by establishing a user-friendly process for healthcare providers (AAP, 2015).

In the BSCM model, several healthcare-provider teams collaborate with external experts to overcome specific barriers that impede the delivery of high-quality care within their organization (Institute of Healthcare Improvement, 2003). The breakthrough series starts with the choice of a specific topic considered ready for improvement. Siller et al. (2013) suggest a leaning collaborative to increase the early identification of ASD. The collaborative would be successful and beneficial because of the high prevalence rates of ASD; additionally, the existing knowledge in ASD screening area is sound but not widely used. The framework guides the

development of the ASD toolkit. Figure 2 presents the key elements of a Breakthrough Series model.

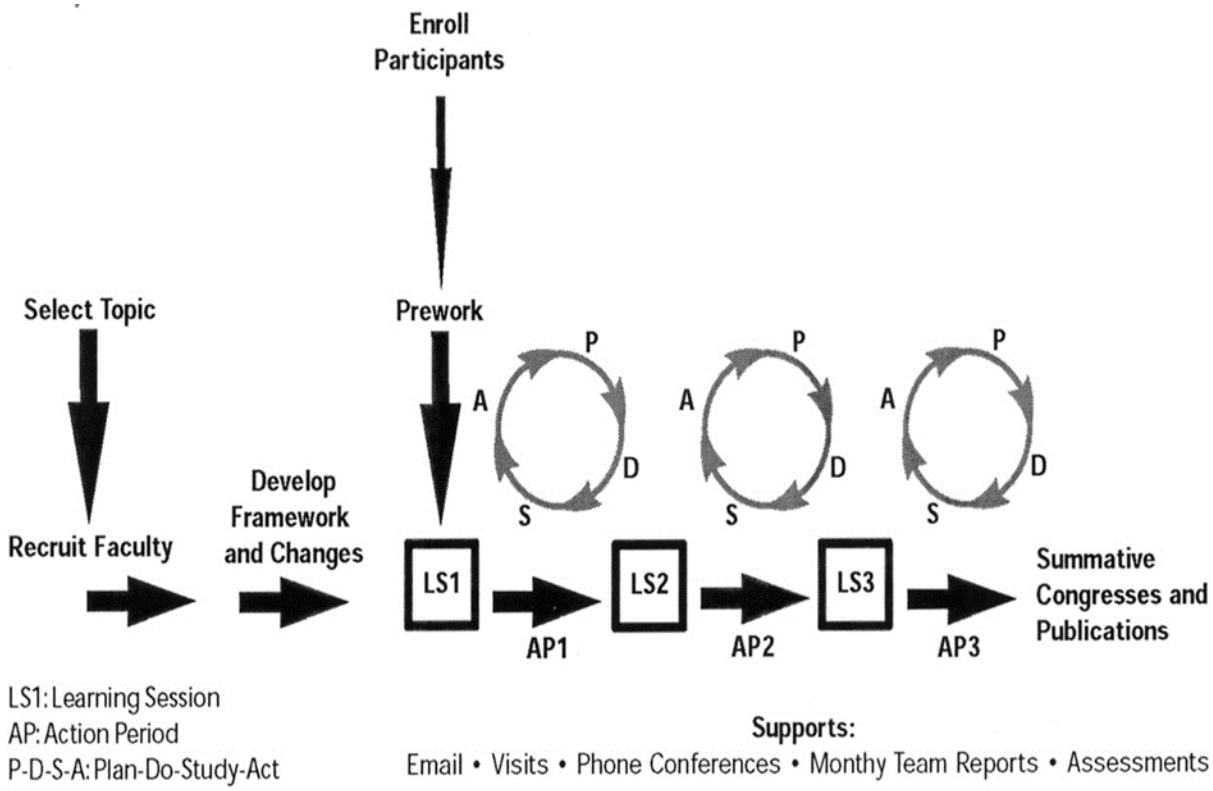

Figure 2. The Breakthrough Series IHI's Collaborative Model for Achieving Breakthrough Improvement.

Key Elements of the Breakthrough Series Collaborative Model

Topic Selection

The group is to identify an area or issue in healthcare that is deemed ready for improvement: existing knowledge is sound but not widely used; better results have been demonstrated in real-world settings; and current defect rates affect many patients somewhat, or at least a few patients profoundly (Institute of Healthcare Improvement, 2003).

Faculty Recruitment

The task force members identified 17 experts in the relevant disciplines. One expert functioned as the task force's chairperson. The members consisted of medical, mental-health,

and developmental-disability professionals; representatives from North Dakota state agencies; educators, a legislator; and family members of persons with an ASD. Committee members were from the state of North Dakota. The chairperson's responsibilities included establishing the vision for a new system of care, leadership, and teaching and coaching the participating teams (Institute of Healthcare Improvement, 2003).

Action Periods

During action periods, teams' pilot and implement changes in their local settings, and people collect data to measure the change's effect. The ND ASD task force members prepare a monthly progress report for the task force to review at monthly meetings. The monthly meetings are supported by conference calls, peer site visits, and web-based discussions. Members exchange information from there subcommittees. During an action period, the goal is to force team collaboration and to support the devilment and implementation of innovative ideas, with team members who are at a distance (Institute of Healthcare Improvement, 2003).

Plan, Do, Study, Act: PDSA

The ASD task force was already set up and was involved with many areas of legislation. The task force continued to adapt to new evidence regarding ASD. The adaptation and introduction of new evidence and new legislation placed the task force in the Plan, Do, Study, Act (PDSA) cycle (Figure 3). The implementation of the ASD toolkit took place during the PDSA cycle.

- PLAN: Plan the test or observation, including a method for collecting data. The first stage of the PDSA cycle involves identifying an opportunity for improvement. Once the need for an ASD screening is recognized, the planning

for the improvement project can begin (Agency for Healthcare Research and Quality, 2015).

- DO: Try the test on a small scale. The purpose of the Do stage is to carry out the ASD toolkit (Agency for Healthcare Research and Quality, 2015).
- STUDY: Enough time should be set aside to analyze the data and to study the results from the ASD toolkit survey (Agency for Healthcare Research and Quality, 2015).
- ACT: Implementation on larger scale takes place when the results have met the goals. If the results fall below the expected level, the cycle is modified and the step repeated until the desired goal is reached (Agency for Healthcare Research and Quality, 2015).

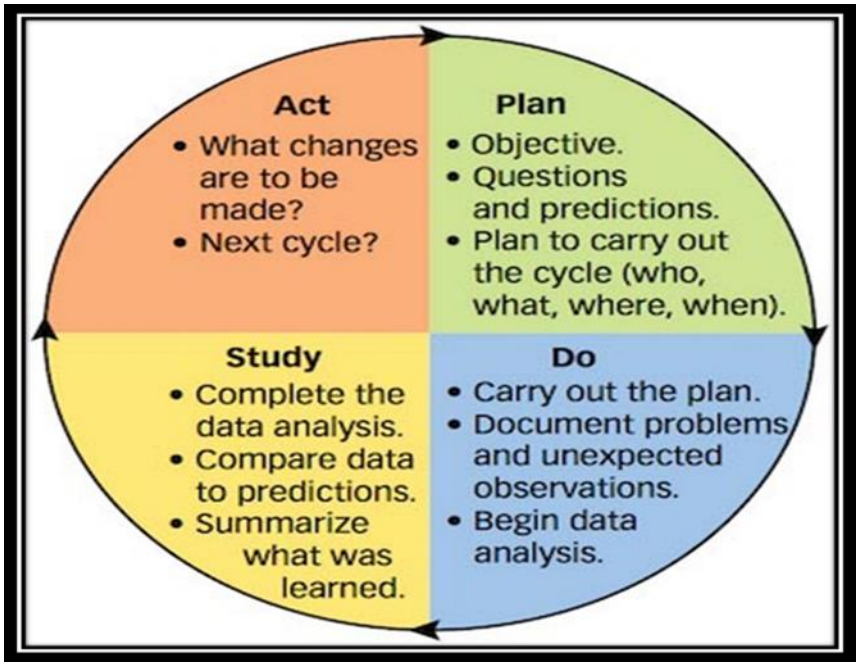

Figure 3. Plan-Do-Study-Act (PDSA) is an iterative, four-stage problem-solving model used for improving a process or carrying out change.

CHAPTER 3. PROJECT DESIGN AND IMPLEMENTATION

The toolkit was meant to be used as a guide for healthcare providers regarding the specific times to screen; the use of a screening tool; when to refer the child to a specialist for further evaluation; and, most importantly, giving accurate and helpful information to the child and the child's parent(s). The project purpose was to create a user-friendly and accessible way to screen and to refer children for a comprehensive ASD evaluation. The project objectives were: (a) the creation of an ASD toolkit with evidence-based screening recommendations, (b) the identification of current screening gaps and additional training needed by healthcare providers in North Dakota, and (c) collaboration with the North Dakota ASD task force and ASD leaders in order to improve ASD screening in primary care.

Project Design

There is often nothing about how people with ASD look that sets them apart from other people; however, these individuals may communicate, interact, behave, and learn are different from most other people (CDC, 2018). The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged (Autism Speaks, n.d.). Individuals with ASD vary greatly regarding the amount of assistance necessary for daily activities; some people need little help while others need full-time support (CDC, 2018).

Around 70%-87% of individuals with ASD exhibit symptoms before the age of 3 (CDC, 2018). ASD is a chronic, lifelong disease. Symptoms may fluctuate; for some people, symptoms worsen, yet others experience an improvement with symptoms (CDC, 2018). Children with ASD show hints of future problems within the first few months of life, and for others, symptoms may not show up until 24 months of later (AAP, 2007). Some individuals with an ASD seem to develop normally until around 18 to 24 months of age; then they stop gaining

new skills, or they lose the skills they once had CDC, 2018). Studies show that one third to one half of parents who have children with an ASD noticed signs or symptoms of the disease before their child's first birthday, and 80%–90% identified symptoms by 24 months of age (Autism Speaks, n.d.).

Healthcare professionals have limited time with patients and distinguishing between mental-health disorders can be difficult and time consuming (AAP, 2007). There is a need to increase provider awareness about ASD's presenting symptoms, as well as implementing more-consistent screening for the disorder (CDC, 2018). The healthcare professional should always be aware that children might present with signs and symptoms of ASD without having an ASD. Children without complaints should still be screened (CDC, 2016).

The project design followed the Breakthrough Series Collaborative Model (BSCM) contains the PDSA cycle. The PDSA cycle was the primary driving force for the project's design. The PDSA cycle begins with "Plan" (Figure 4), the project's launching point. The dissertation involved the NDDoH ASD task force and healthcare providers who were practicing in North Dakota. See Appendix J for the ASD toolkit presentation PowerPoint presentation which was given to members of the NDDoH ASD task force.

1. Review the literature.
2 Recognize the need for an ASD toolkit.
3. Assess the need for an ASD toolkit.
4. Create an evidence-based ASD toolkit.
5. Present the information to the committee.
6. Present the ASD toolkit to the NDDoH ASD task force.

7. Review feedback from the ASD task force using a post presentation survey.
8. Analyze the survey results.
9. Present the ASD toolkit to primary care providers who practice in North Dakota
10. Receive feedback from healthcare providers.
11. Present information to the NDDoH.
12. Use the ASD toolkit statewide

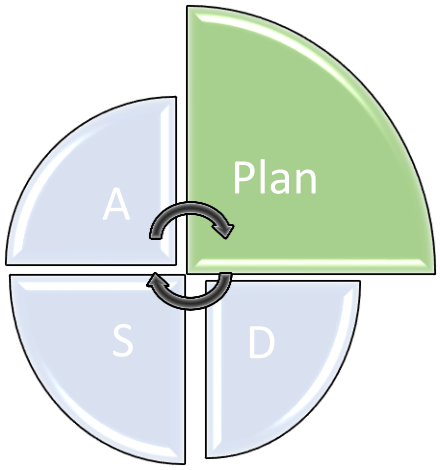

Figure 4. "Plan" of the PDSA cycle.

Modified Checklist for Autism in Toddlers-Revised

There is no universally accepted screening tool that is proper for all populations and all ages. The available screening tools vary from broad, general-developmental screening tools to others that focus on specific areas of development, such as motor or communication skills (Carbone et al., 2010). The psychometric properties of the screening tests vary widely in characteristics, such as their standardization, the comparison group used for determining

sensitivity and specificity, and the population's risk status (Rydz, Shevell, Majnemer, & Oskoui, 2005).

The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R; Appendix B) is a screening tool which has been validated for use in children beginning at 18 months of age and which was designed for a parent or caregiver to complete (Pierce et al., 2016). The M-CHAT-R is a two-step screening instrument that consists of a 20-question checklist and a structured follow-up interview to identify false-positive results from the checklist (AAP, 2006). The M-CHAT-R detects a considerable number of children who have ASD that is not diagnosed by surveillance alone (AAP, 2007). Other primary care screening tools are also available; however, the M-CHAT-R is the most effective given time and sensitivity (Carbone et al., 2010).

Although the American Academy of Pediatrics (AAP) recommends using an autism-specific screening test at 18 and 24 months of age, it should not take the place of surveillance (AAP, 2007). Careful clinical observation may uncover subtle social deficits that parents do not report. In addition to inquiring about a family history of ASDs, surveillance involves combining developmental surveillance, increasing the opportunity to detection of early development delays (Johnson et al., 2007).

Delayed attainment of social-skill milestones is the earliest and most-specific sign of an ASD (AAP, 2015). The three milestones (joint attention, social orienting, and pretend play) can be evaluated during an office visit (Carbone et al., 2010). Joint attention is a child's inherent desire to share experiences with others. An example would be, if the healthcare provider points at a toy across the room and says, "Look! A typically developing 12- to 15-month-old child will shift his or her gaze first to the object and then back to the health care provider (Johnson et al., 2007). By the 18-month visit, the child may spontaneously point at the toy and then look back at

his or her caregiver while smiling (AAP, 2007). The response is declarative pointing, which serves the social purpose of experience sharing. In contrast, a child who points to an object to obtain it, known as imperative pointing, is not showing joint attention because the pointing does not serve a social function (AAP, 2007). The response is declarative pointing, which serves the social purpose of experiencing sharing. In contrast, a child who points to an object to obtain it, known as imperative pointing, is not showing joint attention because the pointing does not serve a social function (AAP, 2007). Likewise, a 24-month-old child who brings a toy to his or her father and smiles is engaging in joint attention, while a child who brings a jar of bubbles to his or her mother so that she will open it is not exhibiting joint attention (Carbone et al., 2010).

ASD Algorithm

A quality-improvement approach is the most- effective means of building surveillance and screening (Siller, et al., 2013). Improving developmental screening and surveillance is a "whole-office" endeavor and is not simply a matter of a clinician continuing education or the addition of tasks to well-child visits (Johnson et al., 2007). For example, a "whole-office" endeavor starts at the front-desk, with screening visits and procedures for flagging children who have showed risk factors (Siller, et al., 2013).

Siller et al (2013) explained that each staff member must work together for the whole group to accomplish the goal. Evidence supports a standardized process when screening for ASD in primary healthcare. The ASD Screening and Surveillance Algorithm (Appendix A) incorporates the entire staff working together from start to finish with every child who has a well-child visit (Siller, et al., 2013). The algorithm was developed by multiple agencies: Council on Children with Disabilities, Section on Developmental Behavior Pediatrics, Bright Futures Steering Committee, and Medical Home Initiatives for Children with Special Needs Project

Advisory Committee. A particularly crucial algorithm step is considering the parents' concerns (AAP, 2007). Parents need education on the reasons for screening, prior to screening. Educate parent or caregiver on screening recommendations, what the screening is for and the possible outcomes of the screening tests (Siller, et al., 2013).

Healthcare providers have multiple screening tools and guidelines available for screening visits (Siller et al., 2013). The CDC and AAP have multiple resources available for parents as well as for increased education of the healthcare providers who are screening children. A small list of examples is as follows:

- Autism is prevalent; Listen to parents; Act early; Refer and; Monitor (A.L.A.R.M) is a flyer which highlights the prevalence of ASD, the importance of screening and listening to parents concerns, and the urgency of making simultaneous referrals to ASD specialists and early intervention programs in order to promote improved outcomes (CDC, 2016).
- Is Your One-Year-Old Communicating with You? A brochure that focuses on the early identification of social-communication deficits and behavior problems that may be associated with developmental disorders, primarily ASD. The brochure is for parents of infants at the 9- or 12-month well-child visit. The brochures intent is to urge parents to verbalize and to discuss concerns about their child's language development and social skills as early as possible (AAP, 2007).
- Understanding Autism Spectrum Disorders is a 48-page introductory booklet for parents who have a child who was recently diagnosed with ASD or who was strongly suspected of having ASD (CDC, 2016).

- Autism Speaks.org is a publicly available website. Autism Speaks developed toolkits that provide evidence-based information and treatment suggestions about the most-common issues facing individuals with ASD. The toolkits are accessible and downloadable, at no cost, from the Autism Speaks website.

Bismarck ASD Resource Guide

The current ASD resource guide for parents and healthcare providers is a comprehensive, 46-page booklet about the ASD services provided in North Dakota as well as the services available at the national level. The North Dakota Department of Health created the resource guide that is available free of charge. The goal for a condensed version of the most-current resource guide is to decrease the time needed for healthcare providers refer a patient.

A resource guide for the Bismarck area should include all organizations or businesses that provide services for children and adults with ASD within 50 miles of the Bismarck community. In addition to the organization's name, a correct phone number, a contact name, the physical address, and the website (if applicable) are of utmost importance (Appendix C). The resource guide was distributed along with the ASD algorithm and M-CHAT-R instructions to primary care providers in the Bismarck, ND, region.

The next step was to present the Bismarck, ND, region-specific ASD resource guide to the ASD task force. A presentation to the ASD task force occurred in August 2018 at an official ASD task force meeting (Appendix, K). Members of the task force praised the condensed resource guide. The cost of the region-specific ASD resource guide was miniscule because the North Dakota Department of Health has all the needed information.

ASD Presentation

The presentation consisted of a professional PowerPoint during a scheduled ASD task force meeting. The PowerPoint (Appendix J) included ASD-specific background information, current statistics, and the ASD toolkit. The professional presentation had specific information about the ASD toolkit with the intent of gathering feedback on the toolkits creation and use in North Dakota. Following the presentation, the task force was asked to fill out and return a post-presentation survey (Appendix H). Members and guests were informed that the survey would be used for feedback about the presentation's strengths and weaknesses. The post-presentation evaluation form would have been used to gather influential information.

Institutional Review Board Approval

The protection of human rights and human subjects was carried out by obtaining approval from the North Dakota State University (NDSU) Institutional Review Board (IRB). NDSU is committed to protecting the rights, safety, and welfare of all individuals taking part in NDSU research projects. Research with human subjects was conducted following the regulations of the U.S. Department of Health and Human Services, the Food and Drug Administration, and other applicable agencies. These protections ensure minimal risks, that the risks are reasonable in relation to benefits, that recruitment procedures are fair, that subjects are sufficiently informed and able to make a voluntary choice, that their privacy and confidentiality are respected, and that extra protections are in place for vulnerable groups (NDSU Policy #345). Exemption status was given to the dissertation project, and the documentation is in Appendix I.

CHAPTER 4. EVALUATION

Project evaluation is important, not only to determine if objectives were met, but also to determine if the project contributed to patient care and would be worthwhile to continue. The evaluation of objectives was achieved by following the PDSA cycle, specifically "Do" and partially "Study" (Figure 5). A complete evaluation of objectives two and three could not be completed because of multiple constraints.

- Geographical data were not part of the ASD toolkit survey.
- Evaluation of the responses from the ASD task force survey did not occur.
- The small sample size did not allow for a statistical analysis.
- The ASD toolkit survey did not contain the needed questions to evaluate the current needs, current gaps, and current services.

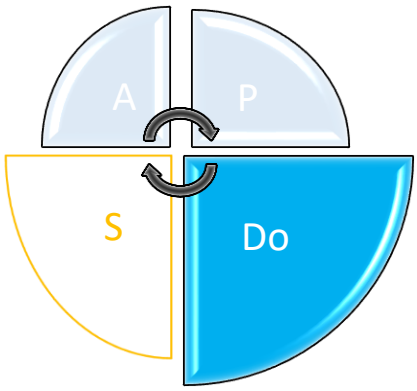

Figure 5. "Do" and "Study" cycle of the PDSA model. "Study" is uniquely colored to show partial use in the evaluation of outcomes.

Evaluation of Objective One

Objective one was to create an ASD toolkit with evidence-based screening recommendations. Items one, four, and five on the ASD toolkit questionnaire were measured in

the evaluation of objective one. The responses were placed in bar graphs and are presented in Chapter 5. The three questions were as follows.

- Question one of the ASD toolkit survey: "You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice."
- Question four: "The use of an ASD algorithm and toolkit would be useful in your practice."
- Question five: "What kind of training or resources would be useful to you? (Check all that apply)"

Evaluation of Objective Two

Objective two was the identification of current screening gaps and additional training needed by healthcare providers in North Dakota. The evaluation involved responses from a post-presentation survey, the ASD task force's statewide survey to health care providers, and conversations with ASD task force members. The evaluation also involved responses to question five of the ASD toolkit survey and a review of literature.

The ASD toolkit survey did not contain the needed questions to evaluate the current screening gaps. The responses for ASD toolkit survey were evaluated for current gaps and additional training. The additional training was evaluated by question five of the ASD survey. Question five: "What kind of training or resources would be useful to you? (Check all that apply)"

Evaluation of Objective Three

Collaboration with the North Dakota ASD task force and ASD leaders to improve ASD screening in primary care was objective three. Evaluation of the collaboration involved tracking multiple emails, face-to-face encounters, professional phone calls, a professional PowerPoint

presentation, and two surveys. A third survey from the ASD task force, which was sent statewide to multiple healthcare providers, would have been used to evaluate objective three. To the co-investigators' dismay, data from the ASD task force survey were not shared.

CHAPTER 5. RESULTS

The project's first purpose was to improve the screening process for ASD in primary care with the creation and implementation of an ASD toolkit. The second purpose was to collaborate with the NDDoH and to implement the toolkit statewide. The goal was accomplished by creating an ASD toolkit, working in conjunction with the Autism Spectrum Disorder Task Force, and receiving results from the ASD toolkit's evaluation form. Implementation began in August 2018 and concluded in December 2018. The results in Chapter 5 are part of the "Study" cycle (Figure 6) in which the results are gathered and are prepared to analyze.

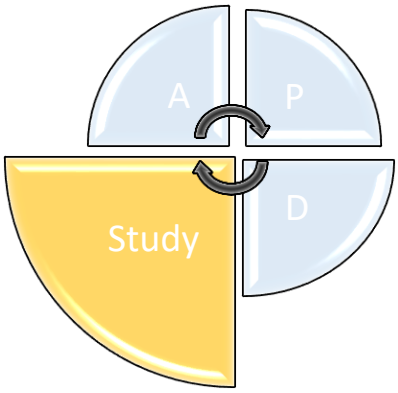

Figure 6. Representation of the "Study" cycle of the PDSA model.

Objective One Results

Objective one was the creation of an ASD toolkit with evidence-based guidelines. The providers practiced in rural and urban settings in North Dakota. Specific provider information was kept confidential in order to have no ties with a specific healthcare facility. Of the 14 primary care providers, 10 returned the completed survey. Before the questionnaire was given to the providers, informed consent was obtained according to the NDSU IRB policy (Appendix I).

A five-point Likert scale, with response choices ranging from strongly disagree (1) to strongly agree (5), was utilized for four questions. The fifth question allowed multiple choices. The survey tool had a comment area following the questions. The only demographic information requested was profession, i.e., medical doctor, physician assistant, or nurse practitioner. Two providers commented. Under each statement in the following sections is a bar chart which gives a visual representation of the providers' responses. Statements one and four were used to evaluate objective one.

Question 1

Question 1 "Do you have adequate tools/referral resources/practice models to accommodate people with ASD in your practice."

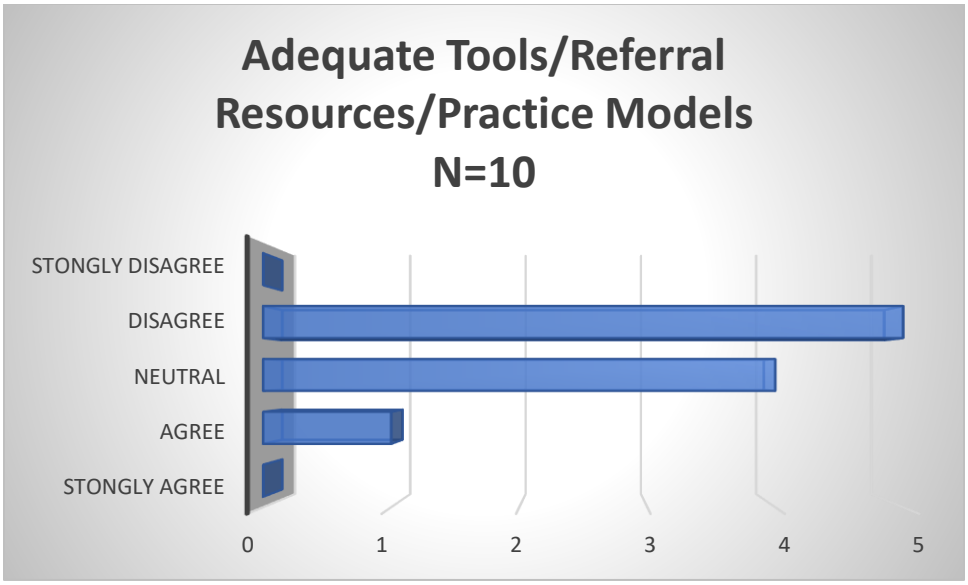

Figure 7. Healthcare provider responses to question one of ASD toolkit questionnaire.

Question 4

Question 4 "The use of an ASD algorithm and toolkit would be useful in your practice."

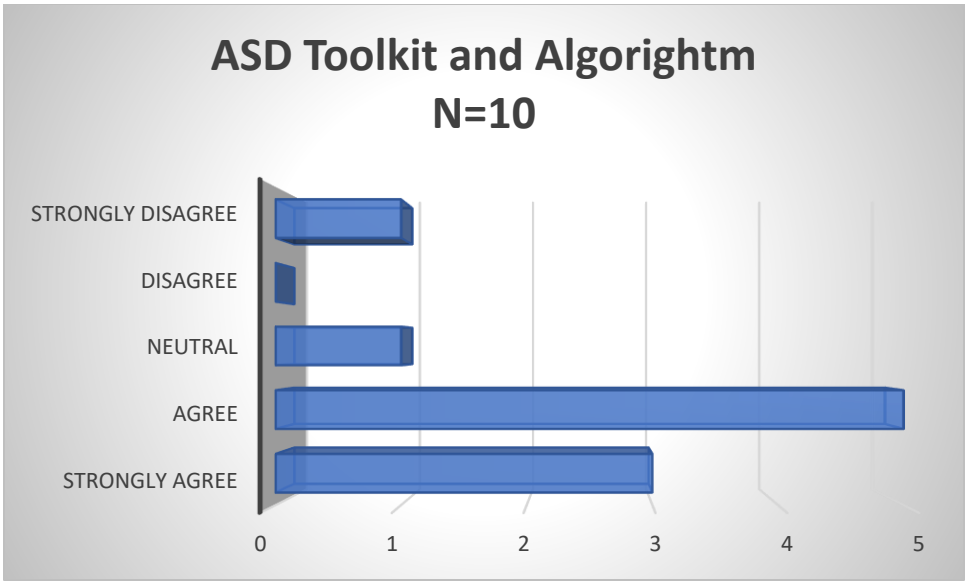

Figure 8. Healthcare provider responses to question four of ASD toolkit questionnaire.

Objective Two Results

Objective two was twofold: identifying the current screening gaps and the preferred educational delivery methods. Data were not collected to identify the screening gaps in North Dakota due to the multiple factors, discussed, in detail, in Chapter 6. Question five (Figure 9) allowed providers to choose from four multiple-choice options of preferred resources and educational methods (Figure 10). Providers were asked to "check all that apply." Questions two (Figure 10) and three (Figure 11) partially evaluated objective two. Information gathered from the Autism Spectrum Disorder Task Force, the Autism Spectrum Disorder Task Force's website (https://www.nd.gov/dhs/autism/taskforce.html), and an extensive literature review delineated current screening gaps in the USA.

Question 5

Question 5 "What kind of training or resources would be useful to you? (Check all that apply)"

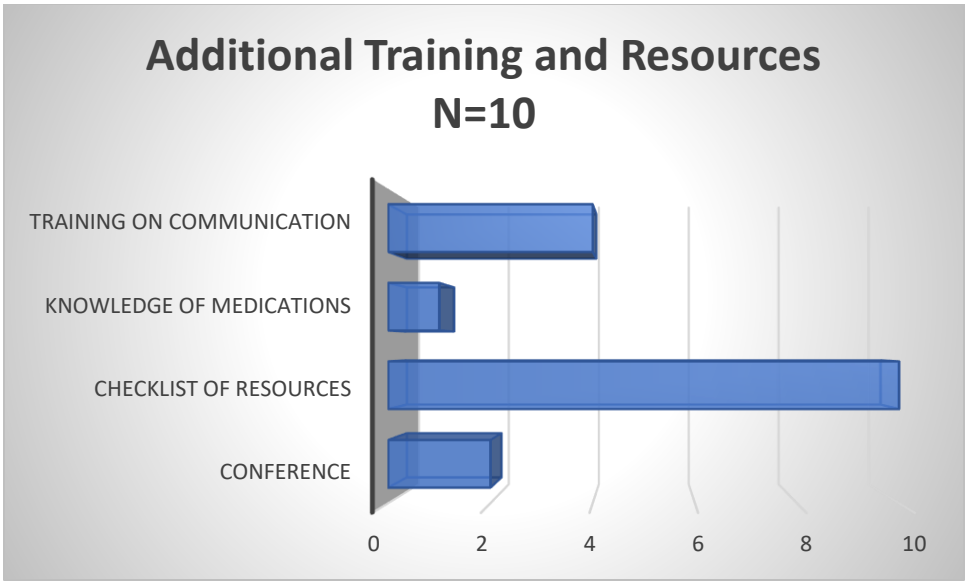

Figure 9. Healthcare provider responses to question five of ASD toolkit questionnaire.

Question 2

Question 2 "Do your patients with ASD have adequate support to partner with you effectively.

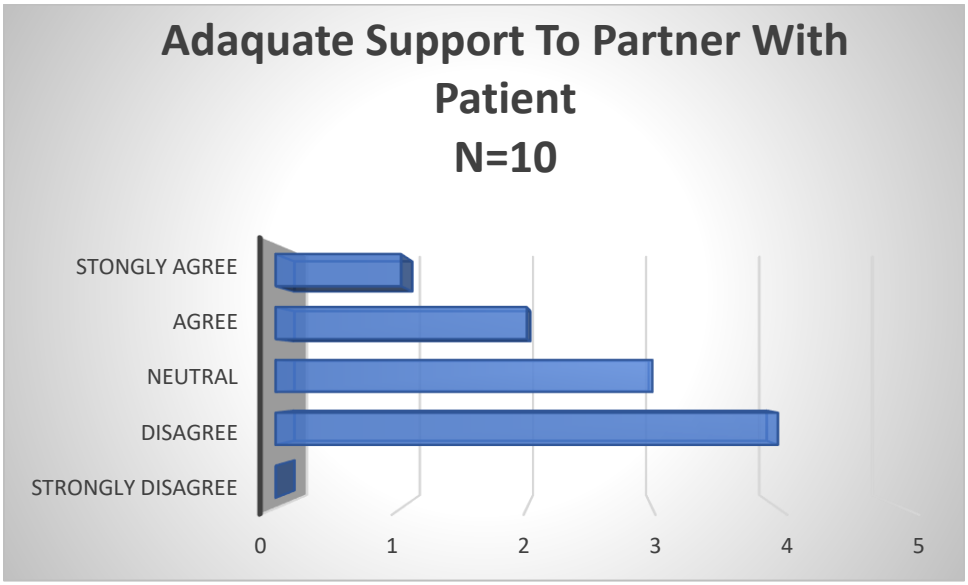

Figure 10. Healthcare provider responses to question two of ASD toolkit questionnaire.

Question 3

Question 3 “The caregivers of your patients with ASD have adequate services and support to partner with you effectively.”

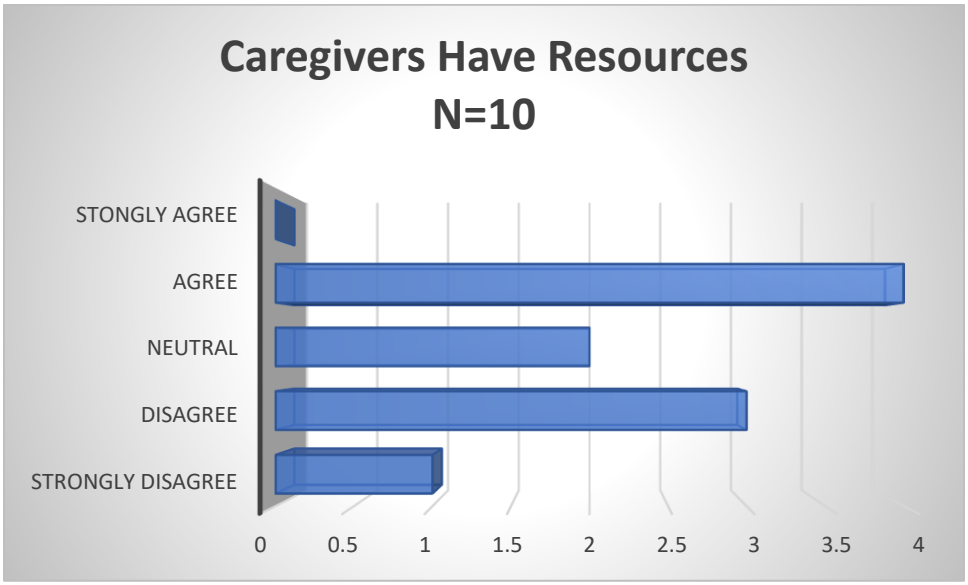

Figure 11. Healthcare provider responses to question three of ASD toolkit questionnaire.

Additional Comments

At the bottom of the survey, space was intentionally left for the respondents to make additional comments. The following comments were made.

- “I find there are not enough autism waivers available in the state. There is a problem finding back-up options.”
- “Having readily available tools, screening resources to utilize with routine well visits would be extremely helpful! In addition, a list of available options to refer to with concerns of ASD and further evaluation to confirm make diagnosis-nearby facilities/providers. Effective communication strategies would also be helpful for schools regarding coordinating care and management.”

Objective Three Results

Objective three was collaboration with North Dakota's Autism Spectrum Disorder Task Force and ASD leaders to improve ASD screening in primary care. The collaboration involved multiple emails, phone calls, and face-to-face meetings. A communication log can be found in Appendix L and collaborative results are presented in Appendix K.

The coinvestigator attended task force meetings to gather insight and guidance about current screening gaps and additional training needs of healthcare providers in North Dakota. The meetings attended were on February 12, 2018, May 14, 2018, and August 20, 2018. During the August 20, 2018 meeting, a 35-minute PowerPoint (Appendix I) was presented to task force members and guests. The presentation covered the coinvestigator's project; specifically, the creation and distribution of an ASD toolkit to primary care providers in the Bismarck area. Upon conclusion, a post-presentation survey was given to the members who were present at the Bismarck meeting (Appendix G). The post-presentation survey was to be returned to the co-investigator via mail or directly after the presentation. Upon conclusion of this dissertation project, no post presentation surveys had been received from any of the members attending the Autism Spectrum Disorder Task Force meeting. Therefore, the presentation was not evaluated.

Summary

The results of the ASD toolkit survey were analyzed. Because no surveys were returned, subsequently the presentation was not evaluated. Ten providers completed the toolkit questionnaire. Five out of the 10 providers (n=5) disagreed that they had adequate tools, referral resources or practice models to accommodate people with ASD in their practice. Four out of the ten providers (n=4) were neutral about resource adequacy. Four of the ten provider respondents (n=4) disagreed that they had adequate support in partnering with their patients, however three

(n=3) agreed or strongly agreed that they had enough support. When asked if their patients had adequate services, four disagreed or strongly disagreed and four agreed. Eight providers agreed or strongly agreed that the toolkit would be useful in practice; the remainder were neutral (n=1) or strongly disagreed (n=1). Question 5 asked about preferred training and resources. All of the providers (N=10) wanted a checklist of ASD resources, four (n=4) communication training, two (n=2) a conference, and one provider was interested in more knowledge of medications. Chapter 6 begins with a discussion about the ASD toolkit and Autism Spectrum Disorder Task Force, concludes with recommendations, and plans for dissemination of the results.

CHAPTER 6. DISCUSSION AND RECOMMENDATIONS

This project's purpose was twofold: to provide primary care providers the tools necessary to screen for ASD at well-child visits and to supply a list of resources for local ASD services. The second purpose was to form an alliance with the NDDoH for the purpose of producing and distributing the toolkit to healthcare providers statewide to further benefit provider practice.

Evidence suggests that early intervention can positively affect outcomes for most children with ASD (Gura, Champagne, & Blood-Siegfried, 2011). Early identification is the prerequisite to early intervention and diagnosis (CDC, 2018). The trajectory of healthcare is to do more with less time for a visit (Gura et al., 2011).

Chapter 6 encompasses the final two PDSA cycles, Study and Act. Study involves the gathering and analyzing of data while Act is the application of the data. The results are discussed; recommendations are made; and the evaluation of another PDSA cycle is decided (Figure 12).

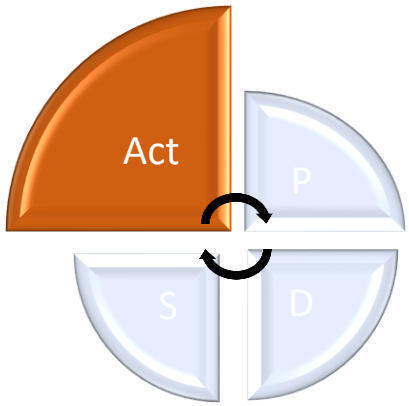

Figure 12. "Act" cycle of the PDSA model.

Objective One Discussion

Toolkits have the potential to increase knowledge and support practice change (Yamada, Shorkey, Barwick, Widger, & Stevens, 2015). Objective one was the creation of an ASD toolkit for primary care providers in western ND. The toolkit was created and implemented for the western ND providers; hence, objective one was met. Ten (n=10) of the 14 providers that received the toolkit completed the questionnaire. In addition, the co-investigator had several informal, face-to-face conversations about the toolkit with the providers. The ASD toolkit folder contained an introductory script, an AAP screening algorithm, the M-CHAT-R (with instructions), a local resource guide, and the questionnaire. Each of the documents has been thoroughly discussed in previous chapters and will not be described in detail in Chapter 6.

The purpose of the toolkit questionnaire was to garner providers' feedback about the toolkit, the adequacy of resources, and support in their practice for screening and management of children with ASD. Unfortunately, the questions were nonspecific and did not capture the data the coinvestigator intended to collect. In retrospect, questions about the providers' current ASD screening practices, use of the MCHAT-R, perceived usefulness of the algorithm, and inclusiveness of the resource guide would have provided richer information about the toolkit. For example, five-point Likert scale responses from none of the time (1) all of the time (5).

- I perform a formal developmental and behavioral screening at the 12-and 18-month well-child visit. A five-point Likert scale form none of the time (1) to all of the time (5).
- I use the M-CHAT-R for ASD screening. A five-point Likert scale from none of the time (1) to all of the time (5).

- I use an ASD screening algorithm in clinical practice. A five-point Likert scale from none of the time (1) to all of the time (5).
- I know where to refer children with a positive ASD screen. A five-point Likert scale from none of the time (1) to all of the time (5).
- I believe the resource guide with contact numbers and addresses of referral agencies would be helpful to me in practice. A five-point Likert scale from none of the time (1) to all of the time (5).
- The ASD toolkit would be useful to me in practice. A five-point Likert scale from none of the time (1) to all of the time (5).

The toolkit was given to 14 providers, 10 of which completed the questionnaire. The completed questionnaire results indicated that the majority of providers responded that they perceived the toolkit would be useful in practice. In addition, the co-investigator spoke with 12 NPs who attended the NDNPA pharmacology conference; they also believed that the ASD algorithm, the MCHAT, and a list of referral resources included in the toolkit would be useful in their practice. However, a few of the NPs reported that they were currently using a similar ASD toolkit. Most of the 12 NPs approached at the NDNPA pharmacology conference expressed concern about the lack of resources in their communities to refer their ASD patients to. Most of the providers said that the toolkit would be useful in practice. The discussions from the ND NPs further helped to confirm the lack of appropriate resources for ASD patients and providers, suggesting further usefulness of this practice improvement project in ND and the potential for future similar projects.

According to Bellando, Fussell, and Lopez, (2016), there are over 40 ASD toolkits available, however many of the toolkits focus on diagnosis, caregiver issues, and treatment

options. The purpose of the project toolkit was to provide the resources and tools for screening toddlers and children at the well-child visit in a primary care setting. The AAP recommends developmental screening at every visit with ASD specific screening at the 18 and 24-month visits (Carbone.et al., 2016). According to a study conducted by Zerbo, Massolo, and Croen (2015) a universal ASD screening toolkit, whether paper or digital, may improve healthcare provider screening practices.

Objective Two Discussion

Objective two, the identification of current screening gaps and additional training needed by healthcare providers in North Dakota, was not met. Results of a literature review indicated that primary care providers are the first to encounter and screen toddlers and children for ASD (Crais et al., 2014). Robins et al. (2016) found that fewer than 25% of providers regularly screened for ASD and less than 10% of providers were using ASD-specific screening instruments. Despite the low screening rates, ASD diagnoses have markedly increased over the past decade (Autism Speaks, 2018). Some experts believe that increased awareness and a change in diagnostic criteria may be the real reason for the surge in prevalence (U.S. Preventative Services Task Force, 2016)

Barton et al., (2012) reported ASD can be diagnosed as young as 18 months, yet the mean age of diagnosis is 5.7 years. In ND, 45% of children are 5-8 years old at the time of first diagnosis (NDDoH, 2017). Consequently, a delay in diagnosis translates into delayed access to specialized services for children with ASD (Autism Speaks, 2018; Carbone et al., 2010).
The most common provider barriers in diagnosing and caring for ASD children are a lack of education, unfamiliarity with treatment options, and difficulty with care coordination (Carbone et al., 2016). Healthcare providers often report lacking the knowledge or training to accurately

assess and diagnosis developmental disorders (Bellando et al., 2016; Carbone et al., 2016; Hus, 2017). The NPs the co-investigator received verbal feedback from at the 2018 NDNPA pharmacology conference also felt poorly educated on ASD, in part due to an absence of ASD content in their graduate programs. The 'wait and see' approach with early symptoms may reflect the providers' low self-efficacy in making a diagnosis (Carbone, Norlin, & Young, 2016). Receiving a diagnosis of ASD often incites a strong emotional reaction on the part of the caregiver(s) that the provider may feel ill prepared or too uncomfortable to manage (Carbone, et al., 2016). Consequently, a delay in diagnosis translates into delayed access to specialized services for children with ASD (Autism Speaks, 2018; Carbone et al., 2010).

The co-investigator attended several ASD educational conferences, ND ASD, Database meetings, and Task force meetings to get a pulse on what is happening in ND as far as ASD screening, prevalence, and initiatives. The lack of return of the presentation evaluations by task members meant a missed opportunity to gather information about the educational value of the PowerPoint presentation, as well as member feedback about the ASD screening gaps in ND. The lack of evaluation return may have been related to the instructions given to the members about the evaluation form. At the time of the presentation, the ASD task force was working on a statewide survey. Conceivably, the task force may have had their focus on their own survey at the time and forgot to complete and return the evaluation form.

In conclusion, the goal of identifying screening and educational gaps in ND was too lofty for the project in regard to project timeline, ASD stakeholder input, and the lack of statewide data available. There were missed opportunities to gather information from the toolkit questionnaire and from the presentation evaluation.

Objective Three Discussion

Objective three was to collaborate with North Dakota's Autism Spectrum Disorder Task Force and the ASD leaders to improve the ASD screening in primary care. Objective three was partially met by developing a network of key stakeholders in addressing ASD issues in ND. Collaboration with the Autism Spectrum Disorder Task Force included multiple professional emails, which were sent to task-force members while creating and planning the implementation of the ASD toolkit (Appendix L). The goal of improving ASD screening in ND was not realized, however there was a great deal of work going on in the state to improve ASD screening and services. In fact, a goal of the ND ASD task force was to increase provider education and ASD services in the North Dakota. Early and continuous accessible screening and assessment continues to be the goal of North Dakota's Autism Spectrum Disorder Task Force (North Dakota Department of Human Services, n.d.). The idea for the toolkit derived from attendance at task force meetings and interaction with task force members. Currently, the task force is working with the state legislature to develop a state autism spectrum disorder plan and to continue reviewing and periodically updating or amending the plan in order to serve the needs of individuals with autism spectrum disorder.

At the time of developing and implementing the ASD toolkit, the Autism Spectrum Disorder Task Force was working with the state legislature and the governor to collect and to compile data about individuals with autism in North Dakota to understand the gaps, barriers, and challenges. In conjunction with representatives of the North Dakota legislative branch, the Autism Spectrum Disorder Task Force developed and distributed a statewide survey to regional healthcare providers. To date, the task force has received 351 returned surveys. The task force survey included demographic information, including age, race, sex, age of diagnosis, healthcare

provider who diagnosed, name of primary care provider, other diagnosis, and current treatment plan. The results of the survey have not yet been released.

Limitations and Recommendations for Future Projects

The evaluation of the co-investigator's objectives was flawed based on the project objectives and evaluation design. The objectives of the project were too general and therefore difficult to evaluate. Objective one, creation of an ASD screening toolkit, was measurable, however, the development and evaluation of the toolkit was without provider input. Early in toolkit planning, after the review of the literature was complete, I should have sought input from pediatric and family medicine providers that routinely care for infants and children. Feedback from providers about lessening barriers to screening, as well as, how to improve the screening, early identification, and referral. The input from providers and literature review should have been the driving force behind the creation of the ASD toolkit.

A revised questionnaire with more specific, succinct data collection about providers' perceptions of each of the components and the overall usefulness of the toolkit would have enriched the evaluation. Only one question pertained to the usefulness of the algorithm and toolkit. The questionnaire was devoid of data collection about MCHAT use, current screening practices, and familiarity with community resources. Furthermore, surveying providers with a new questionnaire after 3-6 months of toolkit use would have provided feedback and enriched evaluation data. The co-investigator would recommend forging a collaborative relationship with stakeholders at a local healthcare organization to pilot the project. A collaborative project model would have the potential for a larger provider pool and opportunity for more sophisticated data collection methods. Project implementation in a larger facility also has the potential for a

systems wide change. A systems wide change is the goal of The Breakthrough Series Collaborative Model.

Dissemination Strategies

In April 2018, a showcase of the Doctor of Nursing Practice projects occurred at North Dakota State University's School of Nursing-Bismarck to demonstrate the progression of the graduate students' progress, outcomes, and recommendations. The showcase included a limited explanation about the problem and/or situation, the project's objectives, the theoretical framework, and the project's design. The event was open to any individual who was interested in attending and allowed the presenter to answer any questions. In April 2019, the second NDSU graduate-student poster presentation is scheduled. Anticipating acceptance, the coinvestigator will display the poster with the project's completed findings. As part of the display, paper copies of the ASD toolkit will be supplied for individuals who are interested in viewing the completed project.

To broaden the use of the toolkit and provide education about ASD, a statewide continuing education could be developed in either web-based or in-person format. Use of a web-based platform increases the availability of the education to a larger number of healthcare providers throughout the state. Ideally, the development and production of the continuing education is accomplished through a collaborative effort with the NDDoH. Educational content should include the pathophysiology, prevalence, screening, diagnosis, and management of ASD for primary care providers. A conference format with a round-table discussion and brainstorming session following the general education could provide insight on strategies to lessen provider screening barriers and increase the number of children in ND who are screened for ASD

The ASD toolkit could also be converted from the paper version to an electronic version that could communicate with the electronic medical record system. Parents and caregiver(s) who have signed up for electronic communication with the healthcare organization could complete the screening forms prior to the child's clinic visit, allowing more time for the provider and caregiver to review the results , discuss concerns, and develop a plan.

Implications for Advanced Practice Nursing

With 89% of the nurse practitioner (NP) population prepared in primary care and more than 75% of actively practicing NP's providing primary care, NP's are a vital part of the U.S. primary care workforce, especially in rural and underserved areas (American Academy of Nurse Practitioners [AANP], 2013). As the gatekeepers in primary care, NPs must be educated and confident in screening and evidence-based guidelines for identification and surveillance of children with symptoms or a diagnosis of ASD (Pierce et al., 2016). Recent studies have indicated that children with ASD who received early, intensive intervention had a decrease in core symptoms and had improvement in intellectual, language, and adaptive skills (Carbone et al., 2016).

The American Academy of Pediatrics (2008) recommends that primary care providers screen for general developmental problems at the 9-, 18-, and 24- or 30- month well-child visits using a standardized screening tool such as the MCHAT-R. Additionally, ASD-specific screening should be done at both 18- and 24-months to identify those children whose symptoms appear after 18 months (CDC, 2016). Family nurse practitioners (FNPs), as well as pediatric nurse practitioners (PNPs) have the opportunity to improve screening and symptom recognition to improve outcomes for their patients. Education is cited as a provider barrier for comprehensive ASD screening and management (Bellando et al. 2016). According to the AAP

(2012), a toolkit is a proven, safe, and effective tool to guide evidence-based practice. The ASD toolkit provides easy access to an ASD guideline, screening tool and a guide for local and regional resources and services for children with suspected or known ASD. Another area to improve ASD education is within medical, nursing, and nurse practitioner curriculums.

Through this project, I have gained a broader understanding of ASD and individuals with ASD. As a NP, I will be on alert for red flags and parental concerns for autism spectrum disorder. I will be better prepared to screen, educate, and refer children who are suspected of having a developmental, emotional, or intellectual delay because of my project.

Conclusion

Autism spectrum disorder (ASD) is a developmental disability that can cause persistent deficits in social communication, behavior, and development. The effect of ASD differs from individual to individual, thus is considered a spectrum disorder. Early screening and intervention are essential for improving outcomes. However, primary care providers' screening rates remain low even though the diagnosis of ASD is possible in children who are 2 years old or younger. On average, children are 4 years or older at the time of diagnosis

It is important to have early and continuous surveillance and screening for ASD to ensure that children are identified and receive access to services as early as possible (AAP, 2015). With early and intensive interventions, children with autism can make remarkable progress in all areas (AAP, 2015). Recent studies indicate that a child with ASD who received early, intensive intervention had a decrease in core symptoms and improvement of intellectual, language, and adaptive skills (CDC, 2018).

Family practice providers and pediatric healthcare providers consider well-child visits to be important for monitoring growth and development; assessing behavior; conducting vision,

hearing or lead screenings; giving immunizations; and coordinating care (Carbone et al., 2010). With everything that must be completed during one well-child visit, ASD screening may be being missed at a younger age, creating an age gap in diagnosis (Carbone et al., 2016). To combat this age gap, ND created a task force to evaluate and implement changes in the ASD arena. One way to close the age gap could be the implementation of an ASD toolkit into the offices of primary care/pediatric healthcare providers (Hus, 2017).

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APPENDIX A. ASD SURVEILLANCE AND SCREENING ALGORITHM

Making an Autism Diagnosis

Handout III: AAP Screening Guidelines

Surveillance and Screening Algorithm: Autism Spectrum Disorders (ASDs)

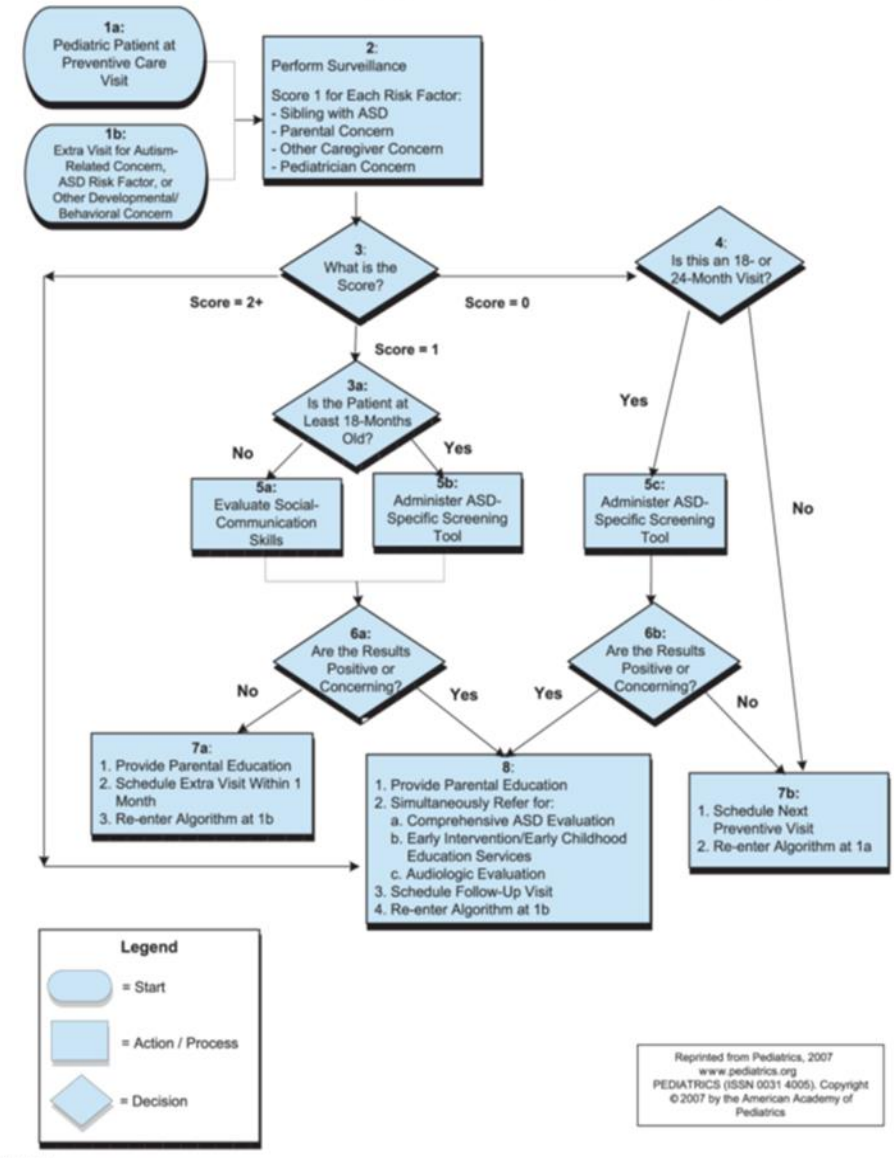

FIGURE 1
Surveillance and screening algorithm: ASDs.

Surveillance and Screening Algorithm: Autism Spectrum Disorders (ASDs)

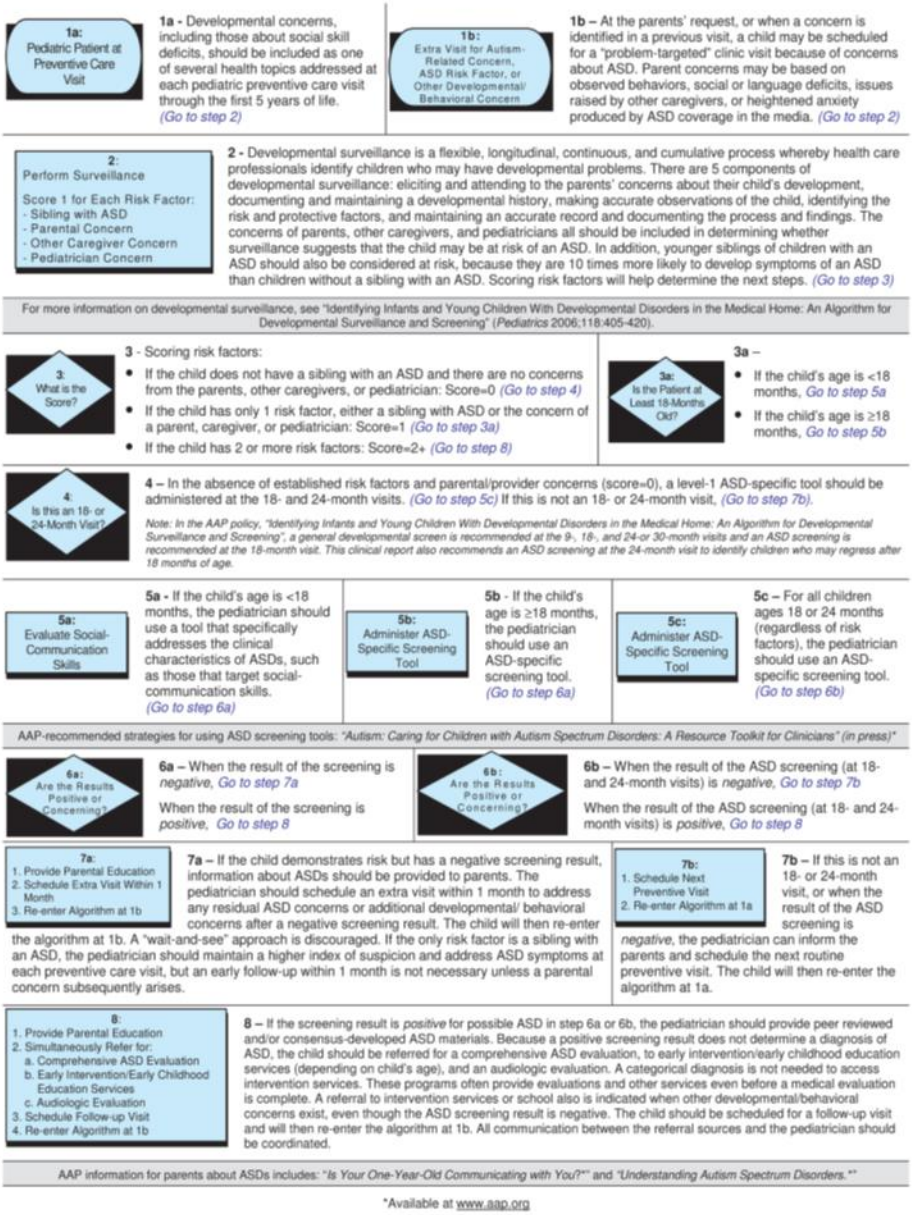

FIGURE 1
Continued

APPENDIX B. M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (**For Example**, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (**FOR EXAMPLE**, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (**FOR EXAMPLE**, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make unusual finger movements near his or her eyes? (**FOR EXAMPLE**, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (**FOR EXAMPLE**, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (**FOR EXAMPLE**, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (**FOR EXAMPLE**, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (**FOR EXAMPLE**, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (**FOR EXAMPLE**, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No

12. Does your child get upset by everyday noises? (**FOR EXAMPLE**, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (**FOR EXAMPLE**, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (**FOR EXAMPLE**, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell him or her to do something? (**FOR EXAMPLE**, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (**FOR EXAMPLE**, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20. Does your child like movement activities? (**FOR EXAMPLE**, being swung or bounced on your knee)	Yes	No

Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com. Associated documents will be available for download as well.

Scoring Algorithm For all items except 2, 5, and 12, the response “NO” indicates ASD risk; for items 2, 5, and 12, “YES” indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

LOW-RISK: **Total Score is 0-2**; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.

MEDIUM-RISK: **Total Score is 3-7**; Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.

HIGH-RISK: **Total Score is 8-20**; It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

APPENDIX C. REGION-SPECIFIC ASD RESOURCE GUIDE

AUTISM SPECTRUM DISORDERS RESOURCE GUIDE: BISMARCK

DIAGNOSTIC CLINICS

ANNE CARLSEN CENTER

The diagnostic team includes a pediatrician, behavior support coordinator, occupational therapist, and speech language pathologist. The evaluation is conducted in a clinical setting utilizing formal and informal assessment tools. Clinics are held twice monthly in Jamestown at the Anne Carlsen Center; each child is typically seen over the course of half of a day. Family members are present during the evaluation to answer questions and offer insight. Families meet with the team that same day to discuss results. For more information, visit www.annecarlsen.org.

1929 Kavaney Drive

Bismarck, ND 58501

Phone: 701.751.3732

Phone: 800.201.8672

RED DOOR PEDIATRIC SERVICES

Red Door offers a functional approach to treatment that focuses on the development of each individual child. New intervention strategies are implemented in speech, language, and occupational therapy. For more information, visit reddoorpediatric.com/

1303 East Central Ave.

Bismarck, ND 58501

Phone: 701.222.3175

THERAPY PROVIDERS FOR AUTISM SPECTRUM DISORDERS (PHYSICAL THERAPY, OCCUPATIONAL THERAPY, AND SPEECH)

CHI ST. ALEXIUS PEDIATRIC THERAPY

701.530.8200

www.st.alexius.org/services/pediatric-therapyservices/pediatric-therapy-services

KIDS THERAPY CENTER

701.751.0384

www.thekidstherapycenter.com/

PEDIATRIC THERAPY PARTNERS

888.875.5262/701.751.6336

www.pediatrictherapypartners.com

RED DOOR PEDIATRIC THERAPY

701.222.3175

reddoorpediatric.com/

SANFORD HEALTH PEDIATRIC REHABILITATION

701.323.6097

bismarck.sanfordhealth.org/rehab/pediatric.asp

THE ENRICHMENT GARDEN, INC.

701-258-1569

www.theenrichmentgardennd.com/

INFORMATION FOR PARENTS AND PROVIDERS

Family Voices of North Dakota

1-888-522-9654

http://fvnd.org/site/

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https://www.autismspeaks.org

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http://www.autism-society.org/

North Dakota Department of Health

CDC

APPENDIX D. PILOT QUESTIONS-ASD TOOLKIT FOR PROVIDERS

AUTISM SPECTRUM DISORDER

SURVEY FOR HEALTHCARE PROVIDERS REGARDING ADEQUACY OF RESOURCES AND TRAINING NEEDS RELATED TO ASD

1) You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

---

2) Your patients with ASD have adequate support to partner with you effectively
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

---

3) The caregivers of your patients with ASD have adequate services and support to partner with you effectively
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

---

4) The use of an ASD algorithm and toolkit would be useful in your practice
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

5) What kind of training or resources would be useful to you? (check all that apply)
   - ☐ Conference with description of ASD
   - ☐ Checklist of community resources for patients with ASD
   - ☐ Knowledge of psychotropic drugs to treat patients with ASD
   - ☐ Training on effective communication strategies with ASD patients

---

*The above questions were developed from information retrieved from http://www.nhcouncilonasd.org/NH_ASD_Needs_Assessment_Report_2014.pdf

Additional Comments:

Credentials: MD PA NP

Please Return to:

Trevor Stavig

2829 Manchester Street

Bismarck ND, 58504

APPENDIX E. PILOT STUDY SCRIPT

NDSU **North Dakota State University**
Department of Nursing
Campus Address
NDSU Dept. of Nursing
PO Box 6050
Fargo, ND 58108-6050
701.231-5692

Autism Spectrum Disorder (ASD) in North Dakota. Database to Screening: Bridging the Gap Between What We Know and Where to Go

Dear participant

My name is Trevor Stavig and I am a Doctor of Nursing Practice student at North Dakota State University School of Nursing. For my dissertation, I am completing a practice improvement project to promote earlier screening of children for Autism Spectrum Disorder in primary care. To facilitate ASD screening, a toolkit has been developed to assist primary care providers with screening, initial evaluation, and appropriate referral of children with positive screening.

Because you are a primary care provider who sees children in your practice, you have been invited to take part in this practice improvement project. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you.

It is not possible to identify all potential risks in research procedures, be assured that reasonable safeguards have been taken to minimize any known risks. These known risks include loss of anonymity and psychological or work stress.

By taking part in this research, you may benefit by increasing your knowledge and efficiency in screening children for ASD and streamlining the referral process for children needing further evaluation. However, you may not get any benefit from being in this study. Benefits to others are likely to include an increased awareness of autism spectrum disorder in the community, the referral process, and the ASD resources available in the Bismarck ND area.

It should take you about 5 minutes to complete the survey pertaining to screening and referral for ASD.

We will keep private all research records that identify you. Your information will be combined with information from other people taking part in the study, we will write about the combined information that we have gathered. You will not be identified in these written materials. We may publish the results of the study; however, we will keep your name and other identifying information private.

APPENDIX F. RIGHT TO USE M-CHAT-R

From: "Stavig, Trevor" <trevor.stavig@ndsu.edu>
Date: Tuesday, December 19, 2017 at 11:32 AM
To: Diana L Robins <dianalrobins@gmail.com>
Subject: Use of M-CHAT-R and Follow-up

Hello,
My name is Trevor Stavig and I am a student at North Dakota State University and I am in the process of attaining my doctorate as a Nurse Practitioner. To achieve this title we must also partake in the creation of a dissertation project. The intent of the project is to use current research. I am in the process of researching and presenting information related to autism spectrum disorder by addressing the need for early identification in the primary care provider setting (NP, MD, PA). The use of the M-CHAT-R and Follow-up is of great importance as seen in the current research. My goal is to create a ASD toolkit that could be provided to the North Dakota Department of Health ASD Task Force. I would be using the M-CHAT-R and Follow-up as part of the toolkit. Would I be able to use your copyrighted version of the M-CHAT-R and Follow-up, in its entirety, as part of the toolkit?
Please feel free to ask any questions.

Thank you for your time,

Trevor Stavig
NDSU DNP Graduate Student

Diana L Robins <dianalrobins@gmail.com>

Fri 12/22/2017, 7:30 AM

Stavig, Trevor

Hi Trevor,
I approve of this use of our copyrighted materials. Please ensure you use our work in its entirety, and retain our copyright. You are welcome to include the URL of our official website as well, www.mchatscreen.com
Please let me know the results of your pilot study. Best, Diana

APPENDIX G. RIGHT TO USE AAP ALGORITHM

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Thank you for your order.

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License number	Reference confirmation email for license number
License date	Sep, 24 2018
Licensed Content Publisher	American Academy of Pediatrics
Licensed Content Publication	Pediatrics
Licensed Content Title	Identification and Evaluation of Children with Autism Spectrum Disorders
Licensed Content Author	Chris Plauché Johnson,Scott M. Myers
Licensed Content Date	Nov 1, 2007
Licensed Content Volume	120
Licensed Content Issue	5
Licensed Content Pages	33
Type of Use	Dissertation/Thesis
Requestor type	Individual
Format	Online

Portion	Figures/tables/images
Number of figures/tables/images	2
Use of a photo?	Yes
Original AAP figure/table/image number(s)	http://pediatrics.aappublications.org/content/120/5/1183.figures-only#fig-data-figures http://pediatrics.aappublications.org/content/120/5/1183.figures-only#fig-data-figures
Order reference number	
Requestor Location	Mr. Trevor Stavig 2829 Manchester Street BISMARCK, ND 58504 United States Attn: Mr. Trevor Stavig
Billing Type	Invoice
Billing address	Mr. Trevor Stavig 2829 Manchester Street BISMARCK, ND 58504 United States Attn: Mr. Trevor Stavig
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APPENDIX H. ASD TASK FORCE PRESENTATION

Autism Spectrum Disorder Toolkit Evaluation

Review Information	
Your Name:	
Date:	Review Period:

Guidelines
Complete this review, using the following scale: **NA = Not Applicable** **1 = Needs Work (Unsatisfactory)** **2 = Gets By (Marginal)** **3 = Meets Requirements** **4 = Exceeds Requirements** **5 = Exceptional**

Presentation	(5) = Exceptional	(4) = Exceeds Requirements	(3) = Meets Requirements	(2) = Gets By	(1) = Needs Work
Provided adequate information	☐	☐	☐	☐	☐
Easy to follow/Organized	☐	☐	☐	☐	☐
Presentation was professional	☐	☐	☐	☐	☐
Problems were identified	☐	☐	☐	☐	☐
Implementation of toolkit is applicable	☐	☐	☐	☐	☐
Realistic	☐	☐	☐	☐	☐

Strengths of Presentation:

Weaknesses of Presentation:

Comments:

Please return to
Trevor Stavig
2829 Manchester Street, Bismarck ND 58504

APPENDIX I. NDSU IRB EXEMPT

NDSU NORTH DAKOTA STATE UNIVERSITY

March 9, 2018

Dr. Tina Lundeen
Nursing

Re: IRB Determination of Exempt Human Subjects Research:
Protocol #PH18200, "Autism Spectrum Disorder (ASD) in North Dakota. Database to Screening: Bridging the Gap Between What We Know and Where to Go"

Co-investigator(s) and research team: Trevor Stavig
Certification Date: 3/9/2018 Expiration Date: 3/8/2021
Study site(s): provider offices in Bismarck, ND
Sponsor: n/a

The above referenced human subjects research project has been certified as exempt (category #1, 2b) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the original protocol (received 2/28/2018) with surveys (received 3/1/20018) and information sheet (received 3/7/2018).

Please also note the following:
• If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
• The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
• Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
• Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.
Sincerely,

Kristy Shirley

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult http://www.ndsu.edu/research/integrity_compliance/irb/. This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

INSTITUTIONAL REVIEW BOARD
NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | ndsu.edu/irb

Shipping address: Research 1, 1735 NDSU Research Park Drive, Fargo ND 58102

APPENDIX J. ASD TASK FORCE PROFESSIONAL POWERPOINT

Project Objectives

- The creation of an ASD specific toolkit that will provide screening recommendations that are peer reviewed and scientifically validated.
- The ASD toolkit would be used to identify methods that can improve coordination in the delivery of service between public and private agencies, health providers, and schools, and to address any geographic discrepancies in the delivery of services.
- The ASD toolkit can increase the availability of information and training for medical providers and educators who identify and provide services to individuals with ASD.

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Project Design

- The design of the dissertation project is based around the overall goal, with that goal being increasing early intervention and awareness of ASD in the community of Bismarck, ND by providing an evidence-based ASD toolkit that can be used by primary care providers.
- The toolkit consists of:
  - Preventative Care Screening Algorithm which has been endorsed by the American Academy of Pediatrics
  - Region-specific guide for referrals, patient education, and provider education
  - Example of M-CHAT-R and how to score as well as the follow-up.

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Problem Statement/Purpose

- In North Dakota and nationally, autism spectrum disorder (ASD) is being diagnosed at later ages then is currently recommended.. With that being said, many studies have found that children were showing signs as early/earlier then 18-months of age.
- This diagnosis age gap delays the process of early interventions. The delay may have a great impact for those children.
- With the age gap in mind, it is important to look at the possible reason(s) why this gap exists, and possible ways for mitigation.

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Project Objectives

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AUTISM SPECTRUM DISORDERS RESOURCE GUIDE: BISMARCK

DIAGNOSTIC CLINICS

ANNE CARLSEN CENTER

The diagnostic team includes a pediatrician, behavior support coordinator, occupational therapist, and speech language pathologist. The evaluation is conducted in a clinical setting utilizing formal and informal assessment tools. Clinics are held twice monthly in Jamestown at the Anne Carlsen Center; each child is typically seen over the course of half of a day. Family members are present during the evaluation to answer questions and offer insight. Families meet with the team that same day to discuss results. For more information, visit www.annecarlsen.org.

1929 Kavaney Drive

Bismarck, ND 58501

Phone: 701.751.3732

Phone: 800.201.8672

RED DOOR PEDIATRIC SERVICES

Red Door offers a functional approach to treatment that focuses on the development of each individual child. New intervention strategies are implemented in speech, language, and occupational therapy. For more information, visit reddoorpediatric.com/

1301 East Central Ave.

Bismarck, ND 58501

Phone: 701.222.3175

THERAPY PROVIDERS FOR AUTISM SPECTRUM DISORDERS

(PHYSICAL THERAPY, OCCUPATIONAL THERAPY, AND SPEECH)

CHI ST. ALEXIUS PEDIATRIC THERAPY

701.530.8200

www.st.alexius.org/services/pediatric-therapyservices/pediatric-therapy-services

KIDS THERAPY CENTER

701.751.0384

www.thekidstherapycenter.com/

PEDIATRIC THERAPY PARTNERS

888.875.5262/701.751.6336

www.pediatrictherapypartners.com

RED DOOR PEDIATRIC THERAPY

701.222.3175

reddoorpediatric.com/

SANFORD HEALTH PEDIATRIC REHABILITATION

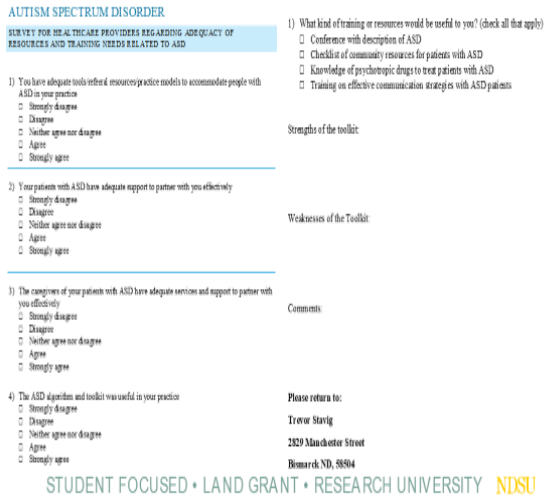
701.323.6097

bismarck.sanfordhealth.org/rehab/pediatric.asp

THE ENRICHMENT GARDEN, INC.

701-258-1589

www.theenrichmentgardennd.com/



AUTISM SPECTRUM DISORDER

SURVEY FOR HEALTHCARE PROVIDERS REGARDING ADEQUACY OF RESOURCES AND TRAINING NEEDS RELATED TO ASD

1) You have adequate tools/referral resources/practice models to accommodate people with ASD in your practice
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

2) Your patients with ASD have adequate support to partner with you effectively
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

3) The caregivers of your patients with ASD have adequate services and support to partner with you effectively
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

4) The ASD algorithm and toolkit was useful in your practice
   - ☐ Strongly disagree
   - ☐ Disagree
   - ☐ Neither agree nor disagree
   - ☐ Agree
   - ☐ Strongly agree

1) What kind of training or resources would be useful to you? (check all that apply)
   - ☐ Conference with description of ASD
   - ☐ Checklist of community resources for patients with ASD
   - ☐ Knowledge of psychotropic drugs to treat patients with ASD
   - ☐ Training on effective communication strategies with ASD patients

Strengths of the toolkit:

Weaknesses of the Toolkit:

Comments:

Please return to:

Trevor Stavig

2829 Manchester Street

Bismarck ND, 58504

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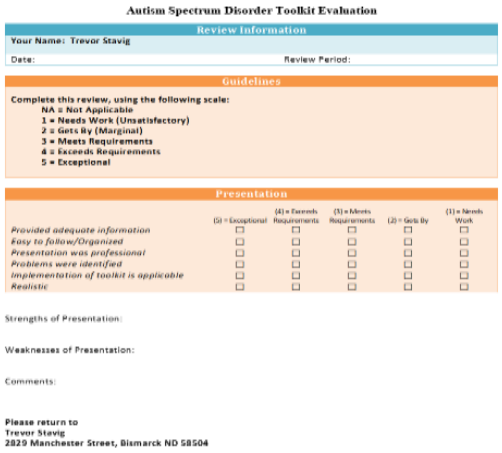

Autism Spectrum Disorder Toolkit Evaluation

Review Information

Your Name: Trevor Stavig

Date: **Review Period:**

Guidelines

Complete this review, using the following scale:

NA = Not Applicable
1 = Needs Work (Unsatisfactory)
2 = Gets By (Marginal)
3 = Meets Requirements
4 = Exceeds Requirements
5 = Exceptional

Presentation

	(5) = Exceptional	(4) = Exceeds Requirements	(3) = Meets Requirements	(2) = Gets By	(1) = Needs Work
Provided adequate information	☐	☐	☐	☐	☐
Easy to follow/Organized	☐	☐	☐	☐	☐
Presentation was professional	☐	☐	☐	☐	☐
Problems were identified	☐	☐	☐	☐	☐
Implementation of toolkit is applicable	☐	☐	☐	☐	☐
Realistic	☐	☐	☐	☐	☐

Strengths of Presentation:

Weaknesses of Presentation:

Comments:

Please return to
Trevor Stavig
2829 Manchester Street, Bismarck ND 58504

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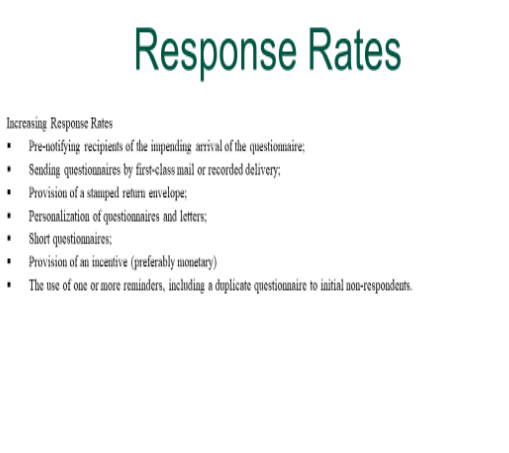

Response Rates

Increasing Response Rates

- Pre-notifying recipients of the impending arrival of the questionnaire;
- Sending questionnaires by first-class mail or recorded delivery;
- Provision of a stamped return envelope;
- Personalization of questionnaires and letters;
- Short questionnaires;
- Provision of an incentive (preferably monetary)
- The use of one or more reminders, including a duplicate questionnaire to initial non-respondents.

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APPENDIX K. ASD TASK FORCE MINUTES

Autism Spectrum Disorder (ASD) Task Force Meeting Minutes

August 20, 2018

Task Force members present Jennifer Flores, Dawn Hanson, Holly Johnson, Teresa Larsen, Connie Lillejord, Vicki Peterson and Kodi Pinks

Task Force members present via polycom/phone: Dr. Thomas Carver, Senator Joan Heckaman, Mary Jaeger, Carol Johnson, Nancy Ulrich-Crotty, and John Watkins

Absent: Maggie Anderson, Heather Opland, Gerry Teevens and Catherine Yeager

A quorum of Task Force members were present.

Guests (present and via polycom/phone): Kaitlin Kurtz, Krista Fremming, Trevor Stavig, Susan Gerenz, Lorena Poppe, Tom Solberg, Heather Steffl, Stephanie Nelson, Carmen Peck, Skylar Hertzog and Farrah Thoreson

Meeting was called to order at 1:05 p.m.

Review of minutes- May 2018 minutes were reviewed.

Teresa Larsen moved approval; Connie Lillejord seconded. 13 yay/0 nay: motion passed.

Presentation from Trevor Stavig, NDSU Doctor of Nurse Practice Student, on his clinical dissertation regarding ASD

- Title of his dissertation: Increasing awareness and screening of ASD in North Dakota with use of an ASD Toolkit
- Main Objectives ○ Provide useful information regarding screening and referral of ASD ○ Continue the promotion of early screening and early referral ○ Creation of a user-friendly ASD toolkit ○ Increase understanding of barriers that providers face in screening and diagnosing ASD
- In North Dakota and nationally, the average age of ASD diagnosis is higher than what experts recommended.
    - Many studies have found children showing signs earlier than 18 months of age. ○ Later diagnosis delays the process of early intervention.
- The toolkit provides screening recommendations that are peer-reviewed and scientifically validated.
- The toolkit includes:
    - A brief survey that asks providers about their awareness of the importance of screening for and diagnosing ASD and barriers they face. ○ Bright Futures Guidelines

for Health Supervision of Infants, Children, and Adolescents endorsed by the American Academy of Pediatrics

o Region specific guide for resources, referrals and patient education o Example of the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (MCHAT-R/F) and how to score

Task Force Membership

- Holly Johnson is the newest member of the Task Force appointed by the Governor. She fills the behavior specialist role.

Current Operations updates:

Waiver

- There are concerns from Task Force members regarding the low waiver expenditures so far this biennium.
- There was discussion about if a child needs service management to access the waiver or could they receive respite and/or assistive technology services without service management. It was clarified that the autism waiver requires a service manager to complete the participant service plan. Respite and assistive technology are optional waiver services.
- Some providers are not taking on more children for service management and instead, putting them on a waitlist. These provider shortages are contributing to lower expenditures than budgeted.
- There are currently 50 children on the waiver waitlist. Most are either waiting for a Medicaid eligibility determination from the county or waiting to receive a diagnosis from a psychologist or psychiatrist.

ABA

- As of October 1, 2018, ND insurance companies will be required to cover applied behavior analysis (ABA) therapy for ASD. This ND Insurance Department mandate will make ABA more accessible but will also exacerbate the workforce shortages in this area. The bulletin issued by the ND Insurance Department can be found at: https://www.nd.gov/ndins/uploads/20/20180711Bulletin20181.pdf.

Autism Voucher

- There was a discussion regarding families on the voucher who do not make regular purchases. Currently, the families receive a letter if they have not made a purchase within 180 days of voucher enrollment. Once the letter is sent, families are provided an additional 30 days to submit a purchase request or their voucher enrollment will be terminated so that another child may access the voucher funds.

- Suggested change - a letter would be sent after 90 days of inactivity and families would be provided an additional 30 days to submit a purchase request. The voucher program rules are outlined in North Dakota Administrative Code, so any changes would need to

  go through the Administrative Code change process. Other suggestions for changes to Administrative Code will be discussed at the October meeting.

- There was also discussion about families needing assistance on what the voucher can purchase.
  - To provide clarification to families and providers, an addition was made to the voucher purchase request form. On the back of the form, it lists the steps to request item(s) and/or service(s) and it lists what the voucher can purchase.
- There was discussion about adding case management/service management as a voucher service.

Autism Waiver renewal

- The waiver has been submitted to the Centers for Medicare and Medicaid Services (CMS) and they have up to 90 days to approve the waiver. The waiver amendment will renew the waiver for five years. Most of the comments submitted during the public comment period related to:
  - Increase the waiver age to 18. ○ Families want to use respite care while the caregiver is at work/school. ○ There is a need for more providers for waiver services.

Autism Voucher Survey

- In June 2018, a survey was sent to families who have accessed the voucher. Surveys were sent to 53 families; 10 responses were returned.
- Summary of survey responses:
  - Seven of 10 respondents agreed that they had a clear understanding of what the voucher program can be used for. ○ The most frequent response was that the families use the voucher program and the outcomes have been helpful.
  - Written comments were generally positive, indicating that families appreciate the assistance the voucher provides them.
  - A question was asked regarding how many families apply for the autism voucher program and are denied due to the family income being over 200% of the federal poverty level. For voucher year July 2017-June 2018, four families were denied; for July 2018-present, three families have been denied.

Workgroup Updates

- The Workgroup leaders gave recommendations on updates to the state plan. The workgroup leaders should send their recommendations via email to Melanie Phillips, so she can compile them into a final draft for the Task Force to approve at the October meeting.

Telemedicine

- ND Medicaid recently revised its telemedicine policy to include coverage of most services via telemedicine, unless Current Procedural Terminology (CPT) guidelines do not allow. These changes should enable more providers to utilize telemedicine for autism services. The policy is located at: http://www.nd.gov/dhs/info/mmis/docs/telemedicine.pdf.

Services to children and families in rural areas

- Rural families are still having trouble receiving services including ABA and waiver services. There was a discussion on how to get services to families in the rural areas:
    - Rural differential-mileage for providers for travel to rural areas
    - Utilizing telemedicine

Training and orientation for county eligibility workers

- The Department of Human Services (DHS) is looking at modifying the application for Medicaid waiver services.
- There have been concerns regarding the varying practices at each county social service office.

The issue of the eligibility workers being better trained to assist their clients was also discussed.

The Role of Developmental Disabilities Program Managers (DDPMs) in Advising Clients/Families to Move from One Waiver to Another

- It was clarified that the DDPM's role is to explain all the services and eligibility criteria for each waiver to the family and then assist the family with making the decision that would be best meet their needs.

ND ASD Conference

- The annual ND ASD Conference will be held October 24 and 25, 2018 in Grand Forks.
    - DHS could provide funding to support stipends for parents/guardians of a child(ren) with ASD or adults with ASD. Krista Fremming will communicate with Anne Carlsen Center regarding the stipends.

Letter from Senator Heckaman to Maggie Anderson

- Senator Heckaman sent a letter to Maggie Anderson requesting clarification on various items related to autism services. Maggie responded with a letter that answered the questions.
    - The Task Force reviewed the letter and the answers.

Meeting adjourned at 4:45 p.m.

Transcribed: 8.23.2018

APPENDIX L. DATES AND DESCRIPTION OF COLLABORATION ATTEMPTS

8/22/17: First email to a member of the ASD task force. Primary focus on screening for ASD in primary care.

9/25/2017: Follow up email about the ASD database and its use.

3/19/18: Email sent to a member of the ASD task force about presenting a PowerPoint

4/19/18: First mentioned email about the possibility of an ASD task force led survey. As mentioned about at an ASD task force in May, there would be no survey this year.

4/30/18: Primary member of the ASD task force gave the coinvestigator the contact information to a children's work group.

5/1/18, 5/14/18 & 5/25/18: Follow up emails sent to primary member of ASD task force, member of children's work group was out of the state. Finally, the primary member indicated the ASD task force survey was implemented and few health care providers had returned the survey.

7/9/18: Survey numbers still low

8/22/18: Sent out first email to the pediatrician involved in the task force.

9/3/18: First phone call to pediatrician. No response.

9/6/18: Second phone call to pediatrician. No response

9/24/18: Contacted the office of the pediatrician. A message was left.

10/1/18: Contacted the office for a third time. Told I would be contacted soon.

10/4/18: Pediatrician contacted via phone. Pediatrician said the current survey was underway. I asked if data could be shared and was met with resistance.

2/14/2019: ASD task force sends out state wide survey to more health care providers, including nurse practitioners.

APPENDIX M. EXECUTIVE SUMMARY

Autism spectrum disorder (ASD) is a developmental disability that can cause persistent deficits in social communication, behavior, and development. The effects of ASD differs from individual to individual, thus is considered a spectrum disorder. Early screening and intervention are essential for improving outcomes. However, primary care providers' screening rates remain low even though the diagnosis of ASD is possible in children who are 2 years old or younger. On average, children are 4 years or older at the time of diagnosis

In North Dakota, 45% of children are at 5-8 years of age at the time of first ASD diagnosis. Ideally, healthcare providers would recognize the symptoms and refer for diagnosis of ASD as early as 18 months of age. The gap in the age of optimal and actual diagnosis in North Dakota coincides with diagnostic ages seen across the country.

Fewer than 25% of healthcare providers are regularly incorporating screening with standardized instruments into well-child visits and fewer than 10% of healthcare providers are using ASD-specific screening instruments. Healthcare providers blame time as one of the primary reasons for skipping formal development screening at well-child visits. How can healthcare providers increase screening and decrease the age gap in diagnosis? Using a screening toolkit specifically created for healthcare providers seeing children has been identified as a way to combat the low screening rates.

The purpose of the project toolkit was to provide the resources and tools for screening toddlers and children at the well-child visit in a primary care setting. The AAP recommends developmental screening at every visit with ASD specific screening at the 18 and 24-month visits. A universal ASD screening toolkit, whether paper or digital, may improve healthcare provider screening practices.

Objective one was the creation of an ASD toolkit with evidence-based guidelines. Of the 14 primary care providers, 10 returned the completed survey. Objective two was twofold: identifying the current screening gaps and identifying providers' preferred educational delivery methods. Objective three was collaboration with North Dakota's Autism Spectrum Disorder Task Force and ASD leaders to improve ASD screening in primary care. The collaboration involved multiple emails, phone calls, and face-to-face meetings.

Early and continuous surveillance and screening for ASD to ensure that children are identified and receive access to services as early as possible is extremely important. With early and intensive interventions, children with autism can make remarkable progress in all areas. Recent studies indicate that a child with ASD who received early, intensive intervention had a decrease in core symptoms and improvement of intellectual, language, and adaptive skills.

Family practice providers and pediatric healthcare providers consider well-child visits to be important for monitoring growth and development; assessing behavior; conducting vision, hearing or lead screenings; giving immunizations; and coordinating care. With everything that must be completed during one well-child visit, ASD screening may be being missed at a younger age, creating an age gap in diagnosis. To combat this age gap, ND created a task force to evaluate and implement changes in the ASD arena. One way to close the age gap could be the implementation of an ASD toolkit into the offices of primary care/pediatric healthcare providers.