Identifying Early Symptoms of Autism in a Childcare Setting – The Development of the 360 Assessment of Child Development
Why autism should be a Maternal and Child Health priority.

Introduction

What is a Developmental Disability?
The Centers for Disease Control (CDC) defines developmental disability as a “diverse group of severe chronic conditions that are due to mental and/or physical impairments.” These impairments can affect a child’s language and communication skills, motor development, cognitive development, and social and emotional development and can have a significant effect on a child’s ability to care for themselves. The term developmental disability is a broad term used to refer primarily to Autism Spectrum Disorders (ASD), Cerebral Palsy, hearing loss, visual impairment, and intellectual disabilities previously categorized by the term mental retardation or intellectual disability.

Autism is one of a spectrum of neurological disorders, commonly known as Autism Spectrum Disorders that affects 1 out of every 110 children born in the United States. Currently, 560,000 children ages birth to 21 years have a diagnosis of an Autism Spectrum Disorder. Autism is characterized by impaired social functioning, impaired verbal and nonverbal communication, and repetitive, stereotyped patterns of behaviors. The 4th, text-revision edition of the Diagnostic Statistical Manual (DSM-IV-TR) specifically outlines that for a child to be given an ASD diagnosis, symptoms must present themselves prior to a child’s third birthday. Yet up until recently, autism has not been diagnosed in children under the age of three.

Once a child has been diagnosed, many parents and caregivers are able to recall symptoms observed prior to the child’s diagnosis. Doctors and researchers now believe that the diagnostic features of ASD do manifest themselves in very young children and therefore should be identifiable and potentially treatable before the age of three.

Early identification and early intervention have been shown to drastically improve a child’s prognosis once identified as at risk for developing ASD. If red flags for
developmental disability can be identified before a child is 18 months old that child can get access to intervention services sooner. There are two key components to the identification and diagnosis of ASD; general developmental screenings and ASD specific screenings (1). The American Academy of Pediatrics believes that these two things combined will lead to an increase in identification (Pediatrics, 2006). If children can be identified before age three than intervention services can be provided and can have a much greater impact than if they were offered at an older age (6, 3).

Early intervention has also been shown to drastically decrease the cost of care of an individual with autism over their lifetime to both their families and to the society as a whole (7). In a study comparing three years of Early Intensive Behavioral Intervention in comparison to 18 years of special education it was found that the state of Texas could save on average $2.09 billion over an 18 year period just by providing access to early intervention services. By allocating funds to provide intervention, the government could decrease national spending on children with Autism. The federal government reserves $18,790 each year to care for children with Autism (8). 6,556 dollars of that is spent on regular education. A follow-up study done in Tennessee found that for every dollar that was spent on early intervention, $7.00 in savings were accumulated over a period of 36 months (9). Early intervention is much more cost effective than public special education alone. Appendix 1 shows how the implementation of a tool like the 360° Developmental Assessment discussed later in this paper, can reduce the overall cost of ASD to the population as a whole.

While early intervention has been shown extremely effective it is crucial that children be identified at an early age in order to receive early intervention services (3). Currently there is no comprehensive screening tool that looks at both typical and atypical development. In order for
children to be identified there needs to be a developmental screening tool that can be easily accessed and administered by care providers. The 360° Developmental Assessment was developed in order to combine a general developmental screening tool and an ASD/developmental disability specific tool into one easy to administer developmental assessment, geared towards childcare providers and parents. This paper looks to refine and improve the current draft of the 360° as well as to discuss the benefit of childcare-based assessment to improve early identification of developmental delay and preautistic symptoms (4) in children ages 0 to 36 months.

Is this a public health problem?

A recent press release from Autism Speaks (10) not only acknowledges and supports the CDC’s estimate that on average 1 in 110 children in the United States has an ASD but also identifies autism as a “major public health crisis, requiring intensified action…” (10). According to a recent study published in *Pediatrics* (11) reports that as many as 1 in 91 children have a diagnosis of autism. While this study primarily used parent-report data which is potentially tainted by recall bias as well as other confounders. Pediatrics does identify the extent to which parent-report data can vary somewhat from actual numbers. In this study parents were asked to identify whether or not their child had autism, there was no specification that the child had to have a clinical diagnosis. This sheds some light on why the figure of 1 in 91 is higher than the CDC’s estimated average of 1 in 110. From 2002 to 2006 the prevalence of autism increased 57% (1). Regardless of where the data is coming from these figures clearly identify that the rate of autism is increasing drastically and the field of Public Health, specifically maternal and child health (MCH) bear some responsibility to address this epidemic prior to the time of diagnosis.
MCH focuses on the “determinants, mechanisms and systems that promote and maintain the health, safety, well-being, and appropriate development of children…” within the broader scope of public health which aims to improve the lives of people and populations. Over the years MCH has made drastic changes in how children with disabilities are treated and the services that they are able to gain access to. The Education for All Handicapped Children Act of 1975, later renamed the Individuals with Disabilities Education Act in 1990 provides a free education to all school-age children with disabilities until the age of 21. In 1986 a law was passed requiring that all children aged 3 to 5 with disabilities receive early intervention services. However data shows that in order to have the greatest impact on a child’s functioning and prognosis therapy must take place prior to a child’s third birthday (3).

Many early intervention services that are funded by state and Federal funds are designed for children who are predisposed to developmental delay and disability. Children who are born at-risk for developmental challenges immediately enter into a system of programs, assessments and treatments meant to help them to reach their fullest potential. This system provides children who suffer from hearing loss with early intervention services including hearing aids and language therapy. Children with Downs Syndrome or Cerebral Palsy receiving continuous care including pediatrician visits and in home help in hopes that they can rise above some of the challenges and limitations they face. These children are all able to receive these early intervention services because at birth they are considered to be ‘at-risk.’ Without knowing what specifically causes each individual case of autism it is impossible to categorize a child at birth as being high-risk. Currently the only children identified as being at high-risk for developing autism are those children who are the younger siblings of children with confirmed diagnoses of
an autism spectrum disorder. It is crucial to identify children who can be called *at-risk* for autism aside from those who have a predisposition to developmental delay.

There are no genetic or diagnostic tests to look for autism when a child is born. No one symptom that every child with autism will exhibit before their first birthday. Not even a list of potential triggers or factors that might increase one’s risk. Only through consistent screening and developmental assessment can children’s development be accurately evaluated. The 2010 Health Care Reform bill addresses the need for more comprehensive treatment of children diagnosed with autism. Among other things, it prohibits insurance companies from denying coverage based on a pre-existing medical condition and requires that maintenance services as well as behavioral therapy such as Applied Behavior Analysis and Verbal Behavior Analysis be covered by health insurance companies. While these changes to the health care system are important and will bring some peace of mind to those who care for individual’s with autism it does not address the need for screening and assessment. The American Academy of Pediatrics has written extensively on this issue and has recommended that all pediatricians screen their patients for ASDs during well-child and other pediatric appointments. In 2004 a survey revealed that 44% of primary care pediatricians had at least 10 children with ASD in their care, however only 8% reported that they routinely and consistently screen for ASD. Another survey found that primary care pediatricians were aware of the American Academy of Pediatrics’ policy on screening and were aware of the DSM-IV-TR diagnostic criteria for ASD, yet they believed that the screening tools available were outdated (13). Some authors argue that recommendations made by both the Academy of Pediatrics and the Maternal and Child Health Bureau are not feasible within the confines of a well-child visit (14, 15)
J. S. Reznick and his colleagues have stated that “From a research and public health perspective, it would be advantageous to identify infants who are at risk for an eventual diagnosis of autism…(16)” There needs to be a change made in the way children are assessed and screened for developmental disorders. The current system of pediatric care does not allow doctors the time necessary to thoroughly assess all aspects of a child’s development in one pediatric well-child visit. To help alleviate this problem the American Academy of Pediatrics has developed flyers and handbooks for parents to encourage them to bring these issues up with their pediatrician and push for a screening if they feel their child may be at risk. While many parents do approach their doctors and pediatricians with concerns about their child’s health and development they can often be unaware that their child’s lack of eye contact or lack of response when his or her name is called is the first sign that there is something wrong.

There are however, preexisting systems and infrastructures that are set up in such a way that they present themselves as an ideal platform for the ongoing assessment of child development. These systems engage with children daily and are designed to follow children typically over a 2 to 5 year period of time. Child care centers see children every day sometimes for up to 10 hours at a time. The system is designed to have 1 or 2 adults per classroom of children who are responsible for following the developmental trajectory of the children in their care. Most centers in North Carolina require that annual or biannual developmental assessments be performed on all children in the center. While children are being assessed many of the assessment tools that can be afforded by smaller, non-profit centers are cumbersome and difficult for the layperson to understand and implement affectively. The infrastructure already exists for public health to make a difference in the lives of children. But without a standardized, updated and easily accessible assessment tool being implemented state- or nationwide the prevalence of
autism among children under the age of 5 will continue to rise and pediatricians will likely continue to believe that screening tools are outdated and ineffective.

As a public health practitioner I see it as my responsibility to address this issue and work towards the goal of implementing ongoing, childcare-based developmental assessment across North Carolina. Public health as a discipline is primarily concerned with the prevention of disease within communities and populations. The core functions of public health (Figure 1) are assessment, policy development, and assurance; each of which applies to the population in question – children under the age of 3-years-old.

Assessment refers to monitoring and investigating a problem. In this case, monitoring the incidence, prevalence and rate of increase in diagnoses of autism over the past decade; Figure 2 clearly shows that since 2000 the number of cases of autism in children age 3- to 22-years-old has more than tripled (17).
Figure 2. Number of cases of autism in the United States and Outlying Areas.

Data specific to North Carolina (Figure 3) show that the number of documented cases of autism for the same age range has increased almost 400% in the last 10 years. When compared to other childhood, neurological disabilities like Down Syndrome which has a prevalence of 1.5 cases per 1250 live births (18), a prevalence of 1 case of autism per 110 live births should be viewed as significant public health crisis.
The American Academy of Pediatrics strives to develop and effectively implement policies to encourage pediatric screening. However, it is time to work outside the confines of pediatric medicine and address the issue of early childhood assessment on a community level within the walls of childcare centers. More than 60% of U.S. children receive center-based care and more than 80% of North Carolina children receive center-based care (19). The policies in place currently focus on screening at a once a year well-child visit when they could also be addressing the issue through bi-annual child development assessments. This paper does not suggest that screenings be eliminated from pediatric care visits only that in-depth assessments also be performed in a suitable environment. Childcare centers are typically community based and would meet the needs of the third and final core function of public health; assurance. Providing center-based assessment would assure that these populations have equitable access to disease and disability prevention services. While autism cannot yet be prevented on the primary level, children can be identified as having preautistic symptoms (4) (symptoms that are not yet diagnosable as autism but suggest unusual develop) and therefore can be prevented on the secondary level. Just as a Pap smear is used to screen women for early, asymptomatic cervical cancer, so should consistent and ongoing developmental assessments be used to screen for sub-clinical or prodromal autism (4).

Existing Methods of Screening

The American Academy of Pediatrics recently revised its recommendations on early detection of children with developmental delay (6). They called for more rigorous screening by doctors and developed training materials for parents to encourage them to be aware of and speak up regarding their child’s development (1). In 2006, the American Academy of Pediatrics developed an algorithm for the identification of infants and children with developmental
disabilities (6). All the steps are laid out that a healthcare professional should take in order to obtain the most accurate picture of a child’s development all starting with the child actually attending well-child, preventative health care visits. The algorithm includes eliciting parent concerns, accurate observations of each child, the identification of possible risk and protective factors, and the documentation of findings. These are all parts of surveying the child. Once surveillance has been done and demonstrates an adequate risk then the algorithm points the health care professional to administer a developmental screening tool that is developmentally age appropriate. Based on the results of the screening children can be referred for further developmental and medical evaluation as well as early developmental intervention services if necessary.

What the American Academy of Pediatrics is trying to suggest with the implementation of this algorithm is that in order to perform an informed and accurate assessment the child’s entire development must be taken into consideration. They are looking for risk factors to be weighed against protective factors and parent’s concerns addressed. Research has shown (4) that parents are often the first to show concerns about their child’s development but rely primarily on their pediatrician to inform them if there is something they should be concerned about. While the development of an algorithm will hopefully encourage pediatricians to bring parents into the conversation about their child’s development it will likely take some time before it is implemented consistently state- and nation-wide. To date there have primarily been two ways that development has been assessed; by healthcare professional report and by professionally administered parent-report assessments. These tools are usually designed to do one of two things; assess for typical development or for atypical, pre-autistic development.
Professional report tools are those administered by a doctor or other health care worker. These are often referred to as standardized assessments of development. They can measure general development or be specific to developmental domains, for example, language development. They can also be specific to different disorders. For the purposes of this paper only those assessing general development and those specific to autistic symptoms, both doctor-report and parent-report will be reviewed. Doctor-report tools can often be lengthy and take time that a pediatrician may not have to spend with each child. Brief interviews and checklists have been developed to overcome the issue of time but some doctors feel these checklists can be limiting due to issues of informality and validation (20). Longer, more in depth screening tools are often administered by a psychologist or developmental specialist and again calls into question if clinic-based observations are more or less accurate than observations taking place in the child’s home environment.

Parent-report tools are often administered by a healthcare professional but completed by the parent. There are some parent-report tools available online, some for free and others at cost, for parents to fill out and bring to a pediatric visit. The Centers for Disease Control has developed a program called Learn the Signs. Act Early (21) which allows parents to print out age-specific checklists of developmental milestones and they are encouraged to speak with their primary pediatric care provider should they have any concerns. The administration of a parent-report tool calls into question a parents ability to accurately represent their child’s development. Issues like recall bias; a parent not accurately recalling when their son or daughter started to crawl or started to say “mama” and “dada” can have adverse effects on the validity of parent report measures. Many parent-report measures consist solely of yes/no style questions leaving a lot up for interpretation. The yes/no format of these questionnaires can drastically reduce the
amount and quality of information being collected. Asking a parent “does your child seem oversensitive to noise (23)” is difficult to answer with a yes or a no and yet, the Modified Checklist for Autism in Toddlers requires a parent to do just that.

Observations made by a doctor or other observer in an office or laboratory setting however may also not be accurate representations of a child’s actual development and skill level (20). Children become shy when faced with new people and new situations often making them appear more withdrawn and socially isolated than they may in fact be in familiar situations. In Great Britain they employ home health visitors to observe children in their natural, home environment in order to better assess development (23). The United States however has no such system in place for children not already identified as at-risk for developmental challenges. What does exist is a system of early childhood educators who see the children 5 days a week for many hours at a time. During this time children have the opportunity to eat, sleep, engage with peers, and engage in other developmentally appropriate activities. All of these are situations that can be used to assess a child’s development perhaps making childcare centers an ideal place to implement a developmental assessment.

*The Childcare Setting*

Observations made in a clinical setting can often be inaccurate (16), parent report screenings have been identified as more accurate and more efficient than much of what takes place in a doctor’s office or an observation room (24). However as cited earlier, parents are not always the most accurate reporters when it comes to their child’s development either. The child care provider has a unique perspective for assessing and addressing the development of the children in his or her care. Preprimary school based assessments have been increasing over the
past few years as rates of autism continue to rise and the benefits of early identification and early intervention becomes more widely understood and accepted (25).

Programs such as Head Start and Early Head Start require that assessments be done covering 8 different developmental domains, three times over the course of the academic year (25). This allows for continual assessment of an at-risk population. This continual assessment however has not been implemented as a regulation for childcare centers in many states. In 1997, the National Association for the Education of Young Children which accredits childcare centers nationwide adopted a policy stating that continuous assessment be integrated into each of their center’s curriculum and be based on ongoing observations of the children. One study indicated that teachers found keeping a running record-style portfolio for each child was the most beneficial way to continually track their development and their skills (25). A limitation to the portfolio however, is that it is time consuming and costly and have been found to be only mildly useful as they require intense training to be created properly and used effectively.

The Erikson Institute for Advanced Study in Child Development found that according to child development specialist, the most desirable and reliable form of assessment that can be implemented in the childcare setting is a “detailed developmental scale (25).” With that being said, encouraging centers to adopt a policy recommending or enforcing the use of developmental scales would take drastic changes to the child care system as a whole. Currently states have individual control over their centers. While the National Association for the Education of Young Children is a national accrediting body not all centers across the country are accredited. The accreditation process is a long and expensive one requiring childcare centers to meet extremely high standards of staff education, performance, nutrition, and family relations (26, personal communication A. Wright).
In 2007 a study of Florida based childcare centers was implemented to identify specific tools used across 61 out of 67 counties in the state (27). Counties were surveyed and asked to report what tools they used and whether or not they involved parents in the assessment process. What they found was that many centers were using multiple tools to assess children’s development. It was also found that some counties were using tools not identified as screening instruments such as the Learning Accomplishment Profile which is designed to be administered by a trained examiner. Eighty-four percent of the counties were using the Ages and Stages Questionnaire which is designed to assess children as young as 6-months-old. The authors of this study identified marketing techniques assessment tool developers, financial resources and limited staffing as factors influencing a center’s choice of assessment tool. While this study specifically looks at early childhood learning centers in Florida it does provide an example of what assessment can look like without guidelines or a standardized tool.

A lot can be learned from Allen’s Florida-based research as well as the recommendations that come from the American Academy of Pediatrics and the Erikson Institute for Advanced Study in Child Development. Each addresses the need for informed assessment of children while addressing the complex nature of assessment. It should be noted that regardless of where it takes place ongoing assessment is a crucial part of early identification of developmental delays. That being said it is important to compare the strengths and limitations of the parent-report, pediatrician-report, and childcare provider-report assessment. It has already been noted that parent-report measures risk recall bias (11) and leave room for much interpretation and pediatrician-report checklists are often considered too informal and lack validation (20). But the use of childcare provider-report has yet to be researched in detail to show whether or not it equals or supersedes parent-report in accuracy and effectiveness. While many parent-report
assessments (e.g. The Ages and Stages Questionnaire [28]) can be administered by child care providers, no standardized assessment exists that is specifically designed to be administered by child care providers who, typically have a greater understanding for the nuances of child development. It stands to reason that given the amount of time child care providers spend with children and the types of activities the children engage in while in their care, that child care provides an excellent platform for a broad spectrum, developmental assessment.

**Literature Review of Existing Tools**

As previously discussed, there are multiple ways currently employed to assess both typical and atypical child development. For the purposes of this paper and the development of the 360° Child Development Assessment Tool atypical development is operationalized as “development that does not meet age appropriate milestones as established by the Centers for Disease Control’s First Signs program and the American Academy of Pediatrics.” There are assessment tools that have been validated to specifically assess neurotypical child development such as the Ages and Stages Questionnaire and the Parental Evaluation of Developmental Status. These tools tend to be sensitive only to significant and severe developmental deficits and are rarely ideal tools for identifying children whose development may only show the early signs of delay. Other tools such as the Modified Checklist for Autism in Toddlers are used exclusively for the identification and diagnosis of Autism in young children.

While approximately 16% of children in 2008 had developmental and behavioral disabilities it has been identified that less than one-third of them were initially detected by their pediatric health care provider (20). Some have theorized that this lack of identification was due to a lack of screening as well as the use of informal, non-validated checklists of developmental...
milestones. Many screening tools have been developed in hopes that they can overcome these barriers to accurate and early identification.

**Developmental Assessment Tools**

*The Parents’ Evaluation of Developmental Status*

The Parents’ Evaluation of Developmental Status (20) was designed to provide pediatricians with an easy to use, validated measure of developmental milestones. The authors identified that only 20% to 30% of cases of developmental disability were identified prior to children entering kindergarten. There is overwhelming evidence showing that early intervention is most effective when implemented prior to the age of five (3) if not before a child reaches their third birthday. The goal of developing and validating the Parent’s Evaluation of Developmental Status was to provide pediatricians with a validated checklist for developmental milestones as well as to establish if this style of assessment could be an accurate indicator of a child’s developmental status.

When developing this checklist the authors remained compliant with the American Academy of Pediatrics’ recommendations on early identification of developmental delay. Items used in this checklist were based on standardized diagnostic tools, the Brigance Inventory of Early Development-II and the Brigance Comprehensive Inventory of Basic Skills-Revised. The former is designed for children birth to 11 years while the latter is designed for children kindergarten through sixth grade. The Inventory of Early Development-II was standardized using children across multiple settings including pediatrician’s offices as well as preschool and day care programs. The Parents’ Evaluation of Developmental Status was tested for reliability and readability. It was standardized on both parent-administration and professional/paraprofessional administration and produced a high level of agreement between the two. Based on testing of
readability the checklist was found to be written on approximately a second grade level making it accessible to parents with little education as well as those not in a medical field. When compared to the Ages and Stage Questionnaire to establish its administration time, cost and accessibility, the Parents’ Evaluation of Developmental Status outperformed the Ages and Stage Questionnaire; it takes less time (4.5 minutes versus 20 minutes), costs less ($0.02 per administration versus $0.42), and reads two grade levels below Ages and Stages. Results from the study also suggest however that the checklist should not be used alone as a measure of child development. The authors suggest that the Parents’ Evaluation of Developmental Status be implemented alongside other evidence-based measures of surveillance in order to get a broader picture of each individual child’s abilities and development.

The Child Development Inventory

The Child Development Inventory (29) was developed as a measure of both developmental disability and typical development. It is meant to measure child development from 1-year of age up to 6.5-years of age. The Child Development Inventory was designed to detect developmental delay and disability as well as neurotypical development across nine developmental domains: social, self-help, gross motor, fine motor, expressive language, receptive language, letters, numbers and overall general development. It is meant to be used as a parent-report measure. One of the authors’ primary goals was to address the difficulties faced by relying on pediatricians to complete thorough developmental screens. Ireton and Glascoe (29) identified parent-report measures as one way to circumvent the need for pediatric screening. Parents often have a broader picture of their child’s behavior outside of a clinical setting making them more aware of subtle changes that may indicate a delay. The authors also identified a
parent-report measure as a way to cut down on the time spent taking a child’s medical history during a pediatric visit allowing doctors more time to address parent’s concerns.

The Child Development Inventory was tested on 568 children ages 1- to 6-years-old with approximately 100 children per age year. The sample used was 95% white making it difficult to generalize the results to a primarily non-white population. The Child Development Inventory was tested for reliability and validity across different categories. It was tested to ensure validity based on children’s actual age and for children with special health care needs. It was studied separately to test for kindergarten validity as well as early childhood and special education validity. Results from this study show that the measure is an accurate identifier of children with developmental delays ranging in severity from mild to severe. It was also found that parents’ reports of their child’s development correlated with their age and most children were identified as being within a defined range of normal. These results suggest that the Child Development Inventory is a useful tool when assessing the development of children in the general white population.

Research found that overall the parents who had concerns about their child’s development were more willing to spend the 30-50 minutes completing the survey in comparison to parents who had little to no concern. However the tool does encourage parents and pediatricians to collaborate and work together when assessing a child’s development. One major limitation of the Child Development Inventory is that it is written on a seventh- to eighth-grade reading level making it inaccessible to some parents. This also makes it not an ideal tool for use in childcare or any setting where parents or caretakers might not meet the level of comprehension necessary to administer the tool effectively.
The Ages and Stages Questionnaire was developed in 1980. It is a developmental assessment made up of 11 sub-questionnaires designed to be completed by the child’s parent or a primary caregiver and to assess different domains of the child’s development. The questionnaire can be used on children as young as 4-months-old and as old as 48-months. It is one of few assessments of neurotypical development that can be used on such young children. The Ages and Stages Questionnaire was designed to not only follow a child’s development across the first four years of their life but also to be cost effective and accessible. While first developed in the 1980s the Ages and Stages Questionnaire was revised in 1997 and then again in 2009. It now assesses children up to the age of 66-months. The latest revision of the assessment has additional questions geared towards identifying children who will later be diagnosed with autism. Revisions made to the 1997 edition consisted of modifications to clarify the meaning of certain questions, as well as removing questions that generated confusion by parents. Test-retest and interobserver reliability tests were done both produced acceptable results. Data also found that parent’s evaluation of their child’s development was consistent over time. There was also a high rate of agreement between parent evaluation of child development and professional evaluation of child development.

One study done in 2010 reviewing the social and emotional sub-questionnaire of the Ages and Stages Questionnaire identified a major limitation of this section of the questionnaire. It was found that parents who had high levels of stress or anxiety tended to score their child’s level of functioning lower than it actually was. Mothers who were diagnosed as clinically depressed were more at risk for misrepresenting their child’s functioning and development. This suggests that the social emotional sub-questionnaire is not necessarily an
accurate measure of a child’s social and emotional development. The Ages and Stages Questionnaire is frequently used by childcare professionals (personal communication P. Anderson) to assess children’s development. While accessible to providers research has shown the questionnaire to be a more valid assessment of development as children become older.

Analysis of the questionnaire shows only 51% sensitivity for children 4-months-old, meaning that approximately half of the 4-month-old children with developmental delays are actually identified as such. As children reached 36-months the questionnaire showed 90% sensitivity. The Ages and Stages Questionnaire however, had a much higher rate of specificity showing that its ability to detect typical development was strong. The authors argue that with such young children it is difficult to recognize significant delay in development. Further analysis of the questionnaire showed that when children with previously identified developmental delays were assessed using the Ages and Stages the scales were able to accurately identify them as delayed.

Autism Specific Measures

The Modified Checklist for Autism in Toddlers

The Modified Checklist for Autism in Toddlers was developed in 2001 when researchers identified a lack of diagnostic tools used to detect autism and other pervasive developmental disorders in very young children (23). Robins, Fein, Barton, and Green (23) noted that for many reasons autism is rarely identified in children under the age of 3. Some of the reasons they noted include the way in which symptoms present themselves case to case, the efficacy and consistency of pediatric screening and suggested age of onset. However, there is significant evidence to suggest a considerable gap between when parents first identify and express concerns about their child’s development, to when the child is first evaluated, to when the child is
diagnosed and begins receiving therapeutic services. This evidence encouraged the development of the Modified Checklist for Autism in Toddlers.

The Modified Checklist for Autism in Toddlers is one of many tools that assess autistic symptoms in children. Most tools however are specific to identifying autism in older children. The primary idea behind the development of the Modified Checklist for Autism in Toddlers was to design a parent-report tool to be utilized by pediatricians during a pediatric well-child visit. The Modified Checklist for Autism in Toddlers is a modified version of the Checklist for Autism in Toddlers which was originally developed in 1992 (32). The Checklist for Autism in Toddlers attempted to identify autistic symptoms in children 18-months old and older. However this tool was developed and validated in Great Britain using home health visitors as assessors of child development and behavior. As the United States health care system has no comparable home visiting system for assessing children’s development the creators of the Modified Checklist for Autism in Toddlers thought it best to utilize parent report of children’s current behavior.

The Modified Checklist for Autism in Toddlers consists of 23 yes/no checklist-style questions to be completed by the child’s parent. It was studied on 1298 children during their 18-24 month well-child visit. Specific questionnaire items were defined as “critical items” meaning that they were the best discriminators of early ASD based on preliminary analysis of data. The study found that the MCHAT was able to accurately identify children who were at risk for autism or PDD-NOS. However, the MCHAT relies on the accurate reporting of parents which is subject to bias. While the administration of such a checklist will likely increase rates of early detection of autism/PDD-NOS the yes/no format and the number of questions asked limit the amount of information that can be collected in order to make an accurate assessment of behavior
and development (16). While yes/no questions leave little room for interpretation it limits the quality of the data being collected (16).

The First Year Inventory

The First Year Inventory (16) is a parent-report instrument meant to identify predictors of autism in children 12-months old. Evidence suggests that the early treatment of autistic symptoms can greatly improve the prognosis of the disorder. As such Reznick, Baranek, Reavis, Watson, and Crais (16) sought to create an autism-specific screening tool to assess the behavior of a community sample of 12-month-old children. It is advantageous to use a community sample rather than those children who are at risk for developmental disorders based on family history, premature birth or other extenuating circumstances. The goal of the researchers was to intervene somewhere between the levels of primary and secondary screening. That being to identify children in the general population who show signs and symptoms of atypical development while also being able to highlight children whose symptomology seems to suggest an eventual diagnosis of an Autism Spectrum Disorder. By doing so, the First Year Inventory ideally can be used to assess both children who are considered at-risk as well as those whose development may not yet be drawing the attention of parents or pediatricians. In order to be identified as having a developmental delay or even being at risk for developmental delay a child’s behavior must be symptomatic in some way. Therefore primary prevention of autism and other ASDs is not likely to be possible unless risk factors and environmental triggers are identified and exposure can be eliminated.

The First Year Inventory was specifically designed to identify one-year-old children at risk for a diagnosis of autism and not to assess development both typical and atypical. Many of the questions included such as “Does your baby use gestures such as raising arms to be picked
up, shaking head, or waving bye-bye (16; p.1706)?” and “Does your baby try to get your attention to obtain a favorite toy or food (16; p.1706)?” can be seen in assessments designed to evaluate typical development such as the Ages and Stages Questionnaire (28). However the questions are primarily designed to identify atypical and symptomatic behaviors. The First Year Inventory was completed by 1,496 families, 25% of the initial sample. This questionnaire was mailed out to families in both rural and urban areas surrounding a small town in the Southern part of the United States. The sample was somewhat limited as it excluded those families who self-identified themselves as Hispanic on their child’s birth record. Because the sample size was rather large, Reznick and colleagues establish a required significance level of $p$ less than .01 when reviewing the effects of all statistical analyses. During evaluation, questions were identified as being scored with either one or two risk points (16; p.1698) - this scoring system was associated with how parents responded to multiple choice questions asking them to rate the occurrence of their child’s behavior on a 4-point Likert scale labeled never, seldom, sometimes, and often. Those questions with the least level of response with fewer than 5% of parents responding were awarded one risk point. Questions were given a second risk point if the behavior was considered extremely unusual, for example a child not looking when their name is called or not attempting to get a parent’s attention (16; p.1698). Level of risk was based on previous research regarding risk factors and red-flags for atypical developmental versus eventual autism diagnosis. When scoring the First Year Inventory an average was taken of each question’s ordinal response value – a higher score was identified to represent more atypical behavior and development. Statistical testing revealed a strong cohesion across all questions of the First Year Inventory as well as strong correlations among the different constructs that were assessed.
The Autism Diagnostic Observation Schedule

The Autism Diagnostic Observation Schedule (33) was designed to provide practitioners with a set of standardized interactions and contexts for social and communication behaviors to take place. These behaviors were intended to be observed in children ages 6- to 18-years of age. In 1989 when this assessment was first published it was meant to discriminate general mental handicaps from autism as well as from normal functioning. Since its publication the Autism Diagnostic Observation Scale has been revised in an attempt to make it applicable to younger populations as well as bring many of its criteria up to date to be congruent with more current research (34).

The Autism Diagnostic Observation Schedule specifically assesses the social and communication skills of children with developmental delays and intellectual disability. As this assessment tool is specific to children already identified as having a developmental delay it is not intended for use by pediatricians, parents or other care providers to aid in the identification of children who are at-risk for autism or other ASD. The 2007 revision of the Autism Diagnostic Observation Schedule allowed for the identification of non-autism ASD is populations with low degrees of functioning. In comparison to the original publication there was a 12-31% increase in the specificity of classifying this population and identifying children who had no words who were included in this population. The revised algorithms did not however improve the Autism Diagnostic Observation Schedule’s ability to deifferentiate autism from other spectrum disorders implying that deficits in social and communication development are representative of many different types of developmental and behavioral delays and diagnoses. As such the Autism Diagnostic Observation Schedule is not recommended as the only assessment of a child’s social
and communication development but should be used in conjunction with other measures of overall development.

The Autism Observation Scale for Infants

The Autism Observation Scale for Infants (35) was developed with the goal of identifying and monitoring the early signs of autism in high risk populations. All children who participated in the study were the younger sibling of a child with a clinical diagnosis of an autism spectrum disorder. Upon evaluation it was determined that Autism Observation Scale for Infants is not yet viable as a screening of the general population as data on the validity of the tool was collected from a high risk population. However, the data do provide researchers with the ability to observe and document the nature and development of early autistic symptoms. What sets the Autism Observation Scale apart from other assessments of at-risk development and autistic behavior in children is that it was designed specifically to be developmentally appropriate for use with an infant population.

For the purposes of evaluating the Autism Observation Scale, *infant* was defined as children ages 6- to 18-months of age. Participants were recruited from self-referrals to the author’s ongoing study of infant siblings of children with clinical, DSM-IV-TR diagnoses of autism or other ASD. Participants were seen at three separate ages, 6-, 12-, and 18-months of age. Most of the infants who participated in the study were seen at all three ages and inter-rater reliability was also assessed at each of the three ages. The study was meant to test the reliability of the assessment and found that both inter-rater reliability and test-retest reliability were acceptable. Results also suggest that the total score is a better predictor of future diagnosis as opposed to looking at the score of each question individually. The authors do note that as the children aged within the study, examiners also became experienced with administering the
assessment and perhaps even more adept at detecting the behaviors of interest. However it is also possible that the slight behavioral differences in children as young as 6-months are difficult to decipher and symptomatic behaviors that do emerge are more easily detectable among children 12-months of age and older. Further research is needed before the clinical application of the Autism Observation Scale can be established.

Discussion

This is a thorough but not exhaustive review of assessment tools. It looks at some of the most commonly used assessments of both typical and atypical development. Some commonly used tools such as the Bayley Scales of Infant Development were not reviewed due to a lack of empirical data to support revisions made to the tool in recent years. Tools like the Fist Year Inventory look for developmental red flags and autistic symptoms in children 12-months of age. A tool such as this does not generalize to older or younger populations nor is it applicable in an early childhood education setting. In order to increase early identification of autism and other developmental delays in non-risk populations there must be a tool that can assess typical and atypical development within the general population with a reduce risk of resulting in false negative conclusions.

There is a significant number of assessment tools designed to measure general child development. An article written by the American Academy of Pediatrics lists the most commonly used general development screening tools along with descriptive statistics from the research as well as the sensitivity and specificity for each assessment. These range from low to high across all assessments. When choosing an assessment tool to use it is important to look at what the tools actually measures in comparison to what it is going to be used for. Some tools while excellent measure of neurotypical development fall short when looking for the presence of
developmental delay. Other tools such as the First Year Inventory (16) and the Autism Diagnostic Observation Scale are designed to look specifically for autistic symptoms and are not designed to measure the development of a neurotypical child.

The 360° Developmental Assessment for Children Ages 0-36 Months seeks to bridge the gap between these two very different types of developmental assessments. Geared towards child care providers the 360° is designed to look for typical development while also looking for red flags consistent with atypical development. Many of the assessments and screening tools mentioned previously struggle with assessing the atypical development of very young children making early identification and early intervention difficult. Even though many of these children would likely still be flagged prior to the age of three, it is important to make accessible an assessment that gives child care providers the tools to accurately assess child development in order to better serve the children in their care.

The 360°

Rationale

The 360° Developmental Assessment for Children Ages 0-36 Months (see Appendix 2) was developed out of a desire to create a comprehensive developmental assessment and developmental screening tool to be used in child care centers. Based on personal experience I have learned that there are few developmental assessment tools that are affordable and accessible to child care providers. Ongoing assessment is not a mandatory part of child care, however many centers try to meet the developmental needs of their children and engage in developmental assessments in order to better meet these needs. Therefore it is important to have an assessment tool that providers can navigate and implement correctly. Often assessment tools like the Ages and Stages Questionnaire monitor development that follows a typical trajectory but fail to
identify early signs of atypical development, preautistic symptoms and regressive symptomology. The primary goal of the 360° is to identify those children who show prordromal signs of autism while still serving as an assessment of general development. It assumes that children develop along a similar typical, trajectory but is designed to identify when children fail to follow this trajectory. However, the 360° is also designed to red flag when children’s development begins to show signs of regression or preautistic symptoms.

Centers that are accredited by the National Association for the Education of Young Children are required to incorporate ongoing assessment into their curriculum. The Creative Curriculum (36) is commonly used by centers as it is evidence based and integrates developmental observation into lesson planning. This method of lesson planning and curriculum development is used by the Early Head Start and Head Start initiatives (personal communication A. Wright, P. Anderson) along with other methods of ongoing developmental assessment. This method helps teachers to make lesson plans developmentally appropriate and allows teachers to track children’s development online using computer based developmental assessments. However, it requires a great deal of training, it can be difficult to implement and is incredibly expensive at approximately $19.95 per child per year (37). For a non-profit center of 80 children, that is about $1,596.00 a year, which in the current economic climate is a major expense. Something like the 360° Developmental Assessment could be implemented for a great deal less than Creative Curriculum. While currently a paper and pencil assessment, it can be completed using a word processing program. While currently not validated and therefore not on the market, one objective of developing the 360° is to make it accessible but also affordable.

The identification of autism and other developmental disorders requires routine assessment and surveillance specifically for delays as well as effective, appropriate diagnosis
(38). The 360° aims to meet the first of these two requirements; routine assessment of all children. A crucial aspect of early childhood assessment is the screening for the possibility of developmental delays (27). The rationale behind this is to provide early intervention services to those who need it as early as possible. Research suggests that current autism-specific screening tools do not address that autism is by definition an “innate inability for interpersonal contact (4, p.22)” and interaction. By creating the 360 to specifically be a center-based assessment it will give care-providers the ability to observe children’s development in an environment where they can adequately assess their ability and desire to interact with adults and peers.

Children who are born at-risk for developmental challenges immediately enter into a system of programs, assessments and treatments meant to help them to reach their fullest potential. This system provides children who suffer from hearing loss with early intervention services including hearing aids and language therapy. Children with Downs Syndrome or Cerebral Palsy receiving continuous care including pediatrician visits and in home help in hopes that they can rise above some of the challenges and limitations they face. These children are all able to receive these early intervention services because at birth they are considered to be ‘at-risk.’ Without knowing what specifically causes each individual case of autism it is impossible to categorize a child at birth as being high-risk. Currently the only children identified as being at high-risk for developing autism are those children who are the younger siblings of children with confirmed diagnoses of an autism spectrum disorder.

The average age of diagnosis is 6 years (38) recent changes in developmental screening tools allow for children to be diagnosed as young as 24 months (39). The use of the 360° would help to identify at-risk or preautistic children as young as 4 months old, decreasing the average age of diagnosis and therefore increasing the number of children receiving early intervention
services (39). Early intensive behavioral intervention programs have been found to accelerate a child’s rate of development, increase language development, and increase social interaction behavior (40). All of this will over time decrease overall spending on special education services and other needs for the developmentally disabled population (41). Studies have shown that three years of early intensive behavioral intervention in comparison to 18 years of special education could save an average of $2.09 billion over an 18 year period (41). In 2005 the federal government allocated an average of $18,790 a year for children with autism (8) of which $6,556 was put towards regular education. A comparable study done in Tennessee found that for every dollar spent on early intervention, $7.00 in savings were accumulated over a period of 36 months (9). These studies show that early intervention is more cost effective than public special education alone. If as a society we rely on pediatricians to screen our children for developmental delay why is it that less than one third of developmentally delayed children are identified by their doctors (20)?

Recently there has been an emphasis placed on developmental assessment of all children enrolled in child care centers (27). This push for better assessment is in part driven by an increased need to identify developmental delays in children as early as possible in order that the child gains access to early intervention services. It is the goal of the 360° to provide child care centers with an accessible assessment tool designed to look for both typical and atypical developmental trends thereby red flagging children in need of further assessment and continuing to monitor the development of all children.

Development

The 360 follows the general outline of the practice parameter for the appropriate and effective identification of children with a developmental disability (38). Figure 4 shows the
algorithm designed to explain the two levels of investigation required to clinically identify children with autism. This algorithm was originally designed for use by pediatric child healthcare providers but for the purposes of the 360° has been modified to be applicable to system of center-based assessments.

The 360° Developmental Assessment does not serve as a formal diagnostic tool, as shown in Appendix 3 delineates what should have if a child should fail the assessment. In the United States between 60,000 and 115,000 children under the age of 15 meet DSM-IV-TR diagnostic criteria for autism (38); approximately 10 to 20 diagnosable cases per 10,000 children. A
diagnosis of ASD should be made by a developmental pediatrician or other healthcare professional specializing in the diagnosis of neurological disorders.

The first step in developing The 360° was to identify an exhaustive list of target behaviors displayed in infants and young children that could be indicative of early developmental delay or pre-clinical autism. This list was compiled from 6 major sources: case studies of children later diagnosed with autism, profiles of child development, texts used for the education of early childhood educators, curricula used in early childhood education, books on infant development, autism-specific books and curricula as well as personal experiences working with both neuro-typical and -atypical children. Behaviors were organized into 4 developmental domains: social/emotional, language/communication, gross/fine motor, and cognitive. The 360° is broken down into an assessment section and a checklist section. While utilizing a checklist is not ideal because of how limited yes/no response options are it was included as a section in the assessment to focus solely on red flags for developmental disability.

I designed the questions to be accessible to child care providers with a range of educational backgrounds. They break down the development of children into 6 age ranges and ask the care provider to rate the child’s behaviors on a scale of 0 to 3 with 0 = *never observed*, 1 = *rarely observed* (<25% of the time), 2 = *sometimes observed* (<50% of the time), 3 = *always observed or child has already reached this milestone and no longer exhibits this skill*. The assessment provides providers with a place to write comments if they need to further explain a specific behavior. The assessment was designed this way in order to make it accessible to providers but also accessible to parents so that when the provider shows the assessment to a parent they can understand the information they are being provided with.
The cover page of the 360° includes instructions on how to effectively implement the assessment and the checklists:

**Directions for using this assessment tool:**
The developmental assessment should be completed for each child from six months below their physical age to six months above their physical age. This means that if a child is 18 months old then they should be assessed from 12 months to 24 months. If a child was more than four weeks premature then the child’s physical age should be adjusted to incorporate their immaturity. This means that if a child’s actual age is 12 months old and they were six weeks premature then you adjust their age back six weeks and assess them as if they were 10.5 months old.

If a child scores a 0 or a 1 two or more times in any single developmental category, six months below their physical age, then that child should be assessed by a trained professional other than the child’s pediatrician. For example, if a 16 month old scores a 0 or 1 in language development section for 8 – 12 month olds 2 or more times, then the child should be referred to a professional.

The yes and no checklists are designed to highlight developmental red flags. They should be filled out for every child when the child reaches 6 months, 9 months, 12 months, 18 months, 24 months, and 36 months. If any question is answered with a no then that child should be assessed by a professional. If a new child enters your care you should fill out the developmental checklist and a yes or no questionnaire for that child. Make sure to give the child ample time to adjust to their new environment. This generally happens after about one month in full time care or six weeks in part time care. Once the child has adjusted they should be assessed. If the child is between ages for the yes or no questionnaire you should fill out the questionnaire below their physical age. For example if the child is 16 months old then use the 12 month old questionnaire. Once the child reaches 18 months old then you should fill out the 18 month questionnaire.

Appendix 3 shows an algorithm for appropriate use of the 360°.

The child’s name and date of birth are also recorded on the forms provided. While the 360° has not been empirically validated it has been implemented with signed, informed consent from parents on approximately 50 children at a local childcare center. The results from these assessments have been used to help many of these children receive early intervention services for multiple different developmental delays including autism, Sensory Processing Disorder, and general language delays. These are children whose development was identified as ‘on-target’ based on other developmental assessments provided by this center. It was the teachers who expressed some concern and asked for a tool to use in assessing each child’s development in order to effectively address the issue with the parents. This assessment has also been reviewed by
members of the early childhood education community who have all agreed that the tool addresses the skills of both typically and atypically developing children.

**Future Research**

The 360° Developmental Assessment for Children Ages 0-36 Months has not yet been validated. While tested on a small population this sample is not representative of the general population and therefore the effectiveness of the tool cannot be generalized. In the future I would like to conduct a validation study of the 360° to examine its effectiveness and its ability to identify children with red flags for developmental delay as well as its ability to assess typical, age appropriate development. The 360° was initially conceived as an assessment to be used with children ages birth to 5-years-old. This age group is considered the early intervention population (3) and as one of the main goals of the assessment is to increase the number of children being served by early intervention this seemed an appropriate age range. Time did not allow the assessment to reach as far as the 4- and 5-year-old population; as such it is currently only applicable to children ages birth to 3-years. In the future I would like to see the assessment reach its full potential and be developed further to include measures of 4- and 5-year-old development as well.

**Conclusion**

Autism is a neurological disorder that affects at least 1 in every 110 children (1). These children deserve every chance at living their lives to their fullest potential and in order to do so require intensive early intervention services. Early intervention is a crucial part of reducing the severity of autistic symptoms and helping children to overcome many of the obstacles that their diagnosis can place in front of them. To date there are many assessment and diagnostic tools that have been designed to diagnose autism and to try and identify children as young as 12-months-
old who may be at risk for autism. Current recommendations from the American Academy of Pediatrics suggest that developmental screening be done by pediatricians during a child’s well-child visit. However research suggests that this is not always an effective measure of child development and that few pediatricians actually screen children during these visits (6, 14).

The 360° Developmental Assessment for Children Ages 0-36 Months was developed not as a diagnostic tool but as an assessment of child development. It was designed for use by childcare providers in order to assess children in their most natural environment. It is my belief that an assessment or developmental screening done in a doctor’s office does not provide an accurate picture of a child’s true developmental status. In North Carolina more than 80% of children are in center-based childcare. This provides this state with a pre-established infrastructure in which to implement and test a center-based assessment such as the 360°.

Public health, specifically maternal and child health practitioners strive to protect the health of mothers and children and prevent disease and disability. The symptoms and the effects of neurological disability such as autism cannot always be prevented however they can be lessened. The consequences of such symptoms can be prevented if children receive necessary and appropriate care beginning at an early age. Autism can be considered either childhood autism or regressive autism (42), both require intensive, behavioral early intervention services in order to make an impact on the child’s prognosis. Children with regressive autism do not typically begin to show any symptoms until around 18-months of age while childhood autism can begin to show symptoms in children as young as 4-months old. All too often these symptoms are only identified once the child is older through the viewing of old home video and parent’s recollections of behaviors their child exhibited from a young age. In 2003 an article out of Johns Hopkins Bloomberg School of Public Health identified autism as an “emerging public health
problem (43).” Autism Speaks, a national science and advocacy organization, has initiated the Autism Speaks Global Autism Public Health (GAPH) Initiative designed to increase professional and public awareness of ASD, to enhance the level of services delivered to the autistic community by providing training to providers in the early identification of ASD and to increase research focusing on screening, early diagnosis and treatment of ASD (44).

It is the responsibility of the maternal and child health community to act now and join in the fight against autism. While autism is a neurological disorder with no known cure, its symptoms and the impact of those symptoms can be alleviated with proper treatment. In order to receive that treatment however those children needing services must to be identified early enough that therapy can make a difference. Early identification does not only benefit the child, it also benefits the parents, and the rest of society whose tax dollars go towards supporting special education. The sooner children receive services the better the prognosis and the less they require of the special education system. In the long run, early identification benefits an entire community, not just those whose lives are touched by a child with autism.

My life has been touched by many children whose autism has left them confined to a world lacking in social and emotional experiences. Many of these children were not diagnosed until they were 4- and 5-years-old. Over the past three years I have seen more and more children under the age of 36 months receiving therapeutic service to counter many of their autistic symptoms. I believe it to be my responsibility as a maternal and child health practitioner to work towards a goal of setting a statewide standard for the assessment of children in childcare. While autism has been identified as a public health problem I do not believe that enough is being done and therefore believe it is my responsibility to use the knowledge learned during my education to further research early identification, to educate others on ASD and how to prevent many of its
symptoms, and to write and implement effective policies assuring all children the access to developmental assessment. I see the 360° Developmental Assessment as the first step towards achieving these goals.
References


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text continues...


14. Barriers to developmental screening according to pediatricians. [available]


42. MedLine Plus. Autism. [available]


44. Autism Speaks – Global Public Health Initiative. [available]
Appendix 1
Impact the 360° can have on the greater population

- Decrease in Federal Spending on ASD
- Improvement in Prognosis

Early Intervention Services Made Available

- Intervention Recommended
- Intervention Not Recommended

Referral for Further Assessment

- On Target (no action taken)
- Not On Target Red Flags Identified

Comprehensive Developmental Assessment
Appendix 2

The 360° Developmental Assessment for Children Ages 0-36 Months
Appendix 3
Flow chart for 360° Developmental Assessment

All Children in Center Assessed using 360°

- Child scores 0 or 1 two or more times in any single developmental category, six months below physical age
  - Child referred to professional for further developmental assessment
    - Child meets diagnostic criteria for ASD
    - Child does not meet diagnostic criteria for ASD
  - Child is re-assessed at the next assessment period

- Child scores 0 or 1 less than two times in any single developmental category, six months below physical age
  - Child is re-assessed at the next assessment period