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Guideline for Autism Screening in Primary Care

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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

GUIDELINE FOR AUTISM SCREENING IN PRIMARY CARE

A Capstone Research Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

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College of Natural and Health Sciences
School of Nursing
Nursing Practice

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ABSTRACT

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Autism spectrum disorder (ASD), once thought to be rare, is now considered prevalent, with 1 of every 68 children diagnosed nationwide (Salley, 2016). There is no treatment for ASD, but early therapeutic interventions can help children with ASD live a higher quality of life and achieve major developmental milestones such as language development (Dreyer, 2016). Because ASD can challenge all members of a family, early identification and intervention is vital. This process improvement project was created to enable higher rates of detection for ASD and other developmental delays. The major process improvement intervention was implementing universal screening for ASD during all well-child exams between 18 and 24 months. A guideline was created to help providers know when to screen, what screening tool to use, and how to respond if the screening is abnormal. An educational seminar for all staff involved in the care of pediatric patients also occurred. A chart audit of the guideline and algorithm's clinical use was done to evaluate the successes of the project. To further evaluate outcomes, a staff and provider basic ASD knowledge survey was conducted before and after the education was provided. Finally, steps were taken to work with IT from the electronic health record (EHR) to integrate documentation prompts for providers to ease the use of ASD screening and appropriate billing. With the conclusion of this project, all data

acquired indicated the clinical guideline, algorithm, and educational platform were a success. Screening for ASD increased after the implementation. Furthermore, provider and staff knowledge regarding ASD and ASD screening was enhanced. Further work with this type of process improvement project should be conducted, as indicated with the findings of this study.

Keywords: Autism Spectrum Disorders, M-CHAT R, universal screening algorithm

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LIST OF ABBREVIATIONS

AACN	American Association of Colleges of Nursing
AAP	American Academy of Pediatrics
APA	American Psychiatric Association
AQ	Autism Spectrum Quotient
ASD	Autism Spectrum Disorder
ASQ3	Ages and Stages Questionnaire
ASSQ	Autism Spectrum Screening Questionnaire
CAST	Childhood Autism Syndrome Test
DBC-ASA	Developmental Behavior Checklist Autism Screening Algorithm
DBC-ES	Developmental Behavior Checklist Early Screen
DNP	Doctor of Nursing Practice
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5 th Ed.
EHR	Electronic health records
IRB	Institutional Review Board
IT	Information technology
MA	Medical assistant
M-CHAT R	Modified Checklist for Autism in Toddlers
M-CHAT R/F	Modified Checklist for Autism in Toddlers--Revised Follow-Up
MD	Medical Doctor

NP	Nurse Practitioner
PA	Physician Assistant
POSI	Parents-Observations of Social Interactions
PPV	Positive predictive value
SCQ	Social-Communication Questionnaire
STAT	Screening for Autism in Two-Year-Olds
USPSTF	U.S. Preventive Services Task Force

CHAPTER I

PROBLEM STATEMENT AND PURPOSE

Autism spectrum disorder (ASD) is a class of neurodevelopmental disorders that affect children and adults. As of yet, there is no cure for ASD but early intervention including therapy and education might improve the lives of those living with ASD (Bradshaw, Mossman-Steiner, Gengoux, & Kern-Koegel, 2015). Historically, ASD has been difficult to identify early in primary care (Barton, Dumont-Mathieu, & Fein, 2012). Because of this, delayed diagnosis is all too common. When delayed diagnosis occurs, early intervention and treatment do not happen.

The median age for diagnosis of ASD is over four-years-old (Augustyn, 2016b). Challenges of early identification include time constraints at a typical office visit, the vague nature of social developmental milestones, and the variability of signs and symptoms in children suspected with ASD (Augustyn, 2016a). Cases of ASD range from mild to severe (Johnson, Myers, and American Academy of Pediatrics Council on Children with Disabilities, 2007). With this being said, appropriate diagnosis of ASD is imperative to enhance specific therapies catered to an individual child's disability.

Surveillance for ASD in the primary care setting should begin at nine months and continue throughout the child's youth (Johnson et al., 2007). Screening is often done by use of the Modified Checklist for Autism in Toddlers-Revised (M-CHAT R) between 18 and 24 months of age (Coury, 2015). The M-CHAT R is one of the most widely used

ASD screening tools (Johnson et al., 2007). In practice, early identification of red flags and subsequent screening are clearly variable. Screening practices vary widely not only between clinics but also between providers within any given clinic. For example, some practice sites complete well-child exams with no screening for ASD.

Even with valid and inexpensive screening instruments available, early identification and prompt referral by primary care providers are poor (Robins, 2008). Unfortunately, lack of recognition and referral lead to delayed diagnosis and therapy, both of which contribute to less favorable outcomes for children with ASD (Robins, 2008). The purpose of this process improvement project was to increase education of providers and their awareness of ASD screening.

Background and Synthesis

Autism spectrum disorder is a spectrum of neurodevelopmental disorders (Augustyn, 2016b). In the past, ASD included four subtypes: autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (American Psychiatric Association [APA], 2013). The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013) published new recommendations regarding the classification of ASD. Currently, the range of diagnoses for ASD falls on one spectrum with no subtypes. The single spectrum helps ensure all children, even those with mild phenotypes, can access therapies appropriate for their needs (APA, 2013).

It is often difficult for providers to conceptualize all the symptoms of ASD due to the spectrum of phenotypes (Centers for Disease Control and Prevention [CDC], 2010). Autism spectrum disorder in any form impacts day-to-day functioning and affects quality

of life (Robins, 2008). Patients who are diagnosed with ASD have two distinct characteristics: (a) deficits in social communication and interaction, and (b) restricted, repetitive patterns of behavior, interests, and activities (Augustyn, 2016a). Those with ASD often struggle with functioning in society because of all the deficits that accompany ASD. A few of these challenges include limited communication skills, restricted and repetitive behaviors, and social deficits (CDC, 2010).

Estimates of ASD prevalence vary with different study methodologies and populations, making it difficult to come to an accurate conclusion about several epidemiological data points (Augustyn, 2016b). Autism spectrum disorder is four times more common in males than in females (CDC, 2010). Recent studies indicate ASD in the United States occurs from approximately 1 in 50 to 1 in 500 people (Augustyn, 2016b). Risk factors for ASD include siblings with ASD, tuberous sclerosis complex, Fragile X, Rhett syndrome, various metabolic conditions, Smith-Lemli-Opitz syndrome, and 15q deletions, duplications, triplications, and known chromosomal hot spots (1, 2, 3q, 5p, 7q, 11q, 12q, 13q, 16p, 17, 18q, 21p, 22q, and X; Augustyn, 2016b). Table 1 presents a breakdown of some of the known chromosomal hot spots, chromosomal changes, and known phenotypic changes seen with chromosomal abnormalities (National Institutes of Health, 2016a). At this time, due to on-going extensive research regarding genetic changes in ASD, experts do not know all the phenotypic changes noted in all the hot spots.

Table 1

Known Chromosomal Hot Spots with Phenotypic Changes

Cytogenic Location	Deletion/Duplication	Phenotypic Change	Reference
1	Microduplication	Developmental delay and intellectual delay	NIH, 2016c
3p	Both	Deletion of axon connection in the developing nervous system	NIH, 2016b
7q	Both	DNA building blocks-unknown phenotypic change	NIH, 2016a
15q	Microdeletion	Intellectual disability, seizures, behavioral problems, psychiatric disorders	NIH, 2016d
16p	Both	Developmental delay and intellectual disability	NIH, 2016e
22q	Deletion	Developmental delay, intellectual disability, hypotonia, absent or delayed speech	NIH, 2016f

Although there is a genetic component to ASD, researchers have yet to unlock all the genetic factors that contribute to the development of ASD (Koch, 2014). What is known is genetic factors do play a role in the different phenotypes seen in the spectrum of the disorder (Koch, 2014). The pathogenesis of ASD is not completely understood, making the general consensus of the disorder etiologies to include genetic, congenital, neurobiological, and possible environmental factors (Augustyn, 2016b). Other factors that might contribute to ASD include maternal use of certain medications and advanced maternal age (Koyama, Kamio, Inada, & Inokuchi, 2011). According to Gardener, Spiegelman, and Buka (2009), more research must be done regarding maternal

medication use and risk of ASD. However, as of date, researchers know maternal use of psychoactive drugs increases the risk of ASD (Goldstein, Naglieri, & Ozonoff, 2009).

“Although they observed no significant association for antiepileptics, antihypertensives, cardiovascular drugs, tocolytics, nor use of steroids, a significant 60% increased risk of autism was observed in relation to use of psychoactive drugs” (Gardener et al., 2009, p. 9).

Currently, the number of ASD diagnoses is increasing (Suresh, 2016). While this appears to be a dichotomy, increases in ASD diagnoses would typically indicate greater identification from providers. However, with ASD this is not the case (CDC, 2010). Increases in ASD diagnosis are believed to be related to changes in diagnostic criteria, increased awareness, changes in study methodology, or a combination of these factors (Augustyn, 2016a). With an increase in ASD seen in children, there is an even greater push to identify ASD early in primary care settings (Daniels, Halladay, Shih, Elder, & Dawson, 2014).

In the primary care setting, screening for ASD is a challenge because of limited visit time, lack of education, lack of resources, vague nature of symptoms, lack of discussion regarding the achievement of milestones, and large variability of symptoms (Augustyn, 2016a). Delayed diagnosis is a concern as it can delay early intervention. Several different screening tools can be utilized by primary care providers for primary screening. Current recommendations for screening are screening for red flags at every well-child visit, conduction of developmental screening tests between 9 and 30 months, conducting autism-specific screening between 18 and 24 months, and raising any

developmental concerns by caregivers (Dreyer, 2016). Table 2 provides a summary of valid screening tools for ASD in primary care.

Table 2

Screening Tools for Autism Spectrum Disorder

Tool	Age	Description	Sensitivity and Specificity in Percentage
M-CHAT R	16-30 months	<ul style="list-style-type: none"> • 20 parent-report items • Takes approximately 5 minutes to administer and 2 minutes to score 	Sensitivity: 85 Specificity: 99
STAT	24-36 months	<ul style="list-style-type: none"> • 12 observed activities during a 20-minute play session • Requires training for administration and scoring 	Sensitivity: 92 to 95 Specificity: 73 to 85
POSI	18-35 months	<ul style="list-style-type: none"> • 7 item parent-report items, a component of the Survey of Wellbeing of Young Children (SWYC) • Takes \leq 5 minutes to complete 	Sensitivity: 83 Specificity: 74
SCQ	4-40 years	<ul style="list-style-type: none"> • 40 parent-report items (yes/no) • Takes < 10 minutes to administer and < 5 minutes to score 	Sensitivity: 85 Specificity: 75
CAST	4-11 years	37 parent reported items	Accuracy varied with case definition
ASSQ	7-16 years	27-item checklist to be completed by parents or teachers and takes about 10 minutes to complete	Sensitivity: 91 Specificity: 86
AQ	4-11 years	Parent report measure	Sensitivity: 95 Specificity: 95
DBC-ASA	4-18 years	29 parent-report items from the DBC-P	Sensitivity: 86 Specificity: 79 (with cut-off score of 17)
DBC-ES	18-48 months	17 parent-report items from the DBC-P	Sensitivity: 88 Specificity: 69

Note. M-CHAT R = Modified checklist for Autism in toddlers with revised follow-up; STAT = Screening for Autism in Two-Year-Olds; POSI = Parents-Observations of Social Interactions; SCQ = Social-Communication Questionnaire; CAST = Childhood Autism Syndrome Test; ASSQ = Autism Spectrum Screening Questionnaire; AQ = Autism Spectrum Quotient; DBC-ASA = Developmental Behavior Checklist Autism Screening Algorithm; DBC-ES = Developmental Behavior Checklist Early Screen
Source. Bridgemohan, 2016a, pp. 13-14

These screening tools include M-CHAT R, screening for autism in two-year-olds (STAT), infant-toddler checklist, parent-observations of social interactions (POSI), social-communication questionnaire (SCQ), childhood autism syndrome test (CAST), autism spectrum screening questionnaire (ASSQ), autism spectrum quotient (AQ), developmental behavior checklist autism screening algorithm (DBC-ASA), and developmental behavior checklist early screen (DBC-ES; Barton et al., 2012).

The M-CHAT R was developed for primary care providers to identify suspected cases of developmental disorders (Robins, 2008). When a suspected case is identified, the child is then referred to a developmental pediatric specialist who administers further testing to narrow down what type of developmental delay the child might have. The instrument utilized to diagnose ASD varies between providers and is considered with the patient's gestational and chronological age (Robins, 2008). In the primary care setting, M-CHAT R is the most widely used questionnaire (Robins, 2008) because it is quick to administer and score, feasible and accurate, free to providers and parents, and is recommended by the American Pediatric Association in practice (Dreyer, 2016).

Unfortunately, both general developmental screening tools and autism-specific screening tools have limitations. For example, they have limited sensitivity, which restricts the tool's ability to identify young children with ASD (Barton et al., 2012). Available tools also have a low specificity, which limits the ability to discriminate ASD from other developmental disorders (Robins, 2008). Another concern is tools largely rely on parental reports that can be inaccurate, particularly when screening older children (Barton et al., 2012). For these reasons, screening and diagnosis of ASD is a challenge for primary care providers. With an abundance of different screening tools, all with

limited specificity and sensitivity, restrictive time during office visits to perform screening, and lack of education for providers regarding high-risk populations and red flags, delayed diagnosis among suspected ASD children might be all too common.

Improving provider education regarding knowledge of high-risk populations and red flags is a modifiable challenge. Furthermore, by improving provider knowledge, restrictive office time could be somewhat alleviated by quicker screening time because of improved knowledge.

As discussed previously, surveillance for ASD should occur at every well-child check starting at nine months (Johnson et al., 2007). Furthermore, the focus of the provider is to identify any red flags and then perform further screening as necessary. Red flags of ASD help providers identify potential risks of developmental delay and ASD. Subsequently, further screening can be performed using an appropriate age-related screening tool or referral to an ASD expert if necessary. Known red flags of ASD are as follows:

- Delayed language and social/communication skills
- No babbling by nine months
- No single words by 16 months
- Avoids or inconsistent eye contact
- Repeats or echoes words or phrases said to them or heard on TV
- Has trouble requesting or expressing needs through typical words or gestures
- No spontaneous, meaningful (not repetitive or echolalic) two-word phrases by 24 months
- Any loss of language or social skills at any age
- Lack of orientation to name by 12 months
- Lack of pretend or symbolic play by 18 months
- No pointing gestures by 12 months
- Restrictive and repetitive behaviors
- Parental concerns about deficits in social skills
- Parental concerns about deficits in language skills or behavior

- Parental concerns about frequent temper tantrums or intolerance to change. (Bridgemohan, 2016b, p. 14)

Recently, the U.S. Preventive Services Task Force (USPSTF) published revised recommendations that state, “The USPSTF found insufficient evidence on screening for ASD in children aged 18 to 30 months for whom no concerns of ASD have been raised by parents, other caregivers, or healthcare professionals (I statement)” (Siu et al., 2016, p. 315). Because of the newly published recommendations about ASD screening, more education for providers, patient care guidelines, and referral and treatment algorithms need to be established for primary care settings to identify high-risk behaviors, times to screen using the autism-specific screening tools, and times to appropriately refer for those screening positive. Identifying these times would promote prompt identification and early interventions for ASD. In light of the USPSTF recommendations, the American Academy of Pediatrics (AAP) still recommends universal screening at 18 and 24 months due to extensive evidence to support these actions:

Although the USPSTF report found evidence for valid screening tools to detect ASD in toddlers and evidence that early intervention has positive effects on prognosis for children, they concluded that the lack of studies showing long-term outcomes from ASD screening means that there is insufficient evidence for universal toddler screening for ASD. (Robins et al., 2016, p. 1880)

For this reason, process improvement strategies must be implemented to improve early detection, increase prompt referral to early intervention, and evaluate long-term outcomes. Having two organizations recommending different screening measures adds confusion and frustration to diagnosing this already complicated disorder. The USPSTF (Siu et al., 2016) recommendation indicates evaluation should occur in instances where concerns have been discussed either by caregivers or other medical professionals

regarding ASD. The barrier to the USPSTF recommendation, however, is caregivers and healthcare professionals alike are not routinely educated regarding ASD red flags and risk factors. According to Rhoades, Scarpa, and Salley (2007), some healthcare professionals have less than adequate training with regard to ASD surveillance. Their study helped provide evidence that more education for medical professionals is necessary. “We recommend that all physicians receive specialized training about ASD to improve upon early screening and diagnosis, and then advise caregivers about empirically-supported services” (Rhoades et al., 2007, p. 1). With the evidentiary support discussed, it was advisable for this study to remain in-line with the AAP universal ASD screening recommendation.

Early screening leading to early intervention is vital to encourage higher quality communication skills as well as child-specific education programs, to decrease challenging behaviors, and to enhance the family’s quality of life. Early intervention and therapy can occur at early intervention programs, school-based special education programs, or by therapists in private settings (Bradshaw et al., 2015). Behavioral and educational interventions are aimed to address deficits in communication, social interactions, interests, and activities (Bradshaw et al., 2015). Psychopharmacologic interventions can also address anxiety, depression, and other symptoms like insomnia or constipation (Bridgemohan, 2016c). “There is increasing evidence that intervention is more effective when initiated as early as possible. The establishment of appropriate management strategies in the early years can help to minimize or even avoid subsequent behavioral problems” (Bridgemohan, 2016c, p. 2). Many specialists are involved in early ASD intervention: developmental pediatricians, child neurologists, child psychiatrists,

psychologists, genetic counselors, speech language pathologists, occupational therapists, audiologists, and social workers. The primary care provider plays a large role in caring for children with ASD in initial identification, caring for the family, and ongoing management of routine care. Early identification by the primary care provider is perhaps the most important role in the promotion of positive outcomes for ASD children and their families (Barton et al., 2012).

An important consideration of ASD is other symptoms that accompany ASD. For example, constipation and insomnia are common symptoms seen in ASD. This is a grave concern for caregivers and patients alike. Lack of sleep for all parties involved can cause depression, fatigue, and anxiety. “In typically developing children sleep problems and insufficient sleep can result in daytime sleepiness, learning problems and behavioral issues such as hyperactivity, inattentiveness and aggression” (Lamm, 2016, p. 1). Figure 1 provides a high-quality summary of the symptoms that can be seen with ASD and are important to consider as a primary care provider. All these factors contribute to the vital importance of early diagnosis and intervention because early intervention has the potential to improve quality of life for children and families.

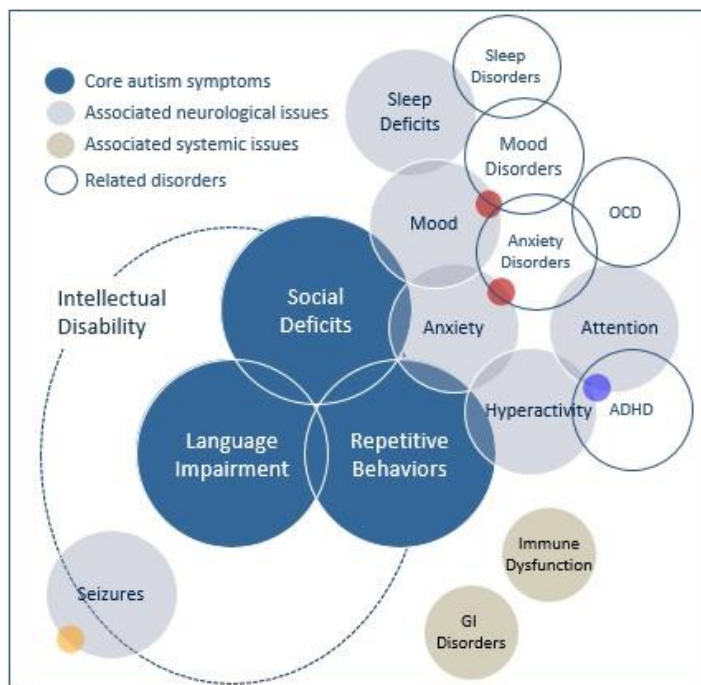


Figure 1. Symptoms of autism spectrum disorder (Lamm, 2016, p. 1).

Parent-reported screening tools play an important role in the care of pediatric patients (Dreyer, 2016). The M-CHAT R and M-CHAT R/F are parent-reported screening tools that can be universally given usually at 18 and 24 months but can also be given up to 30 months (Robins, 2008). These tools screen for ASD in those at risk for ASD or those with developmental delays (Robins, 2008). Both instruments are free and can be found online (Dreyer, 2016). Both screening tests are feasible, simple to use, accurate, and recommended by the AAP in practice (Dreyer, 2016).

The M-CHAT R takes five minutes to administer and score. The M-CHAT R/F takes 10 to 15 minutes to administer and score (Robins, 2008); it is given only at follow-up appointments after the M-CHAT R has been administered and results are shown to be positive or abnormal (Robins, 2008). The M-CHAT R/F is a two-staged tool similar to

the M-CHAT R instrument, which can be utilized from 16 to 30 months of age (Robins, 2008). The first part of the instrument includes 20 questions designed to address core symptoms of ASD (Robins, 2008). The test takes five minutes to administer and two minutes to score. The second part of the exam is a follow-up questionnaire that seeks additional information and examples of any high-risk behaviors (Robins, 2008). The second stage of testing takes 5 to 10 minutes to administer. If a child scores medium or high from the first stage, then the second stage of the tool is to be administered. If the second part of the M-CHAT R/F is positive or if the first part scores 8 to 20, then immediate referral for diagnostic evaluation and early intervention is appropriate (Robins, 2008). The M-CHAT R is provided in Appendix A.

Literature Review

Robins' (2008) research study was important for this type of process improvement project. The study was conducted from March 2005 to October 2007 in Metro-Atlanta (Robins, 2008). It focused on children ages 16 to 26.9 months to cover any overlap from 18 months to 24 months in well-child exams. The purpose of the study was to evaluate if M-CHAT R and M-CHAT R/F were effective in the identification of ASD in primary care (Robins, 2008). The outcome of the study indicated level-one screening for ASD in primary care was feasible. "Therefore, the positive predictive value (PPV) for M-CHAT R plus interview was calculated as 21 of 37 screen-positive completed cases, which brings the PPV to .57" (Robins, 2008, p. 552). These findings indicated a substantial portion of the overall sample size ($n = 4,797$) with a positive screen on the M-CHAT R also screened positive on the M-CHAT R/F and were subsequently diagnosed with ASD by a specialist (Robins, 2008). Furthermore, findings

of the study indicated primary surveillance without ASD specific screening at 18 and 24 months was not sufficient enough to identify and refer those with suspected ASD or other developmental delays (Robins, 2008). As mentioned in the background, primary surveillance is a hyperawareness of ASD red flags and risk factors; consistently monitoring for any abnormalities should occur at every appointment. The recent USPSTF (Siu et al., 2016) recommendations on ASD screening could be argued with this research study, which indicated there was sufficient evidence to screen for ASD in primary care rather than just utilizing primary surveillance for ASD awareness (Robins, 2008).

Robins' (2008) work is important to consider when implementing a guideline for universal ASD screening in primary care because it demonstrated the M-CHAT R had a high PPV and was feasible to implement. The one factor not discussed in current available research was provider satisfaction related to use of this screening tool (Robins, 2008). There is provider resistance any time a provider must take more time away from subjective and objective provider practice to administer another screening.

Unfortunately, Robins does not discuss the feasibility of implementation in practice from the provider's viewpoint. Although false positives in the study were not diagnosed with ASD, developmental delays might still need to be evaluated, addressed, and documented (Robins, 2008). If a child is not diagnosed with ASD, this does not mean speech therapy is not indicated for speech delays. An evidence-based guideline is key to provider buy-in. Robins helps to prove the M-CHAT R and M-CHAT R/F are feasible to utilize as level-one universal ASD screening along with primary surveillance to combat delayed diagnosis and intervention for ASD.

This conclusion is consistent with the recent AAP policy statement and autism-specific screening guidelines which call for ASD specific screening at 18- and 24-month well-child visits, alongside routine ASD surveillance and broad land screening for other developmental disorders. (Robins, 2008, p. 552)

Implementing a guideline for universal screening has the potential to provide plenty of provider strain and ancillary staff frustration. By streamlining the process and supporting the integration of autism-specific screening into primary care by high-quality research, stakeholder buy-in could be simplified. Barton et al.'s (2012) work aimed to simplify the process by reviewing all of the screening tools currently in use in addition to providing specific recommendations of each. Their systematic review provided a thorough review of literature on the best timeframe to screen for ASD as well as the importance of early screening, which was vital to this project. "The use of formal screens in addition to primary care surveillance appears to augment the effectiveness of surveillance in identifying children with ASD and reduces disparities between racial and ethnic groups" (Barton et al., 2012, p. 1166).

Barton et al.'s (2012) research supports the AAP recommendation for universal screening at 18 and 24 months along with primary ASD surveillance: "Therefore, screening at 18 months and again at 24 months, is likely to identify the largest number of children without compromising specificity" (p. 1167). To support the use of universal screening using a screening tool, criteria for the quality of the screening tool are needed. With regard to the M-CHAT R, sensitivity and specificity are reported to be high with levels of accuracy at .87 and .99, respectively (Barton et al., 2012). Acceptable sensitivity, specificity, and PPV signify a high-quality instrument supported for use with patients.

Another interesting component to Barton et al.'s (2012) systematic review was the discussion about barriers to ASD screening in primary care. This discussion could help combat any barriers to implementing a guideline for screening in primary care. The common theme addressed by all providers with regard to screening was demand on provider time and task to time ratio (Barton et al., 2012). Providers do not have enough time to address all components of disease prevention and lifestyle management in a single appointment. On top of this, providers experience staff shortages and frequent turnover. Ancillary staff are vital to patient care and necessary to implement autism-specific screening in primary care (Barton et al., 2012).

As discussed previously, known disparities in the screening for ASD disorders and other developmental delays are based on race, ethnicity, and socioeconomic status (Barton et al., 2012). By implementing universal screening on all 18- and 24-month well-child exams, this disparity could be alleviated. Barton et al. (2012) discussed this disparity in length; by reviewing data on ASD screening, their recommendation was in-line with AAP's recommendation to universally screen:

When providers use validated screening tools to begin a process of discussion and referral, they support all parents in further understanding early development and securing the resources that they may need to facilitate each child's optimal development. (p. 1172)

To have improved provider and patient results when implementing a guideline for autism-specific screening, there must be concrete evidence the process change is beneficial, evidence-based, and feasible. Daniels et al. (2014) conducted a systematic review of literature to provide the support necessary for practice change. The methodology for this review included a search of peer-reviewed and gray literature from January 1990 to January 2013 where ASD testing approaches were utilized to increase

early detection (Daniels et al., 2014). The search discovered 40 studies using 35 different methods of autism-specific screening. These studies were divided into the following categories: awareness, routine screening, and practice improvement to enhance screening. Twenty-five studies used 21 screening approaches directly related to routine screening (Daniels et al., 2014). Of the 25 studies, 22 implemented routine screening during well-child visits only. The two most common screening methods included the Ages and Stages (ASQ3) questionnaire and the M-CHAT R (Daniels et al., 2014).

The outcomes of the studies were all positive with regard to increasing overall provider awareness, referral, and diagnosis of ASD and other developmental delays (Daniels et al., 2014). “With respect to referral rates, one study found a 224% increase in post-intervention, and another documented a significant increase among 3-year old children only” (Daniels et al., 2014, p. 149). By implementing universal screening, there was an increase in awareness, referral rates, diagnosis, improvement of delayed diagnosis, and referral to early therapy. These data showed by performing universal screening for ASD, positive outcomes were more likely to occur (Daniels et al., 2014). Missed opportunities for early intervention are all too common in primary care. By using the M-CHAT R, M-CHAT R/F, and by following the guideline provided from this process improvement project, missed opportunities could be drastically reduced (Daniels et al., 2014).

This systematic review of literature was important for this project because it provided solid evidence necessary to prove change needed to happen and change was feasible (Daniels et al., 2014). With the USPSTF (Siu et al., 2016) publishing new guidelines that stated there was insufficient evidence and with the AAP (Dreyer, 2016)

saying there was sufficient evidence, Daniels et al.'s (2014) systematic review supported the AAP recommendation: "For the most part, studies implementing routine screening found high (>80%) or significantly increased screening and referral rates" (p. 148). With a disorder like ASD and developmental delays, early intervention is the only way to improve the quality of life for these children (Daniels et al., 2014). If primary care providers do not screen, children lose the opportunity for early intervention. Routine screening in primary care is key to reducing delayed diagnosis and improving developmental outcomes and quality of life (Daniels et al., 2014).

Bradshaw et al.'s systematic review (2015) was the concluding piece for this literature review. To implement universal screening for ASD in primary care, treatments and interventions for the disorder need to be available, feasible, and effective; otherwise, screening is wasteful. There must also be adequate physician buy-in, ease of transition, and physician satisfaction. As mentioned previously, early therapy is the only current intervention provided to those believed to have the disorder or those at risk for developmental delay (Bradshaw et al., 2015). Bradshaw et al.'s systematic review provided the evidence regarding the feasibility and effectiveness of early intervention for toddlers--the target age population for this process improvement project (well-child exams at 18 and 24 months).

Bradshaw et al.'s (2015) systematic review focused on reviewing interventions utilized in infants and toddlers under 24 months of age at risk or who had ASD. Nine studies were reviewed for participants, intervention approach, experimental design, and outcomes. The outcome of the studies unanimously indicated early intervention is feasible and effective in infants and toddlers (Bradshaw et al., 2015). "These studies

highlight the feasibility of very early intervention and provide preliminary evidence that intervention for at-risk infants may be beneficial for infants and parents” (Bradshaw et al., 2015, p. 778). Early intervention begun in infancy is vital as it is when early intervention is most impactful. “Beginning at birth, early attentional preferences for social stimuli foster the emergence of social communication” (Bradshaw et al., 2015, p. 779). When utilizing universal screening for ASD and other developmental delays, there must be proof the process change will have a positive impact. Bradshaw et al.’s systematic review provided evidence backed by research that if ASD was identified early by routine screening, early intervention was feasible and effective. Early ASD identification through routine screening allows a higher quality of care be provided to children (Bradshaw et al., 2015).

To conclude, the review of the ASD specific literature provided a summary focusing on the impact of universal screening for ASD and other developmental disorders. The screening process could be simplified with the use of standardized and valid screening tools such as the M-CHAT R and M-CHAT-R/F due to simplicity in both administration and scoring (Robins, 2008). The M-CHAT R and M-CHAT R/F are high-quality instruments when considering PPV, specificity, and sensitivity discussed in Daniels et al.’s (2014) research. In addressing a process improvement change, staff and provider challenges must be addressed. Barton et al. (2012) provided a thorough discussion of these challenges. By highlighting these challenges early, process improvement changes can be implemented with ease because the challenges and frustrations are tackled head on.

Daniels et al.'s (2014) research was vital to this project because it provided a systematic review of ASD screening that backed the use of universal screening in primary care. Their research also lent support to AAP (Dreyer, 2016) recommendations for autism-specific screening. Bradshaw et al.'s (2015) systematic review argued universal screening is important because early intervention is effective and feasible. Routine screening for ASD and other developmental disorders is vital in primary care because it enables early identification and early intervention; it also combats the burden of disease, improves quality of life, and enables developmental milestone successes (Daniels et al., 2014; Robins, 2008).

The purpose of this study was to directly combat the barrier of delayed ASD diagnosis. Implementing universal ASD screening at every well-child visit at 18 and 24 months using the evidence-based M-CHAT R screening tool at a clinic where no screening occurs was the process change of this study. Following the AAP (Dreyer, 2016) ASD screening recommendation, while also taking into consideration the information gathered in the literature review, this study was evidence-based and doable within primary practice.

Synthesis Summary

Surveillance and screening for ASD in the primary care setting is vital to promote health, decrease the burden of disease, and improve the quality of life for children with ASD and their families (Daniels et al., 2014). Early screening and identification of ASD is the most critical role primary care providers can play (Robins, 2008). If delayed diagnosis of ASD occurs, then early intervention is withheld. Primary care providers are the key to decreasing the rate of delayed diagnosis of ASD in children (Barton et al.,

2012). By establishing a guideline and algorithm for surveillance and screening in the primary care setting, providers can consistently provide high-quality, prompt diagnosis and intervention for ASD.

Theoretical Framework

Creating a guideline for a primary care setting required consideration of the impact a potential practice change might have on the facility. By utilizing the Stetler (2001) model, any practice changes that arose from the guideline were considered, addressed, and evaluated. The Stetler model is a research utilization model that can be applied to an individual practice of providers. It ultimately allows providers to incorporate research findings into their individual practice (Stetler, 2001). This model follows six phases that allow for research to enter practice:

- Phase I: Preparation
- Phase I: Validation
- Phase III: Comparative Evaluation
- Phase IV: Decision Making
- Phase V: Translation and Application
- Phase VI: Evaluation

These six phases facilitate the implementation of research. The Stetler (2001) model allocates the following: (a) time for research with preparation, (b) validation of research by extensive literature reviews and a comparative evaluation if applicable, (c) decision making with providers by presenting the research, (d) translating the research to a practice change and applying any practice changes to practice, and (e) evaluating the effectiveness or even flaws of the practice change. By following the Stetler model, any

evidence-based practice guidelines could be created, implemented, and evaluated without making provider practice more challenging. The Stetler model was used to create the guideline for ASD screening in the primary care setting (see Figure 2).

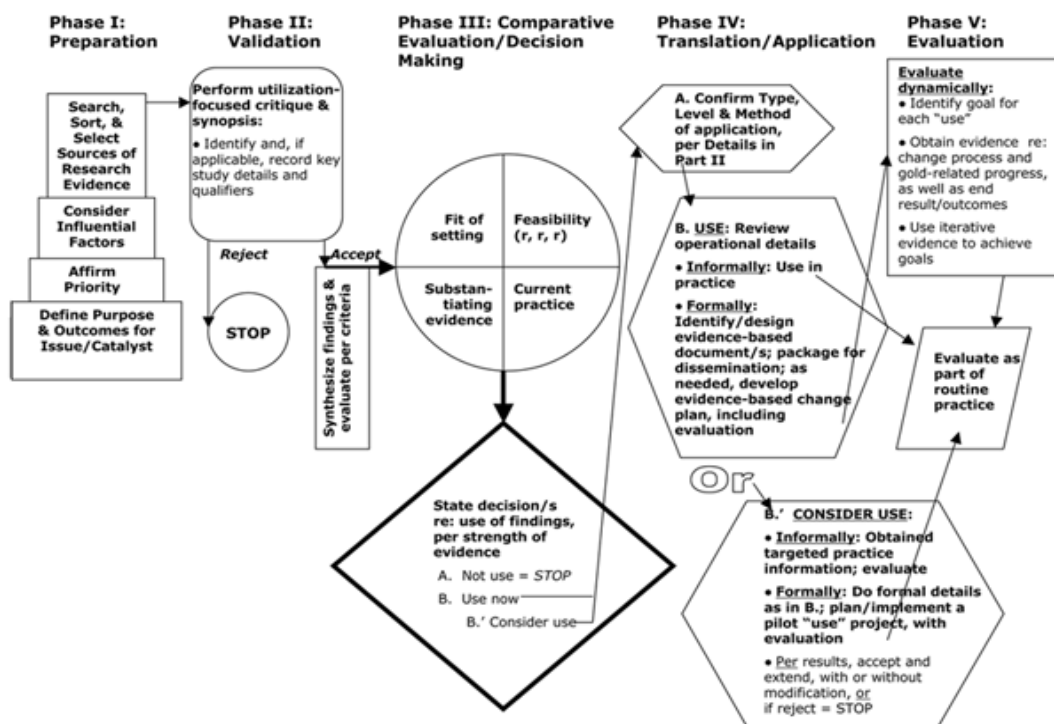


Figure 2. Updating the Stetler model of research utilization to facilitate evidence-based practice (Stetler, 2001, p. 273).

Nursing Theory

Nursing theory is an important component to consider when creating an evidence-based capstone project. In consideration of ASD, developmental delay, and families, nursing theory is a key component in creating a meaningful project that improves the delivery of health care, decreases the burden of disease, and helps providers be empathetic and care for the families as ASD is a challenging disorder. Mishel's (1990) middle-range nursing theory was easily applied to this project (see Figure 3).

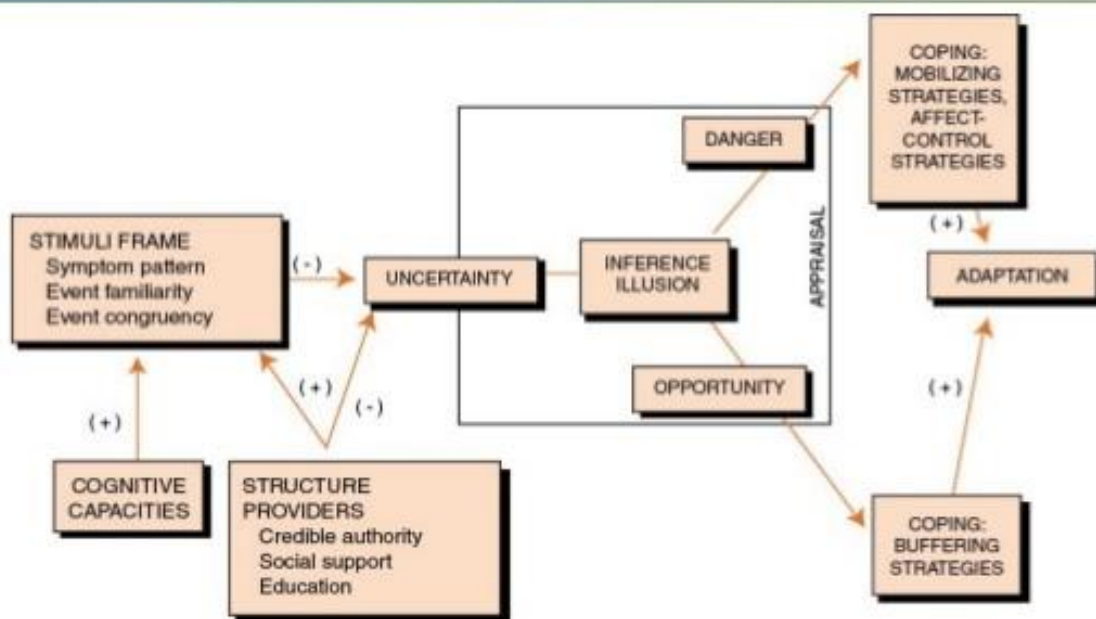


Figure 3. Reconceptualization of the uncertainty in illness theory (Mishel, 1990, p. 256).

The theory was originally created for cancer and chronic-illness but has since evolved (Mishel, 1990). Now, it can be applied to those with cancer, chronic illness, life-threatening illness, and psychological responses to disease. The theory's focus is managing the uncertainty that can accompany disease (Mishel, 1990). Disease, including neurodevelopmental disorders like ASD, as a concept is challenging, even with self-limiting disease. No outcome is ever certain with health care. With ASD, so much uncertainty plagues all parties involved. Even with early intervention, uncertainty is rampant; however, with an available evidence-based screening guideline to enhance early diagnosis and intervention, the uncertainty of ASD can be addressed aggressively to achieve the highest quality of life possible for patients and families.

CHAPTER II

PROJECT OBJECTIVES

Objectives for the capstone project were built upon the preceding review of literature. Other important components that built upon the preceding literature review were consulting with experts in the field and critiquing numerous resources regarding guidelines for autism in the primary care setting. By performing the necessary groundwork, the highest quality guideline and algorithm for ASD screening at a primary care clinic was developed.

There were three main objectives for this project. The first objective of the project was to compile all the information gathered during research to create a guideline and algorithm a primary care clinic could utilize for universal ASD screening. To complete the first objective, it was imperative to work with the clinic manager, medical assistant (MA), and nurse practitioner (NP) staff to make the guideline and algorithm system-specific to fit their needs. The second objective was to work with information technology (IT) to improve electronic health record (EHR) documentation of ASD screening for the same primary care clinic. The third objective was to evaluate the effectiveness of guideline implementation.

To evaluate the outcome of the project and the use of the guideline and algorithm, a chart audit was performed. Secondly, due to the evaluative nature of the educational program, the clinic staff including all providers and MAs were asked to complete a

survey before and after the educational offering. These two outcome objectives provided a thorough summary of the successes of this process improvement project.

Intervention Plan

By using evidence-based practice, the focus of this project was to create a guideline and algorithm for primary care settings with regard to ASD screening. The guideline was created utilizing a literature analysis, expert opinions, and a comparison of other facilities' guidelines for autism screening. Steps that occurred to create the guideline included (a) creating a phenomena of interest for ASD screening in primary care, (b) reviewing literature to back the creation of a new guideline, (c) analyzing the literature, (d) interviewing experts, (e) critiquing at least two other guidelines from other clinics where ASD screening was practiced, (f) working closely with a primary care clinic's protocol department to establish rules and needs of the facility for a guideline, and (g) using all the information gathered to create the guideline.

The burden of disease for children with ASD is high and delayed diagnosis is all too common in primary care (Augustyn, 2016b). Establishing a quick reference and easy to understand guideline for providers to follow on how to screen for ASD appropriately would consider the limited provider and patient face-to-face time. The algorithm would provide a quick reference of red flags providers must catch during any visit with a child, especially with well-child checks. The intervention plan for this project was established by following similar steps from exemplar process improvement projects.

To teach the guideline, two educational seminars were held with all the providers and staff at the clinic to re-educate as well as provide the new guideline and algorithm for autism-specific screening. Being an educational clinic, it is common practice to provide

educational seminars periodically throughout the year. Taking advantage of this format, one of the pre-existing educational seminar topics focused around screening for ASD--the focus of this capstone project. The educational programs lasted approximately 60 minutes.

Data Collection Details

To evaluate the success or failure of this project, a chart audit was performed. Furthermore, due to the evaluative nature of the educational program, the clinic staff (primary care providers including NPs and all the clinic MAs) were asked to complete a survey before and after the educational offering. Providers and staff were approached at the beginning of the educational session and asked to consider being in the study. Consent forms were distributed (see Appendix B) along with Part 1 of the survey. The educational program lasted approximately 60 minutes. After the program ended, the consented participants completed Part 2 of the survey. As seen in Appendix C, Parts 1 and 2 of the survey are very similar other than Part 2 of the survey has some additional questions about the program itself. Parts 1 and 2 of the survey were not connected to participants but rather aggregate data were reported and compared. As one might expect, Part 2 program evaluation data will inform future educational sessions and were also anonymous in nature. Although no strict qualitative evaluation took place on evaluation data from Part 2 of the survey, information was collected to inform future program offerings and was deemed important to the clinic by the outside committee member.

Performing a thorough chart audit of this process improvement project was vital to measure process improvement outcomes. The chart audit focused on the following timeframes: pre-educational seminar (three months) and post-educational seminar (six

weeks--early Spring 2017). The timeframe accounted for the necessary educational seminars so all staff could participate at the clinic in early January and EHR update. The chart audit evaluated all well-child exams from 16 to 30 months (this was the recommended time frame for when the M-CHAT R and M-CHAT R/F should be administered).

Chart review data points included whether or not screening was done with both the general developmental screening, ASQ3 and autism-specific screening, M-CHAT R, whether a referral for diagnosis was made--“yes” or “no,” and whether a referral for disability evaluation for ASD was made--“yes” or “no.” This evaluation method solely focused on assessing if providers screened appropriately and utilized appropriate documentation. Simple descriptive statistics to describe the number of charts reviewed, percentage in each age category, and numbers of positive and negative data points for each variable are reported.

Congruence of Organization’s Strategic Plan to Project

For completion of this project, a key group of organizations agreed on the strategic plan to create the project guideline and algorithm: University of Northern Colorado School of Nursing and three northern Colorado clinics. The clinics provide care for all patients throughout the lifespan, pediatrics, obstetrics, and geriatrics. They average an overall patient base of approximately 90,000. They care for Medicare, Medicaid, private insurance, and self-pay patients. Providers include MDs, Doctors of Osteopathy (DOs), NPs, and physician assistants (PAs). One of the clinics discussed above was the intended sight for the study. This clinic also has a MD residency program, offering an even greater opportunity for provider learning since the facility is a teaching

environment. The clinic has six NPs, seven MD faculty providers, and 38 first to third year family practice resident MDs. The latter two organizations contributed to the project by providing expert opinions and exemplars of similar protocols or guidelines for ASD screening used at their facilities. An expert in the region on ASD and ASD screening provided expert opinions from a multidisciplinary approach including developmental pediatricians, psychologists, therapists, and social work. This facility also provided exemplars of guidelines utilized in primary care for ASD screening. Lastly, Children's Hospital of Colorado's Developmental and Behavioral Clinic provided hands-on clinical experience by allowing participation in the diagnosis of ASD from a multidisciplinary approach. As mentioned, a single primary care clinic was the facility where the initial need for the guideline was identified. Therefore, the ASD screening guideline and algorithm for primary care settings was created for this clinic. The University of Northern Colorado School of Nursing worked closely with the author of the project to follow all rules and regulations regarding any ethical and legal concerns as well as guidance and advice. At this time, these were the only organizations involved with the project.

Timeline of Project Phases

The goal of this project was to follow the timeline below:

Summer 2016—Phenomenon of interest approval

Summer 2016—Literature review and synthesis

Summer 2016—Initial writing of proposal for project completed

Fall 2016—Defense of proposal

Fall 2016—Institutional Review Board (IRB) approval (see Appendix D)

Early Spring 2017—Educational seminar for all staff

Late Spring 2017—Chart audit as well as provider and staff interviews

Summer 2017—Final evaluation

Summer 2017—Capstone project completion

Summer 2017—University of Northern Colorado capstone project approval

Resources

There was no need for a budget because funds were unnecessary to complete any component of the project. There was a need for outside personnel to be involved with the project. The greatest contributor to expert opinion and providing exemplar guidelines was the Children’s Hospital Developmental and Behavioral Department. This department agreed to spend four days with the author of the project to educate the author on (a) ASD, (b) the burden of the disease, (c) screening techniques, (d) multidisciplinary approach of diagnosis, (e) early intervention details and education, and (f) social work aspects of the disorder. The Children’s Hospital Developmental and Behavioral Department also provided exemplar guidelines for ASD screening in the primary care setting. Other personnel utilized to complete research for the project and to provide guidance along the way were aware no financial resources would be used and all had affiliation agreements with the University of Northern Colorado.

Stakeholders

There were many stakeholders for this project. Stakeholders from the University of Northern Colorado included the School of Nursing, the Graduate School, committee members of the project, and the author. Other stakeholders included the primary care

clinic where the study occurred including office managers, program directors, IT, and EHR support staff.

Strategic Analysis

To perform a strategic analysis for this project, a strengths-weaknesses-opportunities-threats (SWOT) exemplar was used. The SWOT tool analyzes all factors contributing to the successes and/or failures of a process improvement project (United States Department of Agriculture, Risk Management Agency, 2008). Change can be challenging, especially in health care. With change comes uncertainty. The reason a strategic analysis should always be done is to assure the process improvement project does improve the process, does not negatively affect patients or providers, and assures the highest quality of care occurs.

Strengths

The strengths of this project included evidence-based, simple-to-use guidelines, improvement of identification of any concerns or red flags of developmental delays and/or ASD, provider education, learning opportunities for the author, expert opinion and literature to support the guideline, thorough evaluation of the process change, and proof there was a need for this type of project.

Weaknesses

The weaknesses of this project included a limited time frame to perform chart audits, implementation of a guideline rather than a protocol, and limited high-quality research (systematic reviews) to support the guideline.

Opportunities

Opportunities of this project included learning, improved patient care, increased awareness of developmental milestones, improved early diagnosis and intervention for ASD, and improved documentation of developmental or lack of developmental milestones.

Threats

Threats of this project included resistance of providers to practice change, lack of willingness of stakeholders to participate, limited timeframe of chart audits, difference of timeframe of the chart audits, and lack of high quality evidence (systematic reviews) to support the guideline.

CHAPTER III

EVALUATION PLAN

To accurately measure and evaluate each objective, it was important to address each objective separately.

Objective One

The goal of the first objective was to compile all the information gathered during research to create the guideline and algorithm the primary care clinic would utilize for universal ASD screening. To complete the first objective, it was imperative to work with the clinic manager, MA, and NP staff to make the guideline and algorithm system was specific to fit their needs. The goal was to allow primary care providers to have a simple, quick guideline to appropriately screen all pediatric patients at 18- and 24-month well-child exams. This objective helped to apply research to practice. Once the guideline was established, education to the providers and staff occurred--two educational seminars were provided with a PowerPoint presentation of the basic education regarding ASD, ASD screening, and the guideline and algorithm . Moreover, paper and electronic copies of the guideline and algorithm were provided. The goal was to re-educate providers and clinic staff regarding ASD, red flags, consequences of delayed diagnosis, and the importance of appropriately identifying and referring any developmental delays. The pre-intervention education and implementation of the interventions occurred from July 2016 to December 2016.

Objective Two

The second objective was to work with IT to improve EHR documentation of ASD screening for the same primary care clinic. This objective occurred in conjunction with the first objective. The overall goal of the second objective was to enable higher rates of provider satisfaction by utilizing EHR technology to allow for quicker screening utilizing a specific designated place to document the screening was performed. By having EHR ability to document the M-CHAT R, improved overall documentation was likely to occur.

Objective Three

The third objective was to evaluate the effectiveness of guideline and algorithm implementation. The overall focus of this objective was to see an improvement in patient care outcomes and improved provider satisfaction. By fulfilling objectives one and two, the intent was to have improved documentation of any red flags raised during well-child exams, overall increase in the awareness of red flags for autism, an increase in the occurrence of M-CHAT R and general developmental screenings, the documentation of these screenings on appropriate patients, an increase in referral to behavioral and developmental specialists and other community resources, and an increase in early diagnosis and early intervention in diagnosed ASD cases. The secondary focus of this project was to increase provider and staff satisfaction. Assessing for outcomes with regard to provider satisfaction, all the clinic staff including providers and MAs were asked to complete a survey before and after the educational offering. The focus of the survey evolved around basic ASD and ASD screening knowledge, resources for referrals

within the community, satisfaction, and ways to improve the educational platform in the future.

Method of Analysis

To evaluate the success of this scholarly project, it was important to consider what type of process would be used to analyze the outcomes. The Donabedian model, which assesses patient care outcomes, was easily applied to this process improvement project (Voyce, Gouveia, Medinas, Santos, & Ferreira, 2015). This model has three main components: system factors, process of care, and health outcomes (see Figure 4).

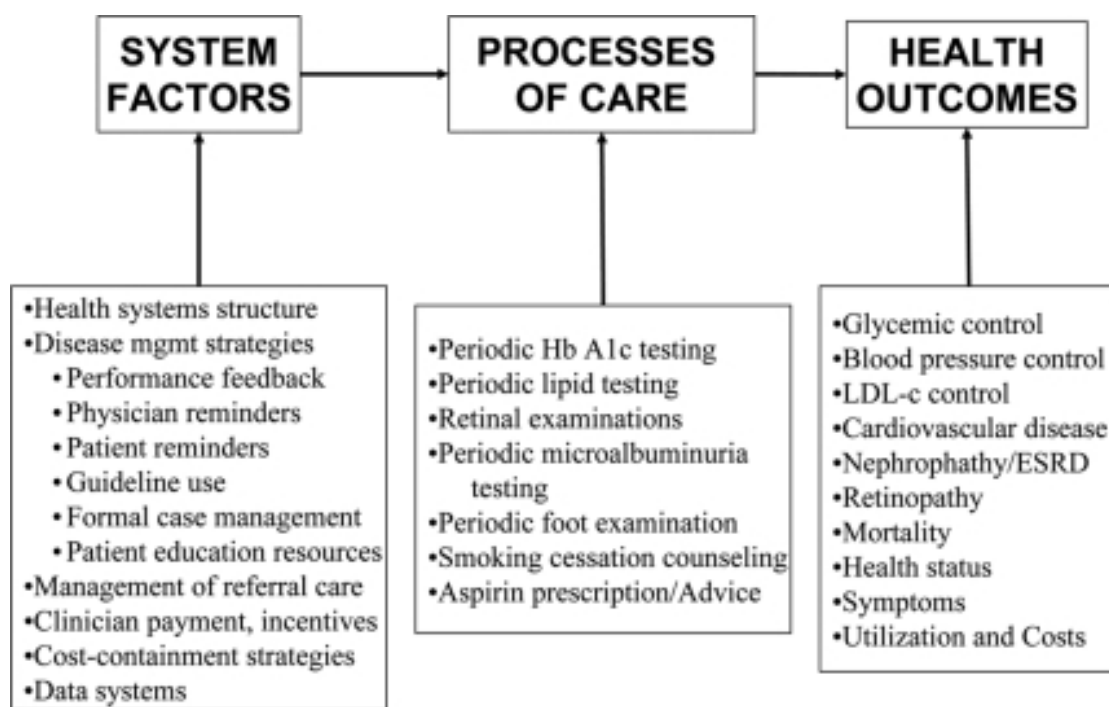


Figure 4. Donabedian model to assess for patient outcomes (TRIAD Study Group, 2010).

System factors, which include guideline usage, are the components of health care by which a certain practice is applied to the patient, e.g., a guideline for autism specific screening in the primary care setting (Voyce et al., 2015). This system factor affects how autism-specific screening occurs in the primary care setting. The guideline and algorithm provides a systematic and simple guide on developmental red flags such as no babbling by nine-months-old (Augustyn, 2016a).

Processes of care is the actual care provided to patients while following the guideline. For example, if a practitioner who follows the ASD screening guideline and algorithm observes a 16-month-old not babbling, this would be an appropriate time to screen for ASD using the M-CHAT R screening tool, which would then further indicate the next step in care.

The final process of the Donabedian model is health outcomes (Voyce et al., 2015). When looking at the patient scenario described above, the provider notes a developmental delay and screens for ASD appropriately (all the while following the ASD guideline and algorithm), and then decides the patient should be referred to Children's Hospital for developmental delay screening and ASD screening. While 16-months-old is young, the goal of all ASD care is early intervention. By following the guideline and subsequently identifying a red flag, screening appropriately, and referring, early intervention will occur for this patient. Also, considering this patient scenario, these concerns as well as the screening tool would be well documented for any provider who might see the patient so the highest quality of care could be consistently provided to the patient. By following the Donabedian model, a thorough method of analysis occurred

and successes of the process improvement project were addressed to improve patient care (Voyce et al., 2015).

Summary

All objectives were evaluated to assure objectives were met. To create and implement an evidence-based guideline and algorithm, the author needed to be well versed in all the information that came with the subject. Through objective three, patient care outcomes were evaluated using the Donabedian (2001) model. This model was then applied to this process improvement project because it focused on patient care outcomes. The overall focus of all three objectives was to improve patient care outcomes regarding developmental delay, ASD, and ASD screening by creating a tailored clinical guideline and algorithm. Improvement in patient care outcomes with this project also included an increase in overall documentation of or lack of developmental milestones. An improvement in provider and staff satisfaction was also a focus.

CHAPTER IV

RESULTS

Theoretical Framework

All necessary preparatory work for this project was completed utilizing the Stetler (2001) model. By framing this scholarly project with the Stetler model, which allocated a research utilization model to be applied to practice, all objectives were met. The Stetler model allows clinicians to incorporate evidence-based research findings into their clinical practice. Phases I-IV of the Stetler Model were utilized in all the necessary preparatory work and included objectives one and two. Phases I-V included preparation, validation, comparative evaluation, decision making, and translation and application (Stetler, 2001). Phase VI (evaluation) was completed with the third objective of this capstone project. Overall, using the Stetler model to implement research into practice made the process improvement project successful. A thorough description of the project's results is discussed as follows.

Objectives

Objective One

Objective one revolved around compiling all the information gathered during the critical research phase, which included Phases I-V of the Stetler (2001) model. At the compilation of Phase V (translation and application), the final clinical guideline and algorithm was established (see Appendices E and F). To incorporate phases II-IV and to

prepare the guideline and algorithm, collaboration with the Children's Hospital Developmental and Behavioral Department occurred. To translate and apply the guideline and algorithm for the fifth phase of the Stetler model, two thorough educational seminars occurred in January 2017. The educational programs lasted approximately 60 minutes. Paper and electronic copies of the documents were also supplied to all the clinicians and clinical ancillary staff to provide a quick reference as needed. The overall goal of objective one was to provide extensive education to all the clinic staff as well as to incorporate the process improvement intervention of a clinical guideline and algorithm for ASD screening in primary care. The main aspect of clinician and clinical staff education was completed with the successful educational seminars.

Objective Two

The focus of objective two was to work with clinical IT to establish an appropriate EHR documentation resource for the M-CHAT R screening tool. This objective worked in conjunction with objective one. After numerous emails and in-person conversations with management and clinicians regarding this EHR step, the objective was fulfilled. During final implementation of objective one, IT created a quick reference box for clinicians to click when the M-CHAT R was completed at the age appropriate well-child check. Furthermore, this imperative clinical documentation step was fulfilled prior to objective one educational seminars. As a result, the educational session was able to cover the specific location of the charting for MCHAT R within the existing EMR. The ability to align these objectives in such a manner enhanced the educational session with real-world application for providers. Unfortunately, IT has not yet been able to create a quick reference box to report the M-CHAT R score, if the M-

CHAT R/F was completed, and the score if available. This aspect of clinical documentation was also imperative to convey. Currently, IT is working to create these documentation aspects within the EHR. Nonetheless, objective two was fulfilled because a quick reference click-box was implemented into the EHR to document the M-CHAT R screening was performed.

Objective Three

Objective three encompassed formal evaluations of objectives one and two--the critical sixth phase of the Stetler (2001) model. Objective three was broken down into two main aspects of project evaluation. First, the results of the chart audit pre-implementation and post-implementation to evaluate if screening with the M-CHAT R improved after the educational seminars and implementation of the guideline and algorithm were presented. Secondly, the clinician and clinical staff's (i.e., participants) general knowledge was evaluated during pre-and post-educational seminars to determine if the education enhanced knowledge.

These two evaluation methods were completed using the following steps. As previously mentioned, a de-identified chart review of all well-child visits between the ages of 16 to 30 months occurred to determine the rate of ASD screening three months prior to the educational intervention. Once these data were collected, an educational session was provided about and screening for ASD. After the educational program, a second de-identified chart audit occurred to review the same information six weeks afterwards. Participants were approached at the beginning of the educational session and asked to consider participating in the study. Consent forms were distributed along with part one of the survey (see Appendices B and C). At the end of the educational session,

the consenting participants completed part two of the survey (see Appendix C). As seen in the appendices, part one and part two of the survey were similar other than part two of the survey having some additional questions about the program itself.

Chart audit results. Overall findings of the chart review indicated the M-CHAT R screening rates as well as the general developmental screening rates improved after the educational seminar. It is important to note that due to the sample size, basic percentages were represented as statistically significant for the chart audit data points. Because of the small sample size, a *t*-test, chi-square, or nonparametric equivalent would not have been applicable.

The information provided by the chart audit lent evidentiary support that increasing provider awareness regarding ASD and ASD screening techniques was valid and applicable in primary care. There were two main findings in the pre- and post-groups (see Tables 3 and 4). First, overall screening for basic developmental delay with the ASQ3 screening questionnaire improved after the educational seminar. Basic developmental delay was an imperative component of the provided educational seminar. This was because clinicians must be able to recognize developmental delays at every well-child check. As mentioned, this was done using the evidence-based ASQ3 screening questionnaire. However, as seen with the chart audit data, basic developmental delay screening did not always occur. For example, basic developmental delay screening in the pre-audit was 92.7% and basic developmental delay screening in the post-audit was 93.6%. The post-audit's improvement in screening was just under 1%. As seen with this data point, gains helped to substantiate that a simple clinician educational seminar

could enhance provider knowledge and improve patient care outcomes by using evidence-based screening methods.

Table 3

Pre-Intervention Chart Audit

	Total Sample Size	ASQ3 Occurrence	M-CHAT R Occurrence	Referral for Diagnosis	Referral for Therapy
Total	41	38	7	0	2
Percentages	$N = 41$	$n = 38$ (92.68%)	$n = 7$ (17.07%)	$n = 0$ (0%)	$n = 2$ (0.04%)

Table 4

Post-Intervention Chart Audit

	Total Sample Size	ASQ3 Occurrence	M-CHAT R Occurrence	Referral for Diagnosis	Referral for Therapy
Total	31	29	14	0	0
Percentages	$N = 31$	$n = 29$ (93.54%)	$n = 14$ (45.16%)	$n = 0$ (0%)	$n = 0$ (0.0%)

With regard to ASD screening rates using the M-CHAT R, screenings in the pre-audit group were approximately 17%; in the post-audit group, screenings jumped to 45.16%. An increase of 28.16% in ASD screenings rates using the M-CHAT R occurred after the educational session and implementation of the guideline and algorithm. As seen with the M-CHAT R, screening increases indicated either many clinicians were previously unaware of the screening tool or there was a general lack of knowledge regarding screening. As stated by the Rhoades et al. (2007) study, specialized training

for ASD surveillance is valuable: “We recommend that all physicians receive specialized training about ASD to improve upon early screening and diagnosis, and then advise caregivers about empirically supported services” (p. 37). To conclude, basic developmental delay screening and universal screening for ASD using the M-CHAT R tool improved after the educational session and the implementation of the guideline and algorithm.

Two other data points were evaluated in the chart audit: referral for diagnosis and referral for therapies. These two data points were not found to be statistically significant in this study. For example, referral for diagnosis remained 0% in the pre- and post-chart audit groups. Furthermore, referral for therapies decreased slightly from 0.04% in the pre-audit group to 0% in the post-audit group.

The overall results for referral for diagnosis and referral for therapies were not surprising. The children within the chart audit timeframe and of the appropriate age grouping (16 to 30 months) might not have needed referral for therapies or diagnosis due to receiving a negative screening. It is also conceivable the children in the pre-audit group who required referral for therapies were identified using the basic developmental screening prior to the implementation of the educational session and the guideline and algorithm. This might mean further referral for therapies after implementation was not necessary. Overall, the process improvement implementation of this project could have no bearing on these two data points as they might be variable due to the intervention. Data like these might mean there were no positive screenings within the given timeframe and/or any positive screenings were caught using the basic developmental screening tool. One important caveat to this was the referral rates for diagnosis remained zero in the pre-

audit sample. In other words, the children referred for therapies in the pre-group were not referred for developmental delay or ASD evaluation they might have needed.

A final component regarding findings from the chart audit was a series of errors or red flags that were never adequately followed through from the perspective of documentation. For example, noted speech delays were provided but there was no mention of further testing or a follow-through plan. First and foremost, any type of developmental delay must be addressed and have a plan. According to the Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, and the Medical Home Initiatives for Children with Special Needs Project Advisory Committee (2006), if any component of a formal developmental screening is positive, it requires a referral for formal evaluation and a referral for appropriate age-related therapy--either Child Find or Early Intervention. Furthermore, any type of speech delay should be referred for a formal audiology evaluation to determine any degree of hearing loss (Feldman, 2005). Referral for diagnostic evaluation and disability evaluation and referral to a pediatric audiologist should have taken place and been documented if a speech delay was noted.

To compound the issue of speech delay, multiple instances of charting noted global delay on the basic developmental screening tool without an action plan to follow through. In the instance of global delay, the same actions should have been taken as mentioned above. These are examples of potential missed opportunities that might represent poor patient outcomes. “Effective interventions at the earliest age possible may be able to modify early experiences—effectively altering cortical organization, enhancing

learning, and potentially improving developmental trajectories” (Bradshaw et al., 2015, p. 778).

Survey results. The results of the surveys were represented in both qualitative and quantitative values. A major focus of the project was to increase provider and staff knowledge regarding ASD screening techniques. Therefore, pre- and post-surveys were conducted to see if knowledge improved with the educational seminar and implementation of the guideline and algorithm. Survey question one was formatted on a basic Likert scale of 1--*Not confident at all* to 5--*Very confident* and asked the participant to rate his or her confidence level with screening for ASD. Question three of the survey was formatted with the same Likert scale as question one but asked the participant to rate his or her confidence level with identifying an abnormal screening for ASD. Participant surveys are provided in Appendix C for reference.

To formulate a formal *t*-test, a series of basic statistical tests for significance using the variables was conducted (see Tables 5-7). Twenty-three participants were surveyed; however, one pre-survey and one post-survey were never completed. As a result, the sample group for the statistical analysis was slightly different as it was decided not to utilize two participants’ data because of the missing surveys.

When evaluating statistical significance, a *t*-test provides a hypothesis to determine whether two independent variables are or are not alike (Stone, 2010):

The independent samples *t*-test is appropriate whenever the researcher wants to know whether two population group means are different and when the observations in each of the groups are independent of the observations in the other group. (p. 402)

With regard to questions one and three on the pre- and post-surveys, the focus was to evaluate for any statistical differences between the pre- and post-answers for both

questions. Survey question one asked the recipient to rate his or her confidence level with screening for ASD and question three asked the participant to rate his or her confidence level with identifying an abnormal screening for ASD.

Table 5

Frequencies of Quantitative Data from Pre- and Post-Surveys

	Question 1 Pre	Question 1 Post	Question 3 Pre	Question 3 Post
<i>N</i>	22	22	22	22
Median	2.0	4.0	2.5	4.0
Mode	1.0	4.0	3.0	4.0
Range	4.0	3.0	4.0	3.0
Minimum	1.0	2.0	1.0	2.0
Maximum	5.0	5.0	5.0	5.0

Table 6

T-Test Paired Sample Statistics

	<i>M</i>	<i>N</i>	<i>SD</i>	Standard Error Mean
Pair 1--QPre 1	2.428	21	1.207	0.263
QPost 1	3.857	21	0.792	0.173
Pair 2--QPre 3	2.381	21	1.160	0.253
QPost 3	3.619	21	0.804	0.175

Table 7

Paired Sample Test

	<i>M</i>	<i>SD</i>	Standard Error Mean	95% Confidence Interval- Lower	95% Confidence Interval- Upper	<i>t</i>	<i>df</i>	Sig. (2-tailed)
Pair 1--Q1 pre and post	-1.428	0.978	0.213	-1.873	-0.983	-6.691	20	0.000
Pair 2--Q3 pre and post	-1.238	0.889	0.194	-1.642	-0.833	-6.638	20	0.000

Note. T = The paired T test statistic; df = The degrees of freedom for this test; Sig. (2-tailed) = The *p*-value corresponding to the given test statistic *t*.

The sig (2-tailed) value of both pairings in Table 7 remained $p \leq 0.05$. It could also be concluded there was a statistical difference between the pre- and post-educational questions (Stone, 2010). The data indicated the participants gained improved basic knowledge with ASD screening, which was the focus of this project.

Evaluating Table 8 provided further statistical value of the data collected. Table 8 indicates the *t*-test correlation and significance derived from the data in Tables 5 through 7. The significance for both pair sets, pre- and post-question one and pre-and post-question three, was $p < 0.05$. A significance of $p < 0.05$ means there is a statistical difference between the two data sets (Stone, 2010). With regard to the pre- and post-educational session and participants' basic comfort levels with ASD screening and abnormal screenings, there was a significant difference between the sample pairs. The educational seminar and implementation of the guideline and algorithm significantly increased clinician and clinical staff's knowledge about ASD screening and further steps to take with positive screenings. The participants scored an improved average of 1.4 points on question one post-survey and 1.3 points on question three post-survey as compared to the pre-surveys. Question one represented a 95% confidence interval of -

1.87390 to -0.98324. Question three represented a confidence interval of -1.64280 to -0.83339. The two confidence intervals measured basic knowledge on screening for ASD and comfort levels with abnormal screenings of ASD before and after the educational intervention and implementation of the guideline and algorithm. The gains noted with both pairs in the confidence intervals represented statistical significance with a $p \leq 0.05$ by the two-tailed pair t -test (Stone, 2010). Furthermore, it could be concluded, using a 95% confidence interval to determine the t -test, that the negative values of the confidence intervals did not change the t -test score as the $p \leq 0.05$ remained consistent. In summary, all the data compiled within Tables 5 through 8 showed the intervention of this project was statistically significant; there was an improvement in knowledge regarding ASD screening and further steps to take for abnormal screenings.

Table 8

T-Test Paired Sample Correlations

	<i>N</i>	Correlation	Significance
Pair 1--Q1 Pre and Post	21	0.590	0.005
Pair 2--Q3 Pre and Post	21	0.645	0.002

Question two on the survey provided great insight into participant knowledge regarding the M-CHAT R that should be utilized for universal screening at every 18- and 24-month well-child check (see Table 9). The question asked the participant to write down the correct answer. Because there was only one correct answer (M-CHAT R), data were represented as a dichotomous response--either “yes” or “no.” For the data

represented as statistically significant, the focus remained on “yes” or correct responses before and after the educational intervention. Participants answering correctly prior to the educational intervention was 43.5%. After the intervention, participants answering correctly soared to 69.6%. The data with this question were represented only as simple percentages because of data limitations. Still, the information indicated basic participant knowledge regarding the M-CHAT R before and after the intervention improved. This data also indicated that providing additional education and resources such as the clinical guideline and algorithm implemented with this project increased clinician and clinical staff knowledge.

Table 9

Survey Question Two Statistics

	<i>N</i>	Pre	Post
Yes	23	10	16
Total Percentage	<i>N</i> = 23	<i>n</i> = 10 (43.5%)	<i>n</i> = 16 (69.6%)
No	23	13	7
Total Percentage	<i>N</i> = 23	<i>n</i> = 13 (56.5%)	<i>n</i> = 7 (30.4%)

The quantitative data represented from the educational intervention of this project lent evidentiary support that clinicians and clinical staff need more education regarding ASD and screening techniques. Data acquired also supported the Rhoades et al.’s (2007) study that stated more education was necessary for clinicians to improve ASD detection. Improving clinician knowledge regarding ASD and ASD screening was the modifiable challenge addressed by this study. Knowledge was further enhanced by implementing a

quick reference guideline and algorithm for ASD screening and further steps to take for abnormal screenings.

Qualitative data analysis from the participant surveys was performed to provide information for future program offerings and was requested per the clinical site. Additionally, it provided high quality insight into the driving factors behind and barriers to ASD screening. Although there were 23 participants, not all surveys were analyzed within the results section. To highlight important takeaways from the participants' surveys, this results section discusses four participants' surveys.

Participant one completed both pre- and post-educational intervention surveys. Comfort level with ASD screening and abnormal screenings improved with the intervention. This participant did know the M-CHAT R was the evidence-based screening tool to utilize; however, this participant stated "unsure" on further steps to take if the screening was abnormal, on further referral resources, and on referral resources for disability evaluation within the community on the pre-survey. After the intervention, the responses improved significantly. Participant one answered correctly on further steps to take if the screening was abnormal, on referral resources for evaluation, and on referral resources for disability evaluation in the community on the post-survey.

Interestingly, participant one's responses for the top three barriers for ASD screening changed from the pre- and post-surveys. On the pre-survey this participant answered "time" as the only response; however, on the post-survey, the participant answered "time, difficulty with ambiguity of screenings, and unfamiliarity with screening tools." One could postulate many reasons for this change. One of the foci of the educational session was a thorough discussion regarding challenges with the screening

tools such as variability of responses. Furthermore, education was also provided regarding research supporting lack of clinician knowledge regarding ASD screening as seen with the Rhoades et al. (2007) study. This participant highlighted these two factors as significant barriers to screening after the educational session.

The top three motivators for ASD screening changed slightly in the pre- and post-surveys. For example, the pre-survey stated the following as motivators for ASD screening: “early diagnosis and treatment and family counseling.” After the intervention, the survey responses for this question changed: “early diagnosis and intervention, family support, and diagnosis of other medical problems (e.g., hearing loss).” There are many potential reasons for the changes in responses. For example, the education provided might have improved clinician knowledge and appreciation for ASD and ASD screening since there was an in-depth discussion during the educational session of many other clinical diagnoses that often occur with ASD such as hearing loss or insomnia.

To conclude, participant one noted the biggest takeaway from the educational intervention was a review of the local resources within the community for those with developmental delay and/or ASD. A large component of the educational intervention focused on educating the participants on the resources within the community such as Child Find or Early Intervention. As discussed with an in-person interview with Dr. Robin Nolan, Developmental and Behavioral Pediatrician with The Children’s Hospital, many clinicians are unaware of the resources within their community and, therefore, children often do not get referred as necessary (R. Nolan, Personal communication, August 23, 2016). Participant one mentioned an improvement in the future for this type of educational intervention would be a presentation from a developmental and behavioral

pediatrician. Primary care clinicians receive minimal education on neurodevelopmental disorders (Rhoades et al., 2007). Therefore, it could be concluded that clinicians would benefit from a specialized training on these disorders (Rhoades et al., 2007).

Participant two's responses were important to highlight because the survey information conveyed basic knowledge on ASD screening and referral resources for abnormalities was lacking for some clinicians. On the pre-educational intervention survey, the participant answered with "little knowledge." When reviewing basic comfort levels on the Likert scale with ASD screening and abnormalities of screenings, participant two answered "2," meaning the participant was not comfortable. Furthermore, the participant was unaware of the M-CHAT R screening tool. The participant listed "unsure" on further steps to take if the screening was abnormal, on referral resources for diagnosis, and on referral resources for disability evaluation in the community. Fortunately, after the educational intervention, comfort levels improved to a 4 on the Likert scale and the responses to the questions regarding specific screening with the M-CHAT R and referral resources were correct.

Important to highlight with this participant were the top three barriers to screening, which were answered only on the pre-intervention survey: "busy with learning everything in residency so I choose to focus on common illnesses, not familiar with resources, and I don't see it that often." The responses to barriers in this survey highlighted common barriers also noted within literature, which might include but were not limited to lack of education and vague nature of the symptoms (Augustyn, 2016b). Furthermore, research indicated ASD is not rare and has increasing prevalence for approximately 1 in 68 children (Salley, 2016). These data showed that while the

participant did not see ASD commonly, it is more common than some clinicians might believe (Ecker, Spooren, & Murphy, 2013): “It is currently estimated that 1% of all children have ASD, and the condition is more common than pediatric cancer, diabetes, and AIDS combined” (p. 308). Participant two highlighted common barriers that are known but also as this participant mentioned, “I don’t see it that often”, is not accurate, this begs for further inquiry. Autism spectrum disorder is more prevalent and is increasing in prevalence (Augustyn, 2016a) than formerly believed. The information provided by participant two indicated the need for educational interventions and a guideline and algorithm to help clinicians increase early detection and decrease the prevalence of an ASD delayed diagnosis.

The third participant of the study offered insight into basic clinician awareness of ASD screening. Additionally, this participant delved into how an educational intervention and guideline and algorithm helped to enhance the knowledge base to transform the clinician’s practice to follow evidence-based recommendations. With regard to basic comfort with ASD screening, the participant scored a 3 on the Likert scale on the pre-survey; this indicated the participant was neither unconfident nor confident with ASD screening. On the post-educational interventional survey, the participant scored a 4, meaning this clinician now felt confident with ASD screening. Furthermore, in the pre-survey, the participant did not understand how to use the M-CHAT R screening tool and on the post-survey, this participant acknowledged understanding of the M-CHAT R.

With regard to basic knowledge of further steps for an abnormal screening, in the pre-survey, the participant stated “referral.” While this answer was accurate, critical

pieces of the referral process were missing; in the post-survey, the participant answered more accurately and specifically to the question: “follow-up M-CHAT R in one month, referral to the Children’s Hospital, the local resource, and audiology.” These comparative survey responses highlighted three vital components that must be addressed. First, of all 23 participants of the study, not a single participant was aware of the M-CHAT R/F screening tool that should be performed if the M-CHAT R indicated a medium or high risk for ASD. As previously indicated, both the M-CHAT R and M-CHAT R/F are feasible, simple to use, accurate, and recommended by the AAP (Dreyer, 2016). This global lack of knowledge regarding the M-CHAT R/F highlighted the true lack of clinician knowledge regarding ASD and ASD screening in primary care (Rhoades et al., 2007).

A formal and comprehensive audiology screening performed by a pediatric audiologist is recommended if the M-CHAT R/F indicates an increased risk of ASD. This recommendation comes directly from the AAP. Harlor and Bower (2009) found the following:

Developmental abnormalities, level of functioning, and behavioral problems (ie, autism/developmental delay) may preclude accurate results on routine audiometric screening and testing. In this situation, referral to an otorhinolaryngologist and a pediatric audiologist who has the necessary equipment and expertise to test infants and young children should be made. (p. 1252)

As all 23 of the pre-educational intervention surveys indicated, an audiology referral was never included as a potential follow-up step if the M-CHAT R was abnormal. This, however, did change in the post-surveys as the third participant’s answer indicated. This was an important piece taught while educating the participants on the

guideline and algorithm created for the clinic as part of the overall intervention of this project.

Last, participant three's answers in the pre-survey further showed an overall lack of knowledge regarding specific referral resources. For example, the pre-survey response for referral resources for disability evaluation was occupational therapy and physical therapy. As stated previously, this answer was correct but was missing important components. The correct answer was Child Find or Early Intervention based on the child's age. These resources then determined what therapies the child qualified for based on his or her level of disability.

As stated previously with regard to the question on further steps to take if an ASD screening was abnormal, there was global confusion among all the participants on what resource to utilize for an actual evaluation and diagnosis of developmental delay and/or ASD. As participant three pointed out, "referral" was appropriate but the question was consistent across the board in the pre-surveys: "referral" where?

Evaluation for ASD should include a comprehensive assessment, preferably by an interdisciplinary team. The evaluation aims to definitely diagnose ASD, exclude conditions that mimic ASD, identify co-morbid conditions, and determine the child's level of functioning. (Sanchack & Thomas, 2016, p. 972)

The statement from Sanchack and Thomas (2016) alluded to the importance of a collaborative approach with neurodevelopmental disorders. This means evaluations should not come solely from psychiatry or neurology. The team approach should include but not be limited to developmental and behavioral pediatrician, psychiatry, neurology, psychology, and speech pathology. The interdisciplinary approach for evaluation and management of neurodevelopmental disorders like ASD is the approach utilized by Children's Hospitals across the nation. For this project, the educational session informed

clinicians that the local Children's Hospital was the recommended resource for developmental delay and/or ASD evaluation and was also represented in the guideline and algorithm.

The fourth and final survey discussed is participant four. Two components must be addressed with this survey. First and foremost, the participant gave one response for the question that asked for the top three barriers for screening for ASD on the post-intervention survey: "lack of experience." Second, in the post-interventional survey response for discussing the most useful part of the educational session, participant four answered, "Shed light on this subject that is often neglected." These responses offered clinician-guided evidence that there is a lack of experience regarding clinician training for ASD and, as a result, this subject could be neglected in primary care. "Primary care physicians report a lack of self-perceived competency, a desire for education, and a need for improvement in primary care for children with autism. Physician education is needed to improve primary care for children with autism" (Golnik, Ireland, & Borowsky, 2009, p. 996).

Participant data from the surveys both before and after the educational intervention provided valuable insight and suggestions for steps to take in the future to improve ASD screening and have a more thorough understanding of the many resources available to those at risk for ASD. For this study, it could be concluded the educational seminar, clinical guideline, and algorithm succeeded in increasing participant knowledge regarding ASD screening. By doing this, the modifiable challenge of lack of clinician knowledge was tackled head on. Another goal of this study was to see an increase in ASD screening with the M-CHAT R. This goal was achieved and was represented with

the chart audit data. Delayed diagnosis is the true concern with regard to ASD screening; however, this was not the focus of this capstone project. By achieving the two goals mentioned above, the hope is over time ASD delayed diagnoses will decrease for the participants in this study.

Overall, basic themes derived from the participant surveys represented the need for continued provider education regarding childhood development and neurodevelopmental disorders such as ASD. Across the board, participants reported improvement of knowledge regarding ASD, ASD screening, and further interventions for abnormal screenings. Participants also reported lack of time, lack of knowledge, and confusion with referral resources as further barriers to screening and intervention for ASD. The qualitative data acquired from the pre- and post-participant surveys lent support to the purpose of this scholarly project. By providing a clinical guideline and algorithm to enable appropriate screening for developmental delay and universal ASD screening, participants were provided the necessary information to combat these barriers. Furthermore, by implementing an educational platform to review the guideline and algorithm, participants reported improved knowledge regarding ASD and ASD screening. The myriad of confusion with regard to referral resources for developmental delay and ASD was a major theme noted throughout the participant surveys. Fortunately, a thorough discussion of the guideline and algorithm detailed the appropriate steps to take if developmental delay and/or risk for ASD was noted on screenings and/or clinical exams.

Important findings from the participant surveys were vast. The most important takeaway was improvement in participant knowledge after the intervention, which lent

evidentiary support to continued provider education and tailoring of a clinical guideline and algorithm to specific clinical sites. By doing so, confusion regarding referral resources would be addressed. Another important takeaway was provider confusion regarding referral resources. Lastly, the qualitative data derived from the participant surveys indicated a theme of limited knowledge regarding ASD and ASD screening in primary care. As stated previously, it is also important to note common themes in barriers to screening such as lack of provider time and lack of knowledge regarding ASD.

Key Facilitators

Key facilitators for the three objectives of this project were vast. First and foremost, Dr. Hessler, Dr. Dunemn, and Mitzi McGarr, FNP were the main facilitators throughout the project as they comprised the project committee. Dr. Hessler was instrumental to this project. She enabled a constant lending hand to the researcher and played a major role in all three objectives. Dr. Dunemn offered guidance and insight, especially with the data evaluation required during the third objective. Mitzi McGarr, FNP was the main point of contact at the implementation site and consistently offered clinical expertise to the researcher. The project committee played the largest role in facilitating the entirety of this project.

The implementation site was also instrumental to this capstone. The site's openness and willingness to allow the researcher to tailor a clinical guideline and algorithm for ASD screening to their practice was unparalleled. Furthermore, the site allocating time for the researcher to hold the educational seminar twice to achieve the highest number of participants possible was invaluable. Leadership associated with the clinical site offered vital clinical insight and a vast pool of knowledge regarding specific

concerns and barriers that were modifiable to the project's success. All the staff of the clinical site were imperative to the project's success as they were open to and excited about the project.

One of the largest key facilitators of this project was the consulting developmental and behavioral pediatrician from the Children's Hospital. Her expertise in the field and clinical advice were impressive. Her clinical guidance with the guideline, algorithm, and educational seminar played a key role in ensuring components were evidence-based and applicable to the project. Success of the project was due in part to her expertise.

By consistently applying the Stetler (2001) model, all clinical expertise provided was appropriately compiled and utilized in the first objective of the project. That being said, the Stetler model was another important key facilitator to the project's success. By following all key six phases of the model, research was implemented into clinical practice and then was further evaluated in the third objective of the project.

The clinical site's IT played the largest role in the second objective of the project. With the lending hand of IT, the EHR documentation change occurred without major issues. All communication was done through Mitzi McGarr, FNP and the clinical site's leadership to assure this process improvement changed prior to the educational intervention. This change allowed for a simple-to-use reference to document the M-CHAT R was performed.

The final key facilitator to this capstone was the IT platform to acquire all the research, literature review resources, and capstone pertinent communication. By having a personal IT platform available, the researcher could consistently research and update the

project. All steps toward moving forward with the many aspects of a scholarly project were made possible by the researcher's personal IT platform.

Key Barriers

Fortunately, this scholarly project had minimal barriers. The main barriers were willingness to participate in the surveys and applying the education, algorithm, and guideline to clinical practice. Multiple surveys were returned with very minimal input on either the pre- or post-surveys, thus yielding minimal statistically significant data. Surveys can be cumbersome so this barrier was to be anticipated when utilizing participant surveying as a method of data collection.

The caveat to this, however, was participant utilization of intervention of this project, specifically participants screening for ASD using the algorithm and guideline and using the education provided to them to enhance their knowledge of ASD. This was a barrier because clinician autonomy is vital, and with a guideline there is always going to be the concern that certain clinicians may not see the importance of the research causing the intervention to go unutilized. Lack of clinician willingness to respond is another potentially anticipated barrier to this type of project.

Another difficult barrier to the success of this project was limited clinician time. Unfortunately, it is difficult to combat this barrier directly; however, by increasing provider education, there was hope clinician time would be enhanced because of quicker recognition of red flags and/or risk factors. Also, clinician time could be enhanced by using a screening tool like the M-CHAT R. The challenge to this, however, was ensuring the screening was completed in a timely manner. This barrier was also addressed hands

on by providing extensive education to the clinical staff as they play a key role in ensuring each clinician's day runs smoothly.

The final barrier to address with this project was a true lack of resources within the community for those with developmental delay and/or ASD. Although Child Find and Early Intervention were available and were eager to help all the children within the community, the number of therapists to provide services is limited. This meant children might not be able to achieve the desirable amount of therapy to move in a positive trajectory because there were not enough resources. This could not be addressed with this project as the focus remained on screening for ASD in primary care; however, extensive discussions occurred with Child Find regarding this concern. The researcher was adequately informed that the best course of action was to refer every patient with suspicion early even if resources were lacking. The goal, hopefully, was to see an increased need and therefore an increased demand for resources. By having an increased demand, increased resources would hopefully be granted.

A further barrier was the challenge presented to clinicians and clinical staff regarding confusion on the referral resources. This barrier was also addressed directly with this project by use of the education session and algorithm. All evidence-based and appropriate referral resources were provided to all clinical staff including the necessary paperwork, names, and appropriate contact information.

Unintended Consequences

Unintended consequences of this scholarly project could be perceived as both negative and positive. With regard to the chart audit, many red flags were raised and addressed with leadership of the clinic. Chart audit documentation findings were not an

intent of the study but required further follow-up as some could be missed opportunities and negatively affected patient care. The consequence of this was positive because it could lead to improved patient outcomes. However, this might also be a negative consequence because it could be a challenge to accept flaws in clinical care.

Second, the discovery that even the basic developmental screening using the evidence based ASQ3 tool was not being consistently performed on all age appropriate well-child exams was a consequence. Moving forward, the clinical staff should ensure that parents have the screening tool completed before the clinician enters the patient's room. This would facilitate the completion of paperwork. Furthermore, there was discussion within the clinical site to have the clinical staff input the results directly into the EHR to ease provider use and enhance provider patient time. These changes were positive consequences of the scholarly project.

When reviewing the participants' survey results, it was enlightening to see many clinicians were unaware of appropriate ASD screening and further steps to take if screening was positive. This was both a positive and negative consequence. First and foremost, the data supported this scholarly project's purpose to provide education and tailor a guideline and algorithm for ASD screening in primary care. Most certainly, this was a positive consequence. However, this could also be negative because it validated limited clinician knowledge even in current practice. The data could infer a direct correlation between lack of physician knowledge and delayed diagnosis of ASD, thus contributing to poor patient outcomes.

Summary

Using the comprehensive Stetler (2001) model, the first objective was achieved by creating a tailored clinical guideline and algorithm for the implementation site. Objective one entailed compiling all the evidence-based data including expert opinion for the Children's Hospital to create the guideline and algorithm. Second, the educational seminar was successfully completed with 23 consenting participants. The 60-minute educational sessions took place in January 2015 without complication. The goal was to provide the educational materials to enhance participant knowledge regarding developmental delay, ASD, and ASD screening.

The second objective was completed in conjunction but prior to the educational sessions in objective one. Information technology was able to create a quick reference box for clinicians to click when the M-CHAT R was completed within the age appropriate well-child check. Objective two allocated improved clinician charting with a simple-to-use text box that stated the M-CHAT R was completed. Completion of this objective occurred after numerous emails and in-person conversations with management and clinicians regarding this EHR step.

The third and final objective was the formal evaluation of objectives one and two. Copious data acquired from both the chart audit and participant pre- and post-surveys supported the overall success of this project. Major findings indicated an increase in both basic developmental screening and M-CHAT R screening after the implementation of the education, guideline, and algorithm. Enhanced participant knowledge was appreciated through the use a *t*-test, which yielded a $p \leq 0.05$. A *t*-test with this statistical significance offered support that the educational intervention was successful as it

improved participant knowledge. Last, participant qualitative input was vastly appreciated, offered guidance for future educational session offerings, and allowed for interesting insight into basic clinician knowledge regarding ASD and screening for ASD.

CHAPTER V

RECOMMENDATIONS AND IMPLICATIONS

With the completion of the three objectives, many recommendations and implications arose with this process-improvement project. The most important net result from this project was the need for more education in primary care regarding developmental delay, ASD, and potentially other types of neurodevelopmental disorders. As indicated with objective one with all the data compilation, literature has shown more education is necessary for primary care providers. Data acquired with this project from objective three unequivocally showed the benefit that could be drawn from increasing clinician education. An ASD screening educational platform, clinical guideline, and algorithm were the interventions of this project. By implementing these critical steps to clinician practice, ASD and basic ASD screening knowledge were enhanced. As shown by the examples provided with the qualitative data from the participant surveys, general knowledge was lacking, which meant this area of clinical practice could be neglected. Furthermore, as indicated by the survey quantitative data from the Likert scale questions, having an educational intervention increased participant knowledge and comfort with ASD screening.

A recommendation that could be assumed with this result was to provide consistent education to primary care clinicians and clinical staff regarding ASD, ASD screening, and any changes recommended for ASD care. An implication of this

recommendation from this project would improve ASD awareness, ASD screening, and overall screening for developmental delay. The overall goal would be to see a decrease in delayed diagnosis of ASD. Furthermore, this recommendation would encourage prompt referral for early intervention, which in turn would improve the child's lifelong developmental trajectory.

As indicated with this capstone project, ASD can be challenging to identify in primary care. According to Daniels et al. (2014),

A recent systematic review of studies examining age at ASD diagnosis identified myriad factors associated with delayed diagnosis at the child, family, and community levels, including greater symptom severity, lower socioeconomic status, racial/ethnic minority status, low levels of caregiver awareness of the early signs of autism, living in resource-poor settings, and visiting greater numbers of clinicians before diagnosis. (p. 141)

Myriad dilemmas contributing to delayed diagnosis of ASD were addressed with this scholarly project by tailoring a clinical guideline and algorithm for a specific clinic to universally screen for ASD every well-child check at 18 and 24 months using the M-CHAT R screening tool. The M-CHAT R did have setbacks. According to Sanchack and Thomas (2016), "When used alone, it has poor positive predictive value and a high-false positive rate" (p. 975). To address this, Sanchack and Thomas created the secondary screening tool (the M-CHAT R/F) to enhance the reliability of both screening measures. A major piece of the clinical guideline and algorithm addressed utilizing both the M-CHAT R and the M-CHAT R/F if the M-CHAT R was high risk for ASD.

A major implication from the project regarding the M-CHAT R and M-CHAT R/F was participants universally stated not having knowledge of the M-CHAT R/F secondary screening tool. Furthermore, the large lack of clinician awareness of the M-CHAT R screening tool was brought to light with the results of this project.

A strong recommendation from this scholarly project was that universal screening for ASD using the M-CHAT R and the M-CHAT R/F, while currently an “I” recommendation from the USPSTF (Siu et al., 2016), was appropriate and might improve patient outcomes. Primary care clinicians might lack the expertise to consistently stay ahead of clinical red flags and risk factors for ASD alone (Rhoades et al., 2007). With this project, there was a general lack of knowledge regarding ASD and ASD screening techniques in the participants. The survey results did show an increase in knowledge from pre-survey to post-survey but the actual increase in knowledge, retention of that knowledge, and any action in the providers was not able to be determined. That being said, universal screening for ASD at every well-child check at 18 and 24 months offers the best surveillance for ASD early, thereby improving developmental outcomes and quality of life.

The project timeline did not allow for long-term data collection to occur. Due to this timeline, it was plausible chart audit data did not facilitate a change in referral status for those children at high risk of ASD. Post-intervention chart audits yielded a statistically significant increase in screening for ASD using the M-CHAT R but there was no increase in referrals for diagnostic evaluation or for disability evaluations using community resources. As discussed previously, the reason for this was not directly related to universal screening. The largest factor was the children within the chart audit timeframe did not test positive and might indeed not have ASD or further developmental delay; however, this was not a negative per se.

An implication and a recommendation from this outcome offer strong need for further research. With regard to this capstone alone, further research could be conducted

over a longer timeframe to evaluate if the interventions, the educational sessions, guideline, and algorithm did in fact improve screening and increase early detection and prompt referrals. It happened to be a lucky coincidence that the implementation clinic was also a primary care MD residency. At this specific location, the residents were also required to complete a type of capstone process-improvement project. The goal of the researcher was to offer guidance and to have a resident or group of residents adopt the model and framework of this scholarly project and research further using the same clinical guideline and algorithm.

Discussed previously was the general concern among the medical community regarding universal screening for ASD because of the recent USPSTF recommendations (Siu et al., 2016). While this project alone did not address improved patient outcomes related to universal screening (meaning there was no statistical change in referral rates given the data), this did not mean the USPSTF recommendation should stay firm. “However, there are no randomized clinical trials assessing the effectiveness of screening for ASD in children three years or younger based on long term outcomes” (Sanchack & Thomas, 2016, p. 974). More long-term empirical research must be conducted to further evaluate universal ASD screening and improve patient outcomes. The strong need for further research was another major implication and outcome of this scholarly project.

Another takeaway from this project was a further need for improvement in documentation regarding developmental screening, developmental delay, ASD, and ASD screening. As discussed in the results section, red flags were noted throughout the chart audit. Some of the red flags were minimal, i.e., no documentation of the developmental screening scoring. This might create future legal woes for the clinician. Further

recommendations and implications of this unintended finding indicated a need for continual quality improvement chart auditing with regard to well-child exams specifically. Based on Gregory, Van Horn, and Kaprielian (2008), chart audits within a practice care setting are valuable: “A chart audit is simply a tool physicians can use to check their own performance, determine how they're doing and identify areas where they might improve” (p. A3).

Interestingly, an unintended outcome of this project lent support to enhancing provider knowledge and raising awareness regarding childhood development, developmental delay, and the potential need for referrals for appropriate disability evaluation. “Primary care physicians are not very confident in their abilities to identify children who might be eligible for special education services” (Hastings, Lumeng, & Clark, 2014, p. 170). As discussed previously, disability evaluation comes from local community resources, Child Find, or Early Intervention. It became clear through the participant surveys as well as with the chart audit, even basic child developmental delays as well as critically important developmental delays varied. As stated previously, according to the Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, and the Medical Home Initiatives for Children with Special Needs Project Advisory Committee (2006), any amount of developmental delay noted on the general developmental screenings warranted referral for disability services and potentially for further diagnostic evaluation. Moreover, speech delays also required further referral for a complete audiology workup (Feldman, 2005). A recommendation and implication to follow this finding also brought up the importance of continued education for providers regarding developmental delay,

ASD, and other types of neurodevelopmental disorders. Addressing this outcome could also be fulfilled with a clinical guideline and algorithm.

Last, as indicated with the participant survey results, confusion was abundant regarding the numerous referral resources for children with developmental delay, ASD, and/or other types of neurodevelopmental disorders. As highlighted with an in-person interview with Dr. Robin Nolan, Developmental and Behavioral Pediatrician with the Children's Hospital, many clinicians were unaware of the resources within their community. Therefore, children often did not get referred as necessary (R. Nolan, Personal communication, August 23, 2016). Further recommendations and implications of this finding unequivocally advocated for a tailor-made clinical guideline and algorithm for clinics and resources within their specific areas. This recommendation was precisely this scholarly project's focus—tailored clinical practice steps. By implementing this critical process-improvement, intervention project, earlier prompt referrals and improved patient outcomes are expected.

Project Limitations

However limited, data from this study still offered statistical significance. Limitations are expected with a survey-type study design. Limitations within this project included but were not limited to restricted geographical location of one clinic, factors in patient demographics (implementation facility primarily caring for a Medicaid type population), and a limited timeframe for chart audits and clinical practice changes. These limitations opened an important discussion regarding ASD prevalence, screening prevalence, and ASD care. Obviously, collected data representing one small geographic area are not representative of a large population sample. Furthermore, data collected

within the chart audit were limited and might not bode the clinical changes desired from the intervention due to time constraints.

Despite these limitations, statistically important clinical outcomes were addressed and process improvement did occur. The project helped identify a need for increasing clinician knowledge regarding ASD and ASD screening, the importance of universal screening, and having the tools, such as a clinical guideline and algorithm, to be successful with screening. The numerous outcomes mentioned and recommendations and implications of such outcomes are clinically important and could improve patient care outcomes and quality of life.

Future of the Project

The subsequent multitudinous recommendations and implications of the capstone project should be expanded mainly because a true need was identified within the background work and literature and a statistically significant intervention was implemented. Taken together, these facts indicated this work should not be reduced or phased out but indeed expanded upon. As stated, more research needs to be done in the field of ASD and ASD screening (Sanchack & Thomas, 2016). Consistent, specialized training should be given to primary care providers on developmental delay, ASD, and other neurodevelopmental disorders to enable earlier identification and prompt action (Rhoades et al., 2007). Findings of this project strongly implied an educational intervention, clinical guideline, and algorithm increased clinician knowledge regarding ASD and ASD screening and improved screening rates. This being said, improved developmental trajectories in children (Bradshaw et al., 2015) could be anticipated; thus, this project should be expanded.

Further evaluations that might need to be included with this type of project outside this Doctor of Nursing Practice (DNP) scholarly project are limited. To expand this project, the same theoretical framework and objectives could be utilized but measured over a longer timeframe to evaluate for any care changes. For example, another study could be conducted on an interval basis to see if screening improved after the initial post-educational intervention but then subsequently dropped after a period of time.

Future phases of this project could be completed by any clinician interested in expanding the framework of this project. As stated previously, the goal of this researcher was to have this project subsequently adopted by one of the clinic's MD residents to evaluate the intervention over a longer term, being they stayed with the facility for three years. However, future DNPs could also adopt this project, tailor the clinical guideline and algorithm to a different clinic, and implement the changes using the same educational intervention to assess if the findings were unique at different institutions. If this were done, data might be interesting because data from different institutions with different educational levels could render new insights. Another aspect that might produce even further intriguing data would be whether clinicians over a long period of practice time experienced less clinical knowledge on developmental delay, ASD, and other types of neurodevelopmental disorders. Furthermore, was there more of a "complacency" with expert clinicians versus novice clinicians? All of this validated further expansion of this project.

Personnel necessary for any future steps would be consistent with the framework of this specific project. For example, if a DNP student was to adopt this project's

framework, another committee would be necessary. Any implementing facility would require leadership and clinician approval. With objective two, work would be necessary to coordinate with IT at the implementing facility. Coordination with the appropriate community resources such as Child Find and Early Intervention would also need to occur to tailor the clinical guideline and algorithm to a specific location. Furthermore, coordination and collaboration with the Children's Hospital was an integral component of this project. Further multi-disciplinary approach would also be necessary for future success.

As the main researcher for this project, much interest has been generated from other facilities regarding the successful project findings and further implementation of the intervention to other clinics. That being said, this project could likely be applied to other settings. Reasoning for this was two-fold. First, as stated frequently throughout the capstone, general lack of clinician knowledge regarding the subject area was rampant. Second, there was a need for a tailored clinical guideline and algorithm to address ASD and ASD screening. A major reason for this was because of the confusion amongst the clinical community regarding current USPSTF findings (Siu et al., 2016). With a known major clinical gap in care regarding ASD identification, otherwise known as ASD delayed diagnosis (Barton et al., 2012), universal screening is key to prompt identification. Augmenting confusion is unawareness of further steps to take if screening is abnormal as seen from the data of this project. Because of this, the intervention of this project with the clinical guideline and algorithm was imperative to improving pediatric preventive clinical care.

Personal Attainment of Leadership Goals

The concept of a DNP scholarly project surrounds many aspects of DNP clinical care, research, leadership, evidence-based practice, and process improvement strategies. According to the American Association of Colleges of Nursing (AACN; 2015), leadership is an integral component to a DNP scholarly project and to DNP clinical care: “Practice includes leadership, advancing the quality of nursing care and the profession of nursing through policy evaluation, development, and advocacy, and the creation and maintenance of healthy work environments” (p. 3). Through the many processes of this scholarly project, leadership goals of the researcher were successfully attained.

First and foremost, innovative thinking and strategies were utilized by the researcher to conceptualize the initial plan for the project. There were many challenges throughout its implementation, especially with regard to how to evaluate this type of process improvement project. The researcher had to adapt care delivery methods to tailor the educational platform, clinical guideline, and algorithm to the implementation site. Patient advocacy remained at the forefront of the project and was a large piece of collaborative effort with Child Find, Early Intervention, the Children’s Hospital, and the implementation facility.

The transferal of evidence-based practice to actual clinical practice was simplified by use of the Stetler (2001) model. The Donabedian model (TRIAD Study Group, 2010) was utilized to assess patient outcomes in relation to the project. By following theoretical frameworks to guide the project’s purpose, literature evaluation, implementation, and evaluation, the researcher navigated the processes of the DNP project smoothly.

Institutional Review Board processes with the university /required extensive collaboration and effort from the researcher and project committee members. By following the processes of IRB and collaborating with others, leadership and persistence were continually noted. Navigating these processes strengthened the researcher's leadership skills.

The overall purpose of a DNP scholarly project is to demonstrate clinical scholarship and leadership (AACN, 2015). With the educational sessions, the researcher had to command leadership from the participants of the study. Without this, the intervention would not have been successful. Furthermore, for the researcher specifically, the educational sessions were intimidating. As a DNP student, attentiveness and respect from the participants were necessary. This encouraged the researcher to overcome public speaking fears and maintain a high-level of confidence throughout the entire project, especially during the educational sessions. This allowed the researcher to grow tremendously as a future leader.

Summary

With the data acquired through a compilation of the three objectives of this DNP project, project successes were abundant. As seen throughout Chapters IV and V of this scholarly project, ASD and ASD screening awareness were enhanced, provider satisfaction with ASD was addressed, and ASD specific screening was improved. These were the major accomplishments of this project; however, there were also minor takeaways, all of which were thoroughly discussed in Chapters IV and five. A clinical guideline and algorithm regarding universal ASD screening in primary care were instrumental to the educational intervention of this project. By having these resources,

provider satisfaction was also further addressed by having a simplified process to follow. Taken from the successes of this project were further clinical recommendations to be considered. Furthermore, because of the project's success, research and theoretical makeup ascertained from this project should be expanded.

Through this project, it was clear universal screening for ASD using the M-CHAT R at every 18- and 24-month well-child exam was vital, which was supported by copious literature as well as data acquired with the intervention of this project. By implementing universal screening for ASD, improved patient outcomes will occur because of early recognition and prompt referral. This will combat the myriad barriers to identifying ASD. From a clinician standpoint, having a clear-cut clinical guideline and algorithm, ASD screening can be simplified, which in turn will enhance provider satisfaction. All of these factors will combat delayed diagnosis of ASD and improve the quality of life off children and their families.

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APPENDIX A
MODIFIED CHECKLIST FOR AUTISM IN TODDLERS,
REVISED WITH FOLLOW-UP

Acknowledgement: We thank Joaquin Fuentes, M.D. for his work in developing the flow chart format used in this document.

For more information,

please see

www.mchatscreen.com or

contact Diana Robins at

DianaLRobins@gmail.co

**m Permissions for Use of
the M-CHAT-R/FTM**

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

- (1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.
- (2) The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.
- (3) Parties interested in reproducing the M-CHAT-R/F in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (DianaLRobins@gmail.com).
- (4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

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.


www.mchat.org

Child's name _____

Age _____

Relationship to child _____

Date _____

M-CHAT-R™ (*Modified Checklist for Autism in Toddlers Revised*)

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? **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 the phone, or pretend to feed a doll or stuffed animal?) **Yes No**
4. Does your child like climbing things? (For example, furniture, playground, equipment, or stairs) **Yes No**
5. Does your child make unusual finger movements near his or her eyes? (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? (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 noises 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're 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**

APPENDIX B
CONSENT FORM FOR HUMAN PARTICIPANTS
IN RESEARCH



Consent Form for Human Participants in Research
University of Northern Colorado School of Nursing

Project Title: Autism Screening in Primary Care

Researcher: Elizabeth Shedd, BSN, DNP-S Email: eibl6003@bears.unco.edu

Research Advisor: Karen Hessler, PhD, FNP Email: karen.hessler@unco.edu

Phone #: 970-351-2137

Purpose and Description: Thank you for participating in this survey. These questions concern basic clinician knowledge regarding screening for autism spectrum disorder in primary care. The purpose of the survey is to further evaluate process improvement outcomes as part of a DNP Capstone. Participating is not likely to be of any risk or inconvenience to you, and should only take about 5-10 minutes of your time.

Once the study is completed, results will be shared with you if you desire. You are not likely to experience any risks with completing the surveys, and there will not be any compensation for doing so. Your consent form will not be stored with your responses, and your name will not be on your surveys to help protect your anonymity. The survey's will be kept in a locked office in the school of nursing separated from your consent forms, only accessible by the researcher and research advisor. If you have any questions or concerns, please contact the researcher or the research advisor. The advisor may ask your name, but all complaints are kept in confidence.

Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact Sherry May, IRB Administrator, Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

Participant Signature and Date: _____

Researcher Signature and Date: _____

APPENDIX C
SURVEY: PARTS 1 AND 2

Autism Spectrum Disorder Screening Survey – Part 1
Elizabeth Shedd, FNP-Student, DNP-candidate

In order to identify specific needs for screening of Autism Spectrum Disorders, please take a few moments to complete each question below. You will not be identified with your responses and data will be reported in a group or aggregate format. Thank you for your time!

On the scale below, rate your confidence level with screening for Autism Spectrum Disorder (ASD) (please circle one):

1
2
3
4
5
Not confident at all
Very confident

What screening tool should be used to screen for Autism Spectrum Disorder (write in below):

On the scale below, rate your confidence level with identifying an abnormal screening for ASD? (please circle one):

1
2
3
4
5
Not confident at all
Very confident

If a screen for ASD is found to be abnormal, what should the next step(s) be? (write in below):

What are the referral resources in this area for diagnosis of ASD? (write in below):

What are the referral resources in this area for therapies to treat ASD? (write in below):

What are the top 3 motivators for you to participate in screening for ASD?

1. _____
2. _____
3. _____

What are the top 3 barriers that may keep you from screening for ASD?

1. _____
2. _____
3. _____

Autism Spectrum Disorder Screening Survey – Part 2
Elizabeth Shedd, FNP-Student, DNP-candidate

In order to identify specific needs for screening of Autism Spectrum Disorders, please take a few moments to complete each question below. You will not be identified with your responses and data will be reported in a group or aggregate format. Thank you for your time!

On the scale below, rate your *confidence level with screening* for Autism Spectrum Disorder (ASD) (please circle one):

1	2	3	4	5
Not confident at all				Very confident

What screening tool should be used to screen for Autism Spectrum Disorder (write in below):

On the scale below, rate your *confidence level with identifying an abnormal screening* for ASD? (please circle one):

1	2	3	4	5
Not confident at all				Very confident

If a screen for *ASD is found to be abnormal*, what should the next step(s) be? (write in below):

What are the referral resources in this area for diagnosis of ASD? (write in below):

What are the referral resources in this area for therapies to treat ASD? (write in below):

What are the *top 3 motivators* for you to participate in screening for ASD?

1. _____
2. _____
3. _____

What are the *top 3 barriers* that may keep you from screening for ASD?

1. _____
2. _____
3. _____

What was the most useful part of the educational program today? (write in below):

How could the educational program be improved to better serve your needs? (write in below):

Additional Comments:

Thank you!

APPENDIX D

**INSTITUTIONAL REVIEW BOARD APPROVAL
AND STATEMENT OF MUTUAL AGREEMENT**



Institutional Review Board

DATE: January 18, 2017

TO: Elizabeth Shedd, BSN, AAS
FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [993516-1] Guideline for Autism Screening in Primary Care
SUBMISSION TYPE: New Project

ACTION: APPROVAL/VERIFICATION OF EXEMPT STATUS
DECISION DATE: January 18, 2017
EXPIRATION DATE: January 18, 2021

Thank you for your submission of New Project materials for this project. The University of Northern Colorado (UNCO) IRB approves this project and verifies its status as EXEMPT according to federal IRB regulations.

Elizabeth -

Thank you for your extraordinary patience with the IRB process. Your materials and protocols for this study are clear and thorough. There are no requests for modifications or additions.

Your research is verified/approved exempt and you may begin your participant recruitment and data collection for this project.

Best wishes and don't hesitate to contact me with any IRB-related questions or concerns.

Sincerely,

Dr. Megan Stellino, UNC IRB Co-Chair

We will retain a copy of this correspondence within our records for a duration of 4 years.

If you have any questions, please contact Sherry May at 970-351-1910 or Sherry.May@unco.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Northern Colorado (UNCO) IRB's records.

Statement of Agreement between Participant and Community Agency

Statement of Mutual Agreement
 University of Northern Colorado
 Doctorate of Nursing Practice Capstone Project
 Student Name: Elizabeth A. Shedd, RN, BSN, DNP-S
 Date: September, 2016

The purpose of the "Statement of Mutual Agreement" is to describe the shared view between [Agency name] and [DNP Student name], DNP Candidate from University of Northern Colorado, concerning his/her proposed capstone project.

Proposed Project Title: Guideline for autism-specific screening in primary care.

Brief Description of Proposed Project: Creating and implementing of a specific guideline for autism-specific screening with the M-CHAT and M-CHAT R/F screening tools following the AAP recommendations for NCMC.


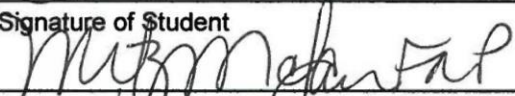
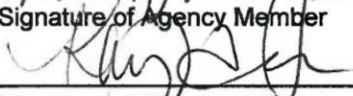
Goal of Capstone Project: To increase awareness and improve detection rates of ASD and other developmental delays.

Proposed On-site Activities: M-CHAT and M-CHAT R/F (if needed) at 18 and 24 months w/ ASQ3 questionnaire, lunch and learn with staff and providers, and 6 month pre and post chart audit in Cerner.

Confidentiality of Patient Records: (If applicable)

The designated Capstone Community/Agency member will agree to participate in the review and approval of the proposal and presentation of the final version of the project. He/she will attend (on campus or remotely) the meetings for both.

The DNP Capstone project will include a final report, an abstract, potential publication or oral presentation of the report. No personal identifiers will be included and all data will be reported in aggregate form. The author welcomes any comments or suggestions from the Agency, but reserves the right to publish findings and analysis according to professional standards and principles of academic freedom. For any work of a scholarly nature, the Author agrees to follow the Agency preferences in how it is to be named (or not) in the work.

	9-12-16
Signature of Student	Date
	9-12-16
Signature of Agency Member	Date
	9-12-16
Signature of Capstone Chair	Date

APPENDIX E

GUIDELINE

GUIDELINE TITLE

Screening for autism spectrum disorder in primary care.

SUMMARY OF RECOMMENDATION AND EVIDENCE

The AAP concludes that there is still strong evidence to support universal screening for autism spectrum disorder in primary care. This recommendation does take into consideration the USPSTF recommendation stating there is insufficient evidence to universally screen and more research must be conducted. However, there is strong research to support the use of screening with tools such as the M-CHAT R and M-CHAT R/F.

This type of level 1 screening is designed to be applied to a general population, and not just those that exhibit symptoms. This helps to further prove that using general screening for autism spectrum disorder along with primary surveillance, is key to early identification. “This type of screening can identify children with significant developmental and behavioral challenges early, when they may benefit most from intervention, as well as those with other developmental difficulties” (Dreyer, 2016).

The current recommendation is as follows; universal screening for autism spectrum disorder at **18 and 24 months well child exam using the M-CHAT R questionnaire** along with the age appropriate ASQ3. The M-CHAT R questionnaire should also be conducted on new patients 5> with an unknown history and no access to previous medical records. If the M-CHAT R and/or ASQ3 is abnormal or positive, the patient and care-giver should return for a follow-up interview and appointment within one month. This follow-up interview is conducted using the M-CHAT R/F and takes 15 minutes to administer and score. If, after the follow-up interview the questionnaire indicates a high risk for ASD, refer to the appropriate developmental and behavioral pediatrician AND appropriate disability evaluation resources within the community (see algorithm 1 for Greeley and surrounding areas). No matter the outcome of the M-CHAT R and/or M-CHAT R/F continue developmental screening questionnaire until 5 years of age. Lastly, regular developmental primary surveillance should be conducted at every appointment. If for any abnormality noted on the general developmental screening (ASQ3) it is strongly recommended that referral for disability evaluation occur and consider further evaluation for developmental delay with The Children’s Hospital. Always consider further referral for a complete audiology exam performed by a pediatric expert with any amount of speech delay or parental concern for speech delay.

Screening Tests-

According to Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents the recommended screening test for autism spectrum disorder in primary care is the M-CHAT R. This stands for Modified Checklist for Autism in Toddlers-Revised. This screening tool takes five minutes to administer and score and can be administered during normal developmental screening. If the M-CHAT R is positive or increased risk for ASD the secondary screening tool that is to be administered at another

appointment within one month is the M-CHAT R/F. This stands for Modified Checklist for Autism in Toddlers Revised with Follow-up. These screening tools are parent-rated scales that can indicate autism spectrum disorder signs and symptoms. Please see clinical algorithm for further direction.

Treatments and Interventions-

Autism spectrum disorder treatments and interventions include; behavioral, medical, educational, language, and occupational therapy. The most effective therapy for those with autism spectrum disorder is applied behavioral analysis. To qualify for applied behavioral analysis a child requires an ASD diagnosis. However, to qualify for any other appropriate therapies, a specific diagnosis isn't required! This encourages prompt evaluations to qualify for therapies. Appropriate therapy is jointly determined by the diagnostic evaluation facility and the disability evaluation resource (either Early Intervention or Child Find, based on the child's age). Severity levels of disability is as follows; level one- requires support, level two- requires substantial support, and level three- requires very substantial support. If there is any provider concern, it is recommended that referral occur for both or either resources for evaluations as the "watch and wait approach" isn't appropriate and can affect the child's long-term developmental trajectory. Prompt referral is key!

There are also many complementary and alternative medicine approaches to autism spectrum disorder. Intense behavioral and developmental interventions improve the health-related quality of life of those with autism spectrum disorder and care-givers. Interventions can be delivered in a wide range of settings; home, school, group related workshops, etc. The main goal of treatments and interventions for those with autism spectrum disorder is early identification and prompt referral.

SUGGESTIONS FOR PRACTICE

Children's Hospital Child Development and Behavioral Pediatrician's-

Phone#: 720-777-6630

Fax#: 720-777-7868

Contact Information for Greeley 6-

Child Find (>3 years old):

Contact Person: Beth Dick MA, ECSE

Phone #: 970-475-1079

Fax #: 970-475-1090

Early Intervention of CO (<3 years old) (Envision CCB):

Contact Person: Desiree Lujan

Phone #: 970-313-2629

Fax#: 970-330-0153

Audiology: Audiology Associates of Greeley

Phone #: 970-352-2881

Clinical Pearls-

It's important to remember that children develop at different times. With this said, good documentation can help other providers know if milestones are being met. If you have any questions about a delay in milestones, or other question related to childhood behaviors and development call the pediatricians at Children's Hospital Developmental and Behavioral Department. See the contact information above.

Burden of Disease-

Delayed diagnosis of autism spectrum disorder affects the outcome of the child and families forever. Early intervention is key to improve the health related quality of life.

- Prevalence of 7.6 per 1000 or one in 132 persons.
- Autism spectrum disorders account for substantial health loss across the life span.
- National costs of autism at around \$137 billion annually.
- Average lifetime cost of \$1.4 million for a person affected by autism that is not complicated by intellectual disability.
- Increasing prevalence.
- Increasing evidence for the role of genetic factors in the etiology of ASD.
- Environmental factors may constitute a "second-hit," modulating existing genetic factors predisposing to ASD.

(Augustyn, M. (2016, July 3). *Autism screening disorder: Terminology, epidemiology, and pathogenesis*. Retrieved from UpToDate: http://0-www.uptodate.com.source.unco.edu/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?source=search_result&search=autism&selectedTitle=4~150.)

Potential Harms-

When implementing a screening protocol, it's important to consider the burden on those administering and scoring the questionnaire. The M-CHAT R questionnaire takes 5 minutes to administer and score. The M-CHAT R/F takes 15 minutes to administer and score. The 18 month and 24 month WCC are covered by Medicaid and other insurances. With this screening guideline there is the potential for misdiagnosis and an increase in anxiety related to having an abnormality on screening and subsequently further testing. Because of resource restrictions it's important to have referrals completed quickly. It can take up to six months to get an appointment at the Sie Center at Children's Hospital.

Useful Resources-

<https://www.autismspeaks.org/>

<https://m-chat.org/print.php>

https://brightfutures.aap.org/bright%20Futures%20Documents/BF3%20pocket%20guide_final.pdf

<http://www.eicolorado.org/index.cfm?fuseaction=Documents.content&linkid=431>

<https://www.cde.state.co.us/early/childfind>
<https://www.childrenscolorado.org/doctors-and-departments/departments/down-syndrome/our-team/>

The M-CHAT R and M-CHAT R/F are available for free at <https://www.m-chat.org/print.php>.

The USPSTF has made a recommendation on screening for speech and language delays and disorders among children 5 years or younger (see the National Guideline Clearinghouse [NGC] summary of the USPSTF guideline [Screening for speech and language delay and disorders in children aged 5 years or younger: U.S. Preventive Services Task Force recommendation statement](#)).

SEE CLINICAL TREATMENT ALGORITHM FOR FURTHER DETAILS SCOPE

Disease/Conditions:

Autism spectrum disorder (ASD)

Guideline Category:

Screening

Clinical Specialty:

Family Practice

Pediatrics

Development and Behavior

Neurology

Intended Users:

Advanced Practice Nurses

Health Care Providers

Nurses

Physician Assistants

Physicians

Guideline Objectives:

To provide recommendations on screening for autism spectrum disorder in young children in a primary care.

Target Population:

Children aged 18 to 30 months or those <5 with unknown screening and no known medical records who haven't been diagnosed with autism spectrum disorder or other developmental delays in primary care. Also, for those where no concerns for autism spectrum disorder have been presented by care-givers.

Interventions and Practices Considered:

Screening for autism spectrum disorder in primary care using M-CHAT and M-CHAT R/F.

METHODOLOGY

Methods Used to Collect Evidence:

Searches of electronic databases

Databases:

CINAHL Plus with Full Text, Cochrane Central Register of Controlled Trials, Nursing and Allied Health, PsycExtra, PsycInfo, Psychology and Behavioral Sciences, Psychiatry Online, PubMed, and UpToDate.

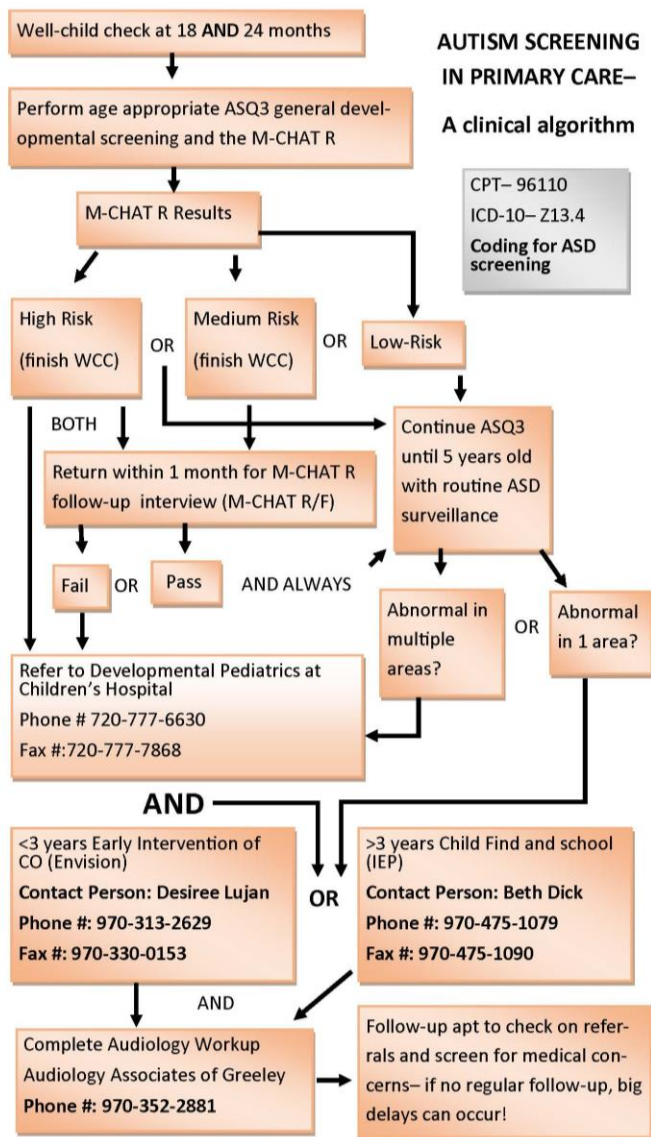
Types of Evidence Supporting the Recommendations:

Systematic Reviews, expert opinion, and AAP recommendations

BIBLIOGRAPHIC SOURCES

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- Dreyer, B. (2016). AAP statement on U.S. Preventive Services Task Force final recommendation statement on autism screening. *American Academy of Pediatrics*.
- Johnson, C. P., Myers, S. M., & American Academy of Pediatrics Council on Children With Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183.
- Robins, D. L. (2008). Screening for autism spectrum disorders in primary care settings. *Autism*, 12(5), 537-556. doi:10.1177/1362361308094502
- Siu, A. L., Bibbins-Domingo, K., Grossman, D. C., Baumann, L. C., Davidson, K. W., Ebell, M., & U.S. Preventive Services Task Force. (2016). Screening for autism spectrum disorder in young children: US preventive services task force recommendation statement. *Jama*, 315(7), 691-696. doi: 10.1001/jama.2016

APPENDIX F
ALGORITHM



ASD RISK FACTORS-

- Male gender
- Advanced paternal age
- Hearing loss
- Maternal family history of mental health concerns, especially schizophrenia
- Family hx (sibling with ASD)
- Pre-term infants
- FAS- Consider other prenatal exposures
- Tuberous sclerosis complex
- Fragile X
- Rhett Syndrome
- Genetic conditions (>50 genes associated)
- Various metabolic conditions- PKU, mitochondrial disorders, smith lemli opitz

- CLINICAL RED FLAGS-**
- No pointing at objects to show interest
 - Not looking at objects when another person points at them
 - Having trouble relating to others or not having an interest in other people
 - Avoid eye contact and want to be alone
 - Have trouble understanding other people's feelings or talking about their feelings
 - Prefer not to be held or cuddled or might cuddle only when they want
 - Appear to be unaware when other people talk to them but respond to other sounds
 - Be very interested in people, but not know how to talk, play, or relate to them
 - Repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
 - Have trouble expressing their needs using typical words or motions
 - No pretend play games
 - Repeat actions over and over
 - Having trouble adapting when a routine changes
 - Have an unusual reaction to the way things smell, taste, look, feel, or sound
 - Any loss of any language or social skills at any age
 - Avoids or inconsistent eye contact
 - Repeats or echoes words or phrases said to them or heard on TV
 - Has trouble requesting or expressing needs through typical words or gestures
 - Doesn't compensate for language delay with nonverbal strategies
 - PARENTAL CONCERNS!!!

- CLINICAL PEARLS-**
- **Any concerns, call The Children's Hospital on-call developmental pediatrician 720-777-6630!**
 - If you're concerned regarding abnormalities with developmental milestones or failed ASQ3 score contact developmental pediatrics at Children's Hospital. They take Medicaid but have a long waitlist. The earlier the better is the motto, even if you're unsure.
 - It's important to remember that often if the M-CHAT R and M-CHAT R/F are positive, an ASD diagnosis isn't guaranteed, but there are still concerns regarding developmental delay that must be addressed.